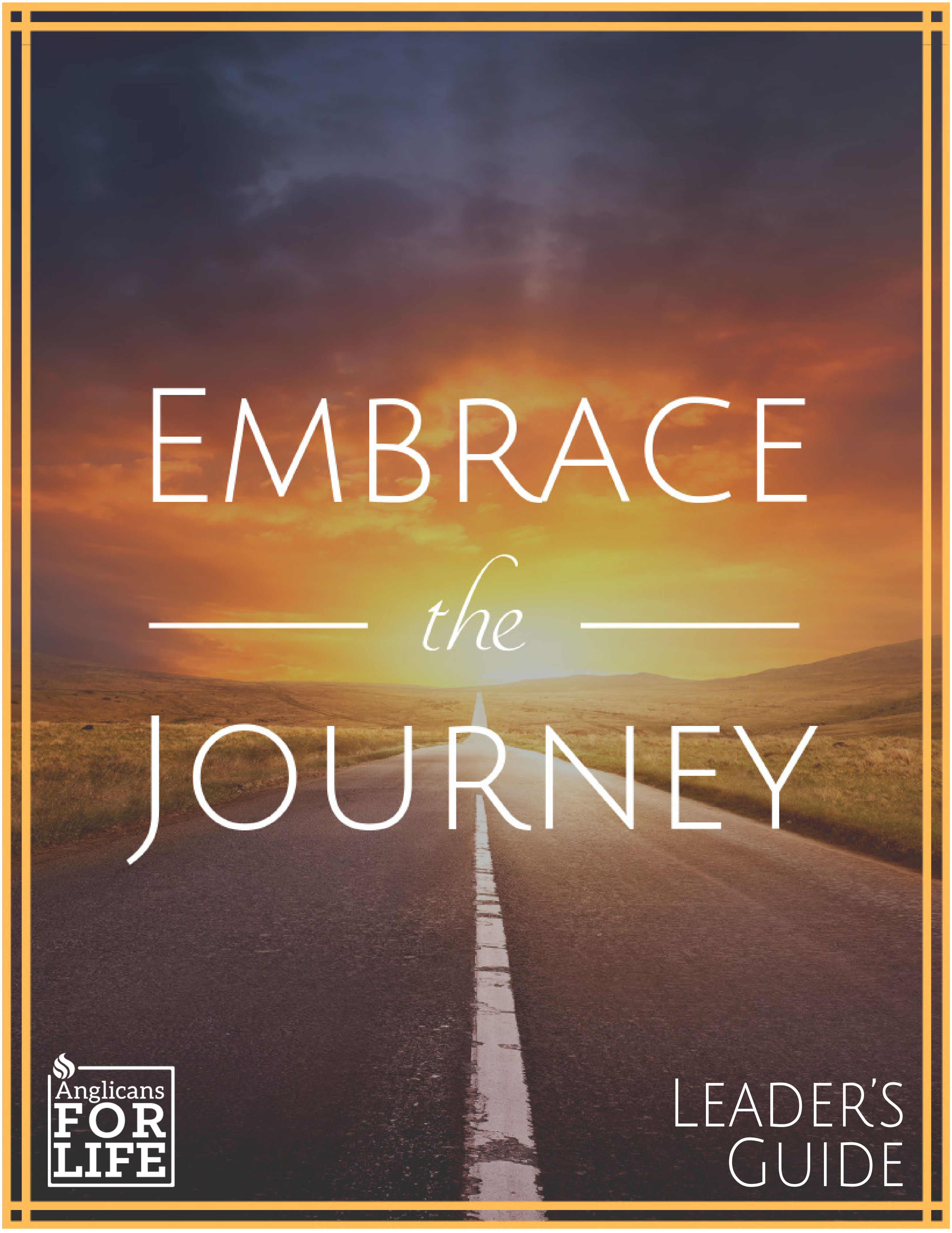

EMBRACE the JOURNEY

LEADER'S GUIDE

Anglicans
FOR
LIFE

Embrace the Journey

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Leader’s Guide

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Thank You

from The Rev. Georgette Forney

President, Anglicans for Life

Dear **Embrace The Journey** Leaders,

Thank you for your willingness to serve as the leader for the Anglicans for Life **Embrace The Journey** Series. There is no other adult-education series in existence that has attempted to address the issues we do in **Embrace the Journey**.

The purpose of this eight week series is to tackle a rarely discussed topic in the Church – aging and dying. No one likes to talk about aging, but God instructs His people in Leviticus 19, verse 32: "Stand up in the presence of the aged, show respect for the elderly and revere your God. I am the Lord."

Clearly, God indicates that He places special value on the aged as He includes them in the same sentence that states His uniqueness. The elderly are to be honored, and God is to be worshipped.

Sadly, many in our culture today no longer hold to God's command to honor and respect the elderly, and it is because of these changing attitudes that Anglicans for Life felt called to produce **Embrace the Journey**.

Because Anglicans for Life believes every life should be respected and protected at every age, from conception to natural death, we want to help prepare and protect the elderly from being ignored or de-valued. We also want to offer assurance of heaven as our eternal home for all who trust in Jesus as their Savior.

While this series does use DVD segments, your role is critical. You will do more than show DVDs. You will facilitate an interactive learning experience designed to prepare class participants to address and understand life and death issues, so people can age gracefully and die faithfully.

We have designed this series recognizing that participants will typically be church members with a wide variety of backgrounds and beliefs. Scripture is our ultimate teacher and source of authority for all we present in the **Embrace The Journey** series. We have included a number of great interviews with bishops, theologians, counselors, and experts to help explain many of the topics we cover.

We hope you will find **Embrace the Journey** user-friendly and easy for your church to implement. Please read through all of the materials in your Leader's Guide, which also has the Participant's Handbook integrated into it. At the end of the series, please complete the Leader's Evaluation and ask members of the class to complete the Participant Evaluations forms. Please return the forms to Anglicans for Life. Your feedback helps us improve our curriculums.

In closing, please know we will be praying for you and are here to support you. May your heart for the aging and dying be strengthened, and may you feel more equipped to witness to the sacredness of every human Life created in God's image.

Thank you for serving in this important endeavor.

For His glory,

Deacon Georgette Forney

Deacon Georgette Forney

INTRODUCTION

During **this course, participants will learn...**

- The biblical foundation for the Sanctity of Life and the promise of Life after death.
- The challenges of aging and practical steps to address them.
- How efforts to hasten death extend beyond Euthanasia and Assisted Suicide.
- Ways the Church can help its elderly members have peace at the end of life.

When you complete **Embrace the Journey**, we pray that participants will be better informed and equipped to help themselves or a loved one die a natural death in God's time, navigate the changes that occur with aging, and accept death as the precursor to life everlasting.

Goals for Embrace the Journey

1. Develop a deeper understanding of death from a biblical perspective.
2. Identify specific ways you or a loved one can prepare for aging and dying.
3. Inspire you to prepare for your death or a loved one's by completing the booklet **Finishing Life** which is included with the Participant's Handbook, signing a Power of Attorney or Protective Medical Decisions Document, and discussing your end-of-life wishes and goals with family members or other valued friends.
4. Appreciate the joy and beauty of aging and develop a deeper love and respect for elderly family members and friends.
5. Recognize methods to hasten death, which are becoming more accepted in our culture.
6. As a church, provide practical help so the people in your parish age with grace and die with faith.

Along with gaining knowledge, during this course we hope *hearts* will grow, so that...

- Particpants will be able to reach out to loved ones and friends who are alone and need an advocate to help them navigate through the aging and dying process.
- Particpants will share the message of salvation with everyone who does not know Jesus and does not have the assurance of heaven as their eternal home.
- Your church will become a beacon of hope to those who have no hope and fear death.

Your Role as an Embrace the Journey Leader

Embrace the Journey's goals include commitment and action. Therefore your role as Leader is especially important. Your responsibilities will include coordinating the following:

- Prayer Support
- Communications
- Logistics
- Facilitation of the **Embrace the Journey** sessions

Keep in mind that you should not try to do each task personally but rather delegate and spread the duties around. With help, you and others can see to these details and contribute to the maximum effectiveness of **Embrace the Journey**.

Furthermore, we at Anglicans for Life are happy to answer questions. Call us at 412-749-0455 or send an email at *Info@AnglicansForLife.org*.

YOUR ROLE COORDINATING PRAYER SUPPORT

You will want to pray daily during the 8 weeks for this series and the participants. Additionally, we suggest you recruit a prayer team of 3-6 discreet, reliable people who will pray for the preparation time leading up to the series, each **Embrace the Journey** session, the participants, and the follow-up from the class. Also, ask them to pray for healing for anyone who may have been affected by the issues raised in the series.

YOUR ROLE COORDINATING COMMUNICATIONS

Your work in communications will involve two areas:

1. Publicity

The first is publicity. For people to remember something, they must read or hear about it at least seven times. This means that, when you are promoting this course in your church, you'll want to do more than produce a couple bulletin announcements.

Here are some additional resources Anglicans for Life has available for you:

- Clergy announcements
- Posters in a prominent area
- Emails to your church members
- Postcards to your church members
- Bulletin inserts

Anglicans for Life has these resources available to be personalized with your class details. You can call the Anglicans for Life headquarters to request them.

2. Coordination

The second area of communication is coordination. It is less public but no less important. You will need to communicate with your clergy and lay leaders to encourage them to share the vision for **Embrace the Journey** with parishioners. You also should give your clergy regular status updates as the series progresses.

In particular, as **Embrace the Journey** touches on several sensitive issues that have probably affected people in the class, you'll want to talk with your clergy about the potential pastoral needs that could arise. The Participant Guide encourages people who find themselves getting upset to excuse themselves from the session and meet with you for a one-on-one catch-up session.

Please encourage your clergy to participate in the class to highlight the importance of the issues addressed in **Embrace the Journey** and to be available to people who may have pastoral care needs.

YOUR ROLE COORDINATING LOGISTICS

You will need to attend to some logistical details to make **Embrace the Journey** run effectively. Carefully attending to the details ahead of time will make a big difference. We've tried to anticipate the typical details you will need to address, but your church is unique, and you will know if there are additional needs.

Set The Dates For the Embrace the Journey Series

You'll want to do this in coordination with your church's leadership and your church's calendar. In some cases, you may need several months lead time to schedule the class. You should also set the sign up dates, which ideally should be on two to three Sundays a month ahead of the start of class.

Reserve Your Room

You will want to reserve a room that has:

- Enough space to accommodate your class with tables and chairs
- Power and equipment for video projection, using either a DVD or online video
- The ability to accommodate drinks and possibly snacks

Materials and Room Set Up

Participant Guides

Please order one **Embrace the Journey** Participant Guide for each couple. The Participant Guide are very important, as they will help people process the teachings with follow up articles. Each Participant Guide also comes with one **Finishing Life booklet**, which features guidance about end-of-life needs and wishes, information about choosing a power of attorney for health care, and inventory lists for critical personal information helpful for survivors after death. *If a couple is sharing a Participant Guide, a second* **Finishing Life** *booklet will need to be ordered.*

In addition, we've designed the Participant Guide to be used like a journal with plenty of space for participants to write and reflect. At sign up, we suggest that you charge at least a nominal amount ($15 recommended) for the Participant Guide to help defray the cost.

We recommend that you distribute the Participant Guide at Week 1 rather than giving them out ahead of time.

DVD

You will need a DVD player and screen big enough for your group to see and hear. A family size television will do well if you have 12 or fewer. Consider using a larger TV screen or projector if your group has 12-24 people. If your group has 25 people or more, you may want a projection size TV. If you are not "technical," we encourage you to work with your church's AV people or recruit a techie if possible. The series is also accessible on **Vimeo** if you have internet access. Contact the AFL office for the password.

Class Supplies

Extra Bibles, pens, and paper are good to have on hand. If possible, please set up your learning space with tables and chairs. Rather than rows of chairs, have tables with 4-6 chairs around each. This will help facilitate interaction. If you have a choice between round tables and rectangle tables, choose round!

Suggestions for Refreshments

Set up for coffee, decaf coffee, and tea. You may also want to offer water. (If it is warm, consider offering ice tea and lemonade.) Don't forget creamer, sugar, artificial sweetener, and stirrers. Refreshments and snacks may not seem necessary, but people tend to bond around food, and you will want your group to be comfortable with one another.

Your Role Facilitating The Embrace The Journey Weekly Sessions

This is your most critical responsibility. While you will not be directly teaching the materials, you will be helping the **Embrace the Journey** participants think more deeply about aging and dying.

We strongly encourage you to review the DVD segments and the Participant's section at least once before the start of the series.

As you watch the videos and read the Handbook, be in prayer for the **Embrace the Journey** series, asking the Lord to provide His wisdom as you facilitate.

Before Each Embrace the Journey Session

During the week, watch the upcoming **Embrace the Journey** DVD segment and review the week's lesson.

On the Day of Class

On the day of class, arrive at least 30 minutes early to oversee setup and to pray. Be sure to have the **Embrace the Journey** DVD cued to the right segment.

During Each Embrace the Journey Session

Because **Embrace the Journey** emphasizes more than gaining facts, the participants will engage in a variety of activities each week.

All the activities are described in the **Embrace the Journey** Participant Handbook section.

First, you will lead your group in the *Opening Prayer and Opening Activity* time. You can use the prayer provided in the Handbook section or use one of your own. Then you will lead the group in the activity or short discussion that will help prepare their minds and hearts for the topic of the day.

Next, you will introduce the *DVD.* There is space in the **Embrace the Journey** Handbook for taking notes. We have also included the text of each presentation as a reference.

After the DVD Presentation, the participants will engage in a *Group Reflection.* During this time, if you have a class smaller than 12, the whole group could work on the discussion questions listed in the Participant Guide. Otherwise, they should work with the small group at their table. Ideally, the groups should be 4-6 people, but they should be no larger than 12. Ask each group to designate a discussion leader for the session. From week to week, encourage the class to vary groups and discussion leaders.

At the first session, please begin by reading the welcome letter from Georgette found at the front of the Participant Guide (page PG-7) and review the Guidelines for Group Discussion (page PG-11) before they start their Group Reflections.

During Group Reflections time, you should not plan on moderating or participating in a group, but you should move around the room, checking to see that participation is going well and if anyone appears to be having emotional difficulty with the subject. The script from each presentation is included as a reference for you to use as needed during Group Reflections.

If someone is becoming unduly upset or is exhibiting aggressive behavior, you should gently, but firmly, encourage that person to take a break from the session. Let your clergy know that you have done this. (Ideally, your clergy will be there.) Please be discreet and don't mention the incident to others. (You can let your Prayer Team know they need to pray, but don't provide names or details.)

After Group Reflection you will gather the whole group for *Closing Thoughts and Prayer*.

Then, if a few people want to share briefly, they may do so. Make sure people keep their sharing brief.

Next, your group will pray about what was learned and close with the *Prayer for Life* printed at the end of each session in the **Embrace the Journey** Participant Guide.

Please remind people about the "Personal Study and Reflection" at the end of each session in the Handbook. We encourage you and the participants to work through these exercises. This will usually involve reflecting on a Bible passage, answering a question or two, and reading the Recommended Articles included in their Participant Guide. Working through these will help them engage with the topic at a more personal level.

After Each Embrace the Journey Session

Oversee clean up and be sure to retrieve the **Embrace the Journey** DVD. Be available to anyone who wants to talk.

During the week afterward, be sure to work through the Personal Study and Reflection. In addition, watch the next DVD segment and read the next week of **Embrace the Journey** Participant Guide.

Due to the somber and sometimes heavy nature of these discussions about aging and dying, the session may have a spirit of heaviness or sadness associated with it. We have included a few elderly-friendly jokes on page 14 to share in class if you are led by the Holy Spirit to do so!

As the Leader of the **Embrace the Journey** series, you do have a great responsibility and a number of details to consider. Please remember that your prayer team and Anglicans for Life are praying for you. Furthermore, as mentioned earlier, if you have questions or need some support, contact Anglicans for Life at 1-412-749-0455 or email us at: ***Info@anglicansforlife.org***.

GUIDELINES FOR GROUP DISCUSSION

These guidelines also appear on page H-10 of the **Embrace the Journey** Participant Handbook

1. Share respectfully. Please tell what you think but be sensitive to others.
2. Listen respectfully. Let people share. Make sure everyone has a chance to share.
3. Remember, if you really do not want to share, you are not obligated to do so.
4. This course covers some issues that have probably affected you or another person in your class. As such, these topics may become lightning rod type issues, generating strong emotion. Please be understanding if others become upset and be conscious of your own reactions.

   If you find yourself becoming upset, you may want to take a break from the group and spend some time alone in prayer and contemplation. The Leader will be happy to meet with you one-on-one later to catch you up on what you have missed. If you desire further support, consider making an appointment to meet with your priest or pastoral director or read some of the articles found at the back of the book.

NOTE: You may find that you do not have enough time during the **Embrace the Journey** session to complete every activity. If you run short on time, consider skipping a Group Reflection question or shortening the sharing time during Closing Thoughts and Prayer. <u>Ask the Lord for wisdom and remember that what the participants gain from the session is more important than completing all the activities</u>.

Contact info:

☎

Anglicans for Life

Local: 412-749-0455

or email the AFL Team at:

Info@AnglicansforLife.org

A few jokes to relieve the intensity of the topic!

60th High School Reunion

He was a widower and she a widow.

They had known each other for a number of years being high school classmates and having attended class reunions in the past without fail.

This 60th anniversary of their class, the widower and the widow made a foursome with two other singles.

They had a wonderful evening, their spirits high. The widower threw admiring glances across the table. The widow smiled coyly back at him.

Finally, he picked up courage to ask her, "Will you marry me?"

After about six seconds of careful consideration, she said, "Yes, yes I will!"

The evening ended on a happy note for the widower. But the next morning, he was troubled. Did she say" Yes" or did she say "No?"

He couldn't remember. Try as he would, he just could not recall. He went over the conversation of the previous evening, but his mind was blank.

He remembered asking the question, but, for the life of him, he could not recall her response. With fear and trepidation he picked up the phone and called her.

First, he explained that he couldn't remember as well as he used to. Then he reviewed the past evening.

As he gained a little more courage he then inquired of her. "When I asked if you would marry me, did you say 'Yes' or did you say 'No?'"

"Why you silly man, I said 'Yes, I will.' And I meant it with all my heart."

The widower was delighted. He felt his heart skip a beat.

Then she continued. "And I am so glad you called because I couldn't remember who asked me!"

No NURSING HOME for me!!!

No nursing home for us. We'll be checking into a Holiday Inn!

With the average cost for a nursing home care costing $188.00 per day, there is a better way when we get old and too feeble.

I've already checked on reservations at the Holiday Inn.

For a combined long term stay discount and senior discount, it's $59.23 per night.

Breakfast is included, and some have happy hours in the afternoon.

That leaves $128.77 a day for lunch and dinner in any restaurant we want, or room service, laundry, gratuities, and special TV movies.

Plus, they provide a spa, swimming pool, a workout room, a lounge and washer-dryer, etc.

Most have free toothpaste and razors, and all have free shampoo and soap. Five dollars worth of tips a day you'll have the entire staff scrambling to help you.

They treat you like a customer not a patient.

There's a city bus stop out front, and seniors ride free.

The handicap bus will also pick you up (if you fake a decent limp).

To meet other nice people, call a church bus on Sundays.

For a change of scenery, take the airport shuttle bus and eat at one of the nice restaurants there.

While you're at the airport, fly somewhere. Otherwise, the cash keeps building up.

It takes months to get into decent nursing homes. Holiday Inn will take your reservation today.

And you're not stuck in one place forever—you can move from Inn to Inn, or even from city to city.

Want to see Hawaii? They have Holiday Inn there too.

TV broken? Light bulbs need changing? Need a mattress replaced? No problem. They fix everything and apologize for the inconvenience.

The Inn has a night security person and daily room service. The maid checks to see if you are OK. If not, they'll call an ambulance—or the undertaker.

If you fall and break a hip, Medicare will pay for the hip and Holiday Inn will upgrade you to a suite for the rest of your life.

And no worries about visits from family. They will always be glad to find you and probably check in for a few days mini-vacation.

The grandkids can use the pool.

What more could I ask for?

So, when I reach that golden age, I'll face it with a grin.

AIDS WARNING!

To all of you approaching 50 or have REACHED 50 and past, this is especially for you......

DID YOU KNOW SENIOR CITIZENS
ARE THE NATION'S LEADING CARRIERS OF AIDS...
HEARING AIDS
BAND AIDS
ROLL AIDS
WALKING AIDS
MEDICAL AIDS
GOVERNMENT AIDS
MOST OF ALL,
MONETARY AID TO THEIR KIDS!

Embrace the Journey Leader's Checklist ✓

Use this checklist to help you keep track of all these details.
There are also blanks lines for you to add other details as needed.

Three Months Ahead:

- ☐ Preview the **Embrace the Journey** DVD and review the Participant Handbook section included in this manual.
- ☐ Speak with your clergy and/or lay leaders about **Embrace the Journey** and share the vision for **Embrace the Journey**. You may want to show them a couple DVD segments and have them look over the Handbook. If your clergy can participate in the series, that would be all the better!
- ☐ Talk with your clergy about potential pastoral needs that may arise. Share with them the resources in the back of this book. Coordinate with appropriate local resources where people can receive help, such as local Christian counseling agencies.
- ☐ Schedule the dates for the **Embrace the Journey** series and the sign up day. Email Anglicans for Life (*info@anglicansforlife.org)* the dates so that we can pray for you.
- ☐ Assemble your **Embrace the Journey** Prayer Team.
- ☐ First publicity - Bulletin Insert and/or Poster.
- ☐ Reserve your room.
- ☐ ______________________________
- ☐ ______________________________

Two Months Ahead:

- ☐ Generate at least four more publicity efforts including but not limited to
    - ☐ Asking clergy to make an announcement and/or pen a letter.
    - ☐ Placing posters in prominent spots at your church *(Inside bathroom stalls is also very effective!)*
- ☐ Submit an article or paragraph for church newsletter and website
- ☐ Provide a general church e-mail announcement
- ☐ Ask your **Embrace the Journey** prayer team to pray for God to draw the people He wants to this class
- ☐ Make sure you have DVD equipment lined up. If you are not "technical," you should coordinate with your church's AV people or recruit an AV techie to help you.
- ☐ Set and announce sign up dates.
- ☐ ______________________________
- ☐ ______________________________

Six Weeks Ahead:

- ☐ Decide what you will charge for **Embrace the Journey** Participant Guide & Finishing Life booklet.
- ☐ Start sign ups. Have a sign up table after services.
- ☐ Collect money for the **Embrace the Journey** Participant Guide at sign up.
- ☐ ______________________________

One Month Ahead:

☐ Review the **Embrace the Journey** DVD and Leader's Guide again.

☐ Estimate number of participants and order Participant Guides and Finishing Life booklets from Anglicans for Life (Page 3).

☐ Ask your Prayer Team to continue prayers for God to draw the right people and for His protection for you and the class.

☐ Make a special announcement in church using a DVD clip and/or clergy appeal.

☐ Arrange for a **Embrace the Journey** Bulletin Insert.

☐ Plan for set up. Work with your church's set-up staff or recruit people to set up the room with table and chairs.

☐ Recruit others to help with take-down and clean-up.

☐ ______________________________

Three Weeks Ahead:

☐ Finish sign-ups.

☐ Tell your **Embrace the Journey** Prayer Team how many participants and ask for prayer.

☐ Order more Handbooks, if needed.

☐ ______________________________

Two Weeks Ahead:

☐ Get supplies lined up.

☐ Buy coffee, decaf coffee, tea, herbal tea, creamer, sugar, sweetener. You may need two coffee makers, one for regular and one for decaf, and something to make hot water for the tea.

☐ Recruit someone to make coffee, set up, and clean up the refreshment table each week.

☐ ______________________________

One Week Ahead:

☐ Review **Embrace the Journey** Week 1 on the DVD and in the Participant Handbook.

☐ Ask your Prayer Team to pray for the final preparations and for the start of the series.

☐ Do a video and sound check in the room. This is important.

  ☐ "Troubleshoot" and buy cables, etc. Make sure screen is visible.

  ☐ Check sound. Keep in mind, people absorb noise, so what sounds loud enough in an empty room will not sound enough in a full room. Do this with your techie.

☐ Finalize your arrangements to have the room set up with tables and chairs, the DVD equipment set up, and coffee/tea service in place.

☐ Ask a volunteer to bring in a simple snack for Week 1.

☐ ______________________________

☐ ______________________________

Please email AFL as you begin, so we can pray for you and your class weekly.

Info@AnglicansforLife.org

Anglicans
FOR LIFE

WEEK 1
Mortal Life and Eternal Life

BEFORE THE SESSION:

☐ Arrive at least 30 minutes early to make sure set-up is taking place and to pray for the class.
☐ Cue the **Embrace the Journey** DVD to Week 1.

DURING THE SESSION:

☐ Welcome the group and distribute the Participant Guide.
☐ During **Opening Prayer and Activity**: Explain course details to the class by reviewing the Welcome Letter (p. 20 of Leader's Guide or p. PG-7) and Introduction (p. 7 of Leader's Guide or PG-9) in the **Embrace the Journey** Participant's Guide. Be sure to emphasize the Goals of **Embrace the Journey**.
☐ Introduce the **Embrace the Journey** DVD Presentation. The entire script from the DVD is included as a reference for you.
☐ When starting **Group Reflection**, be sure to go over the Guidelines for Group Discussion found on page PG-11 of the **Embrace the Journey** Participant Guide & page 13 of the Leader's Guide.
☐ Remind participants to do **Personal Study and Reflection** in their Participant Guide.
☐ Ask a volunteer to bring snack the next week.

AFTER THE SESSION:

☐ Be available if someone wants to talk.
☐ Make sure clean up takes place.
☐ Retrieve the DVD.
☐ Retrieve supplies. Keep for following week.
☐ Let the clergy know how the session went.

DURING THE WEEK:

☐ Give your Prayer Team an update. Ask them to be in particular prayer for the next session, ***Prepare for the Golden Years***.
☐ Work through the **Personal Study and Reflection**.
☐ Preview the next week on the DVD.
☐ ______________________________
☐ ______________________________
☐ ______________________________
☐ ______________________________

Welcome to *Embrace the Journey!*

Anglicans for Life created this eight week series to address a rarely discussed topic in the Church – aging and dying.

No one likes to talk about aging, but God instructs His people in Leviticus 19:32: *"Stand up in the presence of the aged, show respect for the elderly and revere your God. I am the Lord."*

God clearly indicates that He places special value on the aged as He includes them in the same sentence that states His uniqueness. The elderly are to be honored, and He is to be worshipped.

Sadly, many in our culture today no longer hold to God's command to honor and respect the elderly, and it is because of these changing attitudes that Anglicans for Life felt called to produce **Embrace the Journey**.

AFL wants to help prepare and protect the elderly from being ignored or de-valued. We also want to offer assurances of God's grace as this mortal life ends. Graduation to heaven is a gift for all who trust in Jesus as their Savior.

We hope that as you interact with each week's topics you will feel more comfortable contemplating and planning for the golden years of life for you and/or your loved ones and know with confidence that Heaven is your/their forever home.

As we prepared this information, we struggled with references to changing medical ethics and healthcare providers who support hastening death, fearing some statements could be misconstrued to imply we believe every doctor and nurse endorses imposing death. This is definitely not the case! We know and recognize that the vast majority of healthcare professionals uphold the sanctity of life. However, we must acknowledge we live in a post-Christian culture that emphasizes a utilitarian worldview of life.

Please remember - people of faith often hold different views about life and death. Everyone must respect each other's opinion and withhold judgment of one another. My prayer is that God will sharpen and strengthen your faith as you interact with each other!

I would also like to thank all the wonderful people who were interviewed for this curriculum. Their willingness to share their knowledge and pastoral or personal experience is truly appreciated.

Finally, thank you for attending the **Embrace the Journey** adult education series. I can personally attest to the benefit of going through this curriculum!

My mother died a month after I finished writing **Embrace the Journey**. Many of the teachings shared during the various interviews provided help and guidance, as I had to walk through the issues we talk about in **Embrace the Journey**.

During the 11 days Mom was in the hospital before she died, I recalled advice that I gave or found while writing this guide. At the time of the original writing, it was based on theory, but I gratefully found the advice was very helpful to me in reality. In the fall of 2018, I began revising Embrace the Journey, and this version includes more information I have learned, both from additional research and through personal experience as the Power of Attorney for two dear elderly friends.

While I wish none of us would need to know this information, death is real, and it is hard to go through with our loved ones. I hope **Embrace the Journey** will make it a little easier for you when the time comes, as it did for me.

God bless,

Deacon Georgette Forney

Deacon Georgette Forney

*I dedicate my work on **Embrace the Journey** to*
my mom, Myriam Adela Nutting
1928-2013

WEEK 1

Mortal Life and Eternal Life

The **MAIN OBJECTIVE** of this week's presentation is to provide an overview of **Embrace the Journey** and introduce the topics of aging, dying, and heaven. The session ends with a presentation of the Gospel and an invitation to accept Jesus as Savior and Lord.

Opening Prayer

Dear God, as we begin this series, we start by thanking You for the gift of Life and for Your inspired Scripture that teaches us about Life. Please open our hearts and minds to learn all that You want us to. May this study increase our knowledge about aging and death, inspiring us to take the light of Your love into the world. May the certainty of our eternal home with You give us courage to **Embrace the Journey** and finish life Your way. We ask all this in Jesus' name. Amen.

Opening Activity

Share your name and what motivated you to attend **Embrace the Journey**

DVD Presentation:

Please take notes using this outline:

1. Welcome & Introduction
    a. Anglicans for Life's work on abortion
    b. Devaluing elderly, disabled, & terminally ill
        i. Material applicable to yourself and others
2. Week-by-week topics:
    - Week 1 will look at what God's Word has to say about aging and dying.
    - Week 2 will consider practical steps in preparing for the Golden Years!
    - Week 3 will introduce Advance Directives, Advance Care Planning, and Patient Goals.
    - Week 4 will take us further into Advance Care Planning including POLST, DNR's, Hospice, and Palliative Care.
    - Week 5 will examine good and bad healthcare.
    - Week 6 will discuss the use of assisted suicide to hasten death and why people choose it.

- Week 7 will address funeral planning and grief
- Week 8 will consider the role of the Church in helping people embrace the journey.

3. Life and Aging in the Scriptures

    a. Genesis 1:27, 2:7, Psalm 8:4-5, 139:13-16, Leviticus 19:32, Proverbs 16:31, Isaiah 46:3-4

4. Is it possible to enjoy growing older?

    a. The Rev. Duane Peterson teaching

    b. Psalm 92:12-15 - purpose in old age

5. Death is discussed widely in Scripture - so why aren't we talking about it?

    a. Denying death denies humanity

    b. Post Judeo-Christian world - But we have hope! I Cor. 15:20-23, 54-55

    c. Bishop Keith Ackerman

6. Assurance of Heaven

    a. New challenge - trusting God in process of aging

    b. Putting your faith in Jesus

"If we don't have a good theology of death, we cannot have a good theology of life in Jesus Christ. That is, there is a reason why we live, there is a reason why we die.

Ecclesiastes tells us there is a season. There is a time for all of these things.

Think about what St. Paul tells us. Christ, our Passover, is sacrificed for us; therefore let us keep the feast, not of the old leaven of malice and weakness.

Christ being raised from the dead will never die again. Death has no more dominion over Him. He died once for all, but then He lives. He lives unto God."

Bp. Keith Ackerman

BIBLE VERSES:

Genesis 1:27

So God created mankind in his own image, in the image of God he created them; male and female he created them.

Genesis 2:7

Then the LORD God formed a man from the dust of the ground and breathed into his nostrils the breath of life, and the man became a living being

Psalm 8:4-5

"what is man that you are mindful of him, and the son of man that you care for him? Yet you have made him a little lower than the heavenly beings and crowned him with glory and honor." ESV

Psalm 139:13- 16

"For you formed my inward parts; you knit me together in my mother's womb. I praise you, for I am fearfully and wonderfully made. Wonderful are your works; my soul knows it very well. My frame was not hidden from you, when I was being made in secret, intricately woven in the depths of the earth. Your eyes saw my unformed substance; in your book were written, every one of them, the days that were formed for me, when as yet there was none of them." ESV

Leviticus 19:32

You shall stand up before the gray head and honor the face of an old man, and you shall fear your God: I am the LORD. (ESV)

Proverbs 16:31

Gray hair is a crown of glory; it is gained in a righteous life.

GROUP *Reflection*

1. Georgette mentions a new evil that Anglicans for Life is addressing – devaluing the elderly. Have you seen or experienced a lack of respect or honor exhibited toward the elderly in your community, family, or church?

2. While aging and dying cannot be avoided, how do you feel about getting old? How does your vision of old age align with God's, as stated in Psalm 92:12-15? Should we have hope and a sense of great expectation?

3. What are some reasons we avoid discussing death? What is your go-to euphemism for saying someone has died?

4. What happens when we die? Are Heaven and Hell real? Is death the final word or a scene change?

5. Bp. Ackerman acknowledges that we don't have a good theology of death. Why don't we? Why doesn't the Church? Does softening death minimize the prize of Heaven?

6. Read James 2:10, 1 John 1:7, and Ephesians 2:8-9. What is the one thing that will keep you out of heaven? Do you trust in Jesus for your salvation and have assurance that your forever home is in heaven with Him?

BIBLE VERSES Cont'd.:

Isaiah 46:3-4

"Listen to me, you descendants of Jacob, all the remnant of the people of Israel, you whom I have upheld since your birth, and have carried since you were born. Even to your old age and gray hairs I am he, I am he who will sustain you. I have made you and I will carry you; I will sustain you and I will rescue you. NIV

Psalm 92:12-15

But the godly shall flourish like palm trees and grow tall as the cedars of Lebanon. For they are transplanted into the Lord's own garden and are under his personal care. Even in old age they will still produce fruit and be vital and green. This honors the Lord and exhibits his faithful care. He is my shelter. There is nothing but goodness in him! (Living Bible)

I Cor. 15:20-23, 54-55

But the fact is that Christ did actually rise from the dead and has become the first of millions who will come back to life again someday. Death came into the world because of what one man Adam did, and it is because of what this other man Christ has done that now there is the resurrection from the dead. Everyone dies because all of us are related to Adam, being members of his sinful race, and wherever there is sin, death results. But all who are related to Christ will rise again. Each, however, in his own turn: Christ rose first; then when Christ comes back, all his people will become alive again….

Then at last this Scripture will come true—"Death is swallowed up in victory." where O'death is your victory? Where O Death is your sting? The sting of death is sin, and the power of sin is the law. But thanks be to God! He gives us the victory through our Lord Jesus Christ.

James 2:10
For whoever keeps the whole law and yet stumbles at just one point is guilty of breaking all of it.

1 John 1:7
But if we walk in the light, as he is in the light, we have fellowship with one another, and the blood of Jesus, his Son, purifies us from all sin.

Ephesians 2:8-9
For it is by grace you have been saved, through faith—and this is not from yourselves, it is the gift of God—not by works, so that no one can boast.

Closing Thoughts & Prayers

- **Identify someone you know who doesn't have the assurance of heaven and pray for them to accept Jesus as their Lord and Savior.**
- **Close with praying the Prayer for Life:**

Prayer for Life

Lord God, thank You for creating human life in Your image.
Thank You for my life and the lives of those I love.
Thank You for teaching us through Scripture the value You place on life.
Help me to uphold the sanctity of life in my church and community.
Give me the strength to stand up to those forces that seek to destroy the lives of those most vulnerable, the unborn, the infirm, and the elderly.
Today I commit myself to never being silent, never being passive,
and never being forgetful of respecting life. I commit myself to protecting and defending
the sacredness of life according to Your will, through Christ our Lord.
Amen.

For Further Personal Study & Reflection

- Begin reading Billy Graham's book **Nearing Home**.
- Say out loud – "It is good to get old."
- Write out your theology of death and discuss it with a friend or family member.
- Read article "Heaven is Real" on page H-50.
- Memorize the Scripture that blessed you today.

Sinner's Prayer

O God, I know I am a sinner.

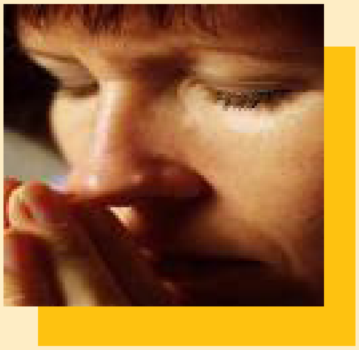
I am sorry for my sins, and I want to turn from them.

I trust Jesus Christ as my Savior, I confess Him as my Lord, and I invite Him to come into my life today.

From this moment on, I want to make Him the foundation of my life and to serve Him and follow Him in the fellowship of His church.

In Christ's name I pray.

Amen.



Week 1 DVD Script

Mortal Life & Eternal Life

1. Welcome and Introduction

Hello, my name is Deacon Georgette Forney and I am your host and the author of Embrace the Journey. I am grateful that you have chosen to take this class, and after serving as Anglicans for Life's president for 20 years, I can say the need to defend life at the end is as critical as it is at the beginning!

a. Anglicans for Life's work on abortion

Since 1966, when Anglicans for Life began, our mission has been to protect the unborn from being killed by abortion. However, when Oregon legalized Physician Assisted Suicide in the late 1990's, we expanded our mission to include protecting the elderly, disabled and terminally ill from being killed through the unnatural hastening of their death instead of naturally in God's time.

b. Devaluing elderly, disabled, and terminally ill

And just as Anglicans for Life works to address the myriad of sub-topics that feed into the acceptance and support for abortion, we have produced Embrace the Journey to highlight not only euthanasia and assisted suicide but also the secondary topics that impact aging and dying, so that as Christians, we may finish life glorifying God and hearing "well done, good and faithful servant" when we graduate to heaven.

i. Material applicable to yourself and others

For many of you, the material in Embrace the Journey will not only apply to you directly but possibly your parents, or other relatives and friends who are older or are facing life-threatening illnesses. My prayer is that our time together will inspire honest and heartfelt conversations amongst you and your loved ones because as I have traveled around the country discussing these topics, many people tell me how uncomfortable they are talking about them let alone actually preparing for them!

2. Week by week topics

First this week, we will look at what God's word has to say about aging and dying.

Next week we will consider practical steps in preparing for the Golden Years!

Week 3 will introduce Advance Directives, Advance Care Planning and Patient Goals.

Week 4 will take us further into Advance Care Planning including POLST, DNR's, Hospice and Palliative Care.

Week 5 will examine good and bad advance care planning.

Week 6 we will discuss the use of assisted suicide to hasten death and why people choose it.

Week 7 will address funeral planning and grief

Finally week 8 will consider the role of the church in helping people embrace the journey.

3. Life and Aging in the Scriptures

So let's start by looking at what the Bible teaches us about life, aging, death, and eternal life.

From the beginning, Genesis 1 establishes that we are made in God's image – unique from everything else God created. Human beings are the only creatures made by God that bear His image.

Genesis 2:7 reminds us that God breathed life into man, we carry God's very breath in our very being.

In Psalm 8:4-5, David reminds us of the place of honor that we hold in God's heart. "what is man that you are mindful of him, and the son of man that you care for him? Yet you have made him a little lower than the heavenly beings and crowned him with glory and honor." ESV

Then in Psalm 139, verses 13- 16, David reminds us that God determines when our life begins, and when it will end.

"For you formed my inward parts; you knit me together in my mother's womb. I praise you, for I am fearfully and wonderfully made. Wonderful are your works; my soul knows it very well. My frame was not hidden from you, when I was being made in secret, intricately woven in the depths of the earth. Your eyes saw my unformed substance; in your book were written, every one of them, the days that were formed for me, when as yet there was none of them.” ESV

But what does God think about us as we age?

Leviticus 19:32 says You shall stand up before the gray head and honor the face of an old man, and you shall fear your God: I am the LORD. (ESV)

Proverbs 16:31 says Gray hair is a crown of glory; it is gained in a righteous life.

And in Isaiah 46:3-4 the prophet declares God’s faithfulness to His people

“Listen to me, you descendants of Jacob, all the remnant of the people of Israel, you whom I have upheld since your birth, and have carried since you were born. 4 Even to your old age and gray hairs I am he, I am he who will sustain you. I have made you and I will carry you; I will sustain you and I will rescue you. NIV

4. Is it possible to enjoy growing older?

It is clear from these 3 examples that God places a special value on the aged and promises to continue caring for us through all stages of life. But is it possible to enjoy growing older? What is God doing with us as our bodies age and fail?

a. Rev. Duane Peterson

I came across this teaching by The Rev. Duane E. Peterson for Trinity School for Ministry’s Lenten Devotional in 2018 that aptly speaks to these questions: he says…

“Growing old, we are told, is not for the faint of heart. My eighty-five year old mother says it best: “If I wake up in the morning and nothing hurts then I’ll know I’m in heaven.”

With each passing year we become more infirm, more isolated by lack of mobility and loss of strength. In addition, we mourn the death of family and friends coupled with the narrowing of human interaction which accompanies these inevitable life events.

It is to be expected, even anticipated, that this reality would produce fear, a sense of foreboding, the dread of abandonment, all feelings expressed by the author of Psalm 71: “Do not cast me off in the time of old age; forsake me not when my strength is spent.”*

For solace, the Psalmist returns to the past, to those times when God’s presence was real, tangible, and visible—much like one does when the photo album is opened and memories of past joys and adventures are brought back to life with stories from long ago, alive in a way the present could never match. The psalmist tells us God was there at his conception and held him in his arms. The Lord guided his every step, saved his life and silenced his enemies. Then the people gathered to give thanks and bless the name of the Lord.

When the psalmist recognizes that God was present in his past, the future fills with hope, a hope which informs his current reality and inspires true worship. “Father, into your hands I commit my spirit” (Luke 23:46)*.

In Lent, we are invited to embrace the reality of aches and pains, loneliness and loss, anxiety and fear, depression and death. The invitation comes from the One who embraced all of life. He took upon himself every aspect of our broken, isolated, and infirmed humanity.*

Therefore, we rejoice knowing that in the midst of death there is life, and in the midst of Good Friday there is Easter: “But I will hope continually and will praise you yet more and more” (Psalm 71:14).

Lord help us to be like the Psalmist recognizing your faithfulness that gives us hope as we age.”

b. Psalm 92:12-15 - Purpose in old age

And Psalm 92:12-15, is one of my favorites, as we are reminded that we still have purpose in old age!

12 But the godly shall flourish like palm trees and grow tall as the cedars of Lebanon. 13 For they are transplanted into the Lord’s own garden and are under his personal care. 14 Even in old age they will still produce fruit and be vital and green. 15 This honors the Lord and exhibits his faithful care. He is my shelter. There is nothing but goodness in him! (Living Bible)

When you put these Scriptures together – I think we can safely say “God made us, sustains us and is carrying us as we age. It is good to get old! Thank you, Lord, for this season of life too!”

5. Death is discussed widely in Scripture - so why aren’t we talking about it?

Now when it comes to discussing death in the bible, there are nearly 1000 references to death, dying, and dead. So, while death gets a lot of attention in Scripture, it is still one of the least discussed topics in polite company! And when we do find it the subject of a conversation, we use euphemisms like kicked the bucket, bought the farm, passed, or dearly departed. How many of us find it easier to say I'm sorry your mother passed, than to say I'm sorry your mother died. I think we believe if we don't talk about death, we can prevent it from happening! But that is not true, in fact the one thing I can say for sure is that all of us watching this presentation will someday die unless the Lord returns first!

a. Denying death denies humanity

Denying death, denies life, it fails to acknowledge our humanity, our mortality. Death should prompt us to honor and cherish life. Culturally, we have disconnected from death by making it a medical issue best handled by appropriate institutions likes hospitals and nursing homes. 100 years ago, people died at home and were laid out for viewing in the parlor. Now we rarely even have funerals where people view the deceased. It's more common to cremate the body and have a memorial service or celebration of life party. Out of sight, equals out of mind! He didn't die, he's just gone!

b. Post Judeo-Christian world - but we have hope!

Recognizing the post-Judeo-Christian culture we live in, it is easy to understand why death has to be denied, as fewer people acknowledge the existence of God, – for them, there is nothing but death! However, for believers – we know that Jesus Christ has been victorous over death. And in first Corinthians, Chapter 15, Paul describes how Christ's death was both a sacrifice to remove the wrath and guilt of our sin and a victory over the demonic powers that held us captive to death. I am only quoting two small portions of that chapter that is laden with promises and hope. Starting with verse 20…

20 But the fact is that Christ did actually rise from the dead and has become the first of millions who will come back to life again someday. 21 Death came into the world because of what one man Adam did, and it is because of what this other man Christ has done that now there is the resurrection from the dead. 22 Everyone dies because all of us are related to Adam, being members of his sinful race, and wherever there is sin, death results. But all who are related to Christ will rise again. 23 Each, however, in his own turn: Christ rose first; then when Christ comes back, all his people will become alive again….

Then further on… in verse 54

54 Then at last this Scripture will come true—"Death is swallowed up in victory." where O death is your victory? Where O Death is your sting? The sting of death is sin, and the power of sin is the law. But thanks be to God! He gives us the victory through our Lord Jesus Christ.

What hope and encouragement we are given in the midst of death

c. Bishop Keith Ackerman

I have asked Bp. Keith Ackerman, retired Bishop of the Diocese of Quincy and psychologist to address death from a shepherd's perspective:

From a pastoral perspective as it relates to the people in the pews, we need to talk about death more as simply not being the final word. The best way to look at it is that death is the end of part 1. Then we have a scene change. Then we're called to be home with Jesus Christ.

Why is that difficult? Lots of reasons, but here's one of them. One is that, if we're really pushed, we discover that even people who think of themselves as Christians don't necessarily believe in Heaven and Hell. They won't admit that, you understand. If you really press them, they have very, very peculiar notions about it. For example, let me ask some of you these questions right now. What happens when we die? Does our soul mysteriously leave our body? You've watched those television shows and those movies. Is that what happens? Body is there, we have an out-of-body experience. We look down. Does an angel with big wings come and shake our hand and say it's time to come? Do we meet St. Peter at the Pearly Gates? Do we become angels, because that's certainly even in "It's a Wonderful Life" what we might think. Keep coming back. It's sort of a Christian reincarnation. You come back til you get it right, I guess.

We have a very, very sloppy theology of death. We look in the Apostle's Creed, the Nicene Creed. What do we talk about? The resurrection of the dead. The life of the world to come. Again, if I would gather a group of people together and say, "What happens when you die," I guarantee you there would be some differences of opinion.

If we don't have a good theology of death, we cannot have a good theology of life in Jesus Christ. That is, there is a reason why we live, there is a reason why we die. Ecclesiastes tells us there is a season. There is a time for all of these things. Think about what St. Paul tells *us. Christ, our passover is sacrificed for us, therefore let us keep the feast, not of the old leaven, leaven of malice and weakness goes on to say, "Christ being raised from the dead will never die again." Death has no more dominion over Him. Then He died, He died his sin once for all, but then He lives. He lives unto God. It is that we're shy about being able to say it.*

I one time went to visit a woman who was dying, as a very, very young priest. I looked at her, and I hedged the subject. Finally, she looked me in the eyes and she said, "Father, I know what the problem is. You don't want to say I know you're dying, do you? Well, let me tell you. Father, I'm dying. Now Father, would you please say that?"

"Yes ma'am, you are dying."

And she said, "Now that wasn't that difficult, was it?" She was joyful because she was ready to meet the Lord, and I was trying to come up with all these pastoral ways in which I could make it a little bit softer. You don't have to soften death, because, to a large extent, to soften death is to minimize the prize of Heaven.

6. Assurance of Heaven

Knowing heaven is our destiny can help us fully embrace each day in our aging earthly bodies. This passage from *Jesus Calling* inspires us:

"Heaven is both present and Future- as you walk along your life-path holding my hand, you are already in touch with the essence of heaven; nearness to Me. You can also find many hints of heaven along your pathway, because the earth is radiantly alive with My presence. Shimmering sunshine awakens your heart, gently reminding you of My brilliant Lights. At the end of your life-path is an entrance to heaven. Only I know when you will reach that destination, but I am preparing you for it each step of the way. The absolute certainty of your heavenly home gives you Peace and Joy, to help you along your journey. You know that you will reach your home in My perfect timing, not one moment too soon or too late. Let the hope of heaven encourage you, as you walk along the path of Life with Me."

a. New challenge - trusting God in process of aging

The promise of where we will spend eternity provides us with a sense of peace and hope. But, the challenge becomes can I trust God in this process of aging and dying!

Questions about the end can haunt us. Will my memory still work? Will I die alone? How will death come to me? The reality is that few people die a sudden death, some die from illnesses like cancer or organ failure, but most of us will die simply from old age, frail, somewhat incapacitated and dependent on others for some level of daily care.

Envisioning these things is hard something we want to ignore, like Scarlett O'Hare declaring, "I'll think about it tomorrow!" But the problem is that not talking about it and not planning for it doesn't make it go away.

This series is designed to help you and your loved ones understand what needs to be done to prepare for aging and dying, knowing that when you have completed the class, you will have a clear sense of what actions need to be taken to be responsible to your loved ones, and to trust God for the rest.

Anglicans for Life created this 8-week curriculum because the church is the logical place to help people finish life well and graduate to heaven. Scripture calls us to encourage one another to embrace the journey of graceful aging and faithful dying. We also want to help folks like myself who desire to honor our aging parents and loved ones but need guidance in helping them transition through the last seasons of life.

As we wrap up this week's teaching I have a few housekeeping items;

First, thank you for attending this class, I hope you can make all 8 sessions as they do build on one another. Also, if you are a couple the Participant Guide workbook, can be shared between you, but you will each need a copy of Finishing Life: How to Prepare for the End of Life, as these booklets are designed for every person in the class to complete by the end of the series! We will go into more detail about them next week.

Also we have included a substantial bibliography of resources that provide additional information related to the topics, so I commend them to you. And I'd like to call special attention to one of my favorite books that I reference alot– Nearing Home by Billy Graham. This is a great resource to share with aging parents or friends as it puts aging in perspective!

Remember death is less scary for us and our loved ones when we are certain we are included in God's plan of heaven and eternal life, so how can we know for certain we will go to heaven when we die?

b. Putting your faith in Jesus

According to Billy Graham in Nearing Home, quote “Only one thing will keep you out of heaven, and that is your sin. God is absolutely pure and holy, and even one sin – just one – would be enough to banish you from His presence forever. But Jesus Christ came to take away your sins by His death on the cross and His resurrection from the dead.

As long as you trust in yourself – your goodness, your religious deeds, for your salvation, you will never have any lasting assurance of your salvation. After all, how will you know if you have been good enough or religious enough? The answer is you won’t.

But salvation doesn’t depend on our goodness; if it did, we could never be saved, for God’s standard is nothing less than perfection. We can never be good enough because James 2:10 says “whoever keeps the whole law yet stumbles at just one point is guilty of breaking all of it”. Our salvation depends instead solely on Jesus Christ and what He has already done for us. Our faith and trust must be in Him, and not in ourselves.

Do you trust Him alone for your salvation? If you don’t, or if you are unsure, I urge you to turn to Jesus Christ in repentance and faith today and by a simple prayer ask Him to come into your life as your Lord and Savior.”

We have included Billy Graham’s famous “Sinner’s Prayer” in the participants workbook, we hope you will pray it if you never have.

As Billy Graham says, “If you put your faith and trust in Christ, you now belong to Him. You have been adopted into His family, and you are now His beloved son or daughter. Because of this, the Bible says, nothing in all creation, will be able to separate us from the love of God that is in Christ Jesus our Lord. You are now part of His family forever! and when you die you will live forevermore in Heaven!”

So with that assurance we come to the end of our 1st week of Embrace the Journey. I hope you return next week as we will discuss practical things you can do to make aging less challenging for you and your loved ones.

WEEK 2

Prepare for the Golden Years

BEFORE THE SESSION:

- ☐ Arrive at least 30 minutes early to make sure set-up is taking place and to pray for the class.
- ☐ Cue the **Embrace the Journey** DVD to Week 2.

DURING THE SESSION:

- ☐ During **Opening Prayer and Activity**: Lead the participants through the prayer and opening activity for this session.
- ☐ Introduce the **Embrace the Journey** DVD Presentation.
- ☐ When starting **Group Reflection**, review the "Guidelines for Group Discussion" on page PG-11of the Handbook.
- ☐ Remind participants to do **Personal Study and Reflection** in their Handbook.
- ☐ Ask a volunteer to bring snack the next week.
- ☐ Lead the group through the **Prayer for Life**.

AFTER THE SESSION:

- ☐ Be available if someone wants to talk.
- ☐ Make sure clean up takes place.
- ☐ Retrieve the DVD.
- ☐ Retrieve supplies. Keep for following week.
- ☐ Let the clergy know how the session went.

DURING THE WEEK:

- ☐ Thank your Prayer Team and give them an update. Ask them to be in particular prayer for the next session, ***Advance Directives & Goals***.
- ☐ Work through the **Personal Study and Reflection**.
- ☐ Preview the next week on the DVD.
- ☐ ______________________________
- ☐ ______________________________
- ☐ ______________________________

*** Please note: FINISHING LIFE - *Preparing for the End of Life*

Each Participant should have a copy of this booklet. Please bring the booklet to everyone's attention and encourage them to begin thinking about the practical plans they need to address. Filling in the information concerning their finances, resources, and passwords can provide a peace of mind to family members, knowing this information is collected in one safe place.

Please emphasize the importance of telling someone where the booklet will be stored!

WEEK 2

Prepare for the Golden Years

The **MAIN OBJECTIVE** of this week's presentation is to talk about many of the practical issues people avoid discussing, because in doing so it makes aging and death more real. We will also learn about what happens when someone is in the last stage of dying and how families can honor their loved ones at this time.

Opening Prayer

Dear Lord, thank you for seasons of life. For those of us in the Golden Years of life, help us to embrace these years with hope and joy, and forgive us when we lose sight of the blessings of this journey. Lord, for those of us who are not in our Golden Years yet, help us to honor those who are. Thank You for our moms, dads, elderly relatives, and our older, wiser friends. Give us grace and guidance to help them, advocate for them, and celebrate their life when You call them to Heaven. Help us address the practical issues of life, so we may have peace in knowing we have been good stewards of this life, until we are with You. In Jesus name, Amen.

Opening Activity

Brainstorm and list some of the things that change as we age.

How senior-friendly is your home? Are there changes you would like to make?

DVD Presentation:

Please take notes using this outline:

1. Introduction - Planning for golden years – Checklist of practical topics
    a. Aging is difficult - guidance and help is needed
    b. Making decisions becomes more difficult - planning will help this
    c. Honor your parents - blessing to children
    d. Finishing Life booklet
2. Making plans for future care
    a. Power of attorney for finances & healthcare

  b. Priorities & goals - ask questions

  c. Talk about it as a family

3. Topics to consider

  a. Finances

  b. Checking account signator

  c. Location of important papers/passwords

  d. Last Will and Testament

  e. Elder care lawyers

  f. Living arrangements, downsizing, & safety issues

  g. Doctor visits & prescription medicines

  h. Sleeping issues

  i. Tough topics - the bathroom & driving

  j. Caregiver needs

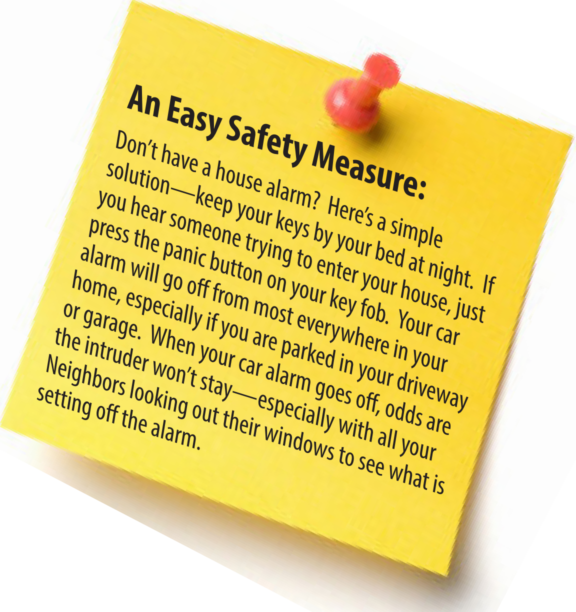
  k. Elder abuse- embarrassed, underreported

4. Understanding the last hours of life

  a. Bp. Jones - Last Rites/Extreme Unction/Anointing the Sick

  b. Cristen Krebs - Last stages of dying

5. Conclusion - Ruth Graham epitaph "End of Construction"



An Easy Safety Measure:

Don't have a house alarm? Here's a simple solution—keep your keys by your bed at night. If you hear someone trying to enter your house, just press the panic button on your key fob. Your car alarm will go off from most everywhere in your home, especially if you are parked in your driveway or garage. When your car alarm goes off, odds are the intruder won't stay—especially with all your Neighbors looking out their windows to see what is setting off the alarm.

BIBLE VERSES:

1 Corinthians 14: 40
But everything should be done in a fitting and orderly way.

Ephesians 6: 2-3
But Honor your father and mother—which is the first commandment with a promise—so that it may go well with you and that you may enjoy long life on earth.

GROUP *Reflection*

1. Aging brings many challenges, including loss of independence. What activity have you prided yourself on doing that now requires help from others or what do you fear losing independence in doing?

2. Which practical topics noted in the video seem to be the most important for you or loved ones? Are there other practical issues you are concerned about that were not mentioned in the video?

3. Do you like the idea of staying in your home until death or is retirement home living a preferred option?

4. The reality of elderly people being victims of abuse is disconcerting. What would you do if you were the victim of abuse or if you suspected or knew someone who was being abused? Would it be hard to report abuse if the perpetrator was a family member or care-giver?

5. The last hours and days before death are hard to think about – did anything Cristen say about the last days surprise you? Has anyone walked with someone through the last days to death? Did anything occur that surprised you?

6. Ruth Graham's epitaph reads, "End of Construction." What do you want your epitaph to say?

Closing Thoughts & Prayers

- The practical issues we face with aging can make us uncomfortable, as they reminds us that time marches on and denial doesn't prevent it. Ask God if there is resistance in your heart about aging, and to help you face what frightens you about it. Let His word and love for you be applied to your fears and receive His peace.
- Bring the fears before the Lord and pray for one another.
- Close with praying the Prayer for Life**:**

Prayer for Life

Lord God, thank You for creating human life in Your image.
Thank You for my life and the lives of those I love.
Thank You for teaching us through Scripture the value You place on life.
Help me to uphold the sanctity of life in my church and community.
Give me the strength to stand up to those forces that seek to destroy the lives of those most vulnerable, the unborn, the infirm, and the elderly.
Today I commit myself to never being silent, never being passive,
and never being forgetful of respecting life. I commit myself to protecting and defending
the sacredness of life according to Your will, through Christ our Lord.
Amen.

For Further Personal Study & Reflection

- Begin working on **Finishing Life** and set a date by which you want to have it completed along with signing your Power of Attorney for Health Care/Protective Medical Decisions Document.
- Tell someone where you are keeping the booklet **Finishing Life** after you have completed it!
- Visit websites listed on PG-101 that provide Home Safety Checklists. Identify areas in your home or a loved one's that need to be addressed or fixed, or idenify some retirement communities you can visit in your area.

Week 2 DVD Script

Practical Planning in the Golden Years

1. Introduction - Planning for Golden Years - Checklist of Practical Topics

Welcome to Week 2 of Embrace the Journey. I'm Georgette Forney president of Anglicans for Life and author of this programme. Last week we began this series by talking about aging and death, two of the least popular words in our vocabulary! Today we will dive into planning for our golden years by reviewing a checklist of practical topics that need to be considered and discussed.

a. Aging is difficult - guidance and help are needed

Since I started working on this curriculum, I have gotten a lot of feedback from people with aging parents, as well those whose spouses, elderly friends or parents have recently died. One common theme runs through their comments – they all wished they would have had some guidance to navigate the ups and downs and changes associated with the Golden Years! I have also personally faced a myriad of these issues myself as my father is 90 and I am Power of Attorney for two elderly friends who happen to be best friends, one of whom introduced me to Jesus over 35 years ago and now has Alzheimer's while the other has dementia.

So, while this information is helpful for those of us providing support and care –keep in mind that for the person who is aging, the challenges can be profound; something as simple as driving to the grocery store is no longer possible, or now they need help remembering what medications to take. Their sense of freedom and autonomy is slipping away, as they find themselves more dependent on others to help with tasks they used to take for granted.

b. Making decisions becomes more difficult - planning will help this

Also, it often becomes harder to deal with important decisions that need to be made. Decision may feel burdensome or complicated or perhaps they would rather avoid potential conflicts. In addition, the strain of an unexpected illness or death of a spouse or some other crisis may stress them to the point they are unable to make good decisions.

One thing I have noticed in talking with folks about these topics is that the younger you are when you begin thinking about them and discussing them with family, the less overwhelming it feels when what was discussed becomes a reality.

c. Honor your parents - blessing to children

And remember as adult children what Ephesians 6, verses 2and 3 says: "Honor your father and mother"— which is the first commandment with a promise "so that it may go well with you and that you may enjoy long life on the earth." Paul makes it clear that not only should the commandment inspires us, but fulfilling it will bring us blessing. Do you think God includes the promise because some day we will likely be in our parents' shoes, and hopefully our children will be inspired to care for us!

But it may not be a parent, it may be a good friend who is aging, and we need to recognize that while they are still very independent, there are some things we should discuss with them and help them think about so that their aging experience can be a blessing.

d. Finishing Life booklet

Before we go further, I want to mention Finishing Life, How to Prepare for the End of Life. Each one of you should have a copy because You are the author of it! It was designed to collect pertinent information about your life, health, wealth, and wishes in one document. We took the questions asked by various entities like funeral homes, financial planners and churches and put them all in one booklet. There is space in it to document details related to many of the topics we will touch on today. Additional copies can be ordered from Anglicans for Life and it is available online as a PDF that can be easily updated. The front section will help guide decisions when considering whom to appoint as your power of attorney for health care and provides discussion points regarding your Advance Care Plans and preferences as you age.

2. Making plans for future care

Also, in laying the foundation to make sure you or your loved one is properly cared for in old age keep these things in mind.

a. Power of Attorney for Finances and/or Health Care

One, empowering someone to be your Power of Attorney for Finances and/or Health Care is the best approach to managing your life when you can't, whether it is temporary or permanent. Two, aging is a process, things my Dad could handle 2 years ago, he now welcomes my brother's help to do like balance his check book. Needs are ever evolving and changing.

b. Priorities and goals - ask questions

Third, to help focus priorities, it helps to determine what is most important to us as we age. A few years before their ability to reason was compromised, I asked the ladies I care for what their goals and priorities were as they age and they both said they wanted to stay in their apartment and stay together. So, now when decisions must be made or they want to do something that could create a problem – I bring up their goals and use them to help evaluate whether the idea is good or could potentially hinder their goals.

c. Talk about it as a family

Finally recognize the value of discussing these things with loved ones who are intimately involved in the person's life –spouses, adult children, significant others, siblings. My suggestion is to plan a time when you can sit down together and talk about one or two topics. Don't try and cover too many issues in one sitting. Also, through all of this, try and put your suggestions or recommendations in the form a question or choice. Everyone is more apt to cooperate if they don't feel like they are being controlled or manipulated.

3. Topics to Consider

The first practical item that may need addressed is the idea of work and retirement. Billy Graham noted in Nearing Home, the word retirement isn't in the Bible; especially in the context we use it today. Many people are ill-prepared for the realities of retirement, either viewing it unrealistically through rose-colored glasses or refusing to think about it at all. But there will come a time for each of us when we need to 'retire' from our life's work. The key is to begin thinking about it and seeking God's counsel before that time comes so we are able to embrace it.

a. Finances

Another tough but critical topic is finances, especially in light of rising health care costs, limited resources and the reality of living longer. Do an inventory of assets, income, expenses, liabilities, credit cards, insurance policies, and prepare a budget to estimate what monthly expenses are. If you have substantial financial resources, you may need to enlist the help of a financial planner to insure your estate is properly prepared. Financial planning gives you a peace of mind in knowing where you stand fiscally. Space for all this is in Finishing Life.

b. Checking account signator

In addition to putting your financial house in order, consider including another person as a signatory on your checking account. If something happens to you, it can be impossible for your family to pay your bills and take care of your needs if no one is authorized to write checks from your account.

c. Location of important papers/passwords

While we all have our own system for organizing important papers and documents, it is necessary that someone other than yourself know where important documents are kept. In times of crisis, when someone might need to know your social security number, how are they going to find it? Also, if you have passwords for computers, online bill paying programmes, all this needs to be recorded, space is included in Finishing Life for you to note them.

My parents have a safe, but none of us knew the combination or where it was! If you have a safe or safety deposit box, give someone trustworthy access to it.

d. Last Will and Testament

One of the key documents that others will need to know about is your last will and testament – where is it stored and if an attorney is involved, what is their contact information. Also, when deciding who to name as your executor, prayerfully consider naming someone other than one of your children! This decision can greatly affect how their relationships with each other continue after your death. This recommendation came from a priest who has presided over many funerals and saw a lot of unnecessary angst between siblings over the role of executor. And if you don't have a will – for the sake of everyone who will be left behind to handle your estate – get one written up!

e. Living arrangements, downsizing, & safety issues

One of the most important topics to consider as we age is the issue of living arrangements. Downsizing is often the first step after the kids leave home but may need to happen multiple times. Make sure the home is free from hazards that can cause a fall. Your workbook has a list of websites with great recommendations for making the home safer and areas like the bathroom more accessible. If retirement home living is an option, visit multiple facilities and make the transition before this type of move becomes too difficult. Many senior living communities have levels of independent living that you can transition through. My in-laws started in a two-bedroom apartment, then went into a one room set-up taking their meals in the dining room. The next step was the nursing home, where my father-in-law was cared for when he needed that, while my mother in law stayed in their room.

A major benefit of moving to a retirement community is protection against isolation and loneliness which can be a major problem as friends die or move away and we experience decreased mobility due to physical limitations or not driving.

Making changes in the living arrangements is best to do when the person is still capable of making their own decisions and can help plan for their new home. Changes related to our home can be a great source of distress for anyone but especially for the elderly.

If you or your loved one has a pet, discussion may need to occur about how they want the pet cared for when they die.

f. Doctor visits & prescription medicines

Aging often leads to multiple health problems, and it's helpful to have someone who can go along to doctor visits and serve as an advocate to make sure medicines, various treatments, tests, and diagnosis are properly and accurately communicated between healthcare providers and family. If regular medications are prescribed, it is helpful to order prescription online, so refills can be shipped directly to the home. Also use pill organizers to help make sure correct doses are taken daily.

Whether or not there are existing health problems – it is important to know if Long-term Care insurance exists. It is an insurance product, sold in the United States, United Kingdom, and Canada that helps pay for the costs associated with long-term care. It generally covers care not covered by health insurance, Medicare, or Medicaid. These policies have substantially changed over the last 20 years, so it may be good to research what the policy covers before its needed.

g. Sleeping issues

Sleeping can be a common problem for many, and I loved Billy Graham's exhortation as he related experiencing this issue– he suggests using sleepless time to meditate on the Lord's goodness to you. My mother–in-law used sleepless nights to say extra prayers for her family.

h. Tough Topics - the bathroom & driving

Incontinence or concern about having bathroom accidents can be a difficult topic to address and is often the reason elderly people stop going out or traveling. I found it helpful to research the different types of products available and give them samples to try that provide comfort and security. Be very matter of fact about it as it is a common problem experienced by many but discussed by few! Water-proof pads for beds are also extremely helpful.

One of the hardest topics I have dealt with for both my Dad who was a truck driver and one of the girls is whether they should still be driving! I just recently used the question approach with my Dad on this one – I asked what would be a good indication that someone shouldn't be driving anymore? He said, when you start getting lost! I laughed as he had gotten lost with me in the car about a year ago! I pointed that out and the silence on the other end of the phone told me I had planted a seed.

As we seek to balance respect for their independence with concern for their safety, helping them come to conclusions about changes they need to make is ideal. Taking their car keys can be very dehumanizing, so helping them make the decision to stop driving is preferred.

i. Caregiver needs

As noted earlier, as we age our needs change, typically we are fine living independently but there may come a time when illness or memory loss requires some day to day assistance. You may need to bring in a care-giver a few hours a day to help with dressing, hygiene, household duties, and meal preparation. Often what starts out as only a few hours a day can progress to 24-hour care.

Providing on-going or around the clock care for a loved one can be exhausting. Caregivers must realize that they may experience feelings of anger or depression from the pressure of such responsibilities. Caregivers need to make every effort to maintain a well-rounded, balanced schedule of social activities. Listed in your workbook are a variety of companies that can provide additional help with caregiving or household chores. You can also ask for referrals from friends who have needed similar services.

If it is a couple – typically one will try to handle life for both for them which can lead to exhaustion or illness. It is important to look for hints and clues that things are falling through the cracks; the girls had their electricity shut off because they forgot to pay the bill even though they had the money. This served as the flag for me to realize they were no longer able to keep up with some basic tasks.

j. Elder abuse - embarrassing, underreported

In doing research about the needs of the elderly, I came across a sad fact – there were almost 6 million reported cases of elderly abuse in 2010. Folks reported physical abuse but also financial, emotional, and sexual abuse as well as neglect. The abuse was often perpetrated by family members, care-givers, and staff of nursing homes. Often times the elderly person is embarrassed, so they rarely report the abuse. Many nursing homes are not adequately staffed which can also lead to gaps in acceptable care. We must be mindful of the possibility of abuse as we interact with elderly friends and family and report it if we see it or carefully discuss it with the person if we suspect it.

I have also included an article about the issue of guardianship abuse that allows the state to appoint a stranger to take full control of the lives and property of elderly people, even when family members exist. It is an eye opening article into just how easy it is for someone to be appointed a guardian of an elderly person and up-end their lives.

4. Understanding the last hours of life

Finally, at some point in time, for ourselves or our loved one- it will become apparent that death is drawing near. There are some practical things to consider at this time also.

First and foremost, you may want to invite a priest or pastor to come and anoint them, hear confession or give last rites.

a. Bishop Jones - Last Rites/Extreme Unction/Annointing the Sick

I've asked Bp. Derek Jones, who oversees the Jurisdiction of the Armed Forces and Chaplaincy to explain the value of these sacraments.

When we consider that what is eternal in us is our soul, that our bodies are in fact temporal, the idea of what becomes permanent at death and essential at death is the eternal condition of our soul and our condition of our relationship.

If you were to simply qualify what is Last Rites, all Last Rites is last chance to make your relationship right. If I were to go away on a journey and you and I had enmity between each other, I would hate to go away on with someone that I love and not have it straight before I left. If you look in terms of Last Rites or Extreme Unction or Anointing of the Sick as being I want to make sure that in this life that I have, that relationship that I have with you as a human being before I begin my eternal journey that I want to be able to make sure that I'm reconciled to that relationship that I have with you. Within the church, we look at that as a means of grace being extended and giving an individual a chance to not die within their sins.

It gives us an option and an opportunity to confess those things to God.

Now for someone who's a Christian, is it going to make a difference? No, not eternally, but from the standpoint of those who are struggling with their identity of who they are, it is a means of bringing last comfort to the physical presence of that person in life and it can be a very, very necessary part of the dying process and a willingness sometimes to be able to let go. I want to be right with everybody around me and I want to be right with God. I will confess, and I will be absolved of those sins and those things. I will die knowing that my soul is safely sealed with the Holy Spirit of God and that I have an eternity that I'm going into at the moment that I leave my body.

b. Christen Krebs - last stages of dying

Thank you Bp. Derek, next, I've asked Cristen Krebs, CEO of a Catholic Hospice here in Pittsburgh to share with us the signs that death is imminent.

How somebody dies is different for everybody, but I truly believe that if that person has had really intimate physical, emotional and spiritual care, death is beautiful and not frightening. It's very peace-filled, it's very graceful.

As the body declines … usually anywhere from 24 to 72 hours before actual death, we start seeing changes. What a lot of people don't understand is that most patients eat and drink, even if it's just a wee little bit, up until the last 24 and 48 hours. If they are properly medicated and not over-medicated or over sedated, they can still take a little by mouth.

Somewhere in that 24, maybe 72-hour window, we start seeing their body decline. That's when they're sleeping a lot more, they might be a little confused, they're definitely withdrawn, when they're awake, they tend to be withdrawn. A lot of families get scared of that and offended sometimes, but it's just part of the mental processing the patients need to go through when they're letting go of earthly life.

As far as the physical decline, again, they don't eat or drink much, sometimes they're talking but it's … sometimes coherent, up until the very end, but for most, again, they're sleeping a lot. They have generalized weakness, so they need to remain in bed most of the time. Their body functions, as far as bowel and bladder, are still at times very regular, they may be incontinent; they may wake to let somebody know they need to use the bathroom still.

If that window starts closing in the last 48 hours, 24 hours, they just begin to sleep. If they've really had all of their needs met, the body just slowly shuts down, the kidneys shut down, so there is no more urinary output. Sometimes there might be one final bowel movement, but normally it's very peaceful and the body just begins shutting down, their respirations start getting a little more shallow. Sometimes it's more frightening to the observers than the patient, sometimes it's a little noisy breathing, but if the patient is sleeping and appears very comfortable, there's not need for concern about it. Most of the time patients have their eyes closed and they just sleep away.

5. Conclusion - "End of Construction"

In Nearing Home, Billy Graham relates a story about his wife, Ruth declaring one day that she wanted her headstone to read "End of Construction. Thank you for your patience." He then goes on to share "Every human being is under construction from conception to death. Each life is made up of mistakes and learning, waiting and growing, practicing patience and being persistent.

Death says, "This is the finality of accomplishment." While we cannot add anything more to our experience, believers in Christ have the hope of hearing our Savior say, "Well done, good and faithful servant" That is my prayer for us.

Thank you for viewing this week's presentation. I hope our discussion of practical concerns will prompt meaningful conversation with you and your loved ones. Next week we will consider Advance Directives, and Advance Care Plans and the benefits and risks associated with them.

WEEK 3
Advance Directives & Goals

BEFORE THE SESSION:

☐ Arrive at least 30 minutes early to make sure set-up is taking place and to pray for the class.
☐ Cue the **Embrace the Journey** DVD to Week 3.

DURING THE SESSION:

☐ During **Opening Prayer and Activity**: Lead the participants through the prayer and thoughts for this session.
☐ Introduce the DVD Presentation.
☐ Remind participants to do **Personal Study and Reflection** in their Handbook.
☐ Ask a volunteer to bring snack the next week.
☐ Lead the group through the **Prayer for Life**.

AFTER THE SESSION:

☐ Be available if someone wants to talk.
☐ Make sure clean up takes place.
☐ Retrieve the DVD and copies of the Resource List.
☐ Retrieve supplies. Keep for following week.
☐ Let the clergy know how the session went.

DURING THE WEEK:

☐ Thank your Prayer Team and give them an update. Ask them to pray for the next session, ***Types of Advance Care Plans.***
☐ Work through the **Personal Study and Reflection**.
☐ Preview the next week on the DVD.
☐ ____________________
☐ ____________________
☐ ____________________
☐ ____________________

FINISHING LIFE - *Preparing for the End of Life*

Each Participant should have a copy of this booklet. Remind everyone about it and encourage them to begin thinking about their practical plans they need to address. Filling in the information concerning their finances, resources, and passwords can provide a peace of mind to family members knowing this information is collected in one safe place.

Please emphasize the importance of telling someone where the booklet will be stored!

WEEK 3

Advance Directives & Goals

The **MAIN OBJECTIVE** of this week's presentation is to understand what Advance Medical Directives are and why the only appropriate type is a Power of Attorney for Health Care. We will also discuss who you should appoint as your advocate, and why having end of life goals can help ensure you finish life God's way!

Opening Prayer

Dear Father God, we thank You for creating life in Your image and for caring so much for every person that You sent Your Son to die for our sins. As we ponder our future and what our end-of-life care will be, help us to remember that Your Holy Spirit is within us to give us strength and courage in the face of suffering and pain. Give us grace to handle the physical challenges that come with age and help us to be spiritually stronger. We ask this in Jesus' Name, Amen.

Opening Activity

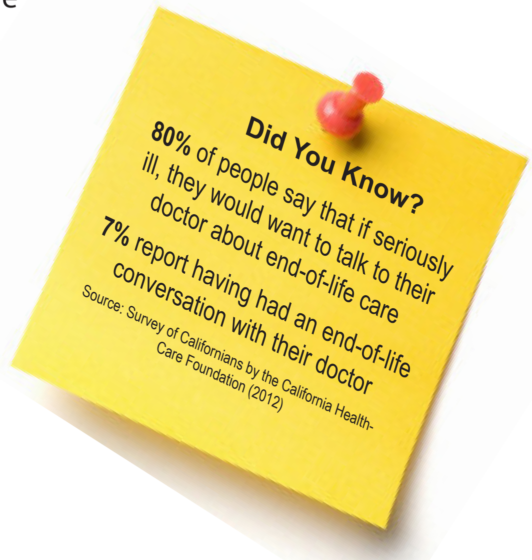
How many of you currently have an Advance Medical Directive?

What type is it, and when did you last update it?

DVD Presentation:

Please take notes using this outline:

1. Importance of having goals concerning end-of-life healthcare
    a. What is an Advance Medical Directive
    b. Two types: Living Will & Power of Attorney
    c. Rita Marker - Patient's Rights Council
    d. Preferred Durable Power of Attorney for Healthcare
    e. Not legally required to have Advance Directive
    f. Who do you appoint to be your Durable Power of Attorney for Healthcare?



Did You Know?

80% of people say that if seriously ill, they would want to talk to their doctor about end-of-life care

7% report having had an end-of-life conversation with their doctor

Source: Survey of Californians by the California Health-Care Foundation (2012)

2. Advance Care Planning
    a. Medical technology and longer living
    b. Define your GOALS that form your Advance Care Plan
    c. Priorities, preferences, and plans for healthcare
3. Finishing Life and Dying Well
    a. Being Mortal - Dr. Atul Gawande
    b. Honoring life in the midst of death
4. Conclusion - Issaac story in Genesis 27

Did You Know?

46% of 736 doctors felt unsure about what to say about dying to patients dealing with a terminal illness .

60% don't initiate discussion, because they aren't sure it's the right time.

BIBLE VERSES:

Revelation 14:13
Blessed are the dead who die in the Lord

Proverbs 14: 15
The simple believe anything, but the prudent give thought to their steps.

GROUP *Reflection*

1. What are some of the concerns and problems with Living Wills? At what age is it recommended that you sign an Advanced Directive? What is the right kind of Advanced Directive? Are you legally required to have an Advanced Directive?

2. One of the most critical decisions that we each need to make is deciding who we should appoint to speak for us and make medical decisions on our behalf if we are unable. What qualities and characteristics should this person have?

3. Does Advance Care Planning - thinking about your priorities, preferences, and goals related to your healthcare choices as you age or face illness -- make sense to you? How do you want to be cared for in a health crisis? Be kept alive at all costs? Fight until the end? Be kept comfortable?

4. Have you thought about dying? Do you want to die at home, in a nursing home?

Closing Thoughts & Prayers

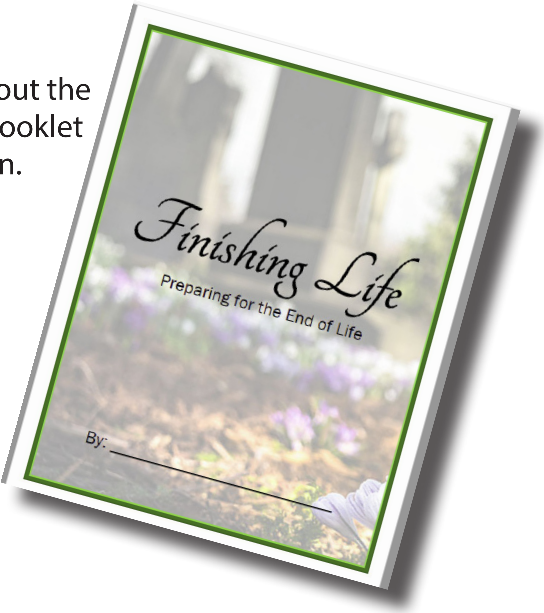
- Every elderly patient needs to have an advocate, someone who will ask questions and seek to ensure the patient gets quality care. Is there someone in your parish who may need an advocate, because they are alone or their family lives far away?
- Compile a list of elderly folks in your church and pray for them regularly. If any of them are alone, consider visiting them, providing a meal, taking them Communion, or sitting and reading to them while their care-giver rests or runs an errand.
- Close with praying the Prayer for Life:

Prayer for Life

Lord God, thank You for creating human life in Your image.
Thank You for my life and the lives of those I love.
Thank You for teaching us through Scripture the value You place on life.
Help me to uphold the sanctity of life in my church and community.
Give me the strength to stand up to those forces that seek to destroy the lives of those most vulnerable, the unborn, the infirm, and the elderly.
Today I commit myself to never being silent, never being passive,
and never being forgetful of respecting life. I commit myself to protecting and defending
the sacredness of life according to Your will, through Christ our Lord.
Amen.

For Further Personal Study & Reflection

- Read the article entitled, "Who Decides What is Best for the Patient?" on page H-92. Does the fact that elderly patients will need a surrogate that can advocate for them in this changing medical environment inspire you to complete the **Protective Medical Decisions Document**?
- Pray about your decisions to sign an Advance Directive, and who you should appoint as your Power of Attorney
- Have a conversation with family members and/or close friends about the type of end of life care you want. Use the booklet **Finishing Life** booklet enclosed with your Participant Guide to help direct your discussion.
- Read definitions of various Heathcare Directives on page PG-116. Which is best for you?



*On page 5 in the AFL booklet, **Finishing Life**, we provide advice on who to choose to be your Health Care Advocate.*

Week 3 DVD Script

Advance Directives & Goals

1. Introduction - Importance of having goals concerning end of life healthcare

Hello. I'm Deacon Georgette Forney, your host and author of Embrace the Journey. Last week we reviewed a lot of practical issues related to aging. I wonder how many of you thought about what you want on your headstone? Remember Ruth Graham said "End of Construction – Thank you for your patience!"

This week we are going discuss Advance Directives, Advance Care Planning, and the need to have goals related to healthcare at the end of life.

a. What are Advance Medical Directives?

First let's define the term advance directive. An Advance Directive, sometimes referred to as an Advance Medical Directive is a written document that tells others what type of medical care you do or don't want should you become incapacitated. There are two types, 1) a living will, which is typically a list of questions like do you want to be on a ventilator, or do you want antibiotics, with check boxes that note your preferences and 2) a durable power of attorney for health care. This type of power of attorney is separate from a financial power of attorney.

An Advance Directive is needed if the patient cannot make his or her wishes known to a healthcare provider. For example, a person may be unconscious, confused, or too badly injured to tell the doctor what kind of care or treatment he or she would like to receive or under what circumstances that doctor should withhold care or stop treatment.

b. Rita Marker - Patient's Rights Council

Recently, I had the opportunity to visit with Rita Marker, an attorney and President of the Patient's Rights Council. She specializes in Advance Directives, and I asked her to explain the difference between living wills and a power of attorney and which she thinks is best to have.

I often describe a living will as giving a very broad authority to an unknown physician. I explained that actually it has so many loopholes, you could drive a hearse through it, because it says something like, "If I'm unable to make treatment decisions, I direct my attending physician to withhold or withdraw life-sustaining treatment and let me die naturally."

People say, "That sounds great," because nobody wants to be hooked up to everything but the toaster and the blender until the machine breaks down. Then you look at those words and you remember that this is a legal document. First of all, "I direct my attending physician..." that may be a doctor you have never met before, because your attending physician is the one caring for you at any particular given moment.

If you are in a car accident and you have a living will, and it's taken to the doctor and the doctor looks at it, and that's your attending physician. "I direct my attending physician to withhold or withdraw life-sustaining treatment." People think of life-sustaining treatment as being heart and lung machines, ventilators, all the bells and whistles and tubes.

In the law, life-sustaining treatment includes anything which sustains or supplants or maintains a vital bodily function. Insulin is considered life-sustaining treatment. It's not just something really, really exotic. Other types of things in fact even food and fluids provided by tube would be considered life-sustaining treatment. Legally, it is considered that.

In some court cases, even the food that the patient receives on a tray in her room in a convalescent care facility has been deemed to be life-sustaining treatment, because the physician authorizes it. That whole thing is so broad and you don't know how that attending physician is going to interpret it, because you don't know who the attending physician is going to be.

It says, "…and to let me die naturally." Of course you are going to die if your food and fluids are taken away or if you are diabetic, if you're not taking your insulin. While many really well-meaning people promote the living will, they aren't going to be interpreting it, and that's the problem, because whenever you sign a legal document you have to look at it and say, "How can this be interpreted?"

When people sign a living will they have to look at it and say, "Okay how could somebody interpret this?"

I am an attorney, I suggest to my clients that they not sign a living will. I tell my family, my friends, my acquaintances, even people I don't like, "Don't sign a living will." People say, well then, shouldn't they have an advance directive? My answer is absolutely yes. Everybody from the age of 18 on up should have an advance directive, but the right kind of advance directive. That is the durable Power of Attorney for healthcare.

In a durable Power of Attorney for healthcare, what you do is you name someone that you know and trust to make healthcare decisions for you at any time you're unable to make them for yourself. It's when it's temporary or if it's permanent, because otherwise the question is, who's going to make your decisions?

Suppose you have an 18 year-old who's in a car accident, can't make decisions and probably will recover, but not for a while. Suppose you say, "This would be best with my son or daughter," and suppose the doctor disagrees. That doctor doesn't have to go by what you say, unless that 18 year-old son or daughter has named you in a durable power of attorney for healthcare.

The only way to be certain that a person you know and trust, who agrees with your views and values is going to step into your shoes to make healthcare decisions for you at any time you can't make them yourself, is to name that person in a legal document. That document is durable power of attorney for healthcare.

c. Durable Power of Attorney for Healthcare

Thanks, Rita. So the best type of Advance Directive is a durable power of attorney for healthcare, because Living wills can be misinterpreted. At the Patients' Rights Council, the organization that Rita leads, their Power of Attorney for Healthcare is called The Protective Medical Decisions Document. Because requirements for these documents vary by state, it is best to contact them to order the one that meets your state's standards. Information to contact the Patients Rights Council is in your workbook.

Remember, the Power of Attorney for healthcare is something that every adult, young and old need to have. Sadly, many people put off addressing this topic because it requires us to face our fears about a catastrophic accident, being hook to machines, feeling like a burden, or being a resident in a medical facility. But not addressing this need has the potential to cause conflict in the midst of a healthcare crisis, which is something no one wants our loved ones to go through. We have included a document entitled "Motivation for Signing Life-Protective Advance Directives" in the articles section that goes into additional detail as to why it is important to only sign a life-protecting Advance Directive.

The ladies I care for had their attorney draw up the Durable Power of Attorney for health care document for each of them. He automatically included a number of living will type directives that they were to initial to indicate their preferences about treatment. I wasn't comfortable with how those could be used in a crisis to limit care choices so instead we crossed them out and used the first part of Finishing Life: to talk about their priorities and goals related to their care.

Those conversations, prayer, and the Principles for Medical Decision-Making (which is also included in the articles section), have guided me through multiple hospital stays. We also made extra copies of the Power of Attorney, which were given to our local hospital, and their doctors which has become part of their permanent medical record. I have a copy when others may need to see it.

d. Not required to have Advanced Medical Directive

Please remember, both federal and state laws prohibit anyone from requiring someone to have an advance directive. Federal Law says that, if a health facility gets Medicare or Medicaid funding, they're to do four things: they're to ask the patient if they have an advance directive; 2) they're to note it in the patient's medical record if they have one; 3) they're supposed to let the patients know of their right under state law to sign an advance directive; and, 4) they're supposed to provide community education about this. Please don't be pressured into signing a living will because you fear you won't be admitted to the hospital or care facility without it.

e. Appointing someone as your medical power of attorney

Which leads to my next point - who do you appoint to serve as your medical power of attorney? If you are married, your spouse would make sense, but circumstances may suggest it is better to appoint someone younger and reasonably close to you in both physical proximity and worldview. This again is one of those decisions that it is wise to make and discuss with your family members, so no one's feelings are hurt. As noted earlier, the booklet Finishing Life: How to Prepare for the End of Life has information not only about who to choose but also how to discuss your priorities and goals.

Finally, I suggest that for the very elderly, those easily confused, or patients who are hard of hearing, the POA accompany them to doctor visits, medical tests, and hospital admissions. If circumstances prevent the POA from being available you may want to have a trusted friend serve as the patient's advocate for regular healthcare needs, with the POA more involved when critical health care decisions need to be made. Remember, if the patient is in nursing home, regularly meet with the nursing home medical team to ensure their care is consistent and in line with the patients expressed goals and priorities.

2. Advance care planning

Our next topic is Advance Care Planning –

Years ago, you only went to the doctor if something was very wrong, such as an accident or traumatic illness. Today, we have access to all kinds of medical treatment; MRI's, transplants, laparoscopic procedures, and an array of medications, all of which are now considered routine healthcare available to everyone.

a.Medical technology and longer living

Medical technology has progressed to the point that the average life expectancy is now 80 years, and the US Census Bureau indicates that the fastest growing demographic are people over the age of 85. In 2010 there were 5.5 million folks over 85! And the Centers for Disease Control projects the number of people over the age of 85 will almost double to 9 million by the year 2030.

While there are a variety of reasons people are living longer, medicine does play a big part, and we need to recognize that we now have a greater life expectancy than our relatives even a generation ago. But this blessing has now created a new set of problems.

As we age, it's common for our healthcare needs to increase, and according to various actuarial tables, a person's last years of life may be the most expensive healthcare wise. Therefore, the elderly and terminally ill are often seen as a drain on healthcare resources and a threat to keeping costs contained. This reality has led to new solutions designed to control the type of care these patients get. These solutions are not focused on honoring an individual's dignity but handling the sheer number of people in the healthcare system.

To manage the demand for medical care for the elderly, terminally ill, and disabled, Medicare, the Affordable Care Act and health insurance providers have begun paying your Primary Care Physician to do Advance Care Planning with you.

b. Priorities, preferences, and plans for healthcare

Advance care planning requires you to think about your priorities, preferences and plans in case of major illness, as well as just the natural aging and dying process. How do you want to be cared for at the end of your life or in a health crisis?

Do you want to explore all avenues of treatment? fight until the very end? or do you feel comfortable letting nature run its course and simply wish to be kept as comfortable for the remainder of your life?

Answers to these types of questions form your advance care plan that you can share with your Power of Attorney for health care. This information will help him or her evaluate what tests or treatments might be necessary or unnecessary, and you can take comfort in knowing that your substitute decision maker is guiding your course of treatment and that your dignity and the value of your life is preserved and respected.

Make sure you take the time to revisit your Advance Care Plans especially during milestones in your life, or when there's a major change, such as a marriage, death or divorce.

Advance Directives and Advance Care Planning that your doctor will try to discuss with you are designed to look into the future and imagine what possible health problems and complications can arise for you. Then a specific form with check boxes next to descriptions of medical treatment are employed, requiring you to check your preferences.

The problem with answering "what if" questions on a form, is that you don't have all the details associated with each illness or health crisis that you are saying "yes" or "no" to. But your checked box yes and no's answers will drive your future medical treatment.

This is bad advance care planning. And it is why it is hard – because you are being compelled to gaze into the future and try to guess what you'll need. Advance Care Planning that Anglicans for Life recommends - encourages you to think about your priorities, preferences and plans in case of major illness, as well as just the natural aging and dying process. How do you want to be cared for at the end of your life or in a health crisis?

I will say Advance Care Planning requires you to understand the common types of care you are likely to encounter in end of life healthcare world, so you can communicate your preferences. For instance, next week we will discuss Hospice, which is a type of care available as the end of life occurs. We will discuss others as well in weeks 5 and 6.

3. Finishing life and dying well

So the key to advance care planning is to think about your wishes, goals, preferences and priorities for health care and treatment at the end of life and then express your desires to those you hold most dear. This is especially important if you or your loved one is dealing with cancer, or a terminal illness.

a. Being Mortal - Dr. Adul Gawande

This idea of talking about how you want to be cared for especially if treatment is no longer beneficial but actually burdensome, or when the elderly body has become frail was first introduced to me by Dr. Atul Gawande. He is a surgeon at Brigham and Women's Hospital in Boston, Massachusetts, and he wrote a book called *Being Mortal*. In the book, he shared that, as a doctor, he was not properly trained to help very ill patients live well and prepare to die as they neared the end of their lives.

A study was recently conducted that confirmed his concern. The survey found 46% of 736 primary care physicians and specialists said they often feel unsure about what to say to patients, and 60% said they frequently don't initiate the discussion, because they aren't sure if it's the right time to do so. One physician is quoted as saying, "If you have the talk too early, it may not be meaningful or clear enough. If you have it too late, they're struggling with their illness and may feel that you're giving up on them."

In his book, Dr. Atul comes to the realization, that doctors and caregivers need to seek more input from patients as to how they want to finish life and die well. He suggests regularly seeking to understand what the patients priorities are related to their treatment and what are their goals, if the time comes when treatment isn't working and death is inevitable. Spending one's remaining days in the hospital hooked to machines may not be best, maybe going home should take priority so family and friends can be enjoyed. I think most of us would prefer a natural death at home instead of a medicalized death in a hospital or facility.

b. Honoring life in the midst of death

What he also discovered was that this approach benefitted the patient immensely, as they felt more in control of their illness and life. It can help the patient decide what treatments should be accepted, or rejected, or even discontinued. As believers, it may help to include a spiritual director, pastor, or priest, and obviously the power of attorney, in these discussions.

Sadly, I recently read two articles that talked about work being done to programme robots to have these discussions with people – implying it is easier to talk with technology than another person about living and dying well. May this never be the case amongst those I know and love. While dying and death can be difficult subjects, anyone invited into such a conversation should know they are standing on holy ground.

4. Conclusion - Isaac's story in Genesis 27

In Chapter four of Billy Graham's book Nearing Home, Rev. Graham teaches from Genesis 27. "We see Isaac preparing for his death. He runs into problems in his effort to give his son his blessing, but the point of what he is doing is preparing others, namely his two sons, for his death; but it didn't go so well. While there are many lessons from this story, one is that Isaac is too old to ensure his final wishes are executed properly, and this causes turmoil within the family."

Whether it is writing a will or deciding to downsize your home, growing older confronts us with a number of challenges. If we don't take care of the necessary details, others will have to, possibly creating conflict among those we leave behind. It is our duty to be responsible for handling matters that affect us.

Now, we recognize that not every decision can be made in advance, but Anglicans for Life urges you to address what you can. I don't believe God wants us to leave behind a legacy of resentment, conflict, or confusion when we die, but this can easily happen if we neglect the practical issues that press upon us as we grow older.

Proverbs says, "A prudent man gives thought to his steps."

Finally, remember as death draws near that the goal in making healthcare decisions must be to keep us comfortable as we progress through the dying stages of life naturally and in God's time. We don't want to artificially prolong life with a "do everything you can to keep me alive at all costs" philosophy nor do we want to hasten death.

Honoring life in the midst of death is another way we honor our Creator. I hope I have inspired you to take time to discuss your personal preferences for end-of-life care with those you love and make an advance care plan naming your power of attorney for personal care. Instructions to obtain these forms are in your workbook.

I'd like to close our time today with this quote from Billy Graham, "The Bible references death and dying in many ways, nearly 1000 times. Yet the Bible remains a book of great hope. Life stands between bookends: birth and death. Outside of the rapture of the Church, there will be one death for every birth. Not everyone will experience old age, but death will come to all. For believers, our hope and comfort comes from God's word, which says, 'Blessed are the dead who die in the Lord' Rev 14:13 NKJV

Thank you for watching today, and I pray that the Lord will show you who to choose as your power of attorney for health care and lead you in discussions with them and your family members regarding these topics – all for the glory of God.

WEEK 4

Types of Advance Care Plans

BEFORE THE SESSION:

- ☐ Arrive at least 30 minutes early to make sure set-up is taking place and to pray for the class.
- ☐ Cue the **Embrace the Journey** DVD to Week 4.

DURING THE SESSION:

- ☐ During **Opening Prayer and Activity**: Lead the participants through the prayer and thoughts for this session.
- ☐ Introduce the DVD Presentation.
- ☐ When starting **Group Reflection**, remind people to follow the "Guidelines for Group Discussion." There should be no need to go over the rules again.
- ☐ Remind participants to do **Personal Study and Reflection** in their Participant Guide.
- ☐ Ask a volunteer to bring snack for the next week.
- ☐ Lead the group through the **Prayer for Life**.

AFTER THE SESSION:

- ☐ Be available if someone wants to talk.
- ☐ Make sure clean up takes place.
- ☐ Retrieve the DVD.
- ☐ Retrieve supplies. Keep for following week.
- ☐ Let the clergy know how the session went.

DURING THE WEEK:

- ☐ Thank your Prayer Team and give them an update. Ask them to be in particular prayer for the next session, ***Types of Care That Hasten Death.***
- ☐ Work through the **Personal Study and Reflection**.
- ☐ Preview the next week on the DVD.
- ☐ ____
- ☐ ____

FINISHING LIFE - *Preparing for the End of Life*

Remind each Participant about the Finishing Life booklet and ask how they are doing in their plans to appoint a power of attorney for healthcare and think through their end-of-life wishes. Filling in the information concerning their priorities can provide a peace of mind to family members, knowing this information is collected in one safe place.

Please emphasize the importance of telling someone where the booklet will be stored!

WEEK 4

Types of Advance Care Plans

The **MAIN OBJECTIVE** of this week's presentation is to help people understand how Advance Care Planning is being employed for costs savings. We will also learn about Physician Orders for Life Sustaining Treatment, Do Not Resuscitate Orders, and Hospice, and how they are being used in today's healthcare environment.

Opening Prayer

Dear Father God, thank You for the assurance that You have conquered satan and our days are in Your hands. Thank You also for healthcare workers who honor Your divine law and uphold the value of every life. Please protect us from those who don't. Now help us embrace this season of life called the Golden Years and give us wisdom to prepare for them. Guide our discussion and help us each understand how healthcare changes impact our lives.

Opening Activity

Has anyone particpated in Advance Care Planining with their doctor? (aka, Wellness Visit)

Do you think people's worldview influences how they think about life and death?

DVD Presentation:

Please take notes using this outline:

1. Introduction
    a. Recognize that the philosphy of your local hospital impacts how they deliver medical care

2. Educated patients - knowing the terms
    a. Physician Orders for Life Sustaining Treatment (POLST)
    b. Julie Grimstad
    c. Do Not Resusitate Orders (DNR)
3. Hospice

   a. History

   b. Cristen Krebs - hospice guidelines

   c. Hospice entitlements

4. Defining palliative care vs. comfort care

5. Surviving Suffering

6. Conclusion

   Role of medicine – keep us healthy until the end, then keep us comfortable without hastening death. We must neither seek every medical treatment available to live forever nor accelerate death by hastening it. Death must be natural in God's time.

DEFINITIONS:

What is respite care?

Respite care is care given to a Hospice patient by another caregiver so that the usual caregiver can rest.

As a Hospice patient, you may have one person that takes care of you every day. That person might be a family member. Sometimes they need someone to take care of you for a short time while they do other things that need to be done.

During a period of respite care, you will be cared for in a Medicare-approved facility, such as a Hospice facility, hospital, or nursing home.

> “I have so many cancer patients whose families or family physician or other advocate for the hospice system to try to steer them into a certain death spiral. As an Interventional Pain Physician I have provided several patients with implanted multi-agent infusion systems administering effective medications into the spinal canal in micro-doses which control pain very effectively and allow the patient to get closure with family and most of all, die naturally. The Medtronic system is one I have used since its FDA approval in 1989. I published the first stability and potency study in December, 2004, Journal of Pain and Symptom Management proving safety and efficacy. It is covered by all insurance including Medicare/Medicaid.”
>
> The Rev. Dr. Ashley M. Classen
> Priest, Episcopal Diocese of Dallas
> Interventional Pain Physician -Medical Director
> Trinity Pain Medicine Associates, PA
> Fort Worth, Texas

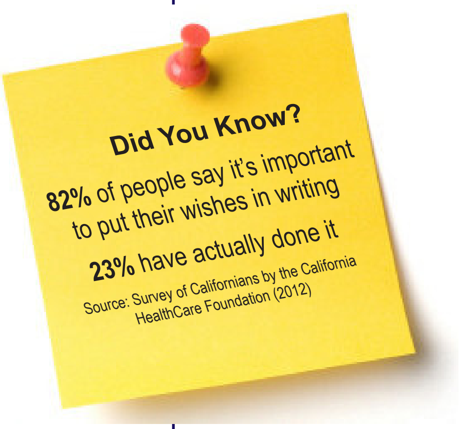
GROUP *Reflection*

1. It is common to trust and believe that all healthcare providers (doctors and nurses) share our ethical values, especially if we have known them for years. But is it wise to assume every one providing care at a hospital, nursing home, or medical care facility is trustworthy?

2. Julie Grimstad described a new type of form called POLST, Physician Orders for Life Sustaining Treatment. What are some of the concerns Julie noted that makes a POLST so bad?

3. When is it appropriate to have a Do Not Resuscitate order?

4. Do you agree with the idea of not artificially prolonging life, with a "do everything you can to keep me alive" philosophy, but letting death happen in God's time?



Did You Know?

82% of people say it's important to put their wishes in writing

23% have actually done it

Source: Survey of Californians by the California HealthCare Foundation (2012)

5. Share any experiences you have had with hospice. Were they helpful or harmful in your opinion?

6. Is Palliative Care, Hospice, and Comfort Care the same thing? Who needs Palliative Care? Who needs Hospice?

3 Different Types of Care

Comfort Care *Hospice* *Palliative Care*

Sometimes used interchangably by medical personal.
Ask for clarification when in doubt.

Closing Thoughts & Prayers

As a group, discuss interest in signing **Protective Medical Decisions Documents**. The leader can order the documents from the Patients' Rights Council. They recommend naming a surrogate and two alternates. Two witnesses are required. There is no charge for the PMDD. A donation of $15 is requested, but not required, for each PMDD packet.

To obtain a PMDD, call 800-958-5678 or 740-282-3810 between 8:30am and 4:30pm (eastern time). The forms can be signed in the privacy of an individual's home or as part of the class time. Consider ordering additional copies for spouses or other family members.

Prayer for Life

Lord God, thank You for creating human life in Your image.
Thank You for my life and the lives of those I love.
Thank You for teaching us through Scripture the value You place on life.
Help me to uphold the sanctity of life in my church and community.
Give me the strength to stand up to those forces that seek to destroy the lives of those most vulnerable, the unborn, the infirm, and the elderly.
Today I commit myself to never being silent, never being passive,
and never being forgetful of respecting life. I commit myself to protecting and defending
the sacredness of life according to Your will, through Christ our Lord.
Amen.

For Further Personal Study & Reflection

- If you or a loved one has had a POLST or MOLST form attached to your medical records, ask to have it removed.
- Do some research and identify the hospice agencies in your area. Talk to others to find out more information about their level of care and make the information available to church members.
- Review the article about common misconceptions related to hospice to clarify your understanding of what hospice is.
- Julie Grimstad touched on people being diagnosed as being in a "persistent vegatative state" - to learn more about the challenges of such diagnosis read the article on page 154 entitled: "Study: Significant Number of Patients Wrongly Diagnosed as in Vegatative State."

Week 4 DVD Script

Types of Advance Care Plans

1. Introduction

Welcome to Week 4 of Embrace the Journey. I hope you are enjoying the class and recall last week's discussion of Advance Care Planning, along with appointing someone as your Power of Attorney for health care.

Today's we focus on various types of medical care that we or our loved ones may encounter as the end of life draws near. I can say for certain, they are topics that'll be brought up by healthcare providers, especially in the context of Advance Care Plans.

a. Reognize that the philosophy of your local hospital impacts how they deliever medcine

In interacting with healthcare providers for my parents and the ladies I care for, I've noticed that age and overall state of health can influence how readily a medical procedure or treatment is offered or recommended to an older patient. Postponing procedures endlessly or using medications to treat symptoms instead of performing a surgery that would cure the ailment has become more common.

Also, in my experiences with them in healthcare settings, I must say, we have come in contact with some truly dedicated healthcare professionals, who serve every patient as if they were family members. But we have also encountered some medical personnel who value policy, profit, and professional authority more than patients. Healthcare is big business and some healthcare providers are now part of big conglomerations, which causes them to lose sight of individual medical needs.

I share these observations for two reasons. First, for any health care worker attending this class, or anyone who has family members working in the medical field, please do not take offense at my words as I am not implying that all medical professionals put policy above the patient. But we need to recognize there are some medical providers who do.

Second, we cannot be naïve and assume everyone, specifically our loved ones will automatically get the level of care they need. We need to advocate for them to ensure they are not discriminated against due to their age or state of health.

2. Educated patients - Knowing the terms

As the world of medicine evolves and changes, we must adjust our assumptions. My parents never questioned what their doctors said or prescribed. But just as we need to be informed consumers, we must be educated patients. And if the patient cannot manage his or her care, we as their POA must, knowing not only the patient's goals but what types of care they want or don't want.

a. Physician orders for Life Sustaining Treament (POLST)

Nowhere is it more important to be informed and well educated than when you hear the phrase Physicians Orders for Life Sustaining Treatment or its acronym POLST or Medical Orders for Life Sustaining Treatment – MOLST. POLST or MOLST forms are designed to eliminate the need for consulting the patient or the patient's representative, or even a living will and is a favorite resource in the medical community for Advance Care Planning.

b. Julie Grimstad - Human Life Alliance

I have asked Julie Grimstad, a nurse, and patient advocate who works with Human Life Alliance to explain what POLST and MOLST are.

POLST – Physician Orders for Life Sustaining Treatment. Additional acronyms. Or scope of treatment. There's a national effort underfoot to control death under the guise of enhancing autonomy. Autonomy is making your own decisions. It's deciding for yourself what you want done. Some aspects of the culture of death are very subtle, POLST is one those – it sounds so safe - Physician orders for life sustaining treatment –but actually what they are hoping you will do is refuse life sustaining treatment. It's a brightly colored form that becomes the first page of a patient's chart. It has boxes on there to be checked off, refusing or accepting specific medical treatment. A POLST document overrides a patient's previous health care directive. DO NOT ever answer POLST questions.

Facilitators, people who are taught how to ask these questions, may be social workers or clergy with no medical training. They visit the patients, and they discuss their treatment options with them or with their decision makers, if the person is already incapable of making their own decisions. Then the facilitator checks off the patient's preferences according to the facilitator's interpretation of what the patient or *the patient's agent meant. There are no witnesses present when this takes place.*

This was designed by bioethicists – the POLST process is tilted towards refusal of treatment. For instance, under medically administered fluids and nutrition the first item is no IV fluids, lastly IV fluids long term. The order you put questions is very important.

The next section, no feeding tube is the first option, feeding tube for a defined trial period is the second, and feeding tube long-term is the 3rd option. The facilitators are trained to focus on what the patient would not want. For instance, one of the things they are taught to say is, "We find that most people would not want to be kept alive in a vegetative state." How many people really know what a vegetative state is? Do you know that 40 to 50% of all people determined to be in a persistent vegetative state are mis-diagnosed, and really have some level of conscientiousness, and have some level of what's going on around them? And what right do we have to call anybody vegetative?

They're not beets and carrots and lettuce. They are human beings. They are human beings with impaired conscientiousness, but when you use terms like vegetative what comes to your mind – of course you're not going to want to live like that, who wants to be a carrot? I just think that it is – leading people to the answers that are desired, not by the patient but by the facilitators. POLST involves a coaching process. It's actually not difficult to clarify away someone's wishes by presenting them with "realistic medical options" – said sarcastically!

The Respecting Choices Programme in Lacrosse, Wisconsin, which trains a lot of people from all over the country on how to be facilitators for POLST, teaches facilitators how to change patients' existing beliefs by explicitly discussing the limitations or consequences of adhering to and acting on those beliefs. In other words, if a person expresses a wish to have tube feeding, they may be told all of the terrible things that could happen - for instance, they could aspirate, they could get pneumonia, all those things, which, yes, that happens sometimes – sometimes they do get infections at the site where the tube is inserted, sometimes, not always, and if it happens, you treat them with antibiotics, that's not the worse that can happen – dehydration to death is worse.

Elderly people are easily manipulated in health care setting. One day the health care provider, a doctor, can tell a patient to accept the IV tube feeding and the next day some social worker has come and convinced her to check the little box that she doesn't want IV.

The doctor's hands are tied because another doctor has signed the form. The doctor who signs the form doesn't even have to know the patient. Never met the patient. The person who fills out the form presents it to any doctor, and any doctor can sign it.

They have all the dangers of a living will but one person who is really aware of POLST compares POLST documents to living wills on steroids.

Because they differ in significant ways, they are signed by a physician, Advance Directives and living wills, where you write down your wishes, all of those are signed by the principal – the POLST doesn't have to be signed by the person, it just has to be signed by a physician

The patient can be invited to sign, but its effective regardless. So someone can come to the patient's bedside and ask a bunch of questions and the patient doesn't even know what happened. That they have just revoked their Advance Directive, and they have got a new one in their charts. There are no witnesses required. Advance Directives, etc. requires notarization.

Why would this document override a document that has been witnessed, and notarized? The POLST carries a lot more weight than your Advance Directive does and, once it is signed by a physician, this travels with you everywhere. It gets posted on your refrigerator

Did you know EMT's have to follow the POLST orders written by a doctor they may not know? If the patient is transferred to another healthcare facility, the POLST travels with them, and the staff there has to follow the orders of a doctor they may not know.

Thank you, Julie.

Whether your state calls it Medical Order for Life Sustaining Treatment –or Physicians Order for Life Sustaining Treatment remember what Julie said: Do not engage anyone who has a brightly colored form in their hand and wants to discuss "what if" healthcare questions!

c. Do Not Resusitate Orders

Another directive that is included on the POLST form but may also exist separately in a patient's medical record is a Do Not Resuscitate order, DNR for short.

"DNR" is a legal medical directive written in a patient's medical record, according to the wishes of a patient who does not want CPR or advanced cardiac life support if his or her heart were to stop, or he or she were to stop breathing.

There are a few variations of "DNR" orders, but the only time it is appropriate to have one is if you or your loved one is near the end of life or in the last stages of a terminal illness.

Our experts warned that we must be cautious about consenting to a DNR, for even a patient with a terminal illness may have years before he or she is actually near death and would not want to be resuscitated or given medical treatment. For example, someone with HIV would be considered terminal but may live 20 or more years with the disease. So a terminal diagnosis should not be the base line for having a Do Not Resuscitate

order.

Also, we need to be vigilant about a DNR order being put on a patient's chart without consent from the patient or patient representative. This happened to Zach McDaniel, a 12-year-old boy from Texas who was shot in the head. His doctor said his prognosis was poor, he was in a Persistent Vegetative State, but he was breathing on his own. The doctor secretly withdrew Zach's food and water directives and slipped a Do Not Resuscitate order into his chart without his parent's knowledge or consent. Zach's mom had to fight to get the DNR order removed. And it good that she did, as Zach went on to make a full recovery.

A study, presented at the American Surgical Association's annual conference, found that elderly patients who sign pre-operative DNR orders are more likely to die from surgical complications because the DNR order effectively prevents aggressive treatment if they do have complications.

3. Hospice

Another type of medical care that we or our loved ones may encounter as the end of life draws near is Hospice.

a. History

Did you know the founder of the Hospice movement, Dame Cicely Saunders, was a prominent Anglican, nurse, and social worker, who went on to become a physician? She started the first Hospice in London and introduced the concept that life is of value, whether you're facing a terminal illness or not. Today, hospice is very different than in Dame Saunders time. We have more for-profit Hospices than ever before, including some that trade on the NY stock exchange. Hospice agencies are the fastest-growing segment of the healthcare industry and receive nearly $16 billion dollars a year from Medicare.

The number of hospice patients grew 167% between 2000 and 2016, to more than 1.4 million, according to a report from the Medicare Payment Advisory Commission.

b. Cristen Krebs - hospice guidelines

Hospices often employ aggressive marketing tactics to sign on patients, but as Cristen Krebs, CEO of a Catholic Hospice in Pittsburgh, explains some are exchanging patient care for high profits.

Typically, the ratio in a not-for-profit Hospice is usually a nurse to about 10 or 12 patients. The national statistics are showing us that in some of the for-profit Hospices those ratios are doubled or even tripled, so that one nurse is assigned 20 to 30 patients. That is impossible to meet the needs of someone who has severe emotional, physical, and spiritual needs, facing people who are terminally ill.

Under the Hospice guidelines, you have to have a terminal illness, so death is foreseeable. Now we have this new concept of care called palliative medicine. Many people under palliative medicine are also terminally ill, but many are not. There is some confusion over the terms, because when I got my start in Hospice, we called it palliative care. In present day, the palliative movement … you don't have to be terminally ill to receive palliative care, and the services are more limited. Patients get much more benefit under traditional Hospice care than they do under palliative medicine, and typically it's palliative home care, which is different than Hospice.

No, there's Hospice at home and then there's traditional home care, which is where palliative medicine now falls. It's very confusing to the average health care consumer that doesn't understand the differences.

All hospices that are Medicare-certified, in other words, they can get reimbursement for their services, they have to follow federal guidelines for Hospice. Those federal guidelines started back in the early '80s, so it's very clear-cut law as to how we're supposed to be providing care to these folks. However, a lot of agencies who aren't in it for the welfare of the patient have found a lot of loopholes in those guidelines, and so unfortunately, patients don't always get what they're entitled to.

There are good for-profit programmes, there are good not-for-profit programmes, but there is this push nationally for companies to be very profit-motivated, even some of the non-profit hospices take on the look of a for-profit. It's just so important that people can educate themselves and look deeper, don't just accept the recommendation of your physician or your Neighbor, research it yourself.

I always tell families, if you're having your roof redone, you call three people to come in and give you an estimate, and yet when you have a loved one dying, you let anybody into your home, and we've got to start working to change the thinking of folks so that they're not so gullible or vulnerable in letting anybody in."

I also asked her if there were specific things she recommended a family ask about when needing Hospice care for a loved one.

I think it's looking for a mission statement, it's looking for a list of core values, a list of the federal hospice guidelines that should be accessible to a patient and a family when they call. You should be offered those things by hospice programmes, so you know what your entitle-

ments are. Being able to speak directly to anybody inside the hospice, an administrator, anybody, that should always be open to you, and, if it isn't, then I would be concerned that if something goes wrong, those people won't be accessible.

Now, with the Internet, it's easier to do some online research, but some of it looks very good, they talk about quality of life and they talk about comfort care and it all sounds great, but you have to delve a lot deeper than that.

I think the biggest thing I encourage people to do is to interview three, sometimes four, different programmes, whether that's call or invite them to the home. I think you will know someone's sincerity when you meet them, and I think if you're asking for that list of entitlements and then you don't get it, you'll clearly know that this Hospice wasn't upholding federal law.

c. Hospice entitlements

Included in your workbook is a list of Medicare entitlements and specific questions to ask when interviewing a Hospice Agency. Also, you have the right to consider Hospices agencies beyond the referrals provided by your health care system. The POA and family need to be involved in advocating for the patient with the Hospice folks, to make sure all the services needed are provided on time, whether it is in the home or at a hospice facility. If home hospice is decided, attention must also be given to caregivers.

From the get-go, the family is instrumental in doing the research and the homework before hospice comes into the home. From there, there is just tremendous hands-on care that needs to be given to patients who are terminally ill. That is, again, where a good hospice programme comes into play, with meeting the needs of the caregiver as much as the patient, because it is a 24/7 job for a caregiver. They need as much spiritual direction and guidance, prayer, and sometimes a little physical care themselves. It's very grueling to care for somebody.

The common pitfalls for families, and again, it comes from not being well-educated and not taking time to learn things about end-of-life care, issues like hydration, lack of nutrition, that scares people, because we feed each other, that's what we do. And so when a patient can no longer eat, they become very concerned. They need a lot of education as to how does it look when someone is declining? How much should they take in, whether it's fluid or food?

Issues like sedation and morphine, they're great concerns to families, because often times it's those caregivers who are expected to give the medications. They need to be well-educated on how much to give and when to give, and why we're giving it in the first place. Also to not just accept it, to trust their gut. If they don't think something is right for their loved one, chances are they're correct, and they really need to lean into that and listen.

No, under home hospice, the way the law is written, it's intermittent services, so we would send nurses, social workers, home health aides, lots of counselors in bereavement and spirituality, out to the house to interact with the patient and their family. The patient really must have a caregiver who can be overseeing the care, so that they can remain at home.

4. Defining Palliative Care and Comfort Care

Thank you Cristen for helping us understand Hospice and the impact it has on the patient and their family. I also commend the article "No One Is Coming" that is included in your book. It addresses specific challenges families have experienced with Hospice.

Cristen mentions two other types of care that can be confused with Hospice but may included in your Advance Care Planning. They are Palliative Care and Comfort Care. I encourage you to ask for clarification when any of these terms are being used, as I have found healthcare providers often use these phrases interchangeably!

Palliative care is defined as "relief of the pain, symptoms, and stress from serious illness, disease or disorder." Palliative care is for people of any age, and at any stage in an illness, whether that illness is curable, chronic, or life-threatening. Palliative care is in essence about pain and symptom management. It has become a specialized field of medicine and should be included in caring for every patient that is experiencing any level of discomfort, regardless of age or status of health.

Obviously, no one wants to feel pain, but pain serves as a reminder that we are alive and that our bodies are working well enough to send up signals of distress. Pain is also different than suffering, and while they are closely identified in our minds as similar, they are distinct.

5. Surviving Suffering

Suffering describes emotional, psychological, and spiritual discomfort, and that can be harder to address, whether it is our suffering or that of a loved one. I have found for both myself and the women I care for, the best source of relief from suffering is the Scriptures. Suffering can draw us nearer to the Lord's suffering and deepen our dependence on Him. I hate to say it, but suffering is something we endure and isn't typical-

ly “fixable” as much as it is tolerated, while pain is manageable especially with palliative medications.

While I would like to go on and address Comfort Care– it feels like we have covered a lot of ground today, and it will be a good place for us to pick up next week as we continue looking at types of Advance Care Planning.

6. Conclusion

It is clear from Cristen and Julie’s comments that patients need supportive POA’s, family, and friends to advocate for them. They are vulnerable and can be misled or coerced into signing forms like POLST without fully understanding the ramifications. I encourage you to ask questions and get second, or third opinions when making health care decisions, as we want to ensure that care is always patient driven, honoring each life so natural death occurs, in God’s time.

Next week we will continue looking at types of end of life care that you probably do not want included in your Advance Care Plan. Recognizing that knowledge is power can help insure that we get good care as we embrace the journey to heaven.

See ya next week.

WEEK 5

Good & Bad Healthcare

BEFORE THE SESSION:

☐ Arrive at least 30 minutes early to make sure set-up is taking place and to pray for the class.
☐ Cue the **Embrace the Journey** DVD to Week 5.

DURING THE SESSION:

☐ During **Opening Prayer and Activity**: Lead the participants through the prayer and activities designated for this session.
☐ Introduce the DVD Presentation.
☐ When starting **Group Reflection**, remind people to follow the "Guidelines for Group Discussion."
☐ Remind participants to do **Personal Study and Reflection** in their Participant Guide.
☐ Ask a volunteer to bring snacks for the next week.
☐ Lead the group through the **Prayer for Life** on the back page of the Handbook.

AFTER THE SESSION:

☐ Be available if someone wants to talk.
☐ Make sure clean up takes place.
☐ Retrieve the DVD and copies of the Resource List.
☐ Retrieve supplies. Keep for following week.
☐ Let the clergy know how the session went.

DURING THE WEEK:

☐ Give your Prayer Team an update and thank them. Ask them to pray for the next session, ***Hastening Death.***
☐ Work through the **Personal Study and Reflection**.
☐ Preview the next week on the DVD.
☐ ______________________________
☐ ______________________________

**SPECIAL NOTE:

Discussion this week includes the pros and cons of being an Organ Donor. Legislation now exists that presumes everyone will allow their organs to be harvested in the case of death. If someone does NOT want their organs donated, they need to specify their preference. We have Organ Donor **Refusal** Cards included for participants who prefer not to have their organs donated (in an envelope in the back of this book). Please offer the cards during Closing Thoughts & Prayers.

WEEK 5

Good & Bad Healthcare

The **MAIN OBJECTIVE** of this week's presentation is to raise awareness of the subtle methods used to hasten death, which include: dehydration, futile care, terminal sedation, and termination of treatment. Recognizing Satan's goal to steal, kill, and destroy life, Christians must seek to let death be natural and in God's time.

Opening Prayer

Dear God, thank You for the gift of life. We praise You that we are made in Your image, and that You care for us so completely that when we were still lost in sin, You sent Your Son Jesus to die for us - that we may live eternally with You. Help us learn about the methods used by Your enemy to hasten death and destroy life. Give us wisdom to discern when these methods are being used to impose death, so we can protect life. Give us ears to hear and hearts that understand the real needs of those who are near death, so their lives may be honored in their final days. In Jesus Name we pray, Amen.

Opening Activity

Share your thought and opinions as you have sought to complete the Finishing Life booklet

DVD Presentation:

Please take notes using this outline:

1. Introduction
2. Comfort Care
    a. Terminal Sedation
    b. Intention
    c. Food & fluids
3. Dehydration
    a. History
    b. Denies patient dignity

- c. Description

4. Futile care - Julie Grimstad explains

    - a. Description - impact on patient

        - i) Law of Texas

5. Organ donation - Julie Grimstad discusses

    - a. Definition of dead changed to make it easier to declare patient dead

    - b. Brain dead and procedures to harvest organs

6. Need to be an advocate for your health and the health of others

7. Conclusion

REALITY Check-

The cardiologist was prepared to pronounce my husband's death on December 18, 2012.

He told me, "There's no hope. He's gone. The odds are against him."

I replied (by God's grace), "Odds count in a random universe, but not in a universe with God. Please try again."

My husband was resuscitated and had a 0.01% chance of surviving, much less having robust recovery. Now, six months later, he is well on the way to a FULL AND COMPLETE recovery. I can't tell you how many times I was urged to "let him go," or warned "he'll be a vegetable." Now the love of my life and I are rejoicing in God's life-restoring power and sharing our blessings as God gives the opportunity.

I am so thankful that I had wrestled through the philosophical, moral, spiritual, and medical aspects of critical life and death incidents BEFORE this happened.

Blessings in Christ,
Gretchen, CA

GROUP *Reflection*

1. Can Comfort Care be a valid course for treatment? What can go wrong?

2. Why would some doctors use the double-effect doctrine to cause death or speed up the death process?

3. Should food and fluids be considered ordinary care or medical care? Why or Why not?

4. Futile care allows doctors to withhold medical treatment they believe is useless. Should they have the right to make that decision independent of the patient?

5. Is it surprising to know that the Uniform Determination of Death Act allows hospitals to set their own standards for determining that a person is brain dead? Are brain dead criteria sufficient for determining that a person is really dead?

6. What should you do if you believe a patient's care is being compromised?

Closing Thoughts & Prayers

- Remember, we do not need to seek every medical treatment available to try and live forever, nor do we want to accelerate death. Death must be natural and in God's time.
- Organ Donation should be a personal choice. If you do NOT want to be an Organ Donor, ask the Leader for an Organ Donor **Refusal** Card. The Card should be carried in your wallet, and your wishes made known to your family, healthcare providers, and healthcare advocate.
- Close with praying the Prayer for Life:

Prayer for Life

Lord God, thank You for creating human life in Your image.
Thank You for my life and the lives of those I love.
Thank You for teaching us through Scripture the value You place on life.
Help me to uphold the sanctity of life in my church and community.
Give me the strength to stand up to those forces that seek to destroy the lives of those most vulnerable, the unborn, the infirm, and the elderly.
Today I commit myself to never being silent, never being passive,
and never being forgetful of respecting life. I commit myself to protecting and defending
the sacredness of life according to Your will, through Christ our Lord.
Amen.

For Further Personal Study & Reflection

- Contact your local hospitals and ask them if they have futile care Policies.
- Read one or more of the additional articles relating to terminal sedation or organ donation, on pages PG-134 through PG-140.
- Pray and discuss with loved ones how they feel about organ donation. Consider the potential problems that can arise and decide if you should carry a Organ Donor REFUSAL card and make your family aware of your preference.

Week 5 DVD Script

Good & Bad Healthcare

1. Introduction

Welcome to week 5 of Embrace the Journey. I'm Deacon Georgette Forney, your host and author of this series.

Last week we discussed Advance Care Planning that included POLST, Hospice and Palliative Care. Cristen Krebs, who explained Hospice Care, mentioned another type of care called Comfort Care, and that's where we pick up today.

2. Comfort Care

Comfort Care is a phrase often used in a hospital settings. At some point, the doctor may come in and talk to the patient, POA, and family members about putting the patient on Comfort Care. What they're saying is… at this point there is nothing else they can do to cure your loved one's disease or illness, but they can keep them comfortable and help them have a natural death. It may mean the medical treatments they have been using are artificially preventing death and have become too burdensome for the patient and that the focus should move towards relieving pain and keeping the patient comfortable. This may be done as a means of honoring the patient's goals and priorities to die naturally, unencumbered by tubes and machines. Typically, basic medications, food, and fluids are continued as long as the patient can tolerate them.

a. Terminal sedation

An important word of caution must be noted here, as it relates to a common problem experienced by many people when a family member enters "Comfort Care" or is assigned to Hospice or Palliative Care. Medications used to manage pain - opiates, sedatives, and barbiturates - can be misused to speed up or hasten death. This action is called Terminal Sedation and Dr Erich Loewy, Chair of Bioethics at UC Davis School of Medicine, explains what it is, "Terminal sedation places a patient under anesthesia during the dying process. Supportive care is stopped, and patients are given a sufficient amount of drugs to render them unconscious. Terminal sedation is done with the full knowledge that no further active treatment will be done and that patients, as rapidly as possible, will now die as a result of their underlying disease process."

A Declaration on Assisted Dying authored at the 13th International Conference of the World Federation of Right to Die Societies in 2000, describes their justification for over-medicating patients with the intention of causing death; "On this occasion, we wish to draw public attention to the practise of "terminal sedation" or "slow Euthanasia" which is performed extensively today throughout the world in hospitals, nursing homes, hospices, and in private homes. This is carried out under the doctrine known as 'double effect' by which a physician may lawfully administer increasing dosages of regular analgesic and sedative drugs that can hasten someone's death as long as the declared intention is to ease pain and suffering. Of course, the key word is 'intention'. Compassionate physicians, without publicly declaring the true intention of their actions, often speed up the dying process in this way. Many thousands of terminally-ill patients are so helped globally every year."

b. Intention

Their double-effect doctrine is discussed in-depth in "Stealth Euthanasia," an article also included in your workbook. For our purpose, it is important to recognize it can happen, but we can prevent a loved one from becoming a victim of it by working with the medical staff to identify the lowest dose of sedation that prevents discomfort but doesn't cause an unconscious state. When the patient is put into a state of unconsciousness, the dying person is deprived of being present at the end of their own life; it undermines their humanity and personhood as a child of God. It can also deny family members the opportunity to have time with the dying person.

According to the Hospice Patients Alliance, Terminal Sedation is becoming more and more common in hospice situations and is used in effect as a means of slow euthanasia where the family and/or health care professionals are not willing to openly admit they are choosing to end the life of the patient. It is often done routinely without the patient's knowledge or permission, and outwardly it appears as a "peaceful death." The term "terminal sedation" as used in this way is not to be confused with the appropriate use of sedation to manage very troublesome symptoms.

c. Food & fluids

Complete sedation of a patient is appropriate when the patient is already actively dying and severely agitated, is in a delirious state, or when sedation combined with pain medication is being used to manage extreme uncontrolled pain. Sedating the patient in these rare circumstances manages the symptoms but does not cause death as does "terminal sedation."

In your workbooks is a story told by Nurse Nancy Valko in her article "Sedated to Death? When Comfort Care Becomes Dangerous" that explains how easily we can be duped into approving terminal sedation for a loved one.

For some who are viewing this, you may have a loved one who has died from being over sedated and now you are questioning the decisions and choices you may have been a part of as it relates to their end-of-life care. I have been in a similar situation, and I believe that the Lord knows our hearts' desire and intention was to help our loved one, not hasten their death.

What we share is not about judging or creating guilt, it is about being informed and seeking God's will in caring for someone dying.

3. Dehydration

And remember, no type of care; hospice, palliative or comfort - should include the removal of food or fluids. They should only be discontinued when death is imminent, and the patient is choosing not to eat or drink. If food and fluids are intentionally withdrawn early, it leads to dehydration, which becomes the real cause of death.

a. History

While food and water are considered by conservative ethical standards to be ordinary care, they are now legally recognized as medical treatment that can be removed. We need to recognize that withdrawing food and fluids doesn't just refer to withdrawing a feeding tube; it can include denying a person a tray of food or a glass of water.

The debate around killing by dehydration surfaced in the 1970's, as bioethicists argued that it should be acceptable to withdraw feeding tubes from people with severe brain damage, so they can die. Then, in 2005, acceptable became legal when a judge ordered a feeding tube removed from Terri Schiavo, despite pleas from family members, including Terri's brother, Bobby Schindler who I interviewed recently. Bobby shares how common the practise of removing basic care has become.

b. Denies patient dignity

Bobby Schindler Sound Bite

What happened to Terry happens, it was happening long before her case made the headlines that it did, and it continues to happen every single day in our nation. What I mean by that, I'm not talking about someone who's terminal, we're not talking about someone that perhaps is hours away … someone who may have a cancer, someone with an underlying terminal disease where they're just hours away from death.

We're talking who had a cognitive disability, was not being sustained by any machines or any types of life support, someone that would live, doctors believe, a normal life span if they were to continue to receive the basic care of food and water. We're talking about these types of individuals that are having their basic care, food feeding tubes, taken away every single day in our country, in order that they die. A few of them say this affects just a few of us. No, we're talking about the possibilities. If you think about this category that we are now defining as people that are vulnerable because of this anti-life movement happening in our country, we're talking about possibly millions of people that could be affected by this issue, of food and water being taken away from them so that they would die by, death by dehydration and starvation.

c. Description

What happens to a person who dehydrates to death? Here's a description from a court transcript: "The mouth dries out, the lips and tongue crack and bleed, the lining of the nose dries out and bleeds, the skin becomes dry and scaly, urine becomes highly concentrated and burns the bladder, the stomach lining dries out causing dry heaves. The patient suffers convulsions as brain cells dry out, thick secretions plug the lungs as the respiratory track dries out. The muscle of the heart is consumed as it searches for proteins and finds it in muscle tissue. Finally, the patient dies."

Not only would I not want to die by dehydration, I wouldn't want anyone I love to die this way. It seems like a painful and slow process to achieve death. So what is the motivation for employing dehydration to hasten death? It is actually a tactic used to make Euthanasia look like a more humane way to help someone die.

At a world conference of right to die organizations, Australian bioethicists, Helga Kuus talked about the strategy of dehydration for the right to die movement. She said, and I quote "If we can get people to accept the removal of all treatment and care, especially the removal of food and fluids, they will see what a painful way this is to die and then in the patient's best interest they will accept the lethal injection."

Clearly, dehydration should not be included in anyone's Advance Care Plan.

4. Futile Care - Julie Grimstad

Another phrase describing healthcare that you may encounter in caring for the elderly, terminally ill or disabled is Futile Care. I've asked Julie Grimstad, whom we met last week to explain what it is and why we need to be aware of it.

a. Description - impact on patient

Futile care is based on the theory that when a patient reaches a certain stage of illness, injury, or age, anything other than comfort care is considered futile and withheld or withdrawn. So not all end-of-life treatments are appropriate, some are truly useless and those nobody has an obligation to provide. But in futile care cases, it's the patient who is considered useless, not the treatment. Boiled down to its essence, this is heartless euthanasia.

i. Law of Texas

I want to look at the worse futile care law in the nation, in my state of Texas. In 1999, Texas added to their medical decisions law a futile care or medical futility amendment, and this allows hospital bioethics committees to take and decide a dispute between a patient and his family and a doctor when there's a disagreement about whether or not treatment should be provided. If the patient wants treatment and the doctor doesn't want it – it goes to the ethics committee. The ethics committee makes the final decision, and there is no appeal. If the ethics committee rubber stamps the doctor's decision not to treat, then the patient is given 10 days to get out of that health care facility, or all medical treatments including food and water will be stopped.

And the patient will only be given comfort care, which means they will probably be sedated until they die. There is no appeal to this death sentence, you're out in 10 days or you're dead in 10 days, they will start to kill you. The Texas law strips patients of their right to make their most important decisions and gives it to strangers on a hospital committee.

In March, Texas RTL got a call from a family of a man named Willy who came under the Texas futile care policy. And his family wanted him to live, he told his daughter, "Fight for me baby, I ain't done living." He had pneumonia and leukemia when he entered the hospital. They treated him for about four weeks. Then they decided it was futile to treat him anymore, even though his family insisted, they had his durable power of attorney in hand appointing an agent, and they asked the hospital to continue treatment and they refused. Finally on the 8th day the family contacted Texas RTL and they tried everything they could to save this man's life, but neither the law nor time were on their side and Willy died.

Patient statements, "What I wouldn't give for one more day or I ain't done living yet" – they ought to be respected. Life is priceless even if it's just another day. It is priceless. Not all hospitals have adopted futile care policies and those that have not and are trying to provide good care for patients have a challenging job on their hands, because they are going against the flow. It's never easy to swim upstream when everybody else is going the other way.

Julie noted the state of Texas has the most extreme Futile Care policies but many hospitals throughout the US have also adopted Futile Care Policies. These policies highlight the tension that exists between the right of the physician to refuse to provide treatment… they believe to be futile, and the rights of the patient to receive treatment that they believe to be beneficial.

5. Organ Donation - Jule Grimstad discusses

Another factor that can also influence some healthcare providers' desire to terminate treatment is their concern for preserving body organs for transplant. Julie once again explains,

In order to donate organs we have to follow what is called the dead donor rule. The patient must be declared dead before the removal of organs for transplantation. But note that must be declared dead is not the same thing as must be dead. Words matter.

a. Definition of dead changed to make it easier to claim patient is dead

In 1968, a committee at the Harvard Medical School suggested revising the definition of "dead," so that patients with devastating neurologic injury could be used as organ donors. The brain dead concept was created at this meeting. Among the tests that are done to determine *brain death is a test called the apnea test. In this test the ventilator can be shut off for about 10 minutes while they see if the patient will start to breathe on their own. If the patient does not breathe on his own, they are put back on the ventilator and considered brain dead. There are other tests that they do, I'm simplifying this, but this is a very dangerous test because the carbon dioxide level builds up during those 10 minutes in these patients and can only cause more harm to the patient who is already neurologically compromised.*

It's not something you want to do to somebody to find out if they are dead. The only thing the apnea test really proves is that the person needs a ventilator; it doesn't prove that they are dead.

Many of the medical community have expressed doubts that brain death is true death and some of them are certain that brain death is not true death. When there is a question we should err on the side of life. We shouldn't just go blindly ahead and say, we need these organs for transplant and anybody who questions brain death is going to cause other people to die because they won't have the organs that they need. Well, when you are taking organs from a living person to give them to another person you are killing someone.

Donation after brain death – under the Uniform Determination of Death Act - all hospitals are allowed to set their own standards for determining brain dead. So in one hospital you could be considered alive and in need of treatment, and in another hospital you can be considered dead. That's confusing. A dead body is a cadaver; death is the absence of life. Okay, but a brain dead patient appears to be alive. Are our eyes deceiving us? They're warm, they're pink, they have blood pressure, the beating heart, their breathing with ventilator support, they digest food, they excrete waste, grow, heal, mature, they can even carry a baby to term if they happen to be pregnant and produce milk.

b. Brain dead and prodcures to harvest organs

A brain dead donor is given a paralyzing drug before the first incision is made in order to prevent them from squirming, grimacing. A cadaver does not squirm or grimace. The reason they started giving the paralyzing drug was because this was disturbing to the transplant team, the nurses, anesthesiologist we getting concerned that these patients that were supposed to be dead were moving. Even paralyzed, their pulse races, their blood pressure raises. In England donors are given an anesthesia in case they can feel pain. In the US most of the time they are not given anything.

Proponents of brain death assure us that we have nothing to fear when rigorous criteria are followed when determining brain death. But the stories of people recovering from a brain dead diagnosis occur often enough that we must proceed with caution, seek God's guidance, get second opinions and always err on the side of life.

In researching organ donation at the end of life, I found a second type of death diagnosis called cardiac death, that allows for the patient to choose to donate organs prior to death occurring but when it is imminent. It is referred to as "imminent death donation." The idea behind this is to harvest organs from patients for whom death is imminent but has not yet occurred so, basically, the removal of the organs causes death. I have included the Christian Medical and Dental Association's Ethics Statement on this topic in the articles section of your notebook.

In Belgium and the Netherlands they are combining euthanasia and subsequent organ donation in a so called 'donation after circulatory death' – as they believe the procedure is feasible on legal and medical grounds, and it is gaining social acceptance

6. Need to be an advocate for your health and the health of others

Clearly in the world we live in today, if you are elderly, disabled, or dealing with a terminal illness, your access to healthcare could be compromised and lead to hastening your death! Julie's comments about Futile Care and Organ Procurement remind us that it is important to have advocates to help us navigate the wild world of end of life care.

Finally, I asked Ron Panzer, nurse, and president of the Hospice Patients Alliance, to advise what signs we should look for if we are concerned that our loved one's care is being compromised:

You need to listen to your instincts. Everybody has a feeling whether this is right or wrong, if the medications being given are appropriate or if medications or treatments are not being given that should be given, because most family members are educated by their doctor in the course of the disease process to know what has been recommended up to that point. Because someone goes into hospice, doesn't mean that the moment they are admitted you throw away all the medications. In fact, that is a method of stealth euthanasia. You take a stable, chronically ill patient who has high blood pressure and remove his blood pressure medications; he will go into a hypertensive crisis, possibly stroke out, and die. If you remove those medications, you're intending his death. If you remove a heart patient's medications, he could have heart failure. If you remove a patient who has COPD or emphysema and you remove the nebulizer treatments that open up the airways and you don't give oxygen, then they're going to have tremendous trouble breathing, and the fluids in their lungs may build up and then on top of that, they give morphine, which suppresses the breathing. They die very quickly.

7. Conclusion

Thank you, Ron. Remember, there is a list of organizations in your book to help you, if you believe someone's care is being compromised.

Thank you all for attending this series! We are on to week 6 next when we will dig deeper into methods to hasten death, and how we can help someone who thinks death is the answer when they fear aging and suffering. So until next week, be blessed in knowing God loves you!

WEEK 6

Hastening Death

BEFORE THE SESSION:

- ☐ Arrive at least 30 minutes early to make sure set-up is taking place and to pray for the class.
- ☐ Cue the **Embrace the Journey** DVD to Week 6.

DURING THE SESSION:

- ☐ During **Opening Prayer and Activity**: Lead the participants through the prayer and activities designated for this session.
- ☐ Introduce the DVD Presentation.
- ☐ When starting **Group Reflection**, remind people to follow the Guidelines for Group Discussions. Remind participants to do **Personal Study and Reflection** in their Participant Guide.
- ☐ Ask a volunteer to bring snacks for the next week.
- ☐ Lead the group through the **Prayer for Life** on the back page of the Participant Guide.

AFTER THE SESSION:

- ☐ Be available if someone wants to talk.
- ☐ Make sure clean up takes place.
- ☐ Retrieve the DVD.
- ☐ Retrieve supplies. Keep for following week.
- ☐ Let the clergy know how the session went.

DURING THE WEEK:

- ☐ Thank and update your Prayer Team. Ask their prayers for the next session, ***Funeral Plans & Grief***
- ☐ Work through the **Personal Study and Reflection**.
- ☐ Preview the next week on the DVD.
- ☐ ______________________________
- ☐ ______________________________

WEEK 6

Hastening Death

The **MAIN OBJECTIVE** of this week's presentation is to explain the reality of Euthanasia and Assisted Suicide and the changes in medical ethics that cause some to advocate for these methods to hasten death. We will also discuss why people may consider dying by Euthanasia or Assisted Suicide.

Opening Prayer

Dear God, thank You for the gift of life. Thank You for the gift of aging, and death, help us to look upon them with hope. Thank You for the promise that we will graduate to heaven and live with You forever. Help us recognize that not everyone Embraces the Journey with You but instead seeks to hasten and control death.
May today's teaching help us understand the ways in which the culture of death tries to impose death on the most vulnerable. We ask all this in Jesus' name, Amen.

Opening Activity

Briefly share what you think of when you hear the words Euthanasia or Assisted Suicide.

Ask if anyone has seen the movie *Million Dollar Baby or Me Before You*? Ask them to describe the message of movie.

DVD Presentation:

Please take notes using this outline:

1. Introduction
    a. Growing support of assisted suicide and euthanasia
2. Definitions of Euthanasia & Assisted Suicide
    a. Euthanasia - Intentional action to cause death of someone else
    b. Assisted Suicide - One person intentionally helping someone end his/her life
    c. Redefining the hastening of death
3. Why hasten death?

   a. Assume Pain, but really fear of loss of dignity

   b. Hasten death to feel in control - but support & understanding eliminates desire to hasten death

   c. Bishop Derek Jones

4. Problems associated with legalized assisted suicide & euthanasia

   a. Assisted suicide and euthanasia offered instead of medical treatment

   b. Not a peaceful, painless end

   c. Lack of mandatory reporting and requirements for doctors

   d. Conscience violation and violated trust between doctors and patients

   e. General increase in suicide rates

5. Promotion of the hastening of death

   a. Assisted suicide and euthanasia in film and television

   b. Use of language

6. Legal Status

   a. United States

   b. International

7. Evolving medical ethics

   a. Ron Panzer - changing ethical standards in legal community

   b. Rita Marker - acceptance of euthanasia and assisted suicide

   c. Acceptance by the Church next?

8. Conclusion

DEFINITIONS:

Euthanasia *is an action done intentionally to cause the death of a patient who is suffering, such as giving a person a lethal injection.*

Euthanasia can also be done by intentionally withdrawing basic medical care with the intent of causing the death of the person who is not otherwise dying. The most common medical treatment withdrawn is food and water.

Assisted Suicide *is defined as when one person is directly and intentionally involved with ending the life of another person or to aid, encourage, or counsel for suicide. Physician assisted suicide involves a doctor prescribing a lethal dose of medication.*

The main difference between euthanasia and assisted suicide is that in assisted suicide you do it to yourself with the help of another person. In the case of euthanasia, it is done to you. In euthanasia I give you the lethal injection. In assisted suicide the doctor writes the prescription for the lethal dose of medicine, knowing you intend to take it. The goal for both is the same – intentional death

GROUP *Reflection*

1. John 10:10 says Satan comes to steal, kill, and destroy. Do you believe Satan is the architect of the culture of death in our society? Do you think Euthanasia and Assisted Suicide are wrong? Who is most vulnerable to becoming victims of Euthanasia and Assisted Suicide?

2. Suicide has never become culturally acceptable, so why would assisted suicide be legalized?

3. When someone expresses a desire to hasten death, it is really a cry for help, companionship, or control. Have you or someone you know talked about hastening death for these reasons? Are there better ways to help someone who wants to die than in helping them kill themselves?

4. The definition of homicide is the intentional killing of another person. How is it different than euthanasia, which is defined as an action done intentionally to cause the death of a patient?

5. Is it possible or probable that a care-giver would hasten a patient's death using Assisted Suicide or Euthanasia without the patient's knowledge? Should this be a concern for us as a society?

6. Ethically speaking: is there a difference between killing and letting someone die? Ron Panzer notes that the quality of life ethic is different than the sanctity of life ethic. The first relies on man to decide, the second defers to God. Which ethical standard do you want applied to your life?

BIBLE VERSES:

John 10:10
The thief comes only to steal and kill and destroy; I have come that they may have life, and have it to the full.

Psalm 31:14-15
But I trust in you, LORD; I say, "You are my God." My times are in your hands;
deliver me from the hands of my enemies, from those who pursue me.

Anglicans For Life's End of Life Philosophy

When we address death: we neither seek every artificial medical treatment available to live forever, nor accelerate death by employing methods to hasten it. Death must be natural, in God's time.

Closing Thoughts & Prayers

- Does a fear of suffering make hastening death acceptable? Pray for those who are suffering or whose loved ones are suffering.
- Discuss how you can help people you know who are vulnerable to having their death hastened.
- Pray together about what you have learned today.
- Close with praying the Prayer for Life:

Prayer for Life

Lord God, thank You for creating human life in Your image.
Thank You for my life and the lives of those I love.
Thank You for teaching us through Scripture the value You place on life.
Help me to uphold the sanctity of life in my church and community.
Give me the strength to stand up to those forces that seek to destroy the lives of those most vulnerable, the unborn, the infirm, and the elderly.
Today I commit myself to never being silent, never being passive,
and never being forgetful of respecting life. I commit myself to protecting and defending
the sacredness of life according to Your will, through Christ our Lord.
Amen.

For Further Personal Study & Reflection

- Meditate on Psalm 31:14-15 - "But I trust in you, O Lord, I say you are my God. My times are in your hands: deliver me from my enemies… even the enemy of pain and suffering!"
- View either movie - *Million Dollar Baby* or *Me Before You* -- and consider how Euthanasia and Assisted Suicide are made to look merciful.
- Read articles on pages PG-156 through PG-176.

Both of these organizations continue to oppose Assisted Suicide &Euthanasia

AMA
AMERICAN
MEDICAL
ASSOCIATION

WMA
WORLD
MEDICAL
ASSOCIATION

Where is it legal?

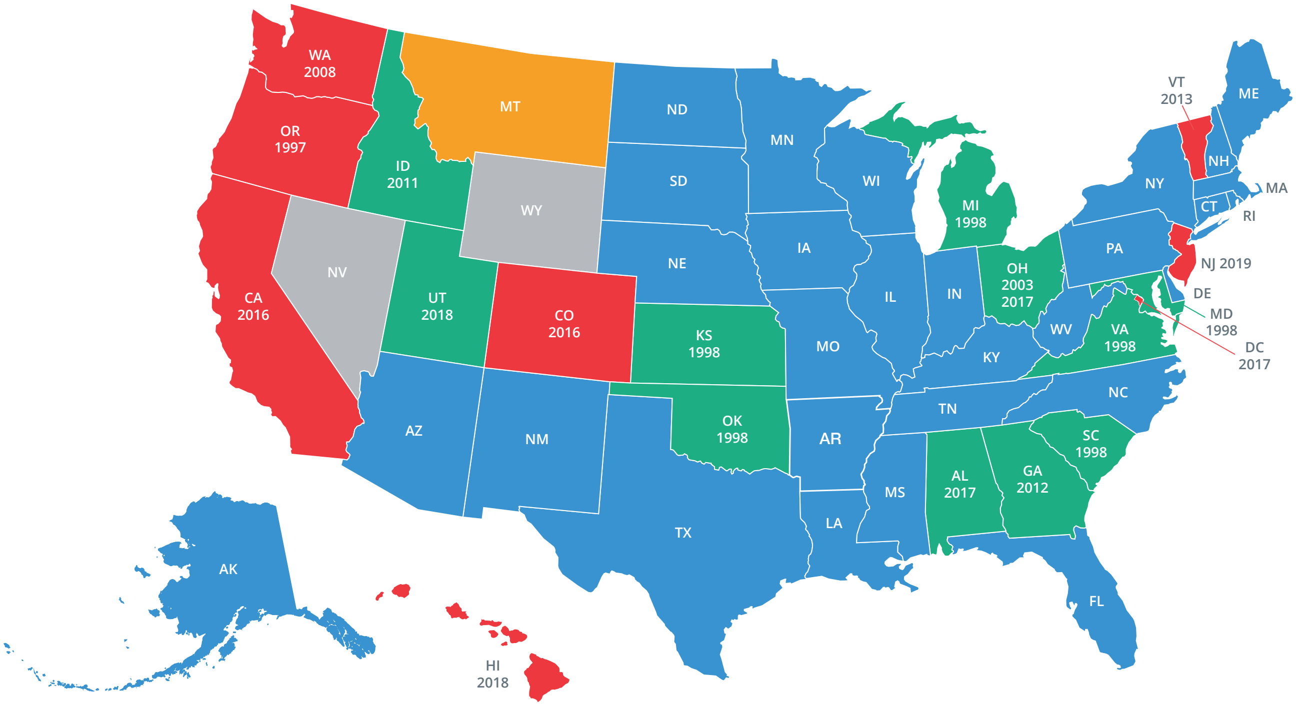
Euthanasia & Assisted Suicide

CHARLOTTE
LOZIER
INSTITUTE
The education and research arm of Susan B. Anthony List

Assisted Suicide in the States

STATE LAWS AND LEGAL POLICY AS OF APRIL 15, 2019

🟥 8	Laws allowing PAS to take effect since 1997
🟩 11	New laws against assisted suicide (including PAS) since 1997
🟦 29	Pre-1997 bans on assisted suicide still in effect
🟧 1	Court decision that may allow PAS in practice
⬜ 2	No clear policy by statute or common law



As of June 2019, **Maine** became the 9th state to legalize assisted suicide. **Massachusetts, North Carolina**, and **West Virginia** have no specific status, but do have a common law tradition allowing prosecution for aiding a suicide. **Montana**: State Supreme Court ruling left older law in place, but said it does not apply to PAS when physician can show patient's consent.

Where is it legal internationally?

Euthanasia & Assisted Suicide

Euthanasia is legal in the Netherlands, Belgium, Columbia, India, Canada, and Luxembourg. Assisted Suicide is legal in Switzerland, Germany, South Korea, Japan, and the US. And in Belgium, Euthanasia is now available for minor aged children, young adults, psychiatric and Alzheimer patients!

What does the U.S. Supreme Court say?

In the 1997 Supreme Court Case, *Washington v. Glucksberg,* 521 U.S. 702, assisted suicide proponents contended that a fundamental right to assisted suicide exists under the Due Process Clauses. The Glucksberg Court **unanimously** held that no such fundamental right to assisted suicide exists.

Week 6 DVD Script

Hastening Death

1. Introduction

Welcome to week 6 of Embrace the Journey.

Over the last 2 weeks we've discussed end of life healthcare options associated with advance care planning. Based on the information shared, it's clear that some end of life care has a hint of killing-is-cheaper-than-caring mentality to it. This week we will discuss how this mindset has morphed into acceptance of Physician Assisted Suicide, currently legal in 7 states.

Christians believe only God creates life, and that life should only end in God's time, God's way. Psalm 139 reminds us that He has our days numbered and John 10:10 recaps Satan's priorities is seeking to steal, kill, and destroy life. The cosmic fight for life continues as today's topic reveals how quickly our culture has bought into the notion that the right to die is morally acceptable.

a. Growing support of assisted suicide and euthanasia

Support and promotion of Assisted Suicide and Euthanasia actually began in 1938 when the Euthanasia Society of America was founded to promote the legalization of Euthanasia. In 1967 they formed an educational council which introduced the living will, a document designed to increase support for Euthanasia. The living will included language that gave a person the right to refuse certain types of medical treatment.

Currently the two most active pro-Euthanasia and Assisted Suicide groups are Compassion & Choices and the Final Exit Network. There is also the Death with Dignity National Center in Washington DC, which promotes pro-death legislation nationwide. These organizations have multi-million-dollar budgets with thousands of members.

I share this because, as we discuss the idea of assisted suicide, you need to know these aren't theories but rather initiatives with growing support. Their intent is to legalize killing certain people via euthanasia and assisted suicide, and their efforts to make it happen are organized and well-funded.

2. Definitions of euthanasia and assisted suicide

So let's begin by defining what Euthanasia and Assisted Suicide are.

a. Euthanasia

Euthanasia is an action intentionally done to cause the death of a person typically by lethal injection. Euthanasia can also be done by deliberately withdrawing all medical care with the goal of causing the death of a person who isn't otherwise dying. The most common medical treatment withdrawn is food and water, which as we noted last week causes dehydration which becomes the real cause of death.

b. Assisted Suicide

Assisted Suicide –is defined as one person directly and intentionally involved in ending the life of another person or aiding, encouraging or counseling for suicide. Physician Assisted Suicide involves a doctor prescribing a lethal dose of medication that the patient administers to them self.

The main difference between Euthanasia and Assisted Suicide is that in the case of Euthanasia, it is done to you. I give you the lethal injection. In Assisted Suicide, the doctor writes the prescription for the lethal dose of medicine, knowing you intend to take it. The goal for both is the same – death.

In both instances, the person who wants to die initiates the procedure, although we are now seeing more cases of involuntary euthanasia, when a doctor or nurse deem it is time for the patient to die and gives the lethal injection without it being requested.

c. Redefining the hastening of death

Now I know for the vast majority of us the concept of Euthanasia and Assisted Suicide is clearly unacceptable and even unthinkable. But we must recognize what is happening in our society, and actively oppose all forms of euthanasia and assisted suicide and prevent it from becoming the law of the land, like abortion has.

Ironically, advocates of euthanasia and assisted suicide prefer the terms "Death with Dignity," "End-of-life

Options," "Medical Aid in Dying," "Physician Assisted Death," "Assisted Dying," and my favorite Dignicide, because the real words don't garner public support! These phrases imply assisting someone in dying is a form of medical treatment to be embraced

3. Why hasten death?

Current US laws require a person to request Assisted Suicide, but why would an individual seek help to die?

a. Assume pain, but really fear of loss of dignity

Assisted Suicide Proponents say people use it to escape intense pain but as we noted 2 weeks ago – Palliative medications are sufficient to handle even the most intense pain. So what's really driving a person's desire to die?

Based on almost 20 years of reports from Oregon which started allowing Physician Assisted Suicide in 1997, the number one reason people want to die is their fear of losing their autonomy, their independence. Close behind that was the concern that they would be less able to engage in activities that make life enjoyable. Over half also said loss of dignity, fear of being a burden, and losing control of bodily functions were additional reasons to want to die.

Fear of pain and financial concerns about treatment costs came in last as reasons to die. One study found that the dominant characteristics of Physician Assisted Suicide patients was a greater than average preoccupation with self-determination, independence, and self-sufficiency. One patient said, "The dying process presented too much risk of becoming dependent."

People who chose Assisted Suicide were described as reclusive, crusty, demanding, solitary old ducks, who did not have meaningful trusting relationships.

In other words, people who want to die are lonely, independent, socially isolated, with fears about being a burden, losing their dignity, and feeling worthless. I think we all know older people like that, especially folks who were defined by their careers and are now lost in retirement from life. One study described this as existential distress and affirmed its validity as a reason to die!

b. Hasten death to feel in control - but support & understanding eliminates desire to hasten death

But if someone wants to die, why not just commit suicide? I think asking for Assisted Suicide should be seen as a cry for help, under the guise of pride that is fed by fear. Hurting, lonely people need care and connection, not help to kill themselves!

Behind each wish to hasten death, researchers wrote, one finds hidden desires for understanding and for someone to accompany them in their suffering and in their mourning for what has already been lost. Researchers also noted that, once the patient felt listened to and not so alone, they often stopped wanting to hasten their death.

The desire for control was also an important factor behind a wish to hasten death. When patients felt that they no longer had any control over facets of their lives, the ability to decide when and how to die was seen by some as the last remnant of their autonomy—their ace in the hole, so to speak. Their sense of control comes from having a hypothetical exit plan… because at the end of the day, they did not act on it.

c. Bishop Derek Jones

Bp. Derek Jones, whom we previously met in Week 2, shares some wise words about the issue of control at the end of life.

When we come to the end of our life, we want to be able to try to exercise some sort of control. We want to be able to exercise some sort of meaningful relationship to what we feel we have ownership of. But just because we've become wiser, older, smarter, doesn't necessarily make us divine and doesn't necessarily negate the gift that God gave us in the first place.

When we look at people who are facing, say someone whose body is just so ravaged with cancer, death is coming and all we're doing is hastening the inevitable. But what we don't understand or what we're not remembering is that God, who is the author of life, who provides us grace, will give us the grace to see us through the difficulty of the body to the point of time that He appoints for us to be returned to Him. For us to hasten that along is really quite an act of narcissism and an idea of "I'm wiser than God."

That body can convince the mind this is a better thing for everybody. For those that are in the midst of it, I've seen people who've said, "Boy, I wish they would just die." Then they feel guilty for it, because they realize that's not really a loving approach. Others would suggest when you create or do Euthanasia in an animal, you're doing the animal a favor. That's because God gave us dominion over the animals, and so *we can't equate the two. We can only look at one and then the other. We have dominion over their lives and therefore, we have exercised our judgment to say this is the time that their life should end. It cannot be equated to the human element that is in relationship with its creator and the one who is the author and holder of our lives, which is God. It needs to be placed and held solely and wholly in His hand.*

Thank you Bp. Derek.

4. Problems associated with legalized assisted suicide and euthanasia

Understanding why someone would seek to die is even harder when you consider the problems often associated with assisted suicide and euthanasia.

a. Assisted suicide and euthanasia offered instead of medical treatment

It seems when assisted suicide is legalized it is considered 'medical treatment' and often becomes the only treatment covered by insurance. Barbra Wagner experienced this first hand when she went to her doctor and found out her lung cancer was back. Her doctor advised that a new drug with fewer side effects than the chemo she had previously taken was available. So he prescribed it for her. She was insured under Oregon's Medicaid Programme. Before she could start the new treatment, she received a letter from the Oregon Health Plan telling her that it would pay for Assisted Suicide but not for the prescribed medication.

b. Not a peaceful, painless end

Limits to care where assisted suicide and euthanasia are available isn't the only problem – patients who have employed assisted suicide imagine a quick, peaceful death without complications, but MD Magazine recently featured an article by two physicians who described multiple cases of assisted suicide that involved difficulty ingesting or regurgitating the drugs, patients regaining consciousness, nausea, vomiting, and gasping.

c. Lack of mandatory reporting and requirements for doctors

Furthermore, we see shady doctors like Lonny Shavelson, becoming the go-to physician for the lethal prescriptions. He is a former ER doctor whose sole practise now is helping people die by prescribing lethal medications in California. Also, there is no mandatory reporting for doctors beyond the number of prescriptions written.

Another problem is lack of accountability of filled prescriptions. No one follows up once the prescriptions is filled, even though there are large discrepancies between the number of people who die by assisted suicide and the larger number of prescriptions filled. These pills can easily be mixed in applesauce or yogurt and given to anyone, without them knowing they are ingesting a lethal dose of medication.

There is also no requirement for a physician to be present when the lethal pills are administered, so no one would know if the patient was force fed them against their will. We know of one such case in the Netherlands, where the doctor enlisted the help of family members to hold down an elderly woman with dementia while he gave her the lethal injection.

Citing issues like self-determination and informed consent, anyone seeking assisted suicide is not required to be examined for lucidity or other psychiatric disorders, so nothing protects someone from being coerced into requesting assisted suicide. The physician can refer for a 2nd opinion as to the patient's mental state but rarely does.

Proponents of assisted suicide and euthanasia also say it is only available for those with 6 months or less to live. However, doctors readily admit it is almost impossible to accurately predict how long a person will live with any given diagnosis.

d. Conscience violation and violated trust between doctors and patients

Legalized killing also creates problems for doctors who object to participating in assisted suicide, as efforts to force them to either write prescriptions or refer to doctors who will help kill, goes against their conscience. Even doctors who support assisted suicide are expressing regret for their actions and feel the emotional burden of helping end life adversely affecting their medical practise.

It also creates trust problems for patients and their doctors. If I know my doctor is willing to help someone die, will I trust him to care for me or do quotas and cost containment goals take priority?

e. General increase in suicide rates

The worst element about assisted suicide is recognizing the impact it has on suicide rates in states where it's legal.

Some of you may remember back in November 2014, Brittany Maynard became the poster child for right to die advocates. She suffered from terminal brain cancer and moved to Oregon so she could die by assisted suicide. Her story garnered tons of publicity.

A few months after her death pro-life Dr. Will Johnston was presented with a twenty-year-old patient brought in by his mother, he was physically healthy but had been acting oddly and talking about death. Dr. Johnston asked the young man if he had a plan. The young man said "yes," that he had watched a video about Ms. Maynard. He said he identified with her and he thought it was a good idea for him to die like her. He also told Dr. Johnston that after watching the video he had been surfing the internet looking for suicide drugs. Dr. Johnston reports the young man agreed to go to the hospital, until it was determined that he was sufficiently safe from self-harm.

It is not surprising then, that by 2014, Oregon's suicide rate was 43% higher than the national average.

5. Promotion of the hastening of death

So why do we see the number of people dying by euthanasia and assisted suicide increase every year, if there are so many problems?

a. Assisted suicide and euthanasia in film and television

One of Satan's most powerful allies is the media…music, television, and movies, spin the morally unthinkable into immoral acceptance. Movies like Million Dollar Baby, Me Before You, and You Don't Know Jack – the story Dr. Jack Kevorkian who helped put Assisted Suicide and Euthanasia on the map, seek to glamorize death. The Media also generates sympathy for characters suffering, whether physically or emotionally to lower people's sense that killing by assisted suicide is morally wrong.

b. Use of language

Another tactic used to increase public support for assisted suicide and euthanasia is in managing the words used to discuss death. For example, "Death with dignity" sounds like something we all want! Who wants to deny someone the "right to die?" Doesn't "Compassion and Choices" sound like an organization you would welcome help from? Just as in the abortion debate – language is employed to distract people from what was really occurring. In Canada, they call euthanasia, medical aid in dying which glosses over what is really happening – medical personnel are intentionally injecting a patient with a lethal substance with the intention of killing them.

6. Legal Status

This map shows what states have legalized assisted suicide.

a. United States

Oregon, Washington, Montana, Vermont, Colorado, Hawaii, the District of Columbia, and California. And every year about 15 to 20 state legislatures see bills introduced, because assisted suicide proponents need a few more states to legalize it before they take can a case to the Supreme Court, demanding a right to die be made available to citizens nationwide.

b. International

Euthanasia is legal in the Netherlands, Belgium, Columbia, India, Canada, and Luxembourg. Assisted Suicide is legal in Switzerland, Germany, South Korea, Japan, and the US.   And in Belgium, Euthanasia is now available for minor aged children, young adults, psychiatric and Alzheimer patients! Once you make the right to die available to some, the slippery slope requires the right to be available for everyone.

7. Evolving medical ethics

Peter Singer, a professor of Bioethics at Princeton University who is considered a premier ethicist holds to the belief that there is no difference between killing and letting die. This sort of thinking is now influencing a new generation of doctors and healthcare professionals as well as policy makers.

a. Ron Panzer - changing ethical standards in legal community

Ron Panzer, whom we met last week, explains what's happening in the world of medical ethics.

We live in a society, a global society, that has been dominated in modern times by secular humanism or modernism that embraces an ethic *of quality of life as the determinate of whether a life is worth living, whereas in the sanctity of life ethic, we recognize life comes from God. Therefore, we have a duty to serve the lives of the patients that we care for, and the patient also has a duty to live, because God created him or her. In the secular mindset, they say man is the determinate of what is right and wrong. The divine law is thrown out. All of the things that we know from the great thinkers of the past, Thomas Aquinas was one of the greatest, but the idea that there is a divine law and there are things that are absolutely right and absolutely wrong, the certainty because we know that God is, then we know that there are things that are right or wrong. Once the secular humanists throw this out, then they can create their own law, their own morality based on whatever they come up with, which is the secular bioethics. Once you throw out the divine law and throw out the idea that we are to be judged actually by God for what we do, you can do anything, and doctors are brought up into that ethic in the modern health care industry throughout the world in many nations. They no longer use the Hippocratic oath, which says, "Do no harm." I won't provide any medication for an abortion, all of these things or do any surgery like that." The doctors are actually taught they can do harm or hasten death in some circumstances, that it's right because the patient may be suffering so therefore to relieve suffering, they say we will relieve the patient of their life to relieve the suffering. It's kind of insanity. It's upside-down morality and upside-down ethics.*

Along with ethical concerns Ron mentioned, there are practical and potentially even criminal issues that arise as support for Euthanasia and Assisted Suicide grows within our society.

b. Rita Marker - acceptance of euthanasia and assisted suicide

Rita Marker from Patients' Rights Council explains

The crime of Assisted Suicide, if it is doctor-prescribed suicide, has been transformed into a medical treatment. This was sold to voters, and it was passed by voter initiative in Oregon in 1994, went into effect in 1997, and then in 2008 in the state of Washington. Those who promoted it said this will just be a choice for people who are suffering terribly and are terminally ill.

It will be used only by a few people and it will be something that is not going to force anybody to do something, but it's going to be a matter of choice. If we look at what happens with choice, and that word sounds so good, but often when things like this are being promoted, you hear a really hard story, a devastating story, a heart wrenching story.

When you hear that, it rightfully makes people feel very bad for the person. The next thing is to say that they should have a choice on this. Once they have the choice for that, then we are on what I call a pathway from choice to requirement, because that choice then inevitably might take a little while, but inevitably it expands. Not only is it a choice, but it is something that should be offered to everyone, because everybody should have the opportunity for this choice.

Then you get quickly to the point not just of saying, "Okay, if the person says they want this, but by offering it to them and eventually it isn't, why would you do this?" It will be, "Why wouldn't you do this?" That choice has become an expectation and once you have the expectation, then if people are expected to at least consider this and many of them to choose it, well, what about people who can't pay for it? Then we have a situation of saying, "It should be funded by the Government," because my goodness, if this is a good medical treatment and something that people could use, why not pay for it?

Once it's paid for, then there's little more pressure to say, "Why wouldn't you choose this?" It begins with a choice and there's a pathway from choice to requirement that happens.

Anglicans for Life's concern is that what starts out as a right to die will morph into the duty to die for the sake of others.

c. Acceptance by the Church next?

Making this all the more disconcerting is a recent survey by LifeWay that found 67% of Americans agree with the statement, "When a person is facing a painful terminal disease, it is morally acceptable to ask for a doctor's help in taking his or her own life."

Sadly 49% of those who attend religious services at least once a month say physician-assisted suicide is morally acceptable.

8. Conclusion

In closing, we must realize support for killing is increasing, and if we want to die naturally and in God's time, we need to see the proverbial writing on the wall – it is saying, Church, stand for life, stand with the vulnerable, recognize the growing need to be the voice of truth.

As Christians we must care for the sick, vulnerable, and dying. We must be there for the lonely, isolated, and frightened men and women who think death is better than life. We must never shrink from the messy and exhausting task of caring, because the best way to undermine assisted suicide and euthanasia is to show the power of God's love rooted in Christ.

Walking with those who are suffering is better than eliminating the sufferer!

Be sure to check out the myriad of articles, and websites available in your book related to this week's topic. See you next week when we will discuss funeral planning.

WEEK 7
Funeral Plans & Grief

BEFORE THE SESSION:

- ☐ Arrive at least 30 minutes early to make sure set-up is taking place and to pray for the class.
- ☐ Cue the **Embrace the Journey** DVD to Week 7.

DURING THE SESSION:

- ☐ During **Opening Prayer and Activity**: Lead the participants through the prayer and activities designated for this session.
- ☐ Introduce the DVD Presentation.
- ☐ Remind participants to do **Personal Study and Reflection** in their Participant Guide.
- ☐ Ask a volunteer to bring snacks for the next week.
- ☐ Lead the group through the **Prayer for Life** on the back page of the Participant Guide.

AFTER THE SESSION:

- ☐ Be available if someone wants to talk.
- ☐ Make sure clean up takes place.
- ☐ Retrieve the DVD.
- ☐ Retrieve supplies. Keep for following week.
- ☐ Let the clergy know how the session went.

DURING THE WEEK:

- ☐ Thank and update your Prayer Team. Ask them to pray for the next and final session ***The Role of the Church in Suffering & Death.***
- ☐ Work through the **Personal Study and Reflection**.
- ☐ Preview the next week on the DVD.
- ☐ Fill out the **Embrace the Journey** Leader's Evaluation form (See page 212)
- ☐ Call attention to the Participant Evaluation Form on page PG-187, ask them to fill it out and return it to you to send to Anglicans for Life's office.
- ☐ ______________________________

FINISHING LIFE - *Preparing for the End of Life*

Please bring the booklet to everyone's attention and encourage them to begin thinking about their funeral plans. Filling in the information concerning their funeral and burial preferences can prevent arguments and angst for family members in the midst of grief.

Please emphasize the importance of telling someone where the booklet will be stored!

WEEK 7

Funeral Plans & Grief

The **MAIN OBJECTIVE** of this week's presentation is to de-mystify what is involved in funeral planning at both the church and funeral home. We also hope to inspire people to pre-plan their funeral so that family members in the midst of grief will be spared the challenge of trying to figure out a loved one's preferences after they have died.

Opening Prayer

Dear Father God, thinking about aging and dying is not easy for us, because we look at it without the perspective of eternity with You. Help us to see the importance of life in honoring the dead and giving the living an opportunity to grieve. Give us the courage to pre-plan our funeral and to bless our loved ones in this final act. Thank You that death in this life allows us to graduate to Heaven and spend eternity with You. Amen.

Opening Activity

Think about funerals you have attended. Which ones were memorable and why?

Poll participants as to their preference for cremation or burial.

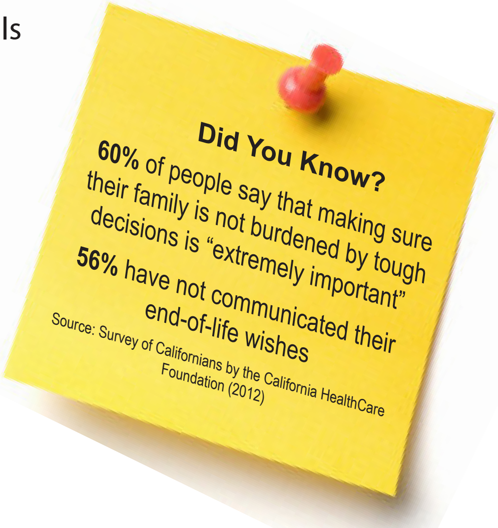
DVD Presentation:

Please take notes using this outline:

1. Introduction
    a. Spiritual perspective - graduating to Heaven
    b. Practical perspective
2. Value of pre-planning funeral - burial or cremation?
    a. Bishop Nolden
3. Planning the funeral
    a. Church plans
        i. Burial Service or Memorial Service - hymns, scripture, communion? Who will conduct service? Who will do eulogy? Graveside committal? Reception?

b. Funeral Home
    i. Vital information for Death Certificate & Obituary
    ii. Number of Death Certificates, Lists of people to contact
    iii. Price list, flowers, car list, thank you notes, memorial items, viewings
    iv. Preparing the body & identification
    v. Caskets, cremation information, & details
    vi. Funeral costs

4. Grieving and learning to live with it
    a. Losing a parent
    b. Fr. Montzingo - grieving families
    c. The Rev. Dee Runner - Widowhood
    d. Bishop Ackerman - Living after losing a loved one



Did You Know?

60% of people say that making sure their family is not burdened by tough decisions is "extremely important"

56% have not communicated their end-of-life wishes

Source: Survey of Californians by the California HealthCare Foundation (2012)

Conclusion – Pre-plan your funeral & graduating to Heaven
    a. Billy Graham
    b. The Rev. Rick Bergh

GROUP *Reflection*

1. Have you ever envisioned your funeral? Is it a somber event or a celebration?

2. Do you agree with Bp. Nolden that addressing the practical issues of funeral planning can help both the person dying and family members? How can it help each person?

3. Jessica discussed practical issues such as ordering death certificates. But as she got into details about preparing the body and casket selection, did any topic make you uncomfortable? Why?

4. Have you thought about these questions: What do you want done with your body? What cemetery do you want to be buried in? Do you want to be placed in a crypt or mausoleum? If cremated, would you like your ashes stored in an urn or scattered? Where?

5. Do you see spiritual implications of burial or cremation? What do you believe them to be?

6. Has funeral planning and burial preferences ever come up in your family discussions?

BIBLE VERSES:

1 Peter 1: 3-4
Praise be to the God and Father of our Lord Jesus Christ! In his great mercy he has given us new birth into a living hope through the resurrection of Jesus Christ from the dead, and into an inheritance that can never perish, spoil or fade. This inheritance is kept in heaven for you.

John 3:16
For God so loved the world that he gave his one and only Son, that whoever believes in him shall not perish but have eternal life.

John 11: 25
Jesus said to her, "I am the resurrection and the life. The one who believes in me will live, even though they die."

Matthew 10: 28
Do not be afraid of those who kill the body but cannot kill the soul. Rather, be afraid of the One who can destroy both soul and body in hell.

Closing Thoughts & Prayers

- Invite your pastor or staff member responsible for funeral planning to share specific details about their plans and procedures for funerals. Have them distribute any standard forms they need filled out. Encourage one another to fill them out and let family know you have done so.
- Give thanks to God for the blessings that come from funerals, even in the midst of grief.
- Close with praying the Prayer for Life**:**

Prayer for Life

Lord God, thank You for creating human life in Your image.
Thank You for my life and the lives of those I love.
Thank You for teaching us through Scripture the value You place on life.
Help me to uphold the sanctity of life in my church and community.
Give me the strength to stand up to those forces that seek to destroy the lives of those most vulnerable, the unborn, the infirm, and the elderly.
Today I commit myself to never being silent, never being passive,
and never being forgetful of respecting life. I commit myself to protecting and defending
the sacredness of life according to Your will, through Christ our Lord.
Amen.

For Further Personal Study & Reflection

- Spend some time thinking about your funeral. What type of atmosphere do you want it to have? Do you see it as an opportunity for the Gospel to be shared with friends and family? Do you want someone to give a eulogy? What would you like them to say about you?

- If during this time of reflection issues have been raised that cause you concern, consider making an appointment to visit with your pastor to discuss it.

- If a family member prefers cremation or burial, and you have an aversion to it, discuss why you feel the way you do, so that you can fulfill their wishes and experience peace.

- Ask friends for funeral home referrals and visit them to discuss pre-planning your funeral. Provide details about your plans in **Finishing Life** booklet.

Week 7 DVD Script

Funeral Planning & Grief

1. Introduction

Hello. I'm Deacon Georgette Forney, host and author of Embrace the Journey. This teaching series has taken us on a long and winding path and has challenged us to look at many complex issues. Thank you for persevering to Week 7!

Last week's discussion forced us to recognize that our golden years may be threatened by the culture of death. This week, we will discuss what happens once death occurs – both the practical funeral planning as well as the emotional after affects.

First, space is provided in Finishing Life for obituary facts to be noted as finding details like the name of your high school or the year you married can be daunting in the midst of grief and funeral planning. Also, there is space to list people you want contacted when you die.

You may recall, in Week 2, Cristen Krebs provided an overview of the imminent signs of death, and we have included the list in week 2 articles in your book to refer to as needed.

a. Spiritual perspective - graduating to heaven

From a spiritual perspective, when death occurs, Christians recognize death as graduating to heaven.

Billy Graham says, "We do not need to fear the grave, because by His death and resurrection, Jesus Christ has opened Heaven's door for us. 1 Peter, Chapter one says, "Praise be to the God and Father of our Lord Jesus Christ! In His great mercy He has given us new birth into a living hope through the resurrection of Jesus Christ from the dead, and into an inheritance that can never perish, spoil or fade – kept in heaven for you."

b. Practical perspective

From a practical perspective, when death occurs, we must recognize the importance of honoring the dead and giving the living an opportunity to grieve. And a funeral is how these things are done.

To be honest, I had never had to plan a funeral when I wrote the first version of Embrace the Journey back in 2013 and the idea of discussing them scared me. But I found that when I went and visited our local funeral home, the knowledge I gained de-mystified the unknown elements that made me fearful. It turned out to be a gift from the Lord because, two weeks later, I had to go back there to help prepare for a dear friend's funeral.

I hope our discussion today will also help you feel less fearful and encourage you to be proactive in addressing your own funeral plans or that of loved ones. Pre-planning for your funeral eliminates the decision-making process for family in the midst of grief.

2. Value of pre-planning funeral - burial or cremation?

When I began writing this project, I asked people their opinion on cremation versus burial, and I was surprised by the number of people who preferred cremation to burial – but regardless of their choice I noticed most people were very adamant about it. If it is important to you whether your body is cremated or buried, or where your body is buried, I strongly recommend that you pre-plan your funeral. All you have to do is choose a funeral home in your area and make an appointment. They will walk you through the process, and then you can advise your family of the details. Remember to include the information in your Finishing Life booklet, so they will know what to do when the time comes. The greatest benefit of pre-planning your funeral is that your family isn't trying to make plans in the midst of grieving.

I suggest that part of your pre-planning include a family discussion that addresses what your wishes after-death are. Letting them know the answers to questions like: What do you want done with your body? What cemetery do you want to be buried in? If you want to be cremated, would you like your ashes stored in an urn or scattered? Where do you want the urn stored? While it may seem awkward to have a discussion about these things, when we die our loved ones want to honor our wishes, but sometimes need help in knowing what they are. Talking about it relieves them of trying to guess or question if they did it right or squabble over decisions.

a. Bishop Nolden

Consider this testimony from Bp. Wesley Nolden, Retired Reformed Episcopal Church bishop from the Diocese of Quincy about his experience with his mother

I will tell you a personal experience that I had. It wasn't from anybody else's funeral. It was from my mother. She and I had the conversation about what she wanted to have happen when she died a long time before she was ever ill and ever died. That was so helpful to both of us.

First of all, there was no artificial barrier on death. We became comfortable discussing that. It also modeled behavior for my wife and our children to see their grandmother talking openly, with their dad, about how do I want to transition into the next life? How do I want to have this happen to me when I die? What do I want to happen after I die?

When that time came, and I actually held my mother as she died. After her death, I knew exactly what to do.

I knew exactly what her wishes were. It was so much easier for me. I didn't have to make that decision than if I'd not discussed it with her. Would she have wanted this? How would she have wanted this? I knew precisely.

In terms of the grieving process, it helps facilitate the grieving process. You don't second guess yourself. You don't try to figure that out. We all have to go through the grieving process in our own way. It takes its own time. There are things to do like this that can help us prepare.

It's really having an opportunity to get to encourage the family to go talk to someone and prepare their funeral. It's not a negative thing. We prepare for a lot of things. One of the things we don't do in our society is prepare for death very well.

I'm not saying that other people do it better than we do. I'm just saying that from what I've seen, we don't do it very well on average. It's almost part of the … I consider it part of a pastoral experience when people come to me and say, "I have cancer, I'm terminal or my mother has cancer", or something like that that we begin the discussion.

We'll pray. We hope God will miraculously heal. He makes His own decisions about those things. When we see that time in a family's life, then to bring them to someone who can help them move forward through that grief, through that time and through that grieving process is really, I found, to be a great help to the family.

Often, it helps the person who's dying. That's something they don't have to worry about. Sometimes they don't even know they're worrying about it, but they really are.

It really helps both sets of folks. It helps the person who's dying. It helps the family, and the loved ones, and the friends. As they move through that process, you really can see some relief often with them.

Thank you Bp. Nolden.

3.Planning the funeral

Once the death of your loved one occurs, it is time to notify the proper authorities. If the death happens in hospital, hospice, or a nursing home, their personnel will declare them dead, and a call to the funeral home can be made.

Typically, as death nears, medical staff will ask which funeral home is to be contacted, and if pre-planning hasn't occurred, someone has to begin making plans about the disposition of the body. If a person dies at home, in Hospice, the Hospice staff will declare the person dead and then you can contact the funeral home. If death occurs at home or any other place and medical personnel are not present, you must call a paramedic/emergency medical service, as they can declare someone dead. Once death is declared, the funeral home can be advised to come and remove your loved ones body.

a. Church plans

Whether you pre-plan your funeral or plan after death occurs, there are typically three elements to planning a funeral. First, there are the details that need to be addressed with your Church for either a Burial Service or Memorial Service, if cremation is chosen. Second, there are the funeral details that relate to preparing your loved one for cremation or funeral. And third, the final resting place for the body; burial in cemetery, ashes in urn to be placed in mausoleum, kept at home, or spread somewhere?

i. Burial Service or Memorial Service? Hymns, scripture, communion? Who will conduct service? Who will do the eulogy? Graveside committal? Reception?

Let's start with the plans at your church –

Churches typically have a form they will ask you to fill out, noting your specific requests. Questions can include: What hymns do you want? What Scripture readings you prefer? Who do you want to conduct the

service? Will a family member or friend give a eulogy? Do you want to have Holy Communion? Where should the service take place? It is possible to hold the entire service in church, or a part of the service may take place at the church followed by a committal at a mausoleum or graveside. You can advise them if you want to hold any type of reception after the service. There is space in Finishing Life for this information, as well as the details the funeral home will need.

b. Funeral home

The second part of planning involves the preparation of the body and the funeral itself. Jessica, the funeral director for Copeland Funeral Homes here in Sewickley, graciously explains what is involved in planning a funeral, beginning with the initial phone call.

Before their visit we make the initial call to let them know that their mom or their dad has come home to be with us. I think that sort of actually makes them feel safe and secure. Then I give them a list of things that they're going to need to bring with them for the conference. There are four different components of the conference that we go through.

i. Vital information for Death Certificate & obituary

One is vital record information, which completes the death certificate. That would include the social security number of the individual, birth date, birth place, parents' names -- including the mother's maiden name -- occupation, education level, where they have lived, what cemetery or crematory they would be using, if they're a veteran -- a copy of their discharge (because they're eligible for some benefits). That's the first part of the arrangement conference.

The second part is gathering information for an obituary. That would be asking who they're related to, where their cities and states of location are, how long they've been a resident here in our area, clubs, lodges, organizations they belonged to, special education, and employment.

ii. Number of Death Certificate? Lists of people to contact

After that component the third one is how many death certificates you might need. We actually use a large checklist. I make numbers on that checklist and notes for the family. Then I give them that checklist as a guideline so that they can just go right down the list and say, "I need to notify these people." Once it's done, then they don't have to rethink anything.

iii. Price list, flowers, car list, thank you notes, memorial items, viewings

The last thing we do is we go over our general price list. All funeral directors are required to have a general price list, and ours just looks like this. It has certain packages available, if people want a cremation package, a traditional package, or a memorial service.

The conference itself, when we work in the original arrangement conference, can last anywhere between one hour to maybe two hours. Then I have my families leave with a little notepad that I fill out for them. Anything that comes across in their minds and it comes out of their mouths, I just record it for them. Then I give them tasks to go ahead and complete, like ordering of flowers, planning a luncheon, when their calling hours are, when the family is to arrive at the funeral home.

With cremation we still ask the same questions to help us with the vital record information, death certificate, the obituary -- most people still want an obituary with cremation. Then we ask how many death certificates you still need.

iv. Preparing the body & identification

When my families come and do our initial conference, I at that time ask for someone in the family to do identification for me so that I know that that person is the proper person. If a death occurs under hospice, or my family is still there at the hospital when we go to make the removal, then I feel comfortable that they don't have to identify. If they're not there then I feel safer with that. Most of my families appreciate the closure and appreciate knowing that person's here with me.

The next step to that is our death certificate is completed; it's faxed to the coroner. The coroner looks over the causes of death, and he will give us a letter of permission -- or a cremation permit-- that says, "You're okay to do the cremation." If there's anything on the death certificate that he's a little skeptical of, he'll pull back and say,"I need to talk to that doctor, can you give me their phone number (or he might already have the phone number)? I need to confirm the cause of death and make sure that everything's in order."

That being said, then we have our documentation from the coroner, we have our cremation permit, and we have our family authorizations. Our families also have to sign-off that that's actually what they want -- for the cremation to occur. Then we take them to our crematory, which is Pittsburgh Cremation Service. They usually have a timeframe of maybe 24 to 48 hours. Then we're able to go and take the human remains that are cremated now and bring them home with us. At that time some people have a memorial service, some people have a burial, or some people just take the cremated remains home.

v. Caskets, cremation information, & details

The last question of the funeral process that needs to be addressed is the final resting place for your loved one. Is there a family burial plot or does one need to be purchased? Typically, the funeral home will help

guide this portion of the discussion, whether you pre-plan or decide as needed. Some of the choices related to disposition of the body will be governed by states laws, so this part of our discussion is very general. Caskets, urns, vaults, and memorial stones or markers all need to be considered, can vary greatly in price, and should reflect the values of the deceased.

vi. Funeral Costs

I should note that the median cost of a funeral with viewing and cremation is more than $6,000, with cemetery and burial services additional. I think these high costs are influencing people's preference for cremation. But funerals and burials can be done on smaller budgets, especially with good pre-planning!

4. Grieving and learning to live with it

The last topic that we need to cover today is grief and learning to live with it. It is one of those experiences that are unique to each person, based on their relationship to the person who dies. I have included a rather lengthy article entitled "The Death of a Parent Affects Even Grown Children Psychologically and Physically," it is a great pastoral resource for people really struggling with grief. I found it helpful, even though it has been 5 years since my mother died. Its opening paragraph states:

a. Losing a parent

"Losing a parent is the closest thing humanity has to a universal emotional experience. But universality doesn't dampen the trauma of the event, which tends to inform and affect the rest of peoples' lives. Even under the best circumstances, studies suggest that losing a parent changes an adult both psychologically and biologically."

We have also included a wonderful article to help you have discussions with children about death and grief.

b. Fr. Montzingo - Grieving families

I asked Fr. David Montzingo, a priest in the Diocese of Western Anglicans what 40 plus years of ministering to grieving families has taught him.

In terms of working with the family, one of the things, of course, that I try to do is I try to alert, particularly if it's been a long term illness, I try to alert family members, surviving spouse, about the incredible emptiness and disorganization that's going to happen. Because a person at home dying long term illness, the whole family system is organized around that person. When a person dies, even if it's expected, even if it's a relief, it's suddenly BOOM! There goes your approximate reason for living. That's a hard adjustment.

c. The Rev. Dee Runner - Widowhood

I also ask Rev. Dee Renner, retired priest from the Diocese of Western Anglicans, whose husband was ill for a long-time before he died, to share what she learned when she became a widow:

Don't do anything drastic for a year. Don't move from your house. Don't leave what you have. Don't just pick up and go if you can avoid it. There are some instances where your home is part of whatever your husband was providing. That didn't happen for me. I wasn't in a rectory or anything like that. We owned our own home. But I say if it's at all possible, don't do anything major for at least a year. Then find things to fill your days with, so that you're not sitting around moping.

d. Bishop Ackerman - Living after losing a loved one

Finally, I asked Bp. Keith Ackerman whom we met in week 1, if he had any words of wisdom concerning the living when a loved one dies.

One of the problems that we are confronted with with death is guilt. If there were no sin, which of course is not true, then why is there still guilt? If a person didn't believe in sin, they have nothing to feel guilty about. Yet, I'm dealing with people often times who don't talk as much about church all the time, but they do talk about their guilt. What's their guilt about? Guilty, because they did not say goodbye to somebody who was hit by a car. Guilt because somebody died and they were unable to make that relationship right.

I think that, in life, if we would learn how to forgive more easily, that we begin the process of healing. I have to deal with people regularly who tell me that intellectually they can allow for God's forgiveness, but they've never forgiven themselves. One of the things I have to say to them is, "I can't believe that you're telling God what to do." They say, "Why, I would never tell God what to do." I say to them, "Yes, but you are. If God has assured you that He has forgiven you, and you can't forgive yourself, you're telling God He doesn't know what He's doing. Don't get into the God business. Let God be God. You are the forgiven." The way we do that is by going before the throne of grace, and we ask for forgiveness.

We also have to go to people with whom we are estranged. We have to learn how to say "I'm sorry." We have to learn how to say "I forgive you." We will have fewer regrets in life if we will resolve relationships during the day. Do not let the sun fall down upon your wrath.

Thank you Bp. Ackerman.

5. Conclusion - Dying is not an individual event

As we conclude this week, I'd like to share some final thoughts about death from Billy Graham

a. Billy Graham

"Death is a reality, but death was not part of God's original plan. When God created Adam and Eve, He gave them physical bodies, just like every other creature on earth. But one thing made them different: God not only gave them a body, but He also implanted within them a soul, a spirit, made in His image. He did this so they could know Him and become His friends, and because of this they were meant to live forever. God cannot die, and as the bearers of His image, they were not meant to die either.

We weren't meant to die, but Sin, like a lethal spiritual cancer, has infected the entire human race and someday you and I will die. It may be soon, it may be far away, but someday your life will come to an end.

The Bible calls death 'the last enemy' and Jesus warned, 'Do not be afraid of those who kill the body but cannot kill the soul. Rather, be afraid of God, the One who can destroy both soul and body in hell.'

Regarding death, Jesus declared, 'I am the resurrection and the life. He who believes in me will live, even though he dies; and whoever lives and believes in me will never die.'

And the best-known verse in the entire Bible underlines this truth: 'For God so loved the world that he gave his one and only Son, that whoever believes in him shall not perish but have eternal life.'"

b. The Rev. Rick Bergh

Finally, I share this comment by the Rev. Rick Bergh to reinforce the importance and eternal value of having conversations with our loved ones about aging and dying. "Dying is not an individual event. It is a communal initiative. The final chapter of life needs to take into consideration the impact our death has on those around us for the sake of the Kingdom. As soon as you make it only about yourself, you eliminate the impact you have on your family and friends. The conversations become totally centered upon what is good for you and that becomes the primary goal in all decision making. I believe in dignity in dying, but I also believe that life has purpose until the very end, and we must allow God to use us as His light till our last breath. I've seen the impact of this over and over again, as families are brought together over a dying loved one."

With the reminder that death is not the end and that along with our funeral, these events can become Kingdom opportunities for the Gospel message to be proclaimed to those who don't have the assurance of eternal life through Jesus Christ, may we be encouraged to start the conversation.

I hope this overview of funeral planning also inspires you to schedule a visit with your church and your local funeral director. Next week is our last week in this series, and we will focus on ways you and your church can help friends and family Embrace the Journey. Our theologian friends will also answer common questions about suffering and death.

WEEK 8

The Role of the Church in Suffering & Death

BEFORE THE SESSION:

- ☐ Arrive at least 30 minutes early to make sure set-up is taking place and to pray for the class.
- ☐ Cue the **Embrace the Journey** DVD to Week 8.
- ☐ Prepare to collect the **Participant Evaluation** forms and put them in a large manila envelope to send to Anglicans for Life.

DURING THE SESSION:

- ☐ During **Opening Prayer and Activity:** Lead the participants through the prayer.
- ☐ Introduce the DVD Presentation.
- ☐ Remind participants to do **Personal Study and Reflection** in their Participant Guide.
- ☐ Distribute Evaluation Forms, ask participants to fill out, and collect them at the end of class.

****FINISHING LIFE - *Preparing for the End of Life*

Remind each participant about the importance of completing the information section of the booklet and discussing their end-of-life wishes with family members or friends so their wishes and preferences will be honored and upheld. Please emphasize the importance of telling someone where the booklet will be stored!

AFTER THE SESSION:

- ☐ Be available if someone wants to talk.
- ☐ Make sure clean up takes place.
- ☐ Retrieve the DVD.
- ☐ Retrieve supplies.
- ☐ Let the clergy know how the **Embrace the Journey** series went.

DURING THE WEEK:

- ☐ Give your prayer team an update. Tell them about people's feedback.
- ☐ Work through the final **Personal Study and Reflection**.
- ☐ Complete your **Leader's Evaluation**. Send copies of the **Participants' Evaluations** and your **Leader's Evaluation** to:

Anglicans for Life, 100 Leetsdale Industrial Drive, Leetsdale, PA 15056.

- ☐ Ask a participant to write a follow-up article about **Embrace the Journey** for your church newsletter. Please send Anglicans for Life a copy of it too!
- ☐ Write thank you notes to key helpers like the Prayer Team, the person who prepared coffee, the techie, those who provided administrative support, and the clergy. (Handwritten notes are really treasured these days!)
- ☐ ***Put your feet up and treat yourself after a job well done!***

WEEK 8

The Role of the Church in Suffering & Death

The **MAIN OBJECTIVE** of this week's presentation is to look at what role the Church can and should play in addressing the issues of aging and dying. We will note some practical ministry ideas to inspire you and will tackle the tough spiritual questions many of us struggle with, related to the reason for suffering, fear of death, and what happens when you die.

Opening Prayer

Dear Heavenly Father, Thank You for being in our midst as we have Embraced the Journey together.

Thank You for our faithful leader who has helped make this class a blessing
for each of us, as participants.

In this last week, open our eyes to see who You are calling us to minister to in our church and
community regardless of our age!

And open our hearts to receive today's teaching so we will be prepared for death in Your time.

For your glory, Amen.

Opening Activity

Make a list of elderly parishioners and friends you know and

what needs might they have that your church could help them with.

DVD Presentation:

Please take notes using this outline:

1. Introduction - Inspired to embrace the journey of life to the fullest
    a. Purpose of curriculum - help Church help people age with grace & die with faith
2. Practical ministry support - ministry ideas for everyone
    a. Compile resource list
    b. Support groups
    c. Spiritual adoption

   d. Communion to shut-ins

   e. Relieve caregivers

   f. Visit those recently widowed & in nursing homes

   g. Help the next generation - see value in spiritual maturity

   h. Preach a sermon about dying or end of life

   i. Elderly evangelism

3. Spiritual teaching to prepare hearts and minds for death - Acknowledge the question of why there is suffering

   a. Fr. Keith Allen

   b. Bp. John Rodgers

   c. Jesus Calling – Be prepared to suffer for Me

   d. Jesus suffering during Holy Week

4. Fear of death - Why?

   a. Bp. Derek Jones

   b. Bp. John Rodgers

5. Conclusion - Doubts and fears become hope and joy

   a. Additional resources & information

   b. Bridge of Triumph

   c. Wishing you God's grace & peace

The Bridge of Triumph
by Chuck Pinson

GROUP *Reflection*

1. Is there a need for a specific type of support group in your area that your church could host? Do you have a lot of folks dealing with one type of illness or serving as care-givers? Could these folks benefit from you helping them start a support group?

2. Is there a ministry you can do in retirement that you are afraid of trying? Do you like the idea of spiritual mentoring?

3. Georgette read from the devotional **Jesus Calling** by Sara Young, "When suffering strikes, remember that I am sovereign and that I can bring good out of everything. Do not try to run from pain or hide from problems. Instead, accept adversity in My Name, offering it up to Me for My purposes. Thus, your suffering gains meaning and draws you closer to Me. Joy emerges from the ashes of adversity through your trust and thankfulness." In the light of the Cross, can these words give you courage in your suffering?

4. What do you fear about death? Try to be specific.

5. What do you think happens when you die?

* Take a minute to reflect on what you learned over the past eight weeks and share on the evaluation forms.

BIBLE VERSES:

2 Timothy 4:7
I have fought the good fight, I have finished the race, I have kept the faith.

Colossians1:29
To this end I strenuously contend with all the energy Christ so powerfully works in me.

Psalm 73:26
My flesh and my heart may fail, but God is the strength of my heart and my portion forever.

Romans 8:16-17
The Spirit himself testifies with our spirit that we are God's children. Now if we are children, then we are heirs—heirs of God and co-heirs with Christ, if indeed we share in his sufferings in order that we may also share in his glory.

Ecclesiastes 12:7
and the dust returns to the ground it came from, and the spirit returns to God who gave it.

2 Peter 3:18
But grow in the grace and knowledge of our Lord and Savior Jesus Christ. To him be glory both now and forever! Amen.

1 Kings 19
The story of Elijah.

Closing Thoughts & Prayers

- Do you feel that you **Embrace the Journey** differently than eight weeks ago? Share your thoughts.
- Ask if anyone in the group would be interested in doing the following activities on their own to create resource lists for your parish:
    - Create a list of facilities in your area where the elderly live in your community.
    - If your church hosts support groups, publish a list of them with times and dates where they meet.
- Close with praying the Prayer for Life together:

Prayer for Life

Lord God, thank You for creating human life in Your image.
Thank You for my life and the lives of those I love.
Thank You for teaching us through Scripture the value You place on life.
Help me to uphold the sanctity of life in my church and community.
Give me the strength to stand up to those forces that seek to destroy the lives of those most vulnerable, the unborn, the infirm, and the elderly.
Today I commit myself to never being silent, never being passive,
and never being forgetful of respecting life. I commit myself to protecting and defending
the sacredness of life according to Your will, through Christ our Lord.
Amen.

For Further Personal Study & Reflection

Meditate on these two beautiful Collects from Palm Sunday and Easter found in the **Book of Common Prayer**.

Almighty and ever living God, in your tender love for the human race you sent your Son our Savior Jesus Christ to take upon him our nature, and to suffer death upon the cross, giving us the example of his great humility: Mercifully grant that we may walk in the way of his suffering, and also share in his resurrection; through Jesus Christ our Lord, who lives and reigns with you and the Holy Spirit, one God, for ever and ever. Amen.

Almighty God, who through your only-begotten Son Jesus Christ overcame death and opened to us the gate of everlasting life: Grant that we, who celebrate with joy the day of the Lord's resurrection, may be raised from the death of sin by your life-giving Spirit; through Jesus Christ our Lord, who lives and reigns with you and the Holy Spirit, one God, now and forever. Amen

Week 8 DVD Script

The Role of the Church in Suffering & Death

1. Introduction - Inspired to embrace the journey of life to the fullest

Welcome to our final week of Embrace the Journey. We have journeyed down some challenging pathways over the last 7 weeks, and my prayer is that this series has inspired you to embrace the journey of life. I know God will use what you have learned for His glory and purpose, both in your life and in the lives of those you love.

For our final week, I want us to consider the calling of the Church in helping people Embrace the Journey. And, while I touched on suffering in Week 4, we will tackle the tough spiritual questions associated with it and what happens when you die.

a. Purpose of curriculum - help Church help people age with grace & die with faith

As I noted in Week 1, we created this curriculum because it is important for the Church to help people age with grace and die in faith. As our Creator, God is interested in every season of our life and, through His Church, God's equips both ordained and laity to help people get to the end of life and be able to say with the Apostle Paul in 2 Timothy, "I have fought the good fight, I have finished the race, I have kept the faith." (2 Tim 4:7)

I recently came across an article entitled A Place for Death in the Life of the Church published in Christianity Today by a young priest from Canada who wrote:

In many churches I've attended, death was pushed to the margins. It was treated like an interruption to God's work in the world, not as an instrument by which God draws people more fully into his own life. I'm not saying we should love death—after all, it's still "the last enemy" (1 Cor. 15:26). But part of living as disciples is learning to die well.

Ephraim Radner, professor of historical theology at Wycliffe College, writes,

"'To die well' is to locate what is good somewhere outside our control—in the God who gives and receives our lives. It is also to allow that alien goodness, the goodness of God's transcendent superintendence over life and its temporal duration, to inform the very meaning of our vulnerability to illness, suffering, and death."

In other words, by embracing death in our churches, we allow our creator to give meaning to our human weakness. Helping one another finish this life faithfully requires us to acknowledge both the practical and spiritual needs of our elderly friends and family in preparation for death.

2. Practical ministry support - ministry ideas for everyone

So let's start by discussing some important practical help that you and I as members of our local church can provide to our elderly, handicapped, or terminally ill brothers and sisters in Christ.

a. Compile resource list

One of my favorite ideas came from the Ft. Worth Diocese, in Texas. They developed an Elder Care Committee that compiled a list of resources available within the Ft. Worth/Dallas area for the elderly. Some of the resources are provided by members of various congregations and some by government agencies – the blessing is that now there is one all-inclusive resource list that is circulated to all the parishes and made available to parishioners. Any diocese can create their own list.

b. Support groups

Support Groups are also very important and a natural opportunity for community outreach – your church can host support groups for people dealing with a variety of challenges such as: grief, Alzheimer's, Full-time Care-giving, cancer. My church hosts a Stroke Victims group every Tuesday.

c. Spiritual adoption

Consider elderly parishioners who are single or have no family members living nearby and spiritually adopt them into your family! Invite them to holiday meals, offer to take them for doctor visits, talk with them about the issues addressed in Embrace the Journey. Offer help in concrete ways, such as, "Can I come over and help you do laundry?” Let them know you will be there for them, so they don’t feel so alone.

Be willing to step in as an advocate to help deal with issues that may confuse them or to speak for them if they have issues with dementia or are hearing impaired. Advocacy for others is a noble calling and is really needed in our fast-paced, electronic-dependent world. Something we take for granted, like using a remote control, can become a barrier for them, denying them the ability to enjoy a simple game show on TV.

d. Communion to shut-ins

Taking communion to shut-ins is such a blessing for them, as it ministers to their soul and connects them to the body of Christ. If they are still mobile, offer to pick them up and drive them to church. One friend of mine loved church but struggled going alone after her husband died because she sat by herself.

e. Relieve caregivers

And please don’t forget the needs of the care-givers. Offer to relieve them for an afternoon so they can get a haircut or take a nap. When you are cooking, make extra and, when you deliver it, and pray with them. Care for the Care-Givers!

f. Visit those recently widowed & in nursing homes

Visit patients, whether you know them or not, in a nursing home. One of my favorite things to do is take children’s books into our local nursing home, gather folks together, and read them the stories – the sing song rhyming rhythm delights them, and their smiles fill you with joy.

Don’t be afraid to visit those who have recently been widowed or had a close friend die. Encourage them to talk about their loved one and share their favorite memories. After my mom died, I was surprised by how much better I felt after talking about her with friends or family.

g. Help the next generation - see value in spiritual maturity

Help your older parishioners see the value of their wisdom and spiritual maturity by starting a ministry of older members mentoring younger members, encourage them to share the spiritual disciplines like prayer and bible study, which have helped them grow in their faith.

h. Preach a sermon about dying or end of life

Finally, I recommend churches set aside at least one Sunday a year to talk about aging and dying. Preach a sermon about dying, do a Sunday School class on the value of signing a power of attorney for health care, or bring in a speaker to address aging issues as a community outreach programme.

Remember, of all the groups, organizations, and agencies that might have something to say about aging and dying, we, the Church, have the best plan to offer – eternal life in Jesus Christ. The Church should be proudly and loudly sharing the good news of salvation with the aged.

i. Elderly evangelism

The idea of Elderly evangelism has inspired the St. Lazarus Mission, an Anglican ministry that is establishing churches in nursing homes in Ohio. They adopt everyone in the nursing home — residents and families, staff, and management. They minister both to and with the residents, filling them with purpose, for the glory of God, instead of just waiting to die. St. Lazarus realized no one was paying attention to this unique group of people and as Father Chris Herman, head of the mission says, “Age is the great equalizer. The folks in the nursing homes are done pursuing wealth and security and now, facing the end, they are much more open to accepting Jesus as Lord or recommitting their lives to Him after years of backsliding. The blessing is that God is still interested in them and bringing them back into fellowship with Him is a great joy, especially when they graduate to heaven, and we know they are meeting Jesus. Based on our records and that of the nursing home staff we work with, we see about 45% of the residents coming to the Lord or recommitting their lives to Him.”

Helping one another finish this race faithfully also requires us to acknowledge how the challenges of aging and suffering can make death seem preferable. Elijah’s struggles in first Kings, chapter 19 reminds us that God is aware of our infirmities, sees purpose in them, and inspires us to trust Him for our daily needs.

I encourage you to take time to read this great story in the Old Testament – the gist of it is that Elijah is afraid because Jezebel has threatened him, so he begs God to end his life, (kinda like requesting the lethal injection!). Instead God sends him on this difficult journey that lasts 40 days and keeps him busy anointing kings and Elisha to insure the future of the Israelites, all while providing for Elijah's needs and revealing Himself to the Prophet.

God doesn't answer his cry to die. In fact, just the opposite, he gives him new purpose in preparing the next generation of leaders for God's people.

Mentoring, volunteering, and leaving a legacy for the next generation are all great things we can do at any age! I encourage you to pray and ask the Lord to show you what you and your church can do to help one another finish well.

3. Spiritual teaching to prepare hearts and minds for death - Acknowledge the question of why there is suffering

Billy Graham says, quote "Remember one of the Bible's central truths: Every day – without exception – is a gift from God, entrusted to us to use for His Glory. This is true for your working years, and it is equally true for your retirement." Later in his book Nearing Home, Billy Graham goes on to say:

"God knows our infirmities. He knows our strength wanes as the years pass. Our dependence on Him delights Him. Paul reminds us in Colossians that he depended on Christ's mighty power that works within, and we can claim this as well. Remember, He knows our bodies won't live forever, and He knows exactly how we feel. We shouldn't spend time thinking about ourselves and how weak we are. Instead we should think about God and how strong He is. We are told to respond to God's voice and He will be our strength. The psalmist wrote 'My flesh and my heart fail; But God is the strength of my heart'"

These truths are critical to keep before us, especially as our strength wanes and infirmities, pain, and suffering seem to be constant companions. While it is normal to ask why God allows these difficulties in our lives, I hope these reflections by some wise shepherds provide solace and encouragement.

a. Fr. Keith Allen

First Canon Keith Allen, Rector of Holy Trinity Anglican Church in Mississippi, answers why God allows pain.

Rather than ask the question why, which I can't answer for you, and I said, "And even if I could say why, is there any answer that would be good enough to justify the pain that we're feeling right now? I don't think so, but what I can tell you is who. I can tell you who holds you in His hand. I can tell you who is sovereign over today and who will be sovereign over tomorrow. I can tell you what, what we should do in this moment.

We should praise God. We should praise God for the people that we knew, that we've lost. We should praise God for the relationships that He gave us. We should praise God for grace that gives us a hope beyond this life."

b. Bishop John Rodgers

Bp. John Rodgers, retired bishop of the Anglican Church in North America addresses suffering

For me, at least, I would say I just have to trust God, that whatever you go through, He's got that in His hands. We're not outside of His care. He says in Romans, through the apostle Paul, he says that, "He makes all things work together for good." He doesn't say that everything is good, he says He makes all things work together for good. That this won't be wasted, the suffering will not be wasted.

Some people say, "If suffering is like this, then I'm not going to believe in God." Then you're just left with the suffering and yourself and maybe your friends. You can say, "I don't fully understand all this suffering, but I understand that God is with me in it and Whose hands I am, and Whose victory is sure." Therefore, you relativize the power of the suffering, it seems to me.

Romans Chapter 8 remind us that suffering is something experienced only on this side of heaven – "The Spirit himself testifies with our spirit that we are God's children. Now if we are children, then we are heirs—heirs of God and co-heirs with Christ, if indeed we share in his sufferings in order that we may also share in his glory. I consider that our present sufferings are not worth comparing with the glory that will be revealed in us."

c. *Jesus Calling* - Be prepared to suffer for Me

This teaching in Jesus Calling has helped me see suffering from God's perspective: quote "BE PREPARED TO SUFFER FOR ME, in My Name. All suffering has meaning in My kingdom. Pain and problems are opportunities to demonstrate your trust in Me. Bearing your circumstances bravely—even thanking Me for them—is one of the highest forms of praise. This sacrifice of thanksgiving rings golden-toned bells of Joy throughout heavenly realms. On earth also, your patient suffering sends out ripples of good tidings in ever-widening circles.

When suffering strikes, remember that I am sovereign and that I can bring good out of everything. Do not try to run from pain or hide from problems. Instead, accept adversity in My Name, offering it up to Me for My purposes. Thus, your suffering gains meaning and draws you closer to Me. Joy emerges from the ashes of adversity through your trust and thankfulness."

d. Jesus suffering during Holy Week

I also think it helps to put our suffering in perspective when we contemplate Jesus' 40 days in the wilderness, where He suffered from heat, thirst, hunger, and temptation. Meditating on the events of Holy Week brings Christ's anguish into focus, as He sweat blood in the Garden of Gethsemane, praying for God to take the cup of suffering from Him. Consider Good Friday when Jesus was stripped, flogged, crowned with thorns, spit on, mocked, forced to carry His cross, nailed to the cross, forsaken, and left dead. Christ suffered all of that for our sins and through that suffering He opened the door of heaven to us, where there is no suffering and death has lost its sting.

4. Fear of death - Why?

So the next question becomes, if death has lost its sting for believers, why do we still fear death?

a. Bishop Derek Jones

I love Bp Derek Jone's answer to this question.

How do you deal with the fear of death? Stop it. Of what value is it to you? Of what gain? You're going to die. Now if you want to … I've heard people and I've heard ministers, "Live everyday as though today were your last." That's not a really great way to live. I'd rather live every day in the grace of Jesus Christ and look for every opportunity to exercise my talents, the gifts, and the things that bring me joy. I would look to do the work and the labors that I've been charged to do for the benefit of others. I should do that every day whether it's out of a fear of death or a love of life. It's far better to be focused on the love of life than it is on the fear of death. It's really just a matter of perspective.

b. Bishop John Rodgers

Bp. Rodgers unpacks the fear of death even more.

We fear death, first of all, because it's unnatural. We also don't understand it. We've never done this before. When we do anything for the first time, we're anxious, tend to be. It's only that Jesus has done this for us, and so we can put our hands in His and be a little bit less afraid. He says, in John's Gospel, He says "I'm going off to prepare a place for you. If not, I wouldn't have told you I did, and I will come." I interpret that, that when we die, He's there to welcome us and to take us to where He is. Wow, that's an exciting thought. Eventually, if we work at it long enough and read long enough, we reverse our anxious culture's view of death to a positive door into a glorious presence.

It was helpful to me just to begin to say, "What do we fear about death?" Loss of relationships, guilt before God, all the different things that I tried to run down, deprivation of just beauty, and all the things that I treasure. Go, gone. Replaced by grimness and guilt and all the things that peek at you at death. Suddenly, they become the defining reality of your life, rather than why you've been happy to be alive.

I think in our culture, people assume that death is extinction. There's nothing in Scripture that supports that. From the beginning of the Scripture right on through, and in most world religions, there's some kind of soul that lives on. The Scripture says in Ecclesiastes 12, that when we die, "Our bodies go to dust but our soul returns unto the Lord." We're standing before God when we die.

Why, then, do we go through death? Why aren't we translated the way some people were? The answer is the old Adam still needs to be put to death, and so it's the final function of our sanctification, it seems to me. He uses that. He will use that suffering. It casts us back on His mercy and His help. He draws us closer to Himself through it all.

Fr. Montzingo answers- what happens to you when you die?

What I think the Bible teaches very clearly is the resurrection of the body. That Jesus' resurrection is a prototype of what we're going to be when he returns. That is, we're going to have a resurrection body. It's going to be similar to who we are now, but there's some differences, just as his body was similar but different. It would be… and there would be new heavens and new earth. The promise in scripture is the reunion of heaven and earth. Not that we go away some place, but that heaven and earth are brought together. Heavens and earth are remade, and we have resurrected bodies. There's huge amounts you could speculate but that seems to be the baseline.

The real rub is what happens between death and resurrection of the body. Because biblically speaking, resurrection of the body in the New Testament is still in the future. It is when Christ returns. Unless I know something that hasn't happened yet. I think you can have differences of opinion about that. My take on that would be there is some sort of an intermediate state where we are in the presence of God. I think there is consciousness, but to put it bluntly, we don't have the full package yet. Because that's what the second coming, final judgment, new heavens, and new earth bring about.

God is out of time and above time and so to be in the presence of God is in some sense to be out of time. From our standpoint, when I die and say Christ return is 500 years in the future, it looks like 500 years. If you're out time, it's all now, it's all presence. My experience of that is not the same, as what it would be on earth.

Of course in terms of pastoral care we're talking about people who still are on earth. It's making sense to them about what they are sensing and experiencing. Not so much about what's actually happened to the person who's died.

5. Conclusion - Doubts and fears become hope and joy

As we, who are still here on earth, think about what happens when our loved ones die, I hope our doubts and fears will be turned into hope and joy as we embrace the journey of this mortal life, trusting in Jesus for eternal life. Only by walking with God will we find the path that leads to eternity.

During these eight weeks together, we have discussed many challenges that come with aging and dying, including the growing influences to end life in man's time instead of God's. Whether you have viewed this programme as the one aging or as one concerned for others, I hope you have been blessed, encouraged, and filled with the knowledge of God's unending love.

a. Additional resources & information in back of book

There is much I have left unsaid for the sake of time, so once again I commend the articles, websites, bibliography, and resources in the back of your book for further study and consideration.

Don't forget to fill-out your evaluation forms – and please know how much I appreciate you participating in Embrace the Journey.

As I prayed for the right words to conclude our time together, God answered my prayer in a totally unexpected way. It was through an email with a link to this video, inspired by a painting done by artist and theologian, Chuck Pinson.

b. Bridge of Triumph

"The Bridge of Triumph" video

VIDEO

c. Wishing you God's grace & peace

Let the promises of God illuminate your pathway as you Embrace the Journey with Him. With praise and thanksgiving, I'm Deacon Georgette Forney, President of Anglicans for Life, wishing you all God's grace and peace until we meet in heaven!

Bibliography, Resources,
&
Recommended Articles for each week

Embrace the Journey

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By Philip Giddings, Martin Down, Elaine Sugden, Gareth Tuckwell
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By Betty Free
Tyndale House, 2002, ISBN 0-8423-5377-1

Fighting for Dear Life
By David Gibbs
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Jesus Calling
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Preparation for a Holy Death in 16th and 17th Century Anglicanism
Texts for this topic include:

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- David W. Atkinson - "The English Ars Moriendi "
- Nancy L. Beaty - "The craft of dying. A study in the literary tradition of the Ars Moriendi in England"
- Jeremy Taylor - "Holy Dying"
- Richard Baxter - "Dying Thoughts of the Rev Richard Baxter"
- Bettie Anne Doebler - "The Quickening Seed: Death in the Sermons of John Donne"
- Frances M.M. Compter (Ed). - "The craft of dying, and other early English tracts concerning death"
- Phillipe Aries - "The Hour of Our Death"

<u>AFL Resources</u> - *available @ AnglicansforLife.org*

<u>Article</u>
"Why Life is Important," by Georgette Forney

<u>Booklets</u>
"Life Affirming Bible Verses, Prayers, Liturgies and Litanies"
"Finishing Life - Preparing for the End of Life"
"Aging & Dying"

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http://www.bereavedparentsusa.org/ (Bereaved Parents of the USA)

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http://www.griefnet.org/

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http://www.missfoundation.org/ (The MISS Foundation online for death of a child)

http://grasphelp.org/ (Grief recovery after a substance passing)

http://www.griefsong.com/ (Healing the Loss w/Paul Alexander, Music, And Bereavement Resources)

http://www.widowswearstilettos.com/ (online support for young widows)

http://bronnieware.com/blog/ We highly recommend Ms. Ware's important book and blog. Each contain insights into caring for others and ourselves.

Week 1 - Ted Talk - https://www.ted.com/talks/peter_saul_let_s_talk_about_dying/transcript

www.retirementreformation.org

Week 2 - https://www.crosswalk.com/family/parenting/new-parents/5-things-you-should-know-about-parenting-your-parents.html

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Week 3 - https://lozierinstitute.org/basic-care-human-dignity-and-care-for-medically-vulnerable-persons/

Week 4 - Information about Hospice Benefits:

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Week 6 - AFL Summit Videos

- Wes Smith - https://youtu.be/CUhFUe3cRFk
- Rick Bergh 2018 - https://youtu.be/lBsiZrU9quk
- Rick Bergh 2019 - https://youtu.be/W9pHy8I0aCU

HELP Resources

Euthanasia Prevention Coalition, 1-800-439-3348

International Association for Hospice & Palliative Care, *HospiceCare.com*, 866-374-2472

For a national list of Hospice facilities: *HospiceDirectory.org*

Additional Secular Resources

Note: Anglicans for Life does not endorse the following materials. They are provided for informational purposes and for further research, if desired.

Children

Baby to preschool

Badger's Parting Gifts, Susan Varley, 1992

Pre-school to age 7

Talking about Death: A Dialogue between Parent and Child, Earl A. Grollman, 1991.

Ages 4 to 8

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The Tenth Good Thing about Barney, Judith Viorst, 1987.

Ages 9 to 12

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Week 1

TRINITY SCHOOL FOR MINISTRY: LENT 2018: THURSDAY, MARCH 1

Growing old, we are told, is not for the faint of heart. My eighty-five year old mother says it best: "If I wake up in the morning and nothing hurts then I'll know I'm in heaven."

With each passing year we become more infirm, more isolated by lack of mobility and loss of strength. In addition, we mourn the death of family and friends coupled with the narrowing of human interaction which accompanies these inevitable life events.

It is to be expected, even anticipated, that this reality would produce—even if the words are never spoken—the fear, the sense of foreboding, the dread of abandonment expressed by the author of Psalm 71: "Do not cast me off in the time of old age; forsake me not when my strength is spent."

For solace, he returns to the past, to those times when God's presence was real, tangible, even tactile and visible—much like one does when the photo album is opened and memories of past joys and adventures are brought back to life with stories from long ago so fresh, so alive in a way the present could never match. The psalmist tells us God was there at his conception and held him in his arms. The Lord guided his every step, saved his life and silenced his enemies. Then the people gathered to give thanks and bless the name of the Lord.

When the psalmist recognizes that God was present in his past, the future fills with hope, a hope which informs his current reality and inspires true worship: "Father, into your hands I commit my spirit" (Luke 23:46).

In Lent, we are invited to embrace the reality of aches and pains, loneliness and loss, anxiety and fear, depression and death. The invitation comes from the One who embraced all of life. He took upon himself every aspect of our broken, isolated, and infirm humanity.

And yet, we rejoice knowing that in the midst of death there is life, and in the midst of Good Friday there is Easter: "But I will hope continually and will praise you yet more and more" (Psalm 71:14).

The Rev. Dr. Duane E. Petersen (DMin 2006)
Lafayette, LA

'Heaven Is Real': Neurosurgeon Who Once Doubted Out-of-Body Experiences Describes His Own

Billy Hallowell

Is Heaven for real?

This age-old question has been debated for centuries. Of late, the subject has been tacked in theological circles and has been extensively covered by mainstream media. Many who have had near-death experiences regularly describe the images they saw after purportedly crossing into the after-life. Who can forget Colton Burpo's story? The young boy claims to have ascended into heaven during a near-death experience back in 2003. His story inevitably made its way into a popular book called, "Heaven Is for Real." But Burpo isn't alone.

There have been similar experiences told in popular media. The latest tale comes from Dr. Eben Alexander, a neurosurgeon who, ironically, never really believed in near-death experiences before falling into a coma. In the October 15 issue of Newsweek, though, Alexander details his purported ascent to heaven and his subsequent change-of-heart.

With a firm understanding of the human brain, Alexander had previously dismissed purported journeys outside of the earthly realm as a byproduct of what happens to human beings in the throes of trauma. However, that changed once he found himself heaven-bound. The neurosurgeon explains:

In the fall of 2008…after seven days in a coma during which the human part of my brain, the neocortex, was inactivated, I experienced something so profound that it gave me a scientific reason to believe in consciousness after death. [...]

Very early one morning four years ago, I awoke with an extremely intense headache. Within hours, my entire cortex—the part of the brain that controls thought and emotion and that in essence makes us human—had shut down. Doctors at Lynchburg General Hospital in Virginia, a hospital where I myself worked as a neurosurgeon, determined that I had somehow contracted a very rare bacterial meningitis that mostly attacks newborns. E. coli bacteria had penetrated my cerebrospinal fluid and were eating my brain.

When I entered the emergency room that morning, my chances of survival in anything beyond a vegetative state were already low. They soon sank to near nonexistent. For seven days I lay in a deep coma, my body unresponsive, my higher-order brain functions totally offline.

Then, on the morning of my seventh day in the hospital, as my doctors weighed whether to discontinue treatment, my eyes popped open.

While that's the recap of what was going on with Alexander's body on the outside, what was occurring within, he claims, was supernatural. Rather than consciousness ending once earthly awareness came to a close, the neurosurgeon said that he discovered that "consciousness exists beyond the body." In the Newsweek article, he describes his journey in detail.

First, he saw white-pink clouds against a blue-black backdrop (purportedly *the sky*). Above the clouds, he claims to have observed "flocks of transparent, shimmering beings arced across the sky." While he isn't able to define exactly what he observed, he called them advanced, higher forms of being. The creatures were so content and overjoyed, Alexander recalls, that they created a "glorious chant" as they moved.

He also stressed the interconnectedness of everything he observed, writing, "Everything was distinct, yet everything was also a part of everything else, like the rich and intermingled designs on a Persian carpet … or a butterfly's wing."

On this journey, Alexander said a woman was with him and that she delivered to him very pointed messages. While she didn't speak in the traditional sense, Alexander was able to understand her every word. The general messages were: "You are loved and cherished, dearly, forever," "You have nothing to fear" and "There is nothing you can do wrong."

The woman also told him that she (and others) would show him many things in this new world, but that he would inevitably return to earth. These are only a few of the elements that he described seeing. Just as surprising as what he observed is the change-of-heart that Alexander has had as a result of the experience:

I know full well how extraordinary, how frankly unbelievable, all this sounds. Had someone—even a doctor—told me a story like this in the old days, I would have been quite certain that they were under the spell of some delusion. But what happened to me was, far from being delusional, as real or more real than any event in my life. That includes my wedding day and the birth of my two sons. [...]

Before my experience these ideas were abstractions. Today they are realities. Not only is the universe defined by unity, it is also—I now know—defined by love. The universe as I experienced it in my coma is—I have come to see with both shock and joy—the same one that both Einstein and Jesus were speaking of in their (very) different ways.

I've spent decades as a neurosurgeon at some of the most prestigious medical institutions in our country. I know that many of my peers hold—as I myself did—to the theory that the brain, and in particular the cortex, generates consciousness and that we live in a universe devoid of any kind of emotion, much less the unconditional love that I now know God and the universe have toward us. But that belief, that theory, now lies broken at our feet. What happened to me destroyed it, and I intend to spend the rest of my life investigating the true nature of consciousness and making the fact that we are more, much more, than our physical brains as clear as I can, both to my fellow scientists and to people at large.

Unlike other scientists and skeptics, he no longer believes that the “living spiritual truths of religion” have lost their power. Church, for Alexander, now has an entirely different meaning, as does the notion that there is a God that has an intense and overwhelming love for humanity. Though he still considers himself a man of science and a doctor, he is in touch with the spiritual realm and he believes that his perspective will never be the same. He concludes that “heaven is real.”

You can read Alexander’s Newsweek article for more information here:

http://www.thedailybeast.com/newsweek/2012/10/07/proof-of-heaven-a-doctor-s-experience-with-the-afterlife.html

The scientist’s new book, “Proof of Heaven,” is also about his near-death experience.

Week 2

PDF Version of Finish Life: How to Prepare for the End of Life can be accessed here:

https://cdn.shopify.com/s/files/1/0058/8985/1481/files/Finishing_Life_BOOK.pdf?16858459926015344733 download the pdf and save it to your computer! You can update as needed. Just remember to document where it is in your computer for those who will need to access it.

Websites for Practical Needs*

List of Websites for Making the Home Safe

http://www.homesafetysmartcheck.com/ - Various printable checklists available for different rooms and levels of needs.

https://www.cdc.gov/homeandrecreationalsafety/pubs/english/booklet_eng_desktop-a.pdf

https://www.americaninhomecare.com/blog/2017/09/25/elderly-home-safety-checklist/

Caregiving Needs:

These two sites provide links to local organizations and additional resources.

https://eldercare.acl.gov/Public/index.aspx - Put your zip code in and it provides links to local services or call 800-677-1116

https://www.asaging.org/blog/25-organizations-take-care-caregivers - American Society on Aging Very broad list of 25 websites that provide support for the elderly, their care-givers and more.

*None of these websites have any Christian affiliation. Care must be taken when bringing care-givers through outside organizations into the home. Referrals from friends is sometimes a better way to find caregivers.

An article about Guardianship & Abuse:

How the Elderly Lose Their Rights

Guardians can sell the assets and control the lives of senior citizens without their consent—
and reap a profit from it.

By Rachel Aviv

For years, Rudy North woke up at 9 A.M. and read the Las Vegas Review-Journal while eating a piece of toast. Then he read a novel—he liked James Patterson and Clive Cussler—or, if he was feeling more ambitious, Freud. On scraps of paper and legal notepads, he jotted down thoughts sparked by his reading. “Deep below the rational part of our brain is an underground ocean where strange things swim,” he wrote on one notepad. On another, “Life: the longer it cooks, the better it tastes.”

Rennie, his wife of fifty-seven years, was slower to rise. She was recovering from lymphoma and suffered from neuropathy so severe that her legs felt like sausages. Each morning, she spent nearly an hour in the bathroom applying makeup and lotions, the same brands she’d used for forty years. She always emerged wearing pale-pink lipstick. Rudy, who was prone to grandiosity, liked to refer to her as “my amour.”

On the Friday before Labor Day, 2013, the Norths had just finished their toast when a nurse, who visited five times a week to help Rennie bathe and dress, came to their house, in Sun City Aliante, an “active adult” community in Las Vegas. They had moved there in 2005, when Rudy, a retired consultant for broadcasters, was sixty-eight and Rennie was sixty-six. They took pride in their view of the golf course, though neither of them played golf.

Rudy chatted with the nurse in the kitchen for twenty minutes, joking about marriage and laundry, until there was a knock at the door. A stocky woman with shiny black hair introduced herself as April Parks, the owner of the company A Private Professional Guardian. She was accompanied by three colleagues, who didn’t give their names. Parks told the Norths that she had an order from the Clark County Family Court to “remove” them from their home. She would be taking them to an assisted-living facility. “Go and gather your things,” she said.

Rennie began crying. “This is my home,” she said.

One of Parks’s colleagues said that if the Norths didn’t comply he would call the police. Rudy remembers thinking, You’re going to put my wife and me in jail for this? But he felt too confused to argue.

Parks drove a Pontiac G-6 convertible with a license plate that read “cRTGRDN,” for “court guardian.” In the past twelve years, she had been a guardian for some four hundred wards of the court. Owing to age or disability, they had been deemed incompetent, a legal term that describes those who are unable to make reasoned choices about their lives or their property. As their guardian, Parks had the authority to manage their assets, and to choose where they lived, whom they associated with, and what medical treatment they received. They lost nearly all their civil rights.

Without realizing it, the Norths had become temporary wards of the court. Parks had filed an emergency ex-parte petition, which provides an exception to the rule that both parties must be notified of any argument before a judge. She had alleged that the Norths posed a “substantial risk for mismanagement of medications, financial loss and physical harm.” She submitted a brief letter from a physician’s assistant, whom Rennie had seen once, stating that “the patient’s husband can no longer effectively take care of the patient at home as his dementia is progressing.” She also submitted a letter from one of Rudy’s doctors, who described him as “confused and agitated.”

Rudy and Rennie had not undergone any cognitive assessments. They had never received a diagnosis of dementia. In addition to Freud, Rudy was working his way through Nietzsche and Plato. Rennie read romance novels.

Parks told the Norths that if they didn’t come willingly an ambulance would take them to the facility, a place she described as a “respite.” Still crying, Rennie put cosmetics and some clothes into a suitcase. She packed so quickly that she forgot her cell phone and Rudy’s hearing aid. After thirty-five minutes, Parks’s assistant led the Norths to her car. When a Neighbor asked what was happening, Rudy told him, “We’ll just be gone for a little bit.” He was too proud to draw attention to their predicament. “Just think of it as a mini-vacation,” he told Rennie.

After the Norths left, Parks walked through the house with Cindy Breck, the owner of Caring Transitions, a company that relocates seniors and sells their belongings at estate sales. Breck and Parks had a routine. “We open drawers,” Parks said at a deposition. “We look in closets. We pull out boxes, anything that would store—that would keep paperwork, would keep valuables.” She took a pocket watch, birth certificates, insurance policies, and several collectible coins.

The Norths’ daughter, Julie Belshe, came to visit later that afternoon. A fifty-three-year -old mother of three sons, she and her husband run a small business designing and constructing pools. She lived ten miles away and visited her parents nearly every day, often taking them to her youngest son’s football games. She was her parents only living child, her brother and sister had died.

She knocked on the front door several times and then tried to push the door open, but it was locked. She was surprised to see the kitchen window closed; her parents always left it slightly open. She drove to the Sun City Aliante clubhouse, where her parents sometimes drank coffee. When she couldn’t find them there, she thought that perhaps they had gone on an errand together—the farthest they usually drove was to Costco.

But, when she returned to the house, it was still empty.

That weekend, she called her parents several times. She also called two hospitals to see if they had been in an accident. She called their landlord, too, and he agreed to visit the house. He reported that there were no signs of them. She told her husband, “I think someone kidnapped my parents.”

On the Tuesday after Labor Day, she drove to the house again and found a note taped to the door: “In case of emergency, contact guardian April Parks.” Belshe dialled the number. Parks, who had a brisk, girlish way of speaking, told Belshe that her parents had been taken to Lakeview Terrace, an assisted-living facility in Boulder City, nine miles from the Arizona border. She assured Belshe that the staff there would take care of all their needs.

“You can’t just walk into somebody’s home and take them!” Belshe told her. Parks responded calmly, “It’s legal. It’s legal.”

Guardianshop derives from the state’s parens patriae power, its duty to act as a parent for those considered too vulnerable to care for themselves. “The King shall have the custody of the lands of natural fools, taking the profits of them without waste or destruction, and shall find them their necessaries,” reads the English statute De Prerogative Regis, from 1324. The law was imported to the colonies—guardianship is still controlled by state, not federal, law—and has remained largely intact for the past eight hundred years. It establishes a relationship between ward and guardian that is rooted in trust.

In the United States, a million and a half adults are under the care of guardians, either family members or professional, who control some two hundred and seventy-three billion dollars programme in Palm Beach County. Little is known about the outcome of these arrangements, because states do not keep complete figures on guardianship cases—statutes vary widely—and, in most jurisdictions, the court records are sealed. A Government Accountability report from 2010 said, “We could not locate a single Web site, federal agency, state or local entity, or any other organization that compiles comprehensive information on this issue.” A study published this year by the American Bar Association found that “an unknown number of adults languish under guardianship” when they no longer need it, or never did. The authors wrote that “guardianship is generally “permanent, leaving no way out—‘until death do us part.’ ”

When the Norths were removed from their home, they joined nearly nine thousand adult wards in the Las Vegas Valley. In the past twenty years, the city has promoted itself as a retirement paradise. Attracted by the state’s low taxes and a dry, sunny climate, elderly people leave their families behind to resettle in newly constructed senior communities. “The whole town sparkled, pulling older people in with the prospect of the American Dream at a reasonable price,” a former real-estate agent named Terry Williams told me. Roughly thirty per cent of the people who move to Las Vegas are senior citizens, and the number of Nevadans older than eighty-five has risen by nearly eighty per cent in the past decade.

In Nevada, as in many states, anyone can become a guardian by taking a course, as long as he or she has not been convicted of a felony or recently declared bankruptcy.

Elizabeth Brickfield, a Las Vegas lawyer who has worked in guardianship law for twenty years, said that about fifteen years ago, as the state's elderly population swelled, "all these private guardians started arriving, and the docket exploded. The court became a factory."

Pamela Teaster, the director of the Center for Gerontology at Virginia Tech and one of the few scholars in the country who study guardianship, told me that, though most guardians assume their duties for good reasons, the guardianship system is "a morass, a total mess." She said, "It is unconscionable that we don't have any data, when you think about the vast power given to a guardian. It is one of society's most drastic interventions."

After talking to Parks, Belshe drove forty miles to Lakeview Terrace, a complex of stucco buildings designed to look like a hacienda. She found her parents in a small room with a kitchenette and a window overlooking the parking lot. Rennie was in a wheelchair beside the bed, and Rudy was curled up on a love seat in the fetal position. There was no phone in the room. Medical-alert buttons were strung around their necks. "They were like two lost children," Belshe said.

She asked her parents who Parks was and where she could find the court order, but, she said, "they were overwhelmed and humiliated, and they didn't know what was going on." They had no idea how or why Parks had targeted them as wards. Belshe was struck by their passive acceptance. "It was like they had Stockholm syndrome or something," she told me.

Belshe acknowledged that her parents needed a few hours of help each day, but she had never questioned their ability to live alone. "They always kept their house really nice and clean, like a museum," she said. Although Rudy's medical records showed that he occasionally had "staring spells," all his medical-progress notes from 2013 described him as alert and oriented. He did most of the couple's cooking and shopping, because Rennie, though lucid, was in so much pain that she rarely left the house. Belshe sometimes worried that her father inadvertently encouraged her mother to be docile: "She's a very smart woman, though she sometimes acts like she's not. I have to tell her, 'That's not cute, Mom.' "

When Belshe called Parks to ask for the court order, Parks told her that she was part of the "sandwich generation," and that it would be too overwhelming for her to continue to care for her children and her parents at the same time. Parks billed her wards' estates for each hour that she spent on their case; the court placed no limits on guardians' fees, as long as they appeared "reasonable." Later, when Belshe called again to express her anger, Parks charged the Norths twenty-four dollars for the eight-minute conversation. "I could not understand what the purpose of the call was other than she wanted me to know they had rights," Parks wrote in a detailed invoice. "I terminated the phone call as she was very hostile and angry."

A month after removing the Norths from their house, Parks petitioned to make the guardianship permanent. She was represented by an attorney who was paid four hundred dollars an hour by the North's estate. A hearing was held at Clark County Family Court.

The Clark County guardianship commissioner, a lawyer named Jon Norheim, has presided over nearly all the guardianship cases in the county since 2005. He works under the supervision of a judge, but his orders have the weight of a formal ruling. Norheim awarded a guardianship to Parks, on average, nearly once a week. She had up to a hundred wards at a time. "I love April Parks," he said at one hearing, describing her and two other professional guardians, who frequently appeared in his courtroom, as "wonderful, good-hearted, social-worker types."

Norheim's court perpetuated a cold, unsentimental view of family relations: the ingredients for a good life seemed to have little to do with one's children and siblings. He often dismissed the objections of relatives, telling them that his only concern was the best interest of the wards, which he seemed to view in a social vacuum. When siblings fought over who would be guardian, Norheim typically ordered a neutral professional to assume control, even when this isolated the wards from their families.

Rudy had assured Belshe that he would protest the guardianship, but, like most wards in the country, Rudy and Rennie were not represented by counsel. As Rudy stood before the commissioner, he convinced himself that guardianship offered him and Rennie a lifetime of care without being a burden to anyone they loved. He told Norheim, "The issue really is her longevity—what suits her." Belshe, who sat in the courtroom, said, "I was shaking my head. No, no, no—don't do that!" Rennie was silent.

Norheim ordered that the Norths become permanent wards of the court. "Chances are, I'll probably never see you folks again; you'll work everything out," he said, laughing. "I very rarely see people after the initial time in court." The hearing lasted ten minutes.

The following month, Even Tide Life Transitions, a company that Parks often hired, sold most of the Norths' belongings. "The general condition of this inventory is good," an appraiser wrote. Two lithographs by Renoir were priced at thirty- eight hundred dollars, and a glass cocktail table ("Client states that it is a Brancusi design") was twelve hundred and fifty dollars. The Norths also had several pastel drawings by their son, Randy, who died in a motorcycle accident at the age of thirty- two, as well as Kachina dolls, a Bose radio, a Dyson vacuum cleaner, a Peruvian tapestry, a motion-step excerciser, a LeRoy Neiman sketch of a bar in Dublin, and two dozen pairs of Clarke shoes. According to Park's calculations, the North's had roughly fifty thousand dollars. Parks transferred their savings, held at the Bank of America, to an account in her name.

Rennie repeatedly asked for her son's drawings, and for the family photographs on her refrigerator. Rudy pined for his car, a midnight-blue 2010 Chrysler, which came to symbolize the life he had lost. He missed the routine interactions that driving had allowed him. "Everybody at the pharmacy was my buddy," he said. Now he and Rennie felt like exiles. Rudy said, "They kept telling me, 'Oh, you don't have to worry: your car is fine, and this and that.' " A month later, he said, "they finally told me, 'Actually, we sold your car.' I said, 'What in the hell did you sell it for?' " It was bought for less than eight thousand dollars, a price that Rudy considered insulting.

Rudy lingered in the dining room after eating breakfast each morning, chatting with other residents of Lakeview Terrace. He soon discovered that ten other wards of April Parks lived there. His next-door Neighbor, Adolfo Gonzalez, a short, bald seventy-one- year-old who had worked as a maître d' at the MGM Grand Las Vegas, had become Parks's ward at a hearing that lasted a minute and thirty-one seconds.

Gonzalez, who had roughly three hundred and fifty thousand dollars in assets, urged Rudy not to accept the nurse's medications. "If you take the pills, they'll make sure you don't make it to court," he said. Gonzalez had been prescribed the antipsychotic medications Risperdal and Depakote, which he hid in the side of his mouth without swallowing. He wanted to remain vigilant. He often spoke of a Salvador Dali painting that had been lost when Parks took over his life. Once, she charged him two hundred and ten dollars for a visit in which, according to her invoice, he expressed that "he feels like a prisoner."

Rudy was so distressed by his conversations with Gonzalez that he asked to see a psychologist. "I thought maybe he'd give me some sort of objective learning as to what I was going through," he said. "I wanted to ask basic questions, like What the hell is going on?" Rudy didn't find the session illuminating, but he felt a little boost to his self- esteem when the psychologist asked that he return for a second appointment. "I guess he found me terribly charming," he told me. Rudy like to fantasize about an alternative life as a psychoanalyst, and he tried to befriend the wards who seemed especially hopeless. Loneliness is a physical pain that hurts all over," he wrote in his notebook. He bought a pharmaceutical encyclopedia and advised the other wards about medications they'd been prescribed. He also ran for president of the residents, promising that under his leadership the kitchen would no longer advertise canned food as homemade. (He lost—he's not sure if anyone besides Rennie voted for him—but he did win a seat on the residents' council.)

He was particularly concerned about a ward of Parks's named Marlene Homer, a seventy-year-old woman who had been a professor. "Now she was almost hiding behind the pillars," Rudy said. "She was so obsequious. She was, like, 'Run me over. Run me over.' " She'd become a ward in 2012, after Parks told the court, "She has admitted to strange thoughts, depression, and doing things she can't explain." On a certificate submitted to the court, an internist had checked a box indicating that Homer was “unable to attend the guardianship court hearing because,” but he didn’t fill in a reason.

The Norths could guess which residents were Parks’s wards by the way they were dressed. Gonzalez wore the same shirt to dinner nearly every day. “Forgive me,” he told the others at his table. When a friend tried to take him shopping, Parks prevented the excursion because she didn’t know the friend. Rennie had also tried to get more clothes. “I reminded ward that she has plenty of clothing in her closet,” Parks wrote. “I let her know that they are on a tight budget.” The Norths’ estate was charged a hundred and eighty dollars for the conversation.

Another resident, Barbara Neely, a fifty-five-year-old with schizophrenia, repeatedly asked Parks to buy her outfits for job interviews. She was applying for a position with the Department of Education. After Neely’s third week at Lakeview Terrace, Parks’s assistant sent Parks a text. “Can you see Barbara Neely anytime this week?” she wrote. “She has questions on the guardianship and how she can get out of it.” Parks responded, “I can and she can’t.” Neely had been in the process of selling her house, for a hundred and sixty-eight thousand dollars, when Parks became her guardian and took charge of the sale.

The rationale for the guardianship of Norbert Wilkening, who lived on the bottom floor of the facility in the memory-care ward, for people with dementia (“the snake pit,” Rudy called it), was also murky. Park’s office manager, who advertised himself as a “Qualified Dementia Care Specialist” – a credential acquired through video training sessions—had given Wilkening a “Mini-Mental State Examination,” a list of eleven questions and tasks, including naming as many animals as possible in a minute.

Wilkening had failed. His daughter, Amy, told me, “I didn’t see anything that was happening to him other than a regular getting-older process, but when I was informed by all these people that he had all these problems I was, like, Well, maybe I’m just in denial. I’m not a professional.” She said that Parks was “so highly touted. By herself, by the social workers, by the judge, by everyone that knew her.”

At a hearing, when Amy complained to Norheim that Parks didn’t have time for her father, he replied, “Yeah, she’s an industry at this point.”

As Belshe spoke to more wards and their families, she began to realize that Lakeview Terrace was not the only place where wards were lodged, and that Parks was not the only guardian removing people from their homes for what appeared to be superficial reasons. Hundreds of cases followed the same pattern. It had become routine for guardians in Clark County to petition for temporary guardianship on an ex- parte basis. They told the court that they had to intervene immediately because the ward faced a medical emergency that was only vaguely described: he or she was demented or disoriented, and at risk of exploitation or abuse. The guardians attached a brief physician’s certificate that contained minimal details and often stated that the ward was too incapacitated to attend a court hearing. Debra Bookout, an attorney at the Legal Aid Center of Southern Nevada, told me, “When a hospital or rehab facility needs to free up a bed, or when the patient is not paying his bills, some doctors get sloppy, and they will sign anything.” A recent study conducted by Hunter College found that a quarter of guardianship petitions in New York were brought by nursing homes and hospitals, sometimes as a means of collecting on overdue bills.

It often took several days for relatives to realize what had happened. When they tried to contest the guardianship or become guardians themselves, they were dismissed as unsuitable, and disparaged in court records as being neglectful, or as drug addicts, gamblers, and exploiters. (Belshe was described by Parks as a “reported addict” who “has no contact with the proposed ward,” an allegation that Belshe didn’t see until it was too late to challenge.) Family who lived out of state were disqualified from serving as guardians because the law prohibited the appointment of anyone who didn’t live in Nevada.

Once the court approved the guardianship, the wards were often removed from their homes, which were eventually sold. Terry Williams, whose father’s estate was taken over by strangers even though he’d named her the executor of his will, has spent years combing through guardianship, probate, and real-estate records in Clark County. “I kept researching, because I was so fascinated that these people could literally take over the lives and assets of people under color of law, in less than ten minutes, and nobody was asking questions,” she told me.

“These people spent their lives accumulating wealth and, in a blink of an eye, it was someone else’s.”

Williams has reviewed hundreds of cases involving Jared Shafer, who is considered the godfather of guardians in Nevada. In the records room of the courthouse, she was afraid to say Shafer’s name out loud. In the course of his thirty-five-year career, Shafer has assumed control of more than three thousand wards and estates and trained a generation of guardians. In 1979, he became the county’s public administrator, handling the estates of people who had no relatives in Nevada, as well as the public guardian, serving wards when no family members or private guardians were available. In 2003, he left government and founded his own private guardianship and fiduciary business; he transferred the number of his government-issued phone to himself.

Williams took records from Shafer’s and other guardians’ cases to the Las Vegas police department several times. She tried to explain, she said, that “this is a racketeering operation that is fee-based. There’s no brown paper bag handed off in an alley. The payoff is the right to bill the estate.” The department repeatedly told her that it was a civil issue, and refused to take a report. In 2006, she submitted a typed statement, listing twenty-three statutes that she thought had been violated, but an officer wrote in the top right corner, “NoT A PoLIcE MATTER.” Adam Woodrum, an estate lawyer in Las Vegas, told me that he’s worked with several wards and their families who have brought their complaints to the police. “They can’t even get their foot in the door,” he said.

Acting as her own attorney, Williams filed a racketeering suit in federal court against Shafer and the lawyers who represented him. At a hearing before the United States District Court of Central California in 2009, she told the judge, “They are trumping up ways and means to deem people incompetent and take their assets.” The case was dismissed. “The scheme is ingenious,” she told me. “How do you come up with a crime that literally none of the victims can articulate without sounding like they’re nuts? The same insane allegations keep surfacing from people who don’t know each other.”

In 2002, in a petition to the Clark County District Court, a fifty-seven-year-old man complained that his mother had lost her constitutional rights because her kitchen was understocked and a few bills hadn’t been paid. The house they shared was then placed on the market. The son wrote, “If the only showing necessary to sell the home right out from under someone is that their ‘estate’ would benefit, then no house in Clark County is safe, nor any homeowner.” Under the guise of benevolent paternalism, guardians seemed to be creating a kind of capitalist dystopia: people’s quality of life was being destroyed in order to maximize their capital.

When Concetta Mormon, a wealthy woman who owned a Montessori school, became Shafer’s ward because she had aphasia, Shafer sold the school midyear, even though students were enrolled. At a hearing after the sale, Mormon’s daughter, Victoria Cloutier, constantly spoke out of turn. The judge, Robert Lueck, ordered that she be handcuffed and placed in a holding cell while the hearing continued. Two hours later, when Cloutier was allowed to return for the conclusion, the judge told her that she had thirty days in which to vacate her mother’s house. If she didn’t leave, she would be evicted and her belongings would be taken to Goodwill.

The opinions of wards were also disregarded. In 2010, Guadalupe Olvera, a ninety-year-old veteran of the second World War, repeatedly asked that his daughter and not Shafer be appointed his guardian. “The ward is not to go to court,” Shafer instructed his assistants. When Olvera was finally permitted to attend a hearing, nearly a year after becoming a ward, he expressed his desire to live with his daughter in California, rather than under Shafer’s care. “Why is everybody against that?” he asked Norheim. “I don’t need that man.” Although Nevada’s guardianship law requires that courts favor relatives over professionals, Norheim continued the guardianship, saying, “The priority ship sailed.”

When Olvera’s daughter eventually defied the court’s orders and took her father to live at her seaside home in Northern California, Norheim’s supervisor, Judge Charles Hoskin, issued an arrest warrant for her “immediate arrest and incarceration” without bail. The warrant was for contempt of court, but Norheim said at least five times from the bench that she had “kidnapped” Olvera. At a hearing, Norheim acknowledged that he wasn’t able to send an officer across state lines to arrest the daughter. Shafer said, “Maybe I can.”

Shafer held so much sway in the courtroom that, in 2013, when an attorney complained that the bank account of a ward named Kristina Berger had “no money left and no records to explain where it went,” Shafer told Norheim, “Close the courtroom.” Norheim immediately complied. A dozen people in attendance were forced to leave.

One of Shafer’s former bookkeepers, Lisa Clifton, who was hired in 2012, told me that Shafer used to brag about his political connections, saying, “I wrote the laws.” In 1995, he persuaded the Nevada Senate Committee on Government Affairs to write a bill that allowed the county to receive interest on money that the public guardian invested. “This is what I want you to put in the statute, and I will tell you that you will get a rousing hand from a couple of judges who practise our probate,” he said. At another hearing, he asked the committee to write an amendment permitting public guardians to take control of people’s property in five days, without a court order. “This bill is not ‘Big Brother’ if you trust the person who is doing the job,” he said. (After a senator expressed concern that the law allowed “intervention into somebody’s life without establishing some sort of reason why you are doing it,” the committee declined to recommend it.)

Clifton observed that Shafer almost always took a cynical view of family members: they were never motivated by love or duty, only by avarice. “’They just want the money’ – that was his answer to everything,” she told me. “And I’m thinking to myself, Well, when family members die they pass it down to their children. Isn’t that just the normal progression of things?”

After a few months on the job, Clifton was asked to work as a guardian, substituting for an absent employee, though she had never been trained. Her first assignment was to supervise a visit with a man named Alvin Passer, who was dying in the memory-care unit of a nursing home. His partner of eight years, Olive Manoli, was permitted a brief visit to say goodbye. Her visits had been restricted by Shafer—his lawyer told the court that Passer became “agitated and sexually aggressive” in her presence—and she hadn’t seen Passer in months. In a futile attempt to persuade the court to allow her to be with him, Manoli had submitted a collection of love letters, as well as notes from ten people describing her desire to care for Passer for the rest of his life. “I was absolutely appalled,” Clifton said. “She was this very sweet lady, and I said, ‘Go in there and spend as much time with him as you want.’ Tears were rolling down her cheeks.”

The family seemed to have suffered a form of court-sanctioned gaslighting. Passer’s daughter, Joyce, a psychiatric nurse who specialized in geriatrics, had been abruptly removed as her father’s co-guardian, because she appeared “unwilling or (more likely) unable to conduct herself rationally in the Ward’s best interests,” according to motions filed by one of Shafer’s attorneys.

She and Manoli had begged Norheim not to appoint Shafer as guardian. “Sir, he’s abusive,” their lawyer said in court.

“He’s as good as we got, and I trust him completely,” Norheim responded.

Joyce Passer was so confused by the situation that, she said, “I thought I was crazy.” Then she received a call from a blocked number. It was Terry Williams, who did not reveal her identity. She had put together a list of a half-dozen family members who she felt were “ready to receive some kind of verbal support.” She told Passer, “Look, you are not nuts. This is real. Everything you are thinking is true. This has been going on for years.”

During Rennie North’s first year at Lakeview Terrance, she gained sixty pounds. Park had switched the North’s insurance for reasons she never explained, and Rennie began seeing new doctors, who prescribed Valium, Prozac, the sedative Temazepam, Oxycodone, and Fentanyl. The doses steadily increased. Rudy, who had hip pain, was prescribed Oxycodone and Valium. When he sat down to read, the sentences floated past his eyes or appeared in duplicate. “Ward seemed very tired and his eyes were glassy,” Parks wrote in an invoice.

Belshe found it increasingly hard to communicate with her parents, who napped for much of the day. “They were being overmedicated to the point where they weren’t really there,” she said. The Norths’ grandsons, who used to see them every week, rarely visited. “It was degrading for them to see us so degraded,” Rudy said. Parks noticed that Rennie was acting helpless, and urged her to “try harder to be more motivated and not be so dependent on others.” Rudy and Rennie began going to Sunday church services at the facility, even though they were Jewish. Rudy was heartened by what he heard in the pastor’s message: “Don’t give up. God will help you get out of here.” He began telling people, “We are living the life of Job.”

At the end of 2014, Lakeview Terrace hired a new director, Julie Liebo, who resisted Parks’s orders that medical information about wards be kept from their families. Liebo told me, “The families were devastated that they couldn’t know if the residents were in surgery or hear anything about their health. They didn’t understand why they’d been taken out of the picture. They’d ask, ‘Can you just tell me if she’s alive?’ ” Liebo tried to comply with the rules, because she didn’t want to violate medical-privacy laws; as guardian, Parks was entitled to choose what was disclosed. Once, though, Liebo took pity on the sister of an eighty-year-old ward named Dorothy Smith, who was mourning a dog that Parks had given away, and told her that Smith was stable. Liebo said that Parks, who was by then the secretary of the Nevada Guardianship Association, called her immediately. “She threatened my license and said she could have me arrested,” Liebo told me.

After Liebo arrived, Parks began removing wards from Lakeview Terrace with less than a day’s notice. A woman named Linda Phillips, who had dementia, was told that she was going to the beauty salon. She never returned. Marlene Homer, the ward whose ailments were depression and “strange thoughts,” was taken away in a van, screaming. Liebo has asked the state ombudsman to come to the facility and stop the removals, but nothing could be done. “We stood there completely helpless.” Liebo said. “We had no idea where they were going.” Liebo said that other wards asked her if they would be next.

Liebo alerted the compliance officer for the Clark County Family Court that Parks was removing residents “without any concern for them and their choice to stay here.” She also reported her complaints to the police, the Department of Health Services, the Bureau of Health Care, and Nevada Adult Protective Services. She said each agency told her that it didn’t have the authority or the jurisdiction to intervene.

At the beginning of 2015, Parks told the Norths that they would be leaving Lakeview Terrace. “Finances are low and the move is out of our control,” Parkswrote. It was all arranged so quickly that, Rudy said, “we didn’t have time to say goodbye to people we’d been eating with for seventeen months.” Parks arranged for Caring Transitions to move them to the Wentworth, a less expensive assisted-living facility. Liebo said that, the night before the move, Rudy began “shouting about the Holocaust, that this was like being in Nazi Germany.” Liebo didn’t think the reference was entirely misguided. “He reverted to a point where he had no rights as a human being,” she said. “He was no longer the caregiver, the man, the husband—all of the things that gave his life meaning.” Liebo also didn’t understand why Belshe had been marginalized. “She seemed like she had a great relationship with her parents,” she said.

Belshe showed up at 9 A.M. to help her parents with the move, but when she arrived Parks’s assistant, Heidi Kramer, told her that her parents had already left. Belshe “emotionally crashed,” as Liebo put it. She yelled that her parents didn’t even wake up until nine or later—what was the rush? In an invoice, Kramer wrote that Belshe “began to yell and scream, her behavior was out of control, she was taking pictures and yelling, ‘April Parks is a thief.’” Kramer called the police. Liebo remembers that an officer “looked at Julie Belshe and told her she had no rights, and she didn’t.

Belshe cried as she drove to the Wentworth, in Las Vegas. When she arrived, Parks was there, and refused to let her see her parents. Parks wrote, “I told her that she was too distraught to see her parents, and that she needed to leave.” Belshe wouldn’t, so Parks asked the receptionist to call the police. When the police arrived, Belshe told them, “I just want to hug my parents and make sure they’re O.K.” An officer handed her a citation for trespassing, saying that if she returned to the facility she would be arrested.

Parks wrote that the Norths were “very happy with the new room and thanked us several times,” but Rudy remembers feeling as if he had “ended up in the sewer.” Their room was smaller than the one at Lakeview Terrace, and the residents at the Wentworth seemed older and sicker. “There were people sitting in their chairs, half- asleep,” Rudy said. “Their tongues hung out.”

Rennie spent nearly all her time in her wheelchair or in bed, her eyes half-closed. Her face had become bloated. One night, she was so agitated that the nurses gave her Haldol, a drug commonly used to treat schizophrenia. When Rudy asked her questions, Rennie said “What?” in a soft, remote voice.

Shortly after her parents’ move, Belshe called an editor of the Vegas Voice, a newspaper distributed to all the mailboxes in senior communities in Las Vegas. In recent months, the paper had published three columns warning readers about Clark County guardians, writing that they “have been lining their pockets at the expense of unwitting seniors for a very long time.”

At Belshe’s urging, the paper’s political editor, Rana Goodman, visited the Norths, and published an article in the Voice, describing Rudy as “the most articulate, soft spoken person I have met in a very long time.” She called Clark County’s guardianship system a “(legal) elder abuse racket” and urged readers to sign a petition demanding that the Nevada legislature reform the laws. More than three thousand people signed.

Two months later, the Review-Journal ran an investigation, titled “Clark County’s Private Guardians May Protect—Or Just Steal and Abuse,” which described complaints against Shafer going back to the early eighties, when two of his employees were arrested for stealing from the estates of dead people.

In May, 2015, a month after the article appeared, when the Norths went to court to discuss their finances local journalists were in the courtroom and Norheim seemed chastened. “I have grave concerns about this case,” he said. He noted that Parks had sold the Norths’ belongings without proper approval from his court. Parks had been doing this routinely for years, and, according to her, the court had always accepted her accounting and her fees. Her lawyer, Aileen Cohen, said, “Everything was done for the wards’ benefit, to support the wards. Norheim announced that he was suspending Parks as the Norths’ guardian—the first time she had been removed from a case for misconduct.

“This is important,” Rudy, who was wearing a double-breasted suit, said in court. “This is hope. I am coming here and I have hope.” He quoted the Bible, Thomas Jefferson, and Euripides, until Belshe finally touched his elbow and said, “Just sit down, Dad.”

When Rudy apologized for being “overzealous,” Norheim told him, “This is your life. This is your liberty. You have every right to be here. You have every right to be involved in this project.”

After the hearing, Parks texted her husband, “I am finished.”

Last March, Parks and her lawyer, along with her office manager and her husband, were indicted for perjury and theft, among other charges. The indictment was narrowly focussed on their double billings and their sloppy accounting, but, in a detailed summary of the investigation, Jaclyn O’Malley, who led the probe for the Nevada Attorney General’s Office, made passing references to the “collusion of hospital social workers and medical staff” who profited from their connection to Parks. At Parks’s grand-jury trial, her assistant testified that she and Parks went to hospitals and attorneys’ offices for the purpose of “building relationships to generate more client leads.” Parks secured a contract with six medical facilities whose staff agreed to refer patients to her—an arrangement that benefitted the facilities, since Parks controlled the decisions of a large pool of their potential consumers. Parks often gave doctors blank certificates and told them exactly what to write in order for their patients to become her wards.

Parks and other private guardians appeared to gravitate toward patients who had considerable assets. O’Malley described a 2010 case in which Parks, after receiving a tip from a social worker, began “cold-calling” rehabilitation centers, searching for a seventy-nine-year-old woman, Patricia Smoak, who had nearly seven hundred thousand dollars and no children. Parks finally found her, but Smoak’s physician wouldn’t sign a certificate of incapacity. “The doctor is not playing ball,” Parks wrote to her lawyer. She quickly found a different doctor to sign the certificate, and Norheim approved the guardianship. (Both Parks and Norhiem declined to speak with me.)

Steve Miller, a former member of the Las Vegas City Council, said he assumed that Shafer would be the next indictment after Parks, who is scheduled to go to trial next spring. “All of the disreputable guardians were taking clues from the Shafer example,” he said. But, as the months passed, “I started to think that this has run its course locally. Only federal intervention is going to give us peace of mind.”

Richard Black, who, after his father-in-law was placed into guardianship, became the director of a grassroots national organization, Americans Against Abusive Probate Guardianship, said that he considered the Parks indictment “irrefutably shallow. It sent a strong message of: We’re not going to go after the real leaders of this, only the easy people, the ones who were arrogant and stupid enough to get caught.” He works with victims in dozens of what he calls “hot spots,” places where guardianship abuse is prevalent, often because they attract retirees: Palm Beach, Sarasota, Naples, Albuquerque, San Antonio. He said that the problems in Clark County are not unusual. “The only thing that is unique is that Clark County is one of the few jurisdictions that doesn’t seal its records, so we can see what is going on.”

Approximately ten per cent of people older than sixty-five are thought to be victims of “elder abuse”—a construct that has yet to enter public consciousness, as child abuse has—but such cases are seldom prosecuted. People who are frail or dying don’t make good witnesses—a fact that Shafer once emphasized at a 1990 U.S. congressional hearing on crimes against the elderly, in which he appeared as an expert at preventing exploitation. “Seniors do not like to testify,” he said, adding that they were either incapable or “mesmerized by the person ripping them off.” He said, “The exploitation of seniors is becoming a real cottage industry right now. This is a good business. Seniors are unable to fend for themselves.”

In the past two years, Nevada has worked to reform its guardianship system through a commission, appointed by the Nevada Supreme Court, to study failures in oversight. In 2018, the Nevada legislature will enact a new law that entitles all wards to be represented by lawyers in court. But the state seems reluctant to reckon with the roots of the problem, as well as with its legacy: a generation of ill and elderly people who were deprived of their autonomy, and also of their families, in the final years of their lives. Last spring, a man bought a storage unit in Henderson, Nevada, and discovered twenty-seven urns – the remains of Clark County wards who had never been buried.

In the wake of Parks’s indictment, no judges have lost their jobs. Norheim was transferred from guardianship court to dependency court, where he now oversees cases involving abused and neglected children. Shafer is still listed in the Clark County court system as a trustee and as an administrator in several open cases. He did not respond to multiple e-mails and messages left with his bookkeeper, who answered his office phone but would not say whether he was still in practise. He did appear at one of the public meetings for the commission appointed to analyze flaws in the guardianship system. “What started all of this was me,” he said. Then he criticized local media coverage of the issue and said that a television reporter, whom he’d talked to briefly, didn’t know the facts. “The system works,” Shafer went on. “It’s not the guardians you have to be aware of, it’s more family members.” He wore a blue polo shirt, untucked, and his head was shaved. He looked aged, his arms dotted with sun spots, but he spoke confidently and casually. “The only person you folks should be thinking about when you change things is the ward. It’s their money, it’s their life, it’s their time. The family members don’t count.”

Belshe is resigned to the fact that she will be supporting her parents for the rest of their lives. Parks spent all the Norths’ money on fees—the hourly wages for her, her assistants, her lawyers, and the various contractors she hired—as well as on their monthly bills, which doubled under her guardianship. Belshe guesses that Parks—or whichever doctor or social worker referred her to the Norths—had assumed that her parents were wealthier than they actually were. Rudy often talked vaguely about deals he had once made in China. “He exaggerates, so he won’t feel emasculated,” Belshe said. “He wasn’t such a big businessman, but he was a great dad.”

The Norths now live in what used to be Belshe’s home office; it has a window onto the living room which Belshe has covered with a tarp. Although the room is tiny, the Norths can fit most of their remaining belongings into it: a small lamp with teardrop crystals, a deflated love seat, and two paintings by their son. Belshe rescued the art work, in 2013, after Caring Transitions placed the Norths’ belongings in trash bags at the edge of their driveway. “My brother’s paintings were folded and smelled,” she said.

The Norths’ bed takes up most of the room, and operates as their little planet. They rarely stray far from it. They lie in bed playing cards or sit against the headboard, reading or watching TV. Rudy’s notebooks are increasingly focused on mortality —“Death may be pleasurable”—and money. “Money monsters do well in this society,” he wrote. “All great fortunes began with a crime.” He creates lists of all the possessions he has lost, some of which he may be imagining: over time, Rennie’s wardrobe has become increasingly elaborate and refined, as have their sets of China. He alternates between feeling that his belongings are nothing—a distraction from the pursuit of meaning—and everything. “It’s an erasure,” he said. “They erase you from the face of the earth.” He told me a few times that he was a distant cousin of Leon Trotsky, “intellect of the revolution,” as he called him, and I wondered whether his newfound pride was connected to his conflicted feelings about the value of material objects.

A few months after the Norths were freed, Rudy talked on the phone with Adolfo Gonzalez, his Neighbor from Lakeview Terrace, who, after a doctor found him competent, had also been discharged. He now lived in a house near the airport, and had been reunited with several of his pets. The two men congratulated each other. “We survived!” Rudy said. “We never thought we’d see each other on the other side.” Three other wards from Lakeview Terrace had died.

Rennie has lost nearly all the weight she gained at Lakeview Terrace, mostly because Belshe and her husband won’t let her lounge in her wheelchair or eat starchy foods. Now she uses a walker, which she makes self-deprecating jokes about. “This is fun—I can teach you!” she told me.

In July, Rennie slipped in the bathroom and spent a night in the hospital. Belshe didn’t want anyone to know about her mother’s fall, because, she said, “this is the kind of thing that gets you into guardianship.” She told me, “I feel like these people are just waiting in the bushes.”

Two days after the fall, Rennie was feeling better—she’d had thirteen stitches—but she was still agitated by a dream she had in the hospital. She wasn’t even sure if she’d been asleep; she remembers talking, and her eyes were open.

“You were loopedy-doopy,” Scott Belshe, Julie’s husband, told her. They were sitting on the couch in their living room.

“It was real,” Rennie said.

“You dreamed it,” Scott told her.

“Maybe I was hallucinating,” she said. “I don’t know—I was scared.” She said that strangers were making decisions about her fate. She felt as if she were frozen: she couldn’t influence what was happening. “I didn’t know what to do,” she told Scott. “I think I yelled for help. Help me.” The worst part, she said, was that she couldn’t find her family. “Honest to God, I thought you guys left me all alone.”

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Caregiving = Burden-Bearing

By Marie K. MacPherson

Recently, I heard a speaker state that loved ones are never burdens. A pro-life champion, I truly believe he meant well, but I have to disagree: caring for those in our midst is often a burden. Whether they are your children, parents, church or community members, or some combination of each, it is easy to feel weighed down by numerous responsibilities to those in our charge. Providing food, shelter, transportation, finance, and medical support to our loved ones, short- or long-term, frequently feels like an overwhelming burden!

To be a "burden-bearer," known in the vernacular as a caregiver, can be a difficult vocation, but the word "burden" in Greek baros carries the connotation of importance. From eternity, the Lord has planned that you would care for another of His children (Ephesians 2:10)! Like a heavy knapsack filled with necessities for an overnight hiking trip, the earthly burden of caring for a loved one is weighty but can contain valuable spiritual lessons, such as patience, gentleness, and selflessness. Caregiving is not only how God serves as a channel of His blessings to others, it is how He shapes you into the new creation He means for you to be (Philippians 1:6). Through the "refining fire" of burden-bearing, your faith is tested to honor your Savior, Jesus Christ (1 Peter 1:7, Romans 8:29).

Like the labor force employed to bear great physical burdens in building the magnificent Temple of Solomon, bearing the burdens of others may prove fraught with struggle. Yet, it contributes to a beautiful 'bigger picture' as we share in the sufferings of Christ (1 Kings 5:14-16, 1 Peter 4:12-13). Jesus promises that His disciples will be faced with trials and burdens but adds that He has already overcome those difficulties, inviting us to trade our heavy burdens for His rest (John 16:33, Matthew 11:28). Saint Paul urges New Testament Christians to "bear one another's burdens, and so fulfill the law of Christ" (Galatians 6:2). We serve others not to gain "points" with God or earn our own salvation (as if we ever could!) but rather in humble thanksgiving to Christ and in sanctified living toward our neighbor.

To feel burdened and weighed down with the care of another soul is not in itself a sin. Old Testament leaders Moses and Solomon felt burdened by their vocations (Numbers 11:11-15, Ecclesiastes 1:12-14). Even several books of the minor prophets begin by acknowledging their oracles as "burdens" from the Lord (Nahum, Habakkuk, Malachi – NKJV). However, we can quickly turn selfish at the prospect of the burden of caring for loved ones. We may grumble about sacrifices such as lost time, money, or sleep. Scripture is clear that we should obey God's commandments and show love to others unselfishly (John 15:12, 1 John 5:2-4), but it even goes so far as to command us to rejoice as we pass through trials (James 1:2). Surely, it is easy to see our own depravity when it comes to bearing others' burdens unselfishly.

Thank God, though, that we have Christ: not only as an example of altruistic giving as He bears our burdens, but also as the actual payment for the burden of our sins as caregivers. On the cross, Christ washed away each and every sin you commit while burden-bearing for others. Heaven is yours, regardless of your wicked thoughts, words, and actions in your vocation. He showers you with this forgiveness as your pastor pronounces it in the Divine Service, as you taste His body and blood in the Lord's Supper, as you remember your Baptism, and as you read His Word. Now forgiven, God graciously gives you the tools of prayer, thanksgiving, and community to point you to your true Strength (Deuteronomy 1:11-13, 2 Corinthians 1:3-4, 1 Thessalonians 5:18, Psalm 55:22).

Whether you struggle with impatience, weariness, or selfishness as a "burden-bearer," God forgives you. He holds you in His almighty hands and uses you to be a blessing to those in your midst. On earth, there will be no shortage of burdens to bear as we care for those in need. But one day, these burdens will be lifted from our shoulders in Heaven, where the Lord will see us through the lens of Christ's perfect sacrifice and will say, "Well done, good and faithful servant! Enter into the joy of your master" (Matthew 25:21). Rest in His unfailing love.

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Hospice Patients Alliance: Consumer Advocacy

SIGNS AND SYMPTOMS OF APPROACHING DEATH

When confronted with approaching death, many of us wonder when exactly will death occur. Many of us ask the question, “How much time is left?” This can often be a difficult question to answer. The dying do not always cooperate with the predictions of the doctors, nurses or others who tell family members or patients how much time is left.

Hospice staff have frequently observed that even the predictions by physicians about the length of time from the original diagnosis till death is often inaccurate. Many families report that “the doctor told us he [the patient] only had so much time left, and he’s lived much longer than that.” ... or a similar story. Statistical averages do not tell us exactly how long a particular patient has to live; they can only serve as a general guideline or point of reference.

Although statistical averages do not help much in an individual case, there are specific signs of approaching death which may be observed, and which do indicate that death is approaching nearer. Each individual patient is different. Not all individuals will show all of these signs, nor are all of the signs of approaching death always present in every case.

Depending on the type of terminal illness and the metabolic condition of the patient, different signs and symptoms arise. An experienced physician or hospice nurse can often explain these signs and symptoms to you. If you have questions about changes in your loved one’s condition, ask your hospice nurse for an explanation, that is one of the reasons she is serving you.

There are two phases which arise prior to the actual time of death: the “pre-active phase of dying,” and the “active phase of dying.” On average, the preactive phase of dying may last approximately two weeks, while on average, the active phase of dying lasts about three days.

We say “on average” because there are often exceptions to the rule. Some patients have exhibited signs of the preactive phase of dying for a month or longer, while some patients exhibit signs of the active phase of dying for two weeks. Many hospice staff have been fooled into thinking that death was about to occur, when the patient had unusually low blood pressure or longer periods of pausing in the breathing rhythym. However, some patients with these symptoms can suddenly recover and live a week, a month or even longer. Low blood pressure alone or long periods of pausing in the breathing (apnea) are not reliable indicators of imminent death in all cases. God alone knows for sure when death will occur.

Signs of the preactive phase of dying:

- increased restlessness, confusion, agitation, inability to stay content in one position and insisting on changing positions frequently (exhausting family and caregivers)
- withdrawal from active participation in social activities
- increased periods of sleep, lethargy
- decreased intake of food and liquids
- beginning to show periods of pausing in the breathing (apnea) whether awake or sleeping
- patient reports seeing persons who had already died
- patient states that he or she is dying
- patient requests family visit to settle “unfinished business” and tie up “loose ends”
- inability to heal or recover from wounds or infections
- increased swelling (edema) of either the extremities or the entire body
- Signs of the Active Phase of Dying

- inability to arouse patient at all (coma) or, ability to only arouse patient with great effort but patient quickly returns to severely unresponsive state (semi-coma)
- severe agitation in patient, hallucinations, acting "crazy" and not in patient's normal manner or personality much longer periods of pausing in the breathing (apnea)
- dramatic changes in the breathing pattern including apnea, but also including very rapid breathing or cyclic changes in the patterns of breathing (such as slow progressing to very fast and then slow again, or shallow progressing to very deep breathing while also changing rate of breathing to very fast and then slow)
- other very abnormal breathing patterns
- severely increased respiratory congestion or fluid buildup in lungs
- inability to swallow any fluids at all (not taking any food by mouth voluntarily as well)
- patient states that he or she is going to die
- patient breathing through wide open mouth continuously and no longer can speak even if awake
- urinary or bowel incontinence in a patient who was not incontinent before
- marked decrease in urine output and darkening color of urine or very abnormal colors (such as red or brown)
- blood pressure dropping dramatically from patient's normal blood pressure range (more than a 20 or 30 point drop)
- systolic blood pressure below 70, diastolic blood pressure below 50
- patient's extremities (such as hands, arms, feet and legs) feel very cold to touch
- patient complains that his or her legs/feet are numb and cannot be felt at all
- cyanosis, or a bluish or purple coloring to the patients arms and legs, especially the feet, knees, and hands)
- patient's body is held in rigid unchanging position
- jaw drop; the patient's jaw is no longer held straight and may drop to the side their head is lying towards

Although all patients do not show all of these signs, many of these signs will be seen in some patients. The reason for the tradition of "keeping a vigil" when someone is dying is that we really don't know exactly when death will occur until it is obviously happening. If you wish to "be there" with your loved one when death occurs, keeping a vigil at the bedside is part of the process.

Always remember that your loved one can often hear you even up till the very end, even though he or she cannot respond by speaking. Your loving presence at the bedside can be a great expression of your love for your loved one and help him to feel calmer and more at peace at the time of death.

If you have questions about any of the changing signs or symptoms appearing in your loved one, ask your hospice nurse to explain them to you.

Week 3

Advance Directive Definitions

Living Wills:

A Living Will is the oldest type of health care advance directive.

It is a signed, witnessed (or notarized) document called a "declaration" or "directive." Most declarations instruct an attending physician to withhold or withdraw medical interventions from its signer if he/she is in a terminal condition and is unable to make decisions about medical treatment.

Since an attending physician who may be unfamiliar with the signer's wishes and values has the power and authority to carry out the signer's directive, certain terms contained in the document may be interpreted by the physician in a manner that was not intended by the signer.

Family members and others who are familiar with the signer's values and wishes have no legal standing to interpret the meaning of the directive.

Advance Directive:

A combination advance directive is a signed, witnessed (or notarized) document which contains specific written directions that are to be followed by a named agent.

Since it is not possible to predict all circumstances that may be faced in the future or to cover all possible interventions, specific directions may severely limit the discretion and flexibility that the agent needs and may restrict the agent's authority in a way the signer did not intend.

In addition, the specific written directions may not be altered through discussions between the signer and the agent. Any changes necessitate a new document to reflect nuances or changed directions.

It is important that all adults consider who will make medical decisions for them if they are temporarily or permanently unable to make them for themselves.

Unless a person has an advance directive, many health care providers and institutions will make critical decisions for him/her or a court may appoint a guardian who is unfamiliar with the person's values and wishes.

Durable Power of Attorney for Healthcare:

A Durable Power of Attorney for Health Care is a signed, witnessed (or notarized) document in which the signer designates an agent to make health care decisions if the signer is temporarily or permanently unable to make such decisions.

Unlike most Living Wills, the Durable Power of Attorney for Health Care does not require that the signer have a terminal condition.

An agent must be chosen with great care since the agent will have great power and authority to make decisions about whether health care will be provided, withheld or withdrawn from the signer.

It is extremely important that the signer carefully discuss his/her values, wishes and instructions with the agent before and at the time the document is signed. Such discussions may also continue after the document is signed.

It is also important that the agent be willing to exercise his/her power and authority to make certain that the signer's values, wishes and instructions are respected.

Protective Medical Decisions Document

The PMDD is a protective Durable Power of Attorney for Health Care which is available from the Patients Rights Council.

In the PMDD the signer names a trusted person to make health care decisions in the event that the signer is temporarily or permanently unable to make such decisions.

The PMDD, which specifically prohibits assisted suicide and euthanasia, is available in a Multi-State version for use in most states. It is also available in state-specific versions for states where particular requirements make a state-specific version necessary.

The PatientsRightsCouncil.org does not charge for the PMDD. A donation of $15 is requested, but not required, for each PMDD packet.

If you would like to obtain a PMDD, call 800-958-5678 or 740-282-3810 between 8:30am and 4:30pm (eastern time).

Advance Care Planning:

From the National Hospice & Plliative Care Organization: Advance care planning is making decisions about the care you would want to receive if you become unable to speak for yourself. These are your decisions to make, regardless of what you choose for your care, and the decisions are based on your personal values, preferences, and discussions with your loved ones. If you are in an accident or have an illness that leaves you unable to talk about your wishes, who will speak for you? You can tell your family, friends and healthcare providers what your wishes and personal beliefs are about continuing or withdrawing medical treatments at the end of life. Advance care planning includes:

- Getting information on the types of life-sustaining treatments that are available.
- Deciding what types of treatment you would or would not want should you be diagnosed with a life-limiting illness.
- Sharing your personal values with your loved ones.
- Completing advance directives to put into writing what types of treatment you would or would not want should you be unable to speak for yourself.

MOTIVATION FOR SIGNING LIFE-PROTECTIVE ADVANCE DIRECTIVES

by Julie Grimstad and Ann Olson

People appreciate personal contact with someone who is knowledgeable, who is sympathetic, and who will help them sort through their feelings, concerns and values regarding medical decision-making for the future. This is why trained Patient Advocates are sorely needed.

We have both telephone conversations and conversations in person. The latter are more successful for a number of reasons, including the fact that we are there to help execute their life-protective directive immediately should they be convinced to do so.

The first thing we do is listen to what they want to tell us. Then we ask questions and listen carefully to the person's responses. We note their tone of voice and the speed at which they talk. (Are they just saying what they think is the "right thing" or are they slow and deliberate in their speech, indicating that they are carefully considering their options or a new idea?) We also note emotional responses and whether the person is relaxed or nervous. Sometimes a person will say something like "I don't think I would want to be a burden to my family," yet their quavering voice or body language says something else. They may actually be expressing fear of being viewed by others as a "burden." They may want to be contradicted and thereby given a reason to sign a directive that, hopefully, will protect their life.

We also explore their reasons for not yet executing a life-protective advance directive or for executing an advance directive in which they have refused treatment or one that is dangerously worded.

The information we have gleaned from listening helps us shape our conversation with the person we are trying to help. The following are the talking points we most often address when we give talks and particularly in one-on-one conversations in order to convince a person that it is in their best interest to sign a life-protective advance directive, preferably the state-specific Protective Medical Decisions Document (PMDD).

Autonomy/Control

We emphasize that they cannot know what they may want or need in a future situation about which they have no current knowledge. We explain why a wise person, therefore, would not refuse treatment in an advance directive which might be used to end their life prematurely. Medical decisions should be made in the moment of need. If they are competent and able to speak, they can make their own decisions. However, who will make decisions for them in the event they cannot speak or physicians determine they are incapable of making their own medical decisions? They can control who makes decisions for them by appointing a person (agent) they trust to look out for their best interests in a medical crisis.

No one wants to be denied life-sustaining treatment and care against their wishes. We highlight the Case in Point articles in our newsletter and other publications. These true stories motivate people to take steps to protect their own lives and the lives of their loved ones. (For an example, see the Chad Simons case.*)

Self-preservation

We try to lead them to conclude that no one really wants to die. Some people, when they are in generally good health, execute advance directives in which they refuse treatment. However, we point out, healthy people sometimes think/say they would rather die than live with a disability or serious illness, yet, when they actually become impaired, they decide they want to continue living. Also, previously expressed wishes to forgo treatment often are not a person's wishes when they actually experience a life-threatening medical crisis. Life is precious and everyone desires (whether consciously or subconsciously) to hang onto theirs as long as possible. Circumstances (e.g., disability, dependency, pain, costly treatment, etc.) they once thought would be intolerable may become tolerable when death is the alternative.

Bottom line: It is never wise to specify conditions under which you would rather be dead because anything you write or say can be used to end your life. Furthermore, you don't want to leave it up to chance or the law to determine who makes medical decisions for you if you cannot do so. You want an agent you have chosen—someone you know and trust—to protect your best interests. Executing a PMDD makes sense in this light.

Religious Values/Sanctity of Life Ethic

People with strong religious/moral values want "to do what is right." Generally speaking, a person who has a deep religious faith, formed in the Judeo-Christian tradition, believes that human life is sacred because it is created by God in the image and likeness of God. Therefore, they recognize their responsibility to protect human life, including their own, until death occurs in God's timing. It is a simple matter to convince this group of people that executing a life-protective advance directive is the right thing to do. However, even though they are "pro-life," they still may need education to understand and apply the moral principles for making medical decisions that respect life and encouragement to protect their own life. It is reassuring to them to have a pro-life Patient Advocate help them obtain the best life-protective document and sign it in front of a notary or two witnesses who meet the requirements of their state law.

Family Concerns

Many people are not solely concerned about themselves, but are concerned about their families. In such cases, we address how appointing an agent may prevent dissension in the family at a stressful time (e.g., one child may want to stop a parent's treatment while another may want to continue it). Some are concerned about a family member who they would not want making medical decisions for them, perhaps because they are a greedy heir, don't share their respect for life, or disagree with their medical treatment wishes.

Also, we have often heard people say they don't want to be "a burden." After a lifetime of serving, giving to and helping others, especially family members, older people may need to be reminded that life is a circle in which we need care, then give care, and then may need care again. We assure them that they are not being selfish for wanting to live. We help them explore measures they can take, short of shortening their life by refusing life-sustaining treatment, like investing in long-term care insurance to help their family provide the care they may need without financial hardship. Fear of being viewed as "a burden" by others (family members, healthcare providers, etc.) and therefore expendable is a motivation to execute a PMDD.

Advertising the Need for a Life-Protective Advance Directive

In our own publications and articles for other publications, in talks to groups of people, and on our websites (HLA and PHA) we employ these and other arguments to convince people of the need for a life-protective advance directive in which they appoint an agent. We warn about dangerous advance directives (Living Wills, POLST, the wrong kind of Medical Power of Attorney) and stress the advantages of a PMDD. For instance, the PMDD limits an agent's authority so that the agent may not approve the intentional ending of their life. The PMDD also states that words which may be misinterpreted by others have the meanings "I have discussed with my agent" and that the agent's interpretation controls medical decisions. Furthermore, we tell them it is important for everyone 18 or older to have a PMDD appointing an agent who will have access to all medical information about them because the healthcare providers' interpretation of HIPPA may hinder family from getting information about an adult.

HLA and PHA always focus on the fact that everyone's life is precious and worth protecting.

*2005 Wisconsin case: Staff Sgt. Chad Simons suffered a severe brain injury while serving in Iraq. He had an advance directive in which he had refused artificially administered nutrition and hydration (AANH) in the event he became terminally ill or permanently unconscious. Chad's wife insisted that his advance directive be followed and a doctor mistakenly determined Chad was permanently unconscious. He was admitted to the Don and Marilyn Anderson Hospice Care Center in Madison for "comfort care" while being starved and dehydrated to death.

A family member called me (Julie), desperately asking what they could do to save Chad's life. She said that, while he was in rehab, he would squeeze a ball with his hand. When he dropped it, he would pick it up by himself and continue with therapy, showing a determination to get better. His best friend told a reporter that Chad was responding “Yes” or “No” to questions and wanted to live.

Nevertheless, because, before going to Iraq, he had checked a box indicating no AANH, Staff Sgt. Chad Simons’ fate was sealed. His life was cut short by deliberate starvation and dehydration to death—even though he had expressed his wish to live.

Principles for Medical Decision-Making Respecting the Value and Dignity of Human life

by Julie Grimstad

1. No matter what life-sustaining procedure/medical treatment is in question, when in doubt, err on the side of life. A medical intervention can be tried with the option of stopping it if it proves ineffective or excessively burdensome/or the patient.
2. It is the physician’s obligation to truthfully and fully, in layperson’s terms, discuss with the patient/agent/family/guardian the benefits, risks, cost, etc. of available medical means that may improve the patient’s condition/prolong life. The focus should be on what the person making medical decisions needs to know in order to give truly informed consent.
3. The patient/agent makes the decision whether or not a treatment is too burdensome. (Note: The patient’s life must never be ended because it is considered a burden to the patient or others.) If a patient wishes to fight for every last moment of life, this is a legitimate interest to be respected.
4. It is impossible to make morally sound, sensible. informed health care decisions based on guesswork about some future illness or injury and possible treatment options. Health care decisions must be based on current information.
5. Two extremes are to be avoided:
    - √ Insistence on physiologically useless or excessively burdensome treatment even when a patient may legitimately wish to forgo it.
    - √ Withdrawal or withholding of treatment with the intention to hasten/cause death.
6. The object and motive for administering pain medication must be to relieve pain. Death must not be sought or intended.
7. Nutrition and hydration, whether a person is fed with a spoon or through a tube, is basic care, not medical treatment. Insertion or surgical implantation of a feeding tube takes medical expertise, but it is an ordinary life-preserving procedure for a person who has a working digestive system but is unable to eat by mouth.
    - √ Acceptable - During the natural dying process, when a person’s organs are shutting down so that the body is no longer able to assimilate food and water or when their administration causes serious complications, stopping tube-feeding or spoon-feeding is both medically and morally appropriate. In these circumstances, the cause of death is the person’s disease or injury, not deliberate dehydration and starvation.
    - √ Unacceptable - When a person is not dying-or notdying quickly enough to suit someone-food and fluids are often withheld with the intent to cause death because the person is viewed as having an unacceptably low quality of life and/or as imposing burdens on others. The direct cause of death is then dehydration and starvation.

Who decides what is best for the patient?

by The Editors

March 27, 2013 (Zenit.org) – There is an interesting juxtaposition of articles in the Feb. 27, 2013, issue of the *Journal of the American Medical Association* (*JAMA*). The first piece is a moving account of a medical student's 90-year-old grandmother undergoing a hip replacement. The medical student describes her grandmother as smart, energetic, and sassy. However, after six months of worsening hip pain and an increasing reliance on either a cane or a walker, her grandmother was ready to take the plunge and have surgery. But not every orthopedic surgeon was willing to take on a nonagenarian for such major surgery. One doctor suggested to her that it would be better to live out the rest of her years with some hip trouble than to submit to the risks of surgery followed by weeks of rehabilitation. This physician had only just met this elderly woman, yet presumed to know what was in her best interest better than she knew herself.

Clearly he had underestimated the strength of this woman. She did have the surgery, and endured six weeks of vigorous rehabilitation. And then she strode into her surgeon's office without pain and without the use of a cane or walker. She had triumphed over both her hip ailment and the naysayers who were ready to write off her remaining years.

In this same issue of *JAMA*, is an article by Drs. Jon Tilburt and Christine Cassel on the merits of parsimonious medicine. The dictionary definition of parsimonious is "frugal to the point of stinginess." The authors explain that their intention is to eliminate wasteful and ineffective diagnostic and treatment modalities, which makes the idea of parsimonious medicine more palatable. There are countless medical practises that have little value yet have worked their way into common use. For example, whole body CT scans are widely employed to screen for hidden illnesses in patients who have no symptoms to suggest the presence of a disease. Pap smears are useless for women who have had complete hysterectomies yet thousands are done every year.

The American Board of Internal Medicine (ABIM) Foundation developed an initiative called "Choosing Wisely" to help medical practitioners identify low value and ineffective interventions. In cooperation with this endeavor, a broad coalition of medical specialty organizations have compiled lists of interventions to be avoided.

In theory, the practise of parsimonious medicine as described by Tilburt and Cassel seems to be a reasonable approach to the ethical practise of medicine. The authors take great pains to distinguish parsimonious medicine from the rationing of medical care. Parsimonious medicine is about maximizing the benefit and minimizing the harm for every individual patient. In health care rationing, beneficial therapy or diagnostics are withheld from one patient category in order to redistribute the resources to another patient category. In the former, medical interventions are being evaluated and judged as to their worthiness for the patient. This is entirely ethical. In the latter, patients are being evaluated and judged as to their worthiness for care. This is ethically unacceptable in routine medical practise.

Of course, the devil is in the details. There are many who would argue that a hip replacement in a 90-year-old woman is both ineffective and wasteful. My own great aunt suffered from congestive heart failure due to ischemic heart disease. She underwent coronary artery bypass surgery when she was in her late 80s. She subsequently lived to be 102, leading a very active life with minimal medications and only routine medical care. Should she have been denied heart surgery because the average woman of her age does not benefit from such aggressive therapy? Does an extra 15 years of life for an octogenarian justify medical care? Many medical professionals would argue that both the 90-year-old grandmother and my 87-year-old great-aunt had lived long enough and were no longer entitled to expensive medical care. But as medical student Kelly Sloane asks in the first article, "When did old age become a crime punishable by death?" Age alone should not be grounds for denying medical care.

Drs. Tilburt and Cassel write:

Thus, the practise of parsimonious medicine, were it to become widespread, could have the additional collateral benefit of freeing resources that could be used to provide care for those who are currently disadvantaged and underinsured or uninsured. But those potential consequences are not the primary ethical basis for parsimonious care—concern for individual patients is the primary focus.

Unfortunately, current health care reform efforts have lost sight of the individual patient. While purportedly aiming to improve medical care, broad generalizations are applied in a one-size-fits-all manner to every patient. For example, a 48-page report by the British Lancet Oncology Commissionoffers recommendations to reduce the costs of cancer care. Among these is the radical assessment that disease-free survival (DFS) and progression-free survival (PFS) are not adequate endpoints for cost effective cancer therapy. The only statistic that matters is overall survival (OS) or cure rate. This means that therapy that merely puts cancer in remission or prevents it from progressing but does not attain a cure is not cost effective. In other words, it may be considered wasteful to extend the life of a cancer patient if he is going to die of his cancer eventually.

The authors of the Lancet report also hold up the British National Health Service National Institute for Clinical Excellence (NICE) as the model for determining who receives care. Under this system, patients are reduced to a number that represents the number of "quality" years they are expected to survive. This is not the same as life expectancy. Quality years are years that they are expected to live with minimal disability and to need minimal outside care. The patients are allotted £30,000 per quality-adjusted life years (QALY). If the therapy exceeds this amount, it is denied. They also note that in the United States, the Patient Centered Outcome Research Institute (PCORI) that was established by the Affordable Care Act can potentially do the same thing, but has not yet been given the legislative authority to make such definitive care recommendations.

Unlike the advocates of parsimonious medicine, these physicians put reducing costs above the well-being of individual patients. They claim that requiring care or assistance with the activities of daily living reduces, if not negates, the value of life. They seek to usurp the authority to make choices about medical care and ignore the uniqueness of each patient and each medical situation. Such a system denies patients their right to weigh the burden of, for example, cancer therapy against the benefits of additional weeks, months or even years of life. Yet, like Drs. Tilburt and Cassel, this group of oncologists asserts they are acting in the best interest of patients.

Clearly, many physicians and other health care professionals think they know what is best for patients. But generalizations are really bell-shaped curves and there will always be outliers. The intrinsic dignity of each patient must be respected, which means every patient deserves to be evaluated in light of his own unique individual circumstances. Health care providers have a duty to educate, inform and guide patients with regards to medical options. In the end, however, it is the patient or his designated surrogate who must weigh the burdens and the potential benefits of care and decide what is in his best interest.

Editor's note: This article originally appeared on Zenit.org and is reprinted with permission.

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Week 4

Medicare Hospice Entitlements:

- Doctor services
- Nursing care
- Medical equipment (such as wheelchairs or walkers)
- Medical supplies (such as bandages and catheters)
- Drugs for symptom control or pain relief (may need to pay a small Copayment)
- Hospice aide and homemaker services
- Physical and occupational therapy
- Speech-language pathology services
- Social worker services
- Dietary counseling
- Grief and loss counseling for you and your family
- Short-term inpatient care (for pain and symptom management)
- Short-term respite care (may need to pay a small copayment)
- Any other Medicare-covered services needed to manage your pain and other symptoms related to your terminal illness, as recommended by your hospice team

Interviewing a Hospice Agency- What Questions Should I Ask?

Hospice programmes are independent from one another and the level of services provided are not the same. For that reason, it's essential that you *interview* hospice agencies *prior* to signing on for care and allowing them into your home. You can also look for Hospice providers beyond doctor or hospital referrals.

1. Is the hospice licensed?
2. Is the hospice Medicare certified?
3. Is the hospice non-profit or for profit? Pro-life?
4. What is the "mission" of the hospice?
5. Does that mission match my own personal beliefs?
6. Has the hospice been caught committing insurance fraud? (we suggest Googling Medicare hospice fraud or the name of the hospice and Medicare fraud)
7. How many counties does the hospice serve?
8. Can I meet with or speak via phone with the hospice administrator ***prior*** to a hospice admission?
9. Can I meet the staff who will be providing care ***prior*** to admission?
10. In detail, what types of services are provided?
11. How often will each of these services be provided to me or my loved one?

12. Will services be provided by the same individuals throughout the course of my care?
13. What kind of support is available to my family/caregivers?
14. How are services provided *after* hours? How long may it take for an on-call nurse to respond to my call? How long may it take for an on-call nurse to get to my home?
15. What do hospice volunteers do? Am I eligible for volunteer services?
16. Can the hospice provide care in a nursing home or personal care home/assisted living?
17. Must someone be with me at all times?
18. Must I commit to a DNR (Do Not Resuscitate) status?
19. Can I receive IV fluids and tube feedings?
20. Can I review all medications and the doses of the medications?
21. Can I refuse certain medications?
22. Do all patients receive the same medications?
23. Will I receive a bill for expenses not covered by insurance?
24. What should I do first if I am having a problem with the care my hospice is providing?
25. What should I do if I feel the hospice hasn't addressed my concerns adequately?

Misconceptions about Hospice Care

1. **Hospice hastens death**
   All human life is inherently valuable. The role of the hospice team is to alleviate distressing symptoms and increase comfort – not to hasten, nor prolong death. A death with dignity allows for a natural death (free of discomfort) in God's time.
2. **Hope is lost with hospice**
   Hospice helps patients and their loved ones focus on living life to the fullest. Hospice assists them with the journey through emotions of anger, sadness, and pain and helps them to emerge with a feeling of hope to make the most out of the life that remains.
3. **Hospice focuses on dying**
   Absolutely NOT! The focus of hospice is not about how you die, but how you LIVE! Patients do not give up hope when turning to hospice for support. Instead the goal is to live life to the fullest, as symptom free as possible.
4. **Hospice services are only for those with cancer**
   While many patients admitted to hospice have cancer diagnoses, a significantly high number have various other end stage diagnoses, such as lung conditions, cardiac conditions, end stage strokes, end stage Alzheimer's, dementias, neurological conditions, and other end stage conditions.
5. **Hospice patients must be homebound/bedridden**
   Under the Medicare guidelines, as well as the guidelines of other insurance plans, a patient does not have to be homebound or bedridden to be admitted to hospice. Admissions to hospice are based upon the progression of a disease, not on patient's current physical abilities. Therefore, upon admission to hospice, many individuals continue to lead independent productive lives.

6. **Hospice is only for Medicare aged patients**
   Any individual experiencing a life limiting illness at any age can be admitted to hospice.

7. **Patients under hospice care no longer receive care from their primary physician**
   Hospice continues to work closely with the patient's attending physician for direction with management of pain and other uncomfortable symptoms.

8. **A patient's physician determines whether a patient should be admitted to hospice**
   While the role of the MD is to *recommend* hospice care, it is the patient's right to decide when hospice care is appropriate. However, the physician must certify that the patient has been diagnosed with a terminal illness and the patient must meet the Medicare criteria for their end stage disease.

9. **Which hospice the patient uses should be determined by the patient's physician, hospital discharge planner or hospital/nursing home social worker**
   The role of physicians and hospital/nursing home social service professionals is to *recommend* hospice care and then provide names of local hospices. **Providing a choice of hospice programmes is federal and state law.** After receiving this list, the patient/family has the right to interview hospice programmes and ask questions before making a decision. Ultimately, it is the patient's right to choose their hospice provider.

10. **A patient is not eligible to receive hospice care beyond six months**
    The Medicare guidelines stipulate that hospice services may be provided to a terminally ill individual with a limited life expectancy of 6 months or less. However, often times the patient lives beyond the initial 6 months. The hospice can continue to provide care as long as the patient continues to meet hospice criteria which supports the terminal diagnosis AND their attending physician and the hospice medical director recertify the patient to continue to receive hospice care.

11. **Once admitted to hospice, patients cannot return to curative medical treatment**
    At any time while a patient is on a hospice programme, the patient and family have the right to reinstate their former medical treatment plan. Furthermore, if a patient's condition improves or the disease goes into a remission, a patient may be discharged from hospice. Also, a patient who has been discharged from hospice may return to hospice care should their condition warrant a readmission.

12. **Pain medications make patients feel "doped up" and are addicting**
    When administered properly for medical reasons, patients find much needed relief and do not feel "high". In addition, when used correctly, pain medications are not addicting to hospice patients. The result of proper pain medication administration is patients who remain more alert and active because they are not exhausted from dealing with uncontrolled symptoms.

13. **Hospice care is only for the last few days of life**
    "If only we had called you sooner…" Hospice care is most effective when it's started early; the education, support and emotional counseling offered by the hospice team can be most beneficial.

Information provided by

Catholic Hospice Pittsburgh

Cristen Krebs, DNP, ANP-BC, Executive Director & Founder

CatholicHospicePgh,org

‘No One Is Coming’: Hospice Patients Abandoned At Death’s Door

by JoNel Aleccia and Melissa Bailey

October 26, 2017

WASILLA, Alaska — As her husband lay moaning in pain from the cancer riddling his body, Patricia Martin searched frantically through his medical bag, looking for a syringe.

She had already called the hospice twice, demanding liquid methadone to ease the agony of Dr. Robert Martin, 66. A family practise physician known to everyone as “Dr. Bob,” he had served this small, remote community for more than 30 years.

But the doctor in charge at Mat-Su Regional Home Health & Hospice wasn’t responding. Staff said he was on vacation, then that he was asleep. Martin had waited four days to get pain pills delivered, but her husband could no longer swallow them. Now, they said, she should just crush the drugs herself, mix them with water and squirt the mixture into his mouth. That’s why she needed the syringe.

This KHN story also ran in Time.com. It can be republished for free (details).

“I thought if I had hospice, I would get the support I needed. They basically said they would provide 24/7 support,” she said, shaking her head in disbelief, three years later. “It was a nightmare.”

The Martins had entrusted the ailing doctor’s final days to one of the nation’s 4,000-plus hospice agencies, which pledge to be on call around-the-clock to tend to a dying person’s physical, emotional and spiritual needs.

Yet the hospice care that people expect — and sign up for — sometimes disappears when they need it most. Families across the country, from Alaska to Appalachia, have called for help in times of crisis and been met with delays, no-shows and unanswered calls, a Kaiser Health News investigation shows.

A KHN analysis of 20,000 government inspection records reveals that missed visits and neglect are common for patients dying at home. Families or caregivers, shocked and angered by substandard care, have filed over 3,200 complaints with state officials in the past five years.

Those complaints led government inspectors to uncover problems in 759 hospices, with more than half cited for missing visits or other services they had promised to provide at the end of life, KHN found.

The horrifying reports, which do not include victims’ names, describe a 31-year-old California woman whose boyfriend tried for 10 hours to reach hospice as she gurgled and turned blue, and a panicked caregiver in New York calling repeatedly for middle-of-the-night assistance from confused hospice workers unaware of who was on duty. In Michigan, a dementia patient moaned and thrashed at home in a broken hospital bed, enduring long waits for pain relief in the last 11 days of life, and prompting the patient’s caregiver to call nurses and ask, “What am I gonna do? No one is coming to help me. I was promised help at the end.”

Only in rare cases were hospices punished for providing poor care, the investigation showed.

Using death records and public records searches, KHN identified some victims of the worst abuse detailed in the complaints and interviewed surviving family members.

I thought if I had hospice, I would get the support I needed. They basically said they would provide 24/7 support . . . It was a nightmare.

Patricia Martin of Wasilla, Alaska, widow of hospice patient Dr. Bob Martin contacted by KHN, Patricia Martin tearfully said she’d given up hope that anyone would take seriously her complaints about her husband’s care. She had enrolled him in hospice when the metastatic prostate cancer reached his brain, expecting the same kind of compassionate, timely attention he had given his own patients.

But Bob Martin had the misfortune to require care during a long holiday weekend, when hospices are often too short-staffed to fulfill written commitments to families. It took six days and three more calls before he received the liquid methadone he needed. Hospice denied his wife's requests for a catheter, and she and her son had to cut away his urine-soaked clothing and bedding, trying not to cause him additional pain. The supervising hospice doctor never responded. A nurse who was supposed to visit didn't show up, saying she was called for jury duty.

Bob Martin died just after midnight on Jan. 4, 2014. Six weeks later, his wife filed a complaint against Mat-Su Regional with the Alaska Department of Health and Social Services. An investigation concluded that the hospice failed to properly coordinate services, jeopardizing his end-of-life care. Hospice officials declined interview requests.

"It was just sheer chaos," Patricia Martin said. "It makes me wonder about other people in this situation. What happens to them?"

Hospice's Holistic Promise

Hospice is available through Medicare to critically ill patients expected to die within six months who agree to forgo further curative treatment. The care is focused on comfort instead of aggressive medical interventions that can lead to unpleasant, drawn-out hospital deaths.

It's a booming industry that served about 1.4 million Medicare patients in the U.S. in 2015, including over a third of Americans who died that year, according to latest industry and government figures.

Although many people think of hospice as a site where people go to die, nearly half of hospice patients receive care at home, according to industry figures.

The mission of hospice is to offer peaceful, holistic care and to leave patients and their loved ones in control at the end of life. Agencies receive nearly $16 billion a year in federal Medicare dollars to send nurses, social workers and aides to care for patients wherever they live. While the vast majority of hospice care is covered by Medicare, some is paid for by private insurance, Medicaid and the U.S. Department of Veterans Affairs.

To get paid a daily fee by Medicare, hospice agencies face many requirements. They must lay out a plan of care for each patient, ensuring they'll treat all symptoms of the person's terminal illness. And they're required to be on call 24/7 to keep patients comfortable, but because each patient is different, there's no mandate spelling out how often staff must show up at the home, except for a bimonthly supervisory visit. Hospices must stipulate in each patient's care plan what services will be provided, when and by whom, and update that plan every 15 days. Hospices are licensed by state health agencies and subject to oversight by federal Medicare officials and private accreditation groups.

At its best, hospice provides a well-coordinated interdisciplinary team that eases patients' pain and worry, tending to the whole family's concerns. For the 86 percent of Americans who say they want to die at home, hospice makes that increasingly possible.

But when it fails, federal records and interviews show it leaves patients and families horrified to find themselves facing death alone, abandoned even as agencies continue to collect taxpayer money for their care.

In St. Stephen, Minn., Leo Fuerstenberg, 63, a retired Veterans Affairs counselor, died panicked and gasping for air on Feb. 22, 2016, with no pain medication, according to his wife. Laure Fuerstenberg, 58, said a shipment sent from Heartland Home Health Care and Hospice included an oxygen tank, a box of eye drops and nose drops, but no painkillers.

"They were prescription drugs, but it didn't say what they were or how to give them," she recalled. "I just panicked. I called the hospice, and I said, 'We're in trouble. I need help right away.' I waited and waited. They never called back."

For more than two hours, she tried desperately to comfort her husband, who had an aggressive form of amyloidosis, a rare disease that affects the organs. But he died in her arms in bed, trapping her under the weight of his body until she managed to call Neighbors for help.

“That last part of it was really horrible,” she said. “The one thing I promised him is that he wouldn’t be in pain, he wouldn’t suffer.”

Later, state investigators determined that Heartland’s on-duty hospice nurse had muted her cellphone, missing 16 calls for help. Hospice officials did not respond to repeated interview requests.

“They never followed their protocol, and I’ve never had anybody from there say ‘We failed, we were wrong,’” said Fuerstenberg, a school counselor who said she relives her husband’s death daily. “If that had been me on my job, I’d be fired.”

Her account was among more than 1,000 citizen complaints that led investigators to uncover wrongdoing from January 2012 to February 2017, federal records show. But experts who study hospice say many more families may be too traumatized to take further action.

The complaints offer only a glimpse of a larger problem, warned Dr. Joan Teno, a researcher at University of Washington in Seattle who has studied hospice quality for 20 years. “These are people who got upset enough to complain.”

Officials with the National Hospice and Palliative Care Organization (NHPCO), an industry trade group, said that such accounts are inexcusable — but rare.

“I would venture to say whatever measure you want to use, there are an exponential number of positive stories about hospice that would overwhelm the negative,” said Jonathan Keyserling, NHPCO’s senior vice president of health policy.

When you serve over a million people and families a year, “you’re going to have instances where care could be improved,” he added.

But even one case is too many and hospices should be held accountable for such lapses, said Amy Tucci, president and chief executive of the Hospice Foundation of America, a nonprofit focused on education about death, dying and grief.

“It’s like medical malpractise. It’s relatively rare, but when it happens, it tarnishes the entire field,” she said.

Dearth Of Hard Data

How often hospices fail to respond to families or patients is an understudied problem, experts say, in part because it’s hard to monitor. But a recent national survey of families of hospice patients suggests the problem is widespread: 1 in 5 respondents said their hospice agency did not always show up when they needed help, according to the Consumer Assessment of Healthcare Providers and Systems (CAHPS) Hospice Survey, designed by the Centers for Medicare & Medicaid Services.

“That’s a failing grade,” Teno said. “We need to do better.”

Hospice care in the U.S. got its start in the 1970s, driven by religious and nonprofit groups aimed at providing humane care at the end of life. Today, however, many providers are part of for-profit companies and large, publicly traded firms. It’s a lucrative business: For-profit hospices saw nearly 15 percent profit margins on Medicare payments in 2014, according to the Medicare Payment Advisory Commission.

Most families are happy with hospice, according to the CAHPS survey. In data collected from 2015 to 2016 from 2,128 hospices, 80 percent of respondents rated hospice a 9 or 10 out of 10.

Kaiser Family Foundation polling conducted for this story found that out of 142 people with hospice experience, 9 percent were “dissatisfied” and 89 percent “satisfied” with hospice. (Kaiser Health News is an editorially independent programme of the foundation.)

Indeed, many people give hospice glowing reviews. Lynn Parés, for instance, gushed about her experience from 2013 to 2014 with Family Hospice of Boulder, Colo. When Parés’ 87-year-old mother cut her leg, staff came daily to treat the wound. A nurse visited every day in the dying woman’s last week of life. The hospice also provided family counseling, spiritual guidance and volunteers who surrounded her mother's bedside, singing old-time songs.

"They were in constant contact with us," Parés said of the hospice. "It's amazing to me how much heart there is involved in hospice care." After her mother died, Parés and her siblings donated part of their inheritance to the hospice. "I can never say enough good about them."

Following industry trends, the small, family-owned Boulder company subsequently got acquired by a large regional chain, New Century Hospice, in 2015. As the industry grows — hospice enrollment has more than doubled since 2000 — some companies are not following through on their promises to patients.

For instance, data show many hospices fail to provide extra care in times of crisis. To get Medicare payments, hospices are required to offer four levels of care: routine care, which is by far the most common; respite care, to give family caregivers a break for short time periods; and two levels of so-called crisis care, continuous care and general inpatient care, when patients suffer acutely. But 21 percent of hospices, which together served over 84,000 patients, failed to provide either form of crisis care in 2015, according to CMS.

While there's no guarantee that a given patient will need crisis care, not offering any such care for an entire year raises a concern about "whether they're providing adequate symptom control," Teno said.

"I'd be very surprised if there wasn't a significant proportion of those people" — at least 5 percent — "who really needed that service," she said.

Other research has found troubling variation in how often hospice staff visit when death is imminent. A patient's final two days of life, when symptoms escalate, can be a scary time for families, who often need professional help, Teno said. She and her co-authors found that 281 hospice programmes, or 8.1 percent of the hospices studied, didn't provide a single skilled visit — from a nurse, doctor, social worker or therapist — to any patients who were receiving routine home care, the most common level of care, in the last two days of life in 2014.

Regardless of how often they visit, hospices collect the same flat daily rate from Medicare for each patient receiving routine care: $191 for the first 60 days, then $150 thereafter, with geographic adjustments as well as extra payments in a patient's last week of life.

I called the hospice, and I said, 'We're in trouble. I need help right away.' I waited and waited. They never called back.

Laure Fuerstenberg, of St. Steven, Minn., widow of hospice patient Leo Fuerstenberg

Overall, 12.3 percent of patients on routine home care received no skilled visits in the last two days of life, the study found. Patients who died on a Sunday had the worst luck: They were more than three times less likely to have a skilled visit than those who died on a Tuesday. Teno said that gives her a strong suspicion that missed visits stem from chronic understaffing, since hospices have fewer staff on weekends.

In Minnesota, Fuerstenberg's pleas for help went unanswered on a Sunday evening; her husband died just after midnight on Monday. She was appalled when she received a bill for care the agency said occurred on that day.

"When they got paid for nothing, it was like a slap in the face," said Fuerstenberg, who filed a complaint with Minnesota health officials last year. She heard nothing about the case from hospice officials and didn't learn it had been investigated until she was contacted by Kaiser Health News.

Left In The Lurch

In St. Paul, Va., a small town in the Appalachian mountains, Virginia Varney enlisted Medical Services of America Home Health and Hospice, a national chain, to care for her son, James Ingle, 42, who was dying of metastatic skin cancer. On his final day, Christmas Day 2012, he was agitated, vomiting blood, and his pain was out of control. Varney called at least four times to get through to hospice. Hours later, she said, the hospice sent an inexperienced licensed practical nurse who looked “really scared” and called a registered nurse for backup. The RN never came. Ingle died that night.

Varney said she felt numb, angry and “very disappointed” in the hospice care: “It’s like they just didn’t do anything. And I know they were getting money for it.”

“They told me 24 hours a day, seven days a week, holidays and all,” Varney said. “I didn’t find that to be true.”

An investigation by Virginia state inspectors, which corroborated Varney’s story, revealed hospice staff changed the records from that night after the fact. The registered nurse was fired that February. The hospice declined to comment for this story.

Just how often are hospice patients left in the lurch? Inspection reports, performed by states and collected by CMS, don’t give a clear answer, in part because hospices are reviewed so infrequently.

Unlike nursing homes, hospices don’t face inspection every year to maintain certification. Based on available funding, CMS has instead set fluctuating annual targets for state hospice inspections. In 2014, CMS tightened the rules, requiring states to increase the frequency to once every three years by 2018.

Often, promising to do better is the only requirement hospices face, even when regulators uncover problems. The Office of the Inspector General at the federal Department of Health and Human Services has called for stricter oversight and monitoring of hospice for a decade, said Nancy Harrison, a New York-based deputy regional inspector general. One problem, she said, is there is no punishment short of termination — barring the hospice from receiving payment from Medicare or Medicare — which is disruptive for dying patients who lose service.

CMS records show termination is rare: Through routine inspections as well as those prompted by complaints, CMS identified deficiencies in more than half of 4,453 hospices from Jan. 1, 2012, to Feb. 1, 2017. During that same time period, only 17 hospices were terminated, according to CMS.

In Alaska, officials at Mat-Su Regional Home Health & Hospice, which cared for Bob Martin, cited patient privacy rules in declining to comment about his case. But “[we] strengthened our policy and procedures” as a result of the investigation, administrator Bernie Jarriel Jr. said in an email. “Members of our caregiving team have been re-educated on these practises.”

In Minnesota, officials with the local Heartland Home Health and Hospice agency referred questions to its corporate owner, HCR ManorCare of Toledo, Ohio. Officials there did not respond to multiple requests for comment about Leo Fuerstenberg’s care. CMS documents indicate the nurse who missed 16 messages “was re-educated on responsibilities of being on call.”

They told me 24 hours a day, seven days a week, holidays and all. I didn’t find that to be true.

Virginia Varney of St. Paul, Va., mother of hospice patient James Ingle

‘Misplaced Expectations’

Hospice industry officials note that resolving hospice complaints can be difficult during the fraught days at the end of life.

“Hospice is like any other health care provider in that there may be misplaced expectations,” said the NHPCO’s Keyserling.

Hospice providers must ensure that communications are clear and understood and patients and families must voice their concerns, he added. When that doesn’t happen, problems can follow.

Jim Mills, 56, a retired Navy submariner from West Liberty, Ky., is still angry about the care his wife, Leeanne Mills, 54, received in the summer of 2016 at Mountain Community Hospice, then run by Hospice of the Bluegrass in nearby Lexington. She was diagnosed in 2011 with ocular melanoma and spent five years in treatment for the rare eye cancer. When all options were exhausted, the couple recalled the excellent hospice care given to Mills’ father and brother-in-law.

"My wife and I saw that, so we said 'OK,'" Mills recalled. "My wife wanted to die in the home that she and I lived in."

But the experience was devastating, he said. Instead of round-the-clock care for his wife, he said the hospice left him alone to grapple with her excruciating pain. He detailed dozens of alleged problems with her care, ranging from a hospice nurse who didn't respond for five hours to a middle-of-the-night call for pain medications to suspicions that use of a drug pump hastened her death.

"I'm in panic mode," Mills recalled. "I don't know what to do. I'm no doctor. I'm no nurse."

Kentucky state health officials who investigated Mills' complaint in October 2016 found "no deficient practise," records show. Mountain Community Hospice, run by the Kentucky agency now known as Bluegrass Care Navigators, also disputed Mills' version of events. Lawyers representing the agency said in a letter that care his wife received was appropriate and suggested that the trauma of loss may have colored his perceptions.

"MCH treated your wife and family with dignity and compassion throughout her hospice stay and was in no way negligent, abusive or harmful to her or your family," the letter said. "Unfortunately, emotional pain and anguish for dying patients and their loved ones are unavoidable in such tragic circumstances despite high quality and supportive hospice care."

Liz Fowler, the hospice president and chief executive, said in an email to KHN, "We are concerned when a family member has a negative perception of our care. We wish we could improve that perception."

But Mills said nothing will shake his belief that his wife was treated badly in her final days.

"There should be some clarity when a family is facing this, in whatever state it happens to be, they should know their rights, they should know what to expect," he said. "I want my wife's death and suffering to not have been in vain."

Help For Families

In a 2016 study, the OIG's Harrison and colleagues called for state surveyors to better scrutinize the plans of care hospices outline for their patients. And they recommended that CMS create a range of different levels of punishment for hospice infractions, such as requiring in-service training, denying payments, civil fines and imposing temporary management.

CMS has no statutory authority to impose those alternative sanctions, said spokesman Jibril Boykin. But it did increase transparency in August by launching a consumer-focused website called Hospice Compare that now includes hospices' self-reported performance on quality measures and, next year, will include family ratings of hospices. Until that happens, there's little information available for families trying to pick a hospice that will show up when it counts. Tucci, of the Hospice Foundation of America, suggests that families of ill or frail relatives consider hospice options before a crisis occurs. The agency recommends 16 questions families should ask before choosing a hospice.

Back in Alaska, Patricia Martin said she's still waiting for officials with Mat-Su Regional Home Health & Hospice to answer questions about her husband's poor care. She urges other families enrolling patients in hospice to be vigilant.

"It is my hope that no other family or patient will ever have to go through the nightmare that we did," she said. "If they promise you they're going to do something, they should do it."

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Study: “Significant Number” of Patients Wrongly Diagnosed as in “Vegetative” State

by Dave Andrusko | LifeNews.com | 4/17/14

A study published in the medical journal “The Lancet” finds that “significant number of people labeled vegetative had received an incorrect diagnosis and actually had some degree of consciousness and the potential to improve,” according to Denise Grady of the New York Times.

The results of the study, led by Dr. Steven Laureys, is consistent with the conclusions of previous research that employed electroencephalogram machines and M.R.I. scanners which “have also found signs of consciousness in supposedly vegetative patients.”

The difference with the latest study, conducted by a team of 15 scientists, is that when researchers used a three-dimensional brain imaging technique called positron emission tomography (PET), they found that even more patients were incorrectly diagnosed as in a “persistent vegetative state” [“Diagnostic precision of PET imaging and functional MRI in disorders of consciousness: a clinical validation study”].

The following is a summary of the study, some of the positive highlights, but also the reasons for concern.

* Of the 122 patients studied, 81 were considered “minimally conscious,” defined by Grady as “meaning they showed intermittent signs of awareness and responsiveness.” The other 41 “had been declared vegetative — awake but with no behavioral signs of awareness.”
* The team used two types of scanning technology, PET and magnetic resonance imaging (MRI). “The researchers then compared their results with an established behavioral test of whether someone is capable of regaining consciousness,” the Washington Post’s Fred Barbash reported. “They found, first, that the PET scan was more accurate than the MRI.”
* “The [PET] imaging tests found minimal consciousness in 13 of the 41 vegetative patients,” Grady reports. “After a year, nine of the 13 had progressed into “minimally conscious states or a higher level of consciousness,” according to the researchers.

Laureys told the Washington Post that sometimes “there’s more going on than we thought”in the brain.

“We can’t make ethical or medical or legal decisions which are right if we we’re not having good diagnoses,” he said. “We need to reduce” the interpretive element as much as possible

That’s the good news. Less promising is what might be made of this increased ability to fine-tune the diagnoses—that is, separate those who supposedly are “truly” in a PVS and those who are in a minimally conscious state. The latter “have a better chance of improving than those who are vegetative, though recovery may take a long time and be incomplete,” Grady writes.

For example, in a statement, Laureys wrote

“Our findings suggest that PET imaging can reveal cognitive processes that aren’t visible through traditional bedside tests, and could substantially complement standard behavioral assessments to identify unresponsive or ‘vegetative’ patients who have the potential for long-term recovery.”

In his interview with the Post, Laureys elaborated. Barbash writes

“While the researchers acknowledge that PET scanning isn’t generally available or practical in most hospital situations, their study is likely to speed the day when it is, perhaps making heated controversies over vegetative states easier to resolve. Laureys said that expensive as the technology may be, it’s less costly than keeping someone who is in a coma alive for months and even years on the chance of revival.

“On the one hand, Laureys said, a scan that shows no brain responsiveness may make families more comfortable about stopping various forms of life support. And if a scan shows consciousness, a patient might be aroused to the point of participating in the decision about life support.

“On the other hand, if life support and feeding are to be withheld, “we better get it right.”

“He said this doesn’t mean a patient deemed conscious should be kept alive for a long time using heroic means. ‘That is often a quality of life’ decision, he said. ‘Too often it’s politically polarized. Pro. Con. The right to life. The right to die. In reality, it’s more nuanced.’”

Three quick points.

First, if there is one overriding lesson from this study, and others like it that we we’ve reported on, it’s that large numbers of patients with severe brain injuries are quickly—and often inaccurately—labeled in a PVS. A study that concludes this or that technique (in this case, a PET) gives you a finer distinction could easily be rendered obsolete within a few months or years. In the meanwhile, offering "assurances" that doctors know with certainty that a patient is in a PVS makes it even easier to pressure families into withholding food and fluids.

Second, scientists Jamie Sleigh and Catherine Warnaby are "encouraged" by the study. Writing in "The Conversation," they note,

"[I]n many cases the accuracy of predicting the outcome is no better than flipping a coin….

"The exciting part of the new study is that we might be starting to make some progress in understanding the parts of the brain that are necessary for the conscious state, and we can use this to look into the brains of problematic patients to see if these critical regions of the brain are functioning – even if there are no outward signs."

But even laymen who follow the search for an "explanation" of what is consciousness know that this could easily be a quest that never finds an answer. It is incredibly complicated and is as much art as science, as much a philosophical question as it is about interpreting "data."

Grady's story ends with quotes from Dr. Joseph J. Fins, the chief of the medical ethics division at Weill Cornell Medical College in New York, who was not involved in the study.

"'[PET scans] help you discriminate who's who,' Dr. Fins said.

"Too often, he and Dr. Laureys said, patients are labeled vegetative and sent to nursing homes where no effort is made to rehabilitate them, and where emerging consciousness might not even be recognized.

"'The first thing we owe these people is a credible diagnosis,' Dr. Fins said.

Which leads me to the last point.

Third, you don't starve anyone to death, regardless of their diagnosis.

LifeNews.com Note: Dave Andrusko is the editor of National Right to Life News and an author and editor of several books on abortion topics. This post originally appeared at National Right to Life News Today

Week 5

Christian Medical & Dental Associations

Imminent Death Organ Donation Ethics Statement

CMDA affirms the sacredness of every human life, recognizing that life is a gift from God and has intrinsic value because all human beings are made in His image and likeness. For persons with illness that threatens life or health, organ transplantation may offer hope of a longer, healthier life. CMDA affirms ethical organ donation, meaning organ donation that is not coerced, in which organs are not purchased or sold, and through which vulnerable persons are not exploited or killed by vital organ procurement.

Ethical donation of solid organs is guided by the dead donor rule, according to which a potential organ donor must be dead before vital organs are removed for transplantation. Although medical criteria for the determination of death have been debated, decisions at the end of life nonetheless must distinguish ethically between acts of killing and allowing to die.[1,2]

Proposals are undergoing evaluation in the U.S.[3-8] and already are implemented in some other countries[9-13] to increase the supply of potentially transplantable organs by procuring organs from patients who are imminently dying.[14] Imminent death donation (IDD) by living patients could potentially apply to several types of donors:

1. The unconscious patient who is imminently dying from a devastating neurologic injury and irreversibly lacks decision-making capacity but is not brain dead.
2. The patient who is not actively dying but, as the result of a devastating neurologic injury, is chronically dependent on life-sustaining technology, and who, through an advance directive (made when the patient had full decision-making capacity) or substituted judgment by a legal surrogate, has made a decision to withdraw such technology. Organ donation would precede or occur simultaneously with such withdrawal. Such a patient might be:
    a. Permanently unconscious
    b. Minimally conscious
    c. Cognitively disabled or demented
    d. Neuromuscularly weak but cognitively unimpaired
3. The conscious, altruistic patient with decision-making capacity who is approaching death as the result of a progressive or devastating neurologic disease and requests assistance in an earlier death in order to donate organs before circulatory collapse renders them nonviable for transplantation.
4. The patient who has been diagnosed with a terminal disease, is dissatisfied with his or her present or anticipated future quality of life, and requests assisted suicide (so called “assistance in dying”) before the disease advances to its final stages.

In each case, death would be accomplished or hastened by the act of organ procurement.[15] The rationale for these proposals includes the following arguments:

It has been argued that the donor’s autonomy to choose the manner and timing of death and to donate organs should be respected.[7,16-18] However, this argument raises a number of concerns:

- * Imminently dying patients are vulnerable and may not be truly autonomous. Illness may deprive the potential donor or surrogate of the capacity to make informed decisions or resist coercive efforts under the guise of persuasion, which may be subtle or prey upon the patient’s despair.
- * The claim that procuring vital organs from the imminently dying honors the donor’s autonomy may be driven by underlying utilitarian or economic motives.

- Individual autonomy is neither incontestable nor an absolute principle. If autonomy were absolute, then a healthy person would have the right to sacrificial assisted suicide by donation of vital organs. The claim of autonomy must always be balanced with the principles of beneficence, nonmaleficence, and justice, as well as the need to preserve the integrity and trustworthiness of the medical profession.
- Elevation of the patient's autonomy to absolute mastery that extends to being killed or assisted in suicide so long as the act is voluntary is a distorted sense of freedom that denies both the giftedness and sacredness of life, over which medicine has a stewardship responsibility, and God's providential purposes for that life.[19,20]
- Whereas the patient's autonomy encompasses the right to receive medical attention and the negative right not to receive a recommended treatment, it does not include the positive right to receive any particular treatment requested that may be outside the physician's expertise, skills, or judgment.
- According a positive right to premature death to those who are autonomous would place at serious risk others who are less fully autonomous, such as patients with dementia, intellectual disabilities, or impaired consciousness.[19]
- Assisted suicide is a moral evil; using organs thus obtained may involve complicity if such use incentivizes or presumes to justify the practise (see CMDA statement on Moral Complicity with Evil).

5. It has been argued that the practise of medicine has evolved in such a manner as to legitimize and even require physician assistance in, and hastening of, medical death when patients no longer consider their lives to be worth living.[16] However,
   - Whereas technologies have evolved, unchanged are the moral conditions at the bedside, which include the reality of illness, the vulnerability of the patient, and the promise of the healthcare professional to endeavor to heal and not to harm.
   - Public opinions that may currently be in vogue are not a valid test of truth.
6. It has been argued that the donor's altruism in donating organs for the purpose of saving another's life should be honored.[15] However,
   - Patients who die as a result of physician-assisted suicide or who may request that their deaths be accomplished in the very act of procurement ("donation euthanasia") are not ethically appropriate sources of organs for transplantation, because they deny the sacredness of life of the dying patient. To accede to such a request is unacceptable, because it communicates that the patient's life has no further meaning.
   - To codify imminent death donation of solid organs would open the door to abuses and coercion and thereby place at risk the most vulnerable.
7. It has been argued that procuring organs from the imminently dying is an act of compassion on behalf of other patients in need of transplantable organs.[16] However,
   - Procuring organs from the imminently dying ignores good palliative medicine and compassion for the dying patient.
   - Assisted suicide and euthanasia violate both the Hippocratic Oath and the Hippocratic directive, "First, do no harm."[20]
8. It has been argued that organs should be procured from the imminently dying or in conjunction with euthanasia because, when retrieved from patients with a functional circulation, they are more viable and lead to better outcomes for the transplant recipient than ischemic organs retrieved from patients without circulation at the time of retrieval.[10] However,

- Organ procurement is not an end to be gained at all costs or through any means. Organ procurement should be performed within a covenantal relationship among patient, physician, and society, eschewing a utilitarian ethic of the greatest good for the greatest number as determined by secular ethical systems that may be susceptible to influence by financial, social, or political interests.
- The argument that the dying patient should relinquish his or her organs sooner presumes that the interests of the potential transplant recipient are of greater importance than and should overrule the needs of the dying patient, and thus that the dying patient is someone of lesser value. This attitude comes very close to asserting a claim of ownership of the dying patient's organs. Human beings' organs are not the property of the state, healthcare institutions, or the transplantation industry.

9. It has been argued that the currently-accepted practise of withdrawing life-sustaining medical interventions is already equivalent to euthanasia;[5,13] therefore, a more aggressive agenda of ending life sooner for the utilitarian purpose of obtaining organs is justified. However,
    - CMDA affirms that there is a meaningful ethical distinction between euthanasia and allowing a patient to die of natural causes. When life-sustaining treatment is withdrawn, the proximate cause of death is the underlying disease.
    - Proposals to procure organs in the imminently dying would necessitate revocation of the "dead donor rule."[18]
    - It is ethically impermissible to kill some people to benefit others.
10. It has been argued that physicians whose religious beliefs or moral conscience prevents them from using their knowledge and skill to terminate their patient's lives are duty bound to refer their patients to others willing to perform such an act, or else should be forced to resign from the practise of medicine.[9,21,22] However,
    - Medicine is a healing vocation into which many healthcare professionals enter as a calling (See CMDA statement on Professionalism) and is fundamentally unlike a service industry defined by a job description. The most exemplary and trustworthy healthcare professionals are those who identify with and live out the moral ethos of their healing vocation. To impose on healthcare professionals, who are committed to healing, a legal duty to kill would dangerously violate their moral integrity and severely damage the trustworthiness of their profession.[23]
    - Whereas the state can legitimately limit healthcare professionals in doing what they believe to be good, the state does not have the legitimate authority to force healthcare professionals to commit acts that they believe to be morally wrong.[24]
11. The opinion has been asserted that time-honored moral prohibitions against taking innocent life, such as those expressed in the Hippocratic Oath and the Bible, "have no legitimate bearing on the practise of 21st century medicine" because there is no scientific test (accepted by atheists) for the existence of God.[21,25] However,
    - Nor can any scientific test limited to empirically-verifiable factual data prove that atheism is correct or disprove the existence of God. Additional sources of knowledge are needed to discern moral values.
    - Medicine, of all the professions, should affirm the value of human life and embody an ethic of healing rather than a rush to death. The healing orientation of medicine benefits all of society.
    - Atheism also is a belief system, but in comparison to theism, atheism provides an impoverished ethical basis for the healing mission of medicine, as it rejects the sacredness of human life and accommodates the view that humans are nothing more than biological machines with interchangeable parts.[26]

Conclusion

Donation euthanasia and procurement of organs from the imminently dying are incompatible with the ethical principles of the Christian Medical & Dental Associations. Specifically:

- * Christian physicians affirm that God, in His mercy, has provided the possibility of organ transplantation for many patients in need and that this life-saving technology comes with great moral responsibility.
- * CMDA upholds the ethical practise of uncoerced solid organ donation, including single kidney or partial liver donation from living patients and vital organ donation from patients determined to be deceased by whole brain or circulatory criteria (see CMDA statements on Death, Overview on Human Organ Transplantation, Organ Transplantation after Assisted Suicide or State Execution, and Organ Donation after Circulatory Death).
- * CMDA upholds the "dead donor rule" as an inviolable boundary for the ethical removal of vital organs for transplantation and opposes efforts to circumvent or abolish it.
- * CMDA emphatically rejects in practise and in public policy organ donation by acts of medical killing, including
  - Assisted suicide in the patient who has been diagnosed with a terminal illness or a severe disability and requests donation of vital organs, the removal of which would cause or hasten the donor's death.
  - Euthanasia with intent to obtain transplantable organs.
- * Under no circumstances should healthcare professionals be encouraged or coerced to participate in the hastening of death for the purpose of organ procurement, nor be required to be complicit in such killing by referral to others who will comply (see CMDA statement on Healthcare Right of Conscience).

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Ridgecrest, North Carolina

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The United States Revised Uniform Anatomical Gift Act (2006): New challenges to balancing patient rights and physician responsibilities

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Editor's Note: *The issue of being declared brain dead or cardiac dead is tied closely to the right to procure a patients organs. The article below is an excerpt from a longer article that addresses concerns about the 2006 act that presumes everyone wants to donate their organs in the event of death. Julie Grimstad notes her concerns:*

"When you are at or near death and those are the words in the law, you're not dead, you're at or near dead, the hospital is required to call the organ procurement organization and they will come and they will look through all your medical records, invade your privacy without anyone's permission or consent. This is one of the things under Hippa that can be done without your permission. They will run tests on you to see if your organs are suitable for transplantation. They can do things to you such as put you on a heart/lung machine or give you heparin to thin your blood or profuse you with fluids. They can do these things to you without your permission, without your families consent and while they are doing these things they can be searching for someone to give their consent or refuse to donate your organs."

*While organ donation is a noble idea, examples of abuse are numerous and worrisome. Furthermore, the revised Anatomical Gift Act infringes on your right of privacy, your right of informed consent, your right to security of person and your right to life. We therefore strongly encourage you to discuss your wishes about organ donation with family and friends. We have attached a "REFUSAL" card to carry in your wallet and recommend informing those you have chosen to serve as health care proxy of your wishes concerning organ donation.*Remember – we neither seek every medical treatment available to live forever, nor accelerate death by imposing our will, death must be natural in God's time.*

Abstract - Advance health care directives and informed consent remain the cornerstones of patients' right to self-determination regarding medical care and preferences at the end-of-life. However, the effectiveness and clinical applicability of advance health care directives to decision-making on the use of life support systems at the end-of-life is questionable. The Uniform Anatomical Gift Act (UAGA) has been revised in 2006 to permit the use of life support systems at or near death for the purpose of maximizing procurement opportunities of organs medically suitable for transplantation. Some states have enacted the Revised UAGA (2006) and a few of those have included amendments while attempting to preserve the uniformity of the revised Act. Other states have introduced the Revised UAGA (2006) for legislation and remaining states are likely to follow soon.

The Revised UAGA (2006) poses challenges to the Patient Self Determination Act (PSDA) embodied in advance health care directives and individual expression about the use of life support systems at the end-of-life. The challenges are predicated on the UAGA revising the default choice to *presumption of donation intent* and the use of life support systems to ensure medical suitability of organs for transplantation. The default choice trumps the expressed intent in an individual's advance health care directive to withhold and/or withdraw life support systems at the end-of-life. The Revised UAGA (2006) overrides advance directives on utilitarian grounds, which is a serious ethical challenge to society. The subtle progression of the Revised UAGA (2006) towards the presumption about how to dispose of one's organs at death can pave the way for an affirmative "duty to donate". There are at least two steps required to resolve these challenges. First, physicians and hospitals must fulfill their responsibilities to educate patients on the new legislations and document their preferences about the use of life support systems for organ donation at the end-of-life. Second, a broad based societal discussion must be initiated to decide if the Revised UAGA (2006) infringes on the PSDA and the individual's right of autonomy. The discussion should also address

other ethical concerns raised by the Revised UAGA (2006), including the moral stance on 1) the interpretation of the refusal of life support systems as not applicable to organ donation and 2) the disregarding of the diversity of cultural beliefs about end-of-life in a pluralistic society.

Background

In 1990, the U.S. Congress passed the Patient Self-Determination Act (PSDA) reinforcing individuals' rights to determine their final health care. The PSDA became effective in 1991 so that patients can make decisions about their medical care and specify whether they want to accept or refuse specific medical care [1]. Patients' wishes can be clearly documented at an earlier point of time in advance health care directives and/or patients can identify legally authorized representatives to make health care decisions (power-of-attorney for health care) on their behalf in the event of an incapacitating illness.

The PSDA requires Medicare and Medicaid providers, including hospitals, to give adult individuals, at the time of inpatient admission, certain information about their rights under state laws governing advance health care directives, including: (1) the right to participate in and direct their own health

care decisions; (2) the right to accept or refuse medical or surgical treatment; (3) the right to prepare advance health care directives and (4) information on the provider's policies governing the utilization of these rights [2]

Complete article can be found here: http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2001294/

Understanding Terri Schiavo's Death

Cognitive Disability vs Persistent Vegetative State
Transcript of Bobby Schindler Interview

Question: So, I'd like for you to tell me what have you gotten out of it? How have you turned Terri's tragedy into something to help others?

B. Schindler: There still exists a tremendous amount of confusion within the public about Terri's case and other cases like her or other situations like her. What our organization is doing now, we're helping other families that are in similar circumstances of what we were faced with in our battle to save Terri.

People are saying, "Why are you still talking about Terri? Her case happened almost eight years ago." The fact of the matter is that it wasn't an isolated case. I think a lot of people have this perception that it just happened to Terri and something like that doesn't happen in other hospitals or in other types of health care settings.

What happened to Terri happens, it was happening long before her case made the headlines that it did, and it continues to happen every single day in our nation. What I mean by that, I'm not talking about someone who's terminal, we're not talking about someone that perhaps is hours away … someone who may have a cancer, someone with an underlying terminal disease where they're just hours away from death.

We're talking who had a cognitive disability, was not being sustained by any machines or any types of life support, someone that would live, doctors believe, a normal life span if they were to continue to receive the basic care of food and water. We're talking about these types of individuals that are having their basic care, food feeding tubes, taken away every single day in our country, in order that they die. A few of them say this affects just a few of us. No, we're talking about the possibilities. If you think about this category that we are now defining as people that are vulnerable because of this anti-life movement happening in our country, we're talking about possibly millions of people that could be affected by this issue, of food and water being taken away from them so that they would die by, death by dehydration and starvation.

I don't know if that answered your question, but …

Question: The way that you're angled, I'm just going to flip this a little. Tell me the proper names of the network and tell me what you're hoping to accomplish now.

B. Schindler: It's the Terri Schiavo Life and Hope Network. The main objective of our organization is to help families faced with similar circumstances to what our families faced with.

When this happened to my sister, our family was very naïve. We didn't know what to do when they said, "Okay, we're going to court to take away your daughter," and my sister's "food and water." Terri was very much alive. We couldn't believe any court could ever rule in favor of taking away her food and water.

We didn't know anything about this issue. We looked to other organizations for help, their resources, attorneys, doctors that could support us as we embarked on this battle as it grew. We couldn't find any. Even as this case started to get more publicity, there were very few organizations out there that were kind of able to have the resources to help us.

We were scrambling and we were reaching out to anybody and everybody we thought could help. We want to be that organization that wasn't there for us. That's what we're trying to do.

We have an enormous amount of resources available to us, attorneys, doctors and other things that we can help families that call us for whatever reason, that are faced with these types of situations.

That's really our main objective. We also do a lot of education, a lot of speaking because there is this confusion that exists, and awareness. I think many people are very apathetic to this issue, unlike we're seeing with the abortion issue. I think it's one of those things, "Well, if it doesn't happen to me, I'm not going to worry about it."

We believe people need to understand because this type of issue can affect potentially so many people. We feel like it is going to affect you at some point in your lifetime.

That's really kind of in a nutshell what we're doing in this organization. We also have a vision and a goal of doing even more in helping people with cognitive disabilities in the future by opening up a brain injury rehabilitation center that will help people that are in similar conditions to what Terri was when she was living.

Question: Tell me a little bit more about cognitive disabilities. What is it and is that really what Terri was dealing with?

B. Schindler: That's what it was. People with brain injuries, all kinds of levels of brain injuries … we have those that simply have a concussion, all types of different brain injuries leading up to perhaps, even death. Then you have someone like Terri with a profound brain injury where she needed 24-hour, seven days of care from other individuals. She had difficulty swallowing and needed other ways to supply her food and water which was a feeding tube. A feeding tube is very common today. Upwards of a million people at any time have feeding tubes, either for short periods of time or more permanently like Terri.

Brain injuries can be anything from a traumatic brain injury to those that, like my sister, had a lack of oxygen, anoxic brain injuries. There all types of brain injuries. Estimates from different brain injury sources will estimate that over a million people, something like upwards of 1.2 million every year, will experience a traumatic brain injury which is different from what my sister had.

We're talking the enormous numbers of people have experienced brain injury and acquire brain injuries every year are soldiers coming back from war. You're seeing a lot of them in the news now where they're getting all types of different levels of brain injuries.

Brain injuries are affecting millions of Americans every year. That's not even including the ones that have experienced brain injuries prior to the current year. We're talking about millions and millions of people who have these types of brain injuries and there's just different levels and depending on that level will depend on how society treats these individuals.

We saw, in my sister's case, we saw society looking at her as having no value, no worth, and therefore we justified in killing her.

Question: Just out of curiosity, persistent vegetative state versus a you called it a cogni …

B. Schindler: Cognitive brain injury.

Question: What's the difference between a cognitive brain injury and a persistent vegetative state?

B. Schindler: In my opinion and speaking to doctors since we've been involved in this issue, persistent vegetative state was created to describe someone that really hasn't reached full consciousness, but someone also who is not in a coma, somewhere in between. It seems to me that it does nothing but dehumanize an individual. We refer to people that have this diagnosis of persistent vegetative state as being vegetables.

It seems to me that, just like we've seen in the abortion issue in the way we want to dehumanize the unborn child, we want to dehumanize people with brain injuries like my sister by putting this very unscientific, inaccurate and completely subjective diagnosis on people like Terri with these brain injuries.

What's so dangerous about the persistent vegetative state diagnosis is not only does it dehumanize, remove, devalue dignity from these individuals in some people's eyes, but it also is being used as criteria to kill people that have these diagnoses attached to them in which it was used in Terri's situation.

There's been several research studies that have come out that have really shed light on how, as I said earlier, how unscientific and inaccurate the PVS diagnosis can be. In fact, they found upwards of 50% of people that they thought were in a persistent vegetative state, were in fact not in a persistent vegetative state.

My belief is that it should be eliminated from our vernacular for those reasons just mentioned. We simply refer to people like Terri with these types of brain injuries as a person with a brain injury, a person with a cognitive disability because that's really what they are.

Doctors Deny Lifesaving Care for Canadian Patient, Say Quality of Life Too Low

by Wesley J. Smith | LifeNews.com

Bioethics pushed personal autonomy to the forefront of medical decision making, helping forge the legal right to say no to unwanted life-extending care. Today, if a person doesn't want to be in an ICU or to be otherwise kept alive with medical treatment, the patient or family can say no. And that's generally a very good thing. Indeed, without the right to say no, the hospice movement would never have materialized.

But what about patients who want to say *yes* to such care? Increasingly, patient autonomy is becoming a one-way street. If you want to die, fine. That decision is sacrosanct. If you want to live, well doctors and bioethicists get to make the final decision. This is sometimes called Futile Care Theory or medical futility.

Futile Care Theory is as much about money as it is about benefiting the patient. It is also about honoring the subjective views of doctors and care givers–even at the expense of rejecting a patient's specific request for efficacious treatment, that is, treatment that would or could achieve the desired medical result of extending the patient's life.

Now, in Canada (yet again), we see a case in which a patient stated he wanted to be kept alive but the doctors don't want to comply. From the *Toronto Star* story:

Joaquim Silva Rodrigues wants to live. It's what the 73-year-old Catholic man repeatedly told his family he wanted after he was diagnosed with a rare disease called progressive supranuclear palsy two years ago. It's what his wife and son have demanded on his behalf from his physicians at Sunnybrook Health Sciences Center where he lies today, motionless and speechless. On May 14, they placed a note in Rodrigues's medical chart saying he has "no reasonable hope of recovery or improvement" and that they have decided to withhold mechanical ventilation in the event of a medical emergency requiring life-saving treatment.

That change in status was made unilaterally, without the consent of his family.

The physicians' point is that Rodrigues has a life not worth living:

Last July, Rodrigues was admitted to Sunnybrook and moved into the ICU in August. Since then, he's had to be placed on medical ventilation three times, Dr. Andre Amaral testified. There won't be a fourth, he and his colleagues have decided. "He has no chances of recovery," Amaral told the panel. "There's no clear benefit in prolonging life when you cannot tell whether the life that's being prolonged is actually worth living for. . . . We're prolonging life for suffering and pain."

Dr. Keith Rose, Sunnybrook's chief medical executive, said the number of high-profile physician/patient conflicts at his hospital reflects the sheer volume of critical care cases it receives as one of Canada's largest trauma centers. "Nobody goes out to try and make families angry, to create confrontation," he said, adding that the hospital administration supports the decision of its doctors in the Rodrigues case. "The final decision-making, after all steps have been gone through and discussions with the family, then, if it's in the best interest of the patient, it is the physician's decision to make."

But *he said* that this was a life *he considered* worth continuing.

I disagree with Rodrigues' decision. If it were me, I'd reject the ICU. But who cares what I think? It isn't my life that's being decided about.

Nor should it be the doctors' choice, since this kind of decision deals with *subjective personal values*. In other words, the treatment *is to be withheld because it will or could work*, not because it won't. Thus, the doctors are really saying that the *patient's life*–as opposed to the treatment–is futile.

Hard cases make bad law. It will be a very worrying thing–particularly in an age of cost containment and potential conflicts of interest thereby created–if doctors and/or bioethicists are given the final legal say about whose life is worth living. I can't think of a more certain way to destroy trust in the healthcare system.

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Michigan Law Helps Patients Stop Denial of Lifesaving Medical Treatment

by Jennifer Popik, J.D. | *LifeNews.com* | *6/6/13*

It is a family's worst nightmare. A loved one is desperately ill but a health care facility or provider refuses life-saving treatment on the grounds that this care is "futile."

This is occurring, with increasing frequency, all across the U.S. In many cases, health care providers call life-saving medical treatment "futile" not because it will fail to preserve the patient's life, but because they deem the life not worth saving – that the "quality of life" is so poor that in their judgment the patient has lost the right to live.

While hospital practises and state laws vary widely, the Michigan legislature unanimously passed a bill that will provide some clarity when "futility" is being invoked to deny treatment.

S. B. 165, known as the "Medical Good-Faith Provisions Act," takes the basic step of prohibiting a health facility or agency from maintaining or implementing a medical futility policy unless it is in writing. Moreover it will require a health facility or agency that maintains a medical futility policy to provide a copy upon request to a patient or resident, prospective patient or resident, or parent or legal guardian of any of those people.

In the wake of the tragic Terri Schiavo case, many authorities urged Americans to complete advance directives which allow you to name someone to speak for you and express treatment preferences. Every state authorizes these legal documents. They allow a person to specify ahead of time whether and under what circumstances she or he wants life-preserving medical treatment, food or fluids when no longer be able to make health care decisions.

However, the laws of most states may allow doctors and hospitals to disregard advance directives when the directive calls for treatment, food, or fluids. Increasingly, health care providers who consider a patient's "quality of life" too low are denying life-preserving measures against the expressed wishes of patients and families. Unfortunately the laws of most states provide no effective protection against this involuntary denial.

The result: in most states, if you want life-saving treatment–or even food and fluids–there is no guarantee your wishes will be honored, even if you make them clear in a valid advance directive.

When challenged by families, health care providers often claim the treatment is being denied because it is "futile".

On its face, the term futile seems like a simple concept: treatment that will not work. However, it is important to distinguish between the narrow physiological and the broader value-laden use of the term. As described by the New York State Task Force on Life and the Law,

"Some physicians use 'futile' narrowly, considering treatments to be futile if they would be physiologically ineffective or would fail to postpone death…. Many physicians embrace a broader, more elastic understanding of the term. … [A] treatment might be seen as futile if it does not offer what physicians consider an acceptable quality of life. For example, in one survey, a majority of physicians agreed that for a severely demented patient with Alzheimer's disease, CPR [cardio-pulmonary resuscitation] would be 'so clearly inappropriate or futile on medical grounds that physicians should be permitted to institute DNR status based on clinical judgment, without obtaining consent.'"[1]

An example of that "broader, more elastic understanding" is a 2011 text, "Wrong Medicine: Doctors, Patients, and Futile Treatment." In it the authors write, "If a patient lacks the capacity to appreciate the benefit of a treatment, . . . that treatment should be regarded as futile. . . . [W]e draw the line at some point between patients' rights to choose their own quality of health and life and the medical profession's obligation to achieve those ends."[2]

What many would find shocking is that these kinds of unilateral decisions by providers to deny treatment are far from uncommon. One study found that "14% of physicians in adult intensive-care units had withheld or withdrawn treatment they considered futile without informing the patient's family. More than 80 percent had withdrawn treatment over the family's objections."[3]

So what is happening in practise is that treatment is being refused not because it is truly medically futile, but because the provider is making value judgments about the life of the person the treatment should go to. Highlighting this problem in the legislative hearings in Michigan, family members of a girl with a disability gave the main testimony.

They described how their daughter was denied routine treatment on the basis of the treatment being "futile", not because it would not be effective, but because she has Trisomy 18.

Although the Michigan bill took aim at clarifying futility, there is larger issue about what the patient's options are once a health care provider is actually denying treatment against the expressed wishes of the patient or their surrogate. While the simple answer would seem to be, "find a new provider," this often takes time–while the patient might go without treatment–or might not be possible.

There are several kinds of state laws governing this very circumstance.

Some states have no protection. The relevant laws of nineteen states provide no effective protection of a patient's wishes for life-preserving measures in the face of an unwilling health care provider.

Fourteen states offer protection. Ten states have laws that essentially protect the choice of a patient whose advance directive specifies that life-preserving measures should be provided in circumstances in which the doctor, hospital or other health care provider disagrees. Typically, the statutes in these states allow the unwilling health care provider to transfer the patient to a provider willing to comply with the patient's advance directive but require that life-sustaining care be provided until the transfer can be completed.

Two states require that unwilling health care providers give the life-preserving measures chosen in advance directives pending transfer of the patient to a willing health care provider, but establish time limits by which a successful transfer must be arranged and authorize denial of treatment, food or fluids if the time runs out. Idaho simply requires life-preserving treatment. And in a new anti-discrimination approach, Oklahoma prevents the denial of treatment based on age, disability, or terminal condition.

The rest of states have statues that offer questionable protection. The state of Michigan is one of seventeen states (including the District of Columbia) that have statutes with language that might be cited to support a right to receive life-preserving measures specified in accordance with an advance directive, but either the language is ambiguous or it could be trumped by other provisions in state law.

While the enactment of the "Medical Good-Faith Provisions Act" is a positive step in Michigan, there is still much ground to make up. Americans are being urged to set down their wishes concerning life-preserving medical treatment, food and fluids in advance directives. To the extent those advance directives call for food, fluids, or life-preserving medical treatment in some or all circumstances, however, in the present state of medicine and the law there is no guarantee they will be honored in most states.

More on the law on your state, including a full report titled "Will Your Advance Directive Be Followed" can be found on nrlc.org.

Notes

[1] New York State Task Force on Life and the Law, When Others Must Choose: Deciding for Patients Without Capacity (New York: n.p., 1992), pp. 196-97, quoting N. Spritz, "Views of Our Membership Concerning the DNR Issue and the New York State DNR Law," in Legislating Medical Ethics: A Study of New York's DNR Law, ed. R. Baker and M. Strosburg, Philosophy and Medicine Series (Dordrecht: Kluwer Academic Publishers).

[2] Lawrence J. Schneiderman and Nancy Ann Silbergeld. Jecker, Wrong Medicine: Doctors, Patients, and Futile Treatment (Baltimore: Johns Hopkins University Publications, 2011).

[3] Cited in Patricia O'Donnell, "Ethical Issues in End-of-Life-Care: Social Work Facilitation and Practise Intervention" in Living with Dying: a Handbook for End-of-Life Healthcare Practitioners, ed. Joan Berzoff and Phyllis R. Silverman (New York: Columbia University Publications, 2004).

LifeNews Note: Jennifer Popik is a medical ethics attorney with National Right to Life. This column originally appeared in its publication National Right to Life News Today.

Should Sedation Be Terminal?

Nancy Valko , October 2002

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Terminal sedation'(TS) has become an important but controversial issue in bioethics during the last several years, especially in light of the ongoing debate about Assisted Suicide. TS has been both condemned and embraced by people on either side of the Assisted Suicide debate. It has been called an ethical form of end-of-life care, a legal alternative to Assisted Suicide, and slow Euthanasia.

Although the term "terminal sedation" was unknown in 1980, the Vatican's Declaration on Euthanasia cites Pope Pius XII's 1957 statement endorsing the use of sufficient medication to control pain, even if there was a risk of unconsciousness or hastening death. However, the Declaration also added the caveat that the intention must be "simply to relieve pain effectively," in keeping with Pope Pius XII's view that such measures are appropriate when "no other means exist" and that should "not prevent the carrying out of other religious and moral duties." He also warned "it is not right to deprive the dying person of consciousness without a serious reason."[1]

Today, supporters define terminal sedation as the deliberate "termination of awareness" for "relief of intractable pain when specific pain relieving protocols or interventions are ineffective" and/or "relief of intractable emotional or spiritual anguish (existential suffering, psychological distress, emotional exhaustion)."[2] Although deep sedation can be provided as a temporary respite, once the decision is made to provide TS, it is considered irrevocable as soon as the person is unconscious. TS is then continued until death occurs.

Thus, terminal sedation has evolved from being a last resort for relieving the pain of the dying to a method of permanently relieving nonphysical psychological or spiritual distress.[3] Ironically, it has been just this kind of relief of psychological suffering, rather than the relief of unbearable pain, that has been cited as one of the primary motivations by people seeking to die under Oregon's physician-Assisted Suicide law.[4]

The Changing Face of Terminal Sedation

The term "terminal sedation" has only come into use in recent years but already there are proposals to change TS to such terms as "total sedation" or "palliative sedation." The proposed changes in terminology are more than just cosmetic.

The use of the word "terminal" has been eschewed by many supporters because of the connotations that TS itself causes death or that the person must be imminently dying to receive TS. Other commentators support more user-friendly terms like "palliative sedation" or another form of "comfort care" to describe permanent deep sedation for other categories of patients "who have no substantial prospect of recovery."[5]

An often-crucial component of TS is the withholding or withdrawing of life-sustaining treatment, primarily food and water,[6] but routine medications such as insulin or blood pressure medicine are also rarely continued. But while there is universal agreement that treatment or care which is medically futile or excessively burdensome can be ethically forgone, TS itself does not depend on such determinations.

For example, in their article "Responding to Intractable Terminal Suffering," Drs. Timothy Quill and Ira Byock describe the case of a retired radiologist with an eventually lethal brain tumor who "feared becoming a burden to his family and developing progressive loss of mental capacity." Concerns about the beginning signs of impending decline motivated the radiologist to talk to his doctor about his decision to stop eating, drinking, and taking his medication with the stated intention of hastening his death. His doctor agreed to help him remain comfortable during the process.

After nine days with a continuous low dose of morphine to control discomfort, the radiologist became confused and agitated, which are some of the symptoms associated with dehydration. TS was then started and maintained until his death.

Quill and Byock justify this manner of death by stating that voluntary refusal of food and water has "the ethical advantage [of] being neither physician-ordered nor directed." They do admit, however, that this "requires the support of the family, physician, and health care team, who must provide appropriate palliative care as the dying process unfolds."

While Dr. Quill is a prominent supporter of Assisted Suicide and Dr. Byock is an equally prominent opponent, both consider TS with voluntary refusal of food, water, and other life-sustaining measures to be a valid alternative to Assisted Suicide and an expression of patient autonomy.

I disagree. We cannot ignore the fact that this radiologist's death was actually accomplished with the physical as well as psychological support of the health care providers. The radiologist could not starve and dehydrate himself without prescribed medication to relieve the suffering. This is far from a natural death and indeed turns the trusted hospice philosophy of neither prolonging nor hastening dying on its head.

TS supporters point to the accepted principle of the "double effect" in these cases. The intention of the doctor is considered paramount, and the good effect of relieving unbearable suffering takes precedence over the bad effect of foreseen death. This is more than a little disingenuous.7 Even doctors like Jack Kevorkian have used this as a legal and moral defense when obviously lethal injections were given.8

In the case of the radiologist above, he clearly stated that his own intention was to cause death. The doctors themselves had to expand the definition of unbearable suffering to include psychological suffering, which, disturbingly, is now also being used in Holland to justify the practise of Euthanasia for physically healthy people.

The Pontifical Council's 1994 Charter for Health Care Workers makes an- other important point when it warns that:

"sometimes the systematic use of narcotics which reduce the consciousness of the patient is a cloak for the frequently unconscious wish of the health care worker to discontinue relating to the dying person. In this case it is not so much the alleviation of the patient's suffering that is sought as the convenience of those in attendance. The dying person is deprived of the possibility of "living his own life," by reducing him to a state of unconsciousness unworthy of a human being. This is why the administration of narcotics for the sole purpose of depriving the dying person of a conscious end is "a truly deplorable practise."9

In the end, we must also consider the outcome if the doctors had refused to participate in the radiologist's desire to end his life prematurely and instead had affirmed the value of his life, however diminished in the future. Would the radiologist have then really persisted in his intention to die as soon as possible, or would he have instead reconsidered his decision because of the doctors' commitment to helping him die comfortably and naturally at a later time?

We will never know.

Nonvoluntary Terminal Sedation?

Although most discussions of TS primarily involve dying cancer patients who request it, supporters of TS now even include incapacitated patients. The rationale for this is supplied by TS supporters such as Dr. Perry Fine who point to an advance directive “that sufficiently suggests or requests sedation in the face of unrelieved distress” or, in the absence of such a directive, asks “a health care proxy” to make the decision.10

In reality, however, decisions to terminate awareness or ensure unawareness are often being made for incapacitated patients with a variety of conditions, some of which are not necessarily terminal.11

For example, it is not unusual to see withdrawal-or-withholding-of-treatment decisions made for patients with conditions such as brain injury or dementia automatically accompanied by pain medicine and/or sedation to ensure that the patient feels no discomfort. It is also common to see continuous sedation and/or pain medication initiated or increased when a ventilator is stopped with the expectation - if not the actual hope - that the patient will not resume breathing.12

Even when a person has a potentially survivable but severe stroke, many families accept doctors’ predic tions of poor future recovery and agree to only give comfort care because "Mom wouldn't want to live like that." Medications given under these circumstances are usually called "comfort care" rather than TS even though the result is almost always unconsciousness or a patient too sleepy to safely eat by mouth.

In one case, an elderly woman I will call Kay was admitted to a hospital with a massive stroke that the doctors deemed a terminal event. Kay had an advance directive from an anti-Euthanasia group and had named her sister as the person to make her health care decisions if or when Kay became incapacitated. This particular advance directive was similar to most others except that it was quite specific that basic life-sustaining care, especially food and water, should be provided unless medically contraindicated or if death was inevitable and imminent.

After several days, one of Kay's nieces called me and said that she was concerned because Kay was still alive and breathing although unconscious. The relative wanted to know if Kay's unconsciousness meant that she was indeed terminal and, if not, should she now receive food and water?

One of the first questions I asked was if Kay was receiving morphine. The niece said Kay was indeed on an intravenous morphine drip, which the doctor had prescribed as comfort care.

Cerebral vascular accidents, commonly known as "strokes," are not usually terminal and also rarely cause pain beyond sometimes an initial headache. The length of time since the stroke argued against Kay's stroke being automatically terminal and therefore also argued for the provision of basic medical treatment, including the requested food and water.

At my suggestion, the niece talked to Kay's sister about stopping or reducing the morphine to assess Kay's level of awareness and to see if she were indeed in any pain. Kay's sister agreed to have Kay fed if she woke up.

The cousin later reported that Kay started to respond not long after the morphine was reduced. She opened her eyes, looked at people when they spoke to her and even seemed to recognize her relatives. However, Kay's sister said a priest told her that such apparent reactions were merely "reflexes" and she had the morphine drip restarted. It was not surprising that Kay died two weeks after her stroke, especially since no one can live without food and water for an extended period of time. The niece and some other concerned relatives had briefly considered talking to a lawyer about enforcing Kay's advance directive before she died but they finally decided against it because they were reluctant to divide the family even further.

While Kay's case evolved at a distance and I was unable to personally review her medical records at the time, her case resonates with my own experiences and those of other nurses around the country who have told me similar stories. Unfortunately, cases like Kay's seem to be increasingly common, and they illustrate the growing concerns about both the controversial practise of TS and the expanding categories of conditions included in end-of-life care.

Although no one would deny an incapacitated or critically ill patient sufficient medication to control pain or other symptoms, traditional comfort care has not included decisions to ensure unawareness until recently.

A Nursing Perspective

After thirty-four years as a nurse, working in such areas as medical-surgical units, home health/hospice, oncology, and ICU, I have had a wide range of experience in end-of-life care for patients as well as for members of my own family. I have also had to work under doctors at all points on the ethical and competency scale, from doctors who magnificently care for their patients' emotional, spiritual, and physical needs to doctors who avoid their dying patients as much as possible.

I have been frustrated both by doctors who will not order adequate pain medication or sedation in even imminently dying patients because of addiction fears and doctors who have demanded that we nurses keep increasing morphine drips “until the patient stops breathing.”

I have also cared for patients and even families who run the gamut from passively accepting any recom mendation from a doctor to patients or families who adamantly demand that we doctors and nurses put them out of their misery.

End-of-life issues now occur almost anywhere in the health care system, from hospitals to nursing homes to the patient's own home. Nurses are a necessary component in implementing and evaluating such care, including standard holistic care as well as controversial interventions such as TS.

Unlike doctors, however, nurses ordinarily cannot pick and choose among the patients they care for because nurses are assigned to their patients. A refusal to participate in the care of a particular patient because of ethical concerns can be seen as an unreasonable demand on other, overworked staffer even as a refusal to honor a patient's legal rights, especially when there is an absence of any protection for the rights of conscience. Thus, nurses can even face termination for refusing to compromise their professional and ethical principles.

With the welcome advent of the campaign to make evaluation of pain "the fifth vital sign," nurses are charged with constantly monitoring the success or failure of pain relief interventions in all patients who experience pain, whatever its etiology, and making adjustments or recommendations to the doctor. For the effort to control pain to be truly effective, however, nurses - as well as doctors - must have a thorough education both in the techniques of pain management in various scenarios and the ethical considerations involved. But while clinical guidelines for pain management are usually rather straightforward and accepted, controversial interventions such as TS depend on a more subjective determination of what constitutes unbearable suffering and evoke ethical concerns in regard to causing or hastening death. Sooner or later, we must answer a critical question: is medical ethics a matter of personal or legal interpretation or are there workable, universal principles upon which a consensus can be built?

The Future of Terminal Sedation

Rather than seeing TS as a rarely used last resort, even the few studies on it report the prevalence of terminal sedation to range from three to fifty-two percent in the terminally ill.13 When the unknown actual incidence of terminating awareness or ensuring unawareness in patients with stroke, dementias, or other serious illnesses is factored in, the use of TS as a form of “comfort care” may well be approaching epidemic proportions, even outside the hospice area.

Legally, TS may be impossible to regulate. Being a process rather than a single lethal overdose, TS can even be technically distinguished from Assisted Suicide.14 But what is legal is not necessarily ethical, and, unfortunately, even well-meaning medical professionals and ethicists may feel a need to “hurry up” the dying process or just spare a patient and his or her family from a perceived poor quality of life.

In addition, the newer health care system problems of cost-containment and stressed, overburdened health care professionals can make TS even more attractive - and dangerous - to patients and caregivers alike.

But alternatives to TS do exist, even in the case of terminal illness.

For years, the usual and trusted approach to severe pain has been to gradually increase dosages of pain medications until a sufficiently strong and effective dosage is reached. When combined with anti-anxiety or sedative medication, this plan almost always helps the patient achieve the highest level of pain control while allowing the person to remain as calm and alert as possible.

Of course, no mere pill or injection can substitute for the genuine compassion and reassurance that are also crucial aspects of good pain management.

Short- or longer-term deep sedation may be indicated in some very rare cases As long as basic medical care, including even medically-assisted feeding,15 If the patient needs and can tolerate it, is continued, the concern about hastening or causing death should be alleviated.

But death is not a purely physical event, as Elizabeth Kubler-Ross’s groundbreaking work on the emotional stages of dying showed us decades ago. It has been my experience that patients facing a terminal illness fluctuate between welcoming and fearing death, hope and despair, and weakness and strength.

Coming to terms with death is often harder than the dying process itself, but I have been privileged to accompany many people on this final, most important journey. This journey is rarely easy or smooth, but the rewards to patients, families, and health professionals are enormous.

The allure of preempting any suffering by dying unconscious may well appeal to a great number of terminally-ill patients as well as the frail elderly, the disabled, the chronically ill, and others. Sometimes no matter how hard we try, some patients, families, and even medical professionals may still demand the right to choose a hastened death.

In those circumstances, as with Assisted Suicide and Euthanasia, the best and only answer should still be "No."

Footnotes

1 Sacred Congregation for the Doctrine of the Faith, Declaration on Euthanasia, May 5, 1980

2 Perry Fine, M.D., "Total Sedation in End-of-Life Care: Clinical Considerations," Journal of Hospice and Palliative Nursing 3.3 (July-September 2001): 82.

3 T. Morita et al., "Pain and Symptom Management: Terminal Sedation for Existential Distress," American Journal of Hospice and Palliative Care 17.3 (May/June, 2000): 189-195.

4 "A startling 63% of these patients (compared to 26% in 1999 and only 12% in 1998) cited fear of being a 'burden on family, friends or caregivers' as a reason for their suicide. The most commonly cited reason for suicide was a concern about 'loss of autonomy' (cited by 93% in 2000, compared to 78% in 1999)." NCCB Secretariat for Pro-Life Activities, "Oregon's Third Year of Physician-Assisted Suicide: Details and Concerns," Life at Risk: A Chronicle of Euthanasia Trends in America, 11.1 (January/February 2001).

5 Timothy E. Quill, M.D. and Ira R. Byock, M.D., for the ACP-ASIM End-of-Life Care Consensus Panel, "Responding to Intractable Terminal Suffering: The Role of Terminal Sedation and Voluntary Refusal of Food and Fluids," Annals of Internal Medicine 132 (March 7,2000): 40S-414. Available online at http://www.worldrtd.org/quill&Bvock.html, last visited on August 30,2002

6 Ibid.

7 "Terminal sedation is done with the full knowledge that no further active treatment will be done and that patients, as rapidly as possible, will now die as a result of their underlying disease process. The claim is made that such a way of proceeding is aimed at providing maximal relief of pain and suffering - the death of the patient is 'not intended.' But that is, to say the least, disingenuous. Patients are intentionally kept asleep, their vital functions are deliberately not artificially supported, and they are allowed to die in comfort. That they should die in comfort is clearly the goal - and I would argue the legitimate goal - of terminal sedation." Erich H. Loewy, M.D., "Terminal Sedation, Self-Starvation, and Orchestrating the End of Life," Archives of Internal Medicine 161.3 (February 12,2001): 329-332.

8 "The best-known American advocate of physician-assisted death. Dr. Jack Kevorkian, is serving a lO-to-25-year sentence in a Michigan prison for the death of an ALS patient. Kevorkian's lawyer, Mayer Morganroth, is appealing the sentence in both state and federal courts. His contention: The trial was unfair because, among other things, the judge wouldn't allow eyewitnesses to testify. 'A physician has the right to administer medicine which will alleviate pain and suffering, even if it causes death,' Morganroth says." Ed Edelson, "Euthanasia in the Netherlands Stirs Concern," HealthScoutNews, May 22, 2002.

9 Pontifical Council for Pastoral Assistance, Charter for Health Care Workers (Boston: Pauline Books & Media, 1994), n. 124, quoting Pope Pius XII.

10 Perry Fine, M.D., "Total Sedation in End-of-Life Care," 86.

11 "Throughout the United States, physicians who support Euthanasia are routinely utilizing a special form of 'terminal sedation,' not as a means of pain control, but with the explicit intention of intentionally causing death. This is routinely being used on patients who are not in immediate danger of dying, but are in other ways considered 'incurable' or 'hopeless.'" Brian Johnston, commentary "Deathly Quiet," WorldNetDaily, April 13, 2002. Available at http://www.worldnetdaily.com/news/article.asp?ARTICLE_ID=27217, last visited on August 30,2002.

12 Robert D. Truog, M.D. et al., "Pharmacologic Paralysis and Withdrawal of Mechanical Ventilation at the End of Life," New England Journal of Medicine 342.7 (February 17, 2000): 508-511. Also "terminal sedation should be distinguished from the common occurrence of a dying patient gradually slipping into an obtunded state as death approaches; this occurrence is a combination of the metabolic changes of dying and the results of usual palliative treatments. Terminal sedation is also distinct from the sedation that occasionally occurs as an unintended side effect of high-dose opioid therapy, which is used to relieve severe terminal pain. In contrast, terminal sedation involves an explicit decision to render the patient unconscious to prevent or respond to otherwise unrelievable physical distress. Terminal sedation is also used regularly in critical care practise to treat symptoms of suffocation in dying patients who are discontinuing mechanical ventilation." Quill and Byock, "Responding to Intractable Terminal Suffering."

13 Tina Maluso-Bolton, M.N., R.N., "Terminal Agitation," Journal of Hospice and Palliative Nursing 2.1 (January/March, 2000). Also see Robert J. Kingsbury, "Palliative Sedation: May We Sleep Before We Die?" Dignity, Summer, 2001.

14 Vacco, Attorney General of New York v. Quill, 117 S.Ct. 2293 (1997); The State of Washington v. Gliicksberg, 117 S. Ct. 2258 (1997).

15 "As ecumenical witness in defense of life develops, a great teaching effort is needed to clarify the substantive moral difference between discontinuing medical procedures that may be burdensome, dangerous or disproportionate to the expected outcome - what the Catechism of the Catholic Church calls 'the refusal of 'over-zealous' treatment' (No. 2278; cf Evangelium vitae, n. 65) - and taking away the ordinary means of preserving life, such as feeding, hydration and normal medical care. The statement of the United States Bishops' Pro-Life Committee, Nutrition and Hydration: Moral and Pastoral Considerations, rightly emphasizes that the omission of nutrition and hydration intended to cause a patient's death must be rejected and that, while giving careful consideration to all the factors involved, the presumption should be in favor of providing medically assisted nutrition and hydration to all patients who need them. To blur this distinction is to introduce a source of countless injustices and much additional anguish, affecting both those already suffering from ill health or the deterioration which comes with age, and their loved ones." Pope John Paul II, ad limina address to the Bishops of California, Nevada, and Hawaii, October 2, 1998, n. 4.

Sedated to Death? When "Comfort Care" becomes dangerous

by Nancy Guilfoy Valko, RN

Families often agree to "comfort care only" for relatives with brain injuries or dementia without realizing that this can also involve TS. (Terminal Sedation)

For example, a few years ago I received a phone call from a niece who was worried about her elderly aunt who had suffered a severe stroke several days before. The aunt had signed a protective document designed by a pro-life group as an alternative to the dangerous "living will". The document specifically said that, unless death was inevitable and imminent, ordinary treatments such as food, water and basic medical care were to be provided. The document also named the aunt's sister as the person to make medical decisions if the aunt became incapacitated.

The problem was that although the doctor had declared the aunt's stroke a "terminal event" (a questionable prognosis at best), she was still alive and breathing, although unconscious. Understandably, the niece began to now question whether her aunt was indeed terminal and whether she should be receiving food, water and basic medical care as her protective document directed.

One of the first questions I asked was whether the aunt was on morphine. (Although strokes rarely cause pain beyond a sometimes initial headache, many doctors and nurses consider unconsciousness a sign that the patient will be severely disabled even if he or she lives, and thus deem such a patient "hopeless".) The niece said that the doctor had ordered the morphine as part of the "comfort care" to prevent any discomfort as the aunt died. I suggested that the niece talk to the doctor and her aunt's sister about stopping or reducing the morphine to see if this was responsible for the aunt's apparent coma. Sure enough, when the morphine was stopped, the aunt began to respond and, according to the niece, even seemed to recognize relatives.

However, the aunt's sister insisted that a priest told her such apparent reactions were "just reflexes" and told the doctor to resume the morphine. The other relatives briefly considered talking to a lawyer about enforcing the aunt's protective document but were reluctant to cause further division in the family. Not surprisingly, the aunt died after two weeks without food and water.

Such scenarios are unfortunately becoming more and more frequent. Terminal sedation is *not* a rarely used last resort, as its supporters maintain. Even the few studies on TS report the prevalence of terminal sedation to range from 3% to 52% in the terminally ill. When the unknown actual incidence of terminating awareness-or insuring unawareness-in patients with stroke, dementia or other serious illnesses is factored in, the use of TS as a form of "comfort care" may well be approaching epidemic proportions, even outside the hospice area.

As a former hospice nurse and now as an ICU nurse caring for some patients who turn out to be dying, I support the appropriate use of pain and sedating medications as ethical comfort care. However, even in circumstances where such medications are necessary, I have never seen a case where a patient "needed" to be made permanently unconscious.

In addition, the newer health care system problems of cost-containment and stressed, overburdened caregivers can make TS even more attractive - and dangerous - to patients, families and medical professionals alike.

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The Rise of Stealth Euthanasia: Imposed Death Disguised as Pain Relief

by Ralph A. Capone, MD, FACP, Kenneth R. Stevens Jr., MD, FACR, Julie Grimstad, and Ron Panzer, LPN

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Medications used to manage pain and other symptoms—opiates, sedatives and barbiturates—can be misused to cause death. The intention to kill a patient, not just to treat pain and other symptoms, is becoming more common in palliative and end-of-life care settings. The purpose of this article is to expose disingenuous arguments used to hide intentionality to kill patients in end-of-life care settings.

A nurse informed one of the authors that a doctor admitted a patient with painful metastatic prostate cancer and then verbally directed the nurse to “warp him out of this world.” She informed the doctor that she and the other nurses would provide the appropriate care for the patient, but the doctor insisted that the patient not be alive the next morning. However, the nurses were able to relieve the patient’s symptoms without causing his death.

Kevin O’Reilly, writer for American Medical News, states that “treatments—when conducted with the consent of patients or surrogate decision-makers and implemented with the intent of alleviating pain or other symptoms in terminally ill patients—are broadly accepted as ethically and legally appropriate, even if they have the secondary effect of speeding the dying process.” 1

The principle of double effect is used to assess a good action that has both an intended good (primary) effect and an unintended bad (secondary) effect. Invoking the principle of double effect to justify speeding the dying process is disingenuous. In some palliative and end-of-life care settings, death from palliative sedation or use of opioids is not a secondary effect, but either the intended primary goal or the unintended result of failure to properly educate clinical staff. Becket Gremmels correctly reported that “the majority of studies have found that palliative sedation does not hasten death when used appropriately” and that there is “overwhelming evidence that the appropriate use of opioids at the end of life does not hasten death, and thus is not amenable to double-effect reasoning.” 2 The key word is “appropriate.”

Hospice and palliative care physicians and nurses must be well trained in the appropriate administration of medications and understand their potential to hasten death. Otherwise, unintentionally caused deaths are inevitable. When the staff is properly educated and the founding principles of hospice—to maintain dignity, to increase quality of life, and to provide comfort and pain control—are followed, hospice is a safe haven for patients in need of expert end-of-life care.

Double-effect reasoning should not be used to justify inappropriate use of opioids and sedation. At best, it is inaccurate to use the principle of double effect to justify an a priori intention to kill. At worst, it is a misleading attempt to justify an evil action.

Proper Titration of Opioid Analgesics

International standards of palliative medicine require careful dosage calculation and titration for administration of opioids to manage moderate to severe pain in patients. It is well established that clinically unnecessary doses of opioid medications or extreme increases in dosage are likely to cause adverse effects, such as respiratory suppression, loss of consciousness, coma, and even death.3 Nazi doctors perfected euthanasia through morphine administration, so pretending that morphine use is always safe is a fantasy.4

When opioids are used to impose death, health care professionals usually cloak their actions by telling families that the signs of approaching death being observed are due to a terminal illness, not to the adverse effects of a clinical overdose, which conveniently mirror some of the signs of the end-stage active phase of dying.5

Misuse of Palliative Sedation

For decades, the praiseworthy goal of the hospice and palliative care mission has been to relieve patients’ distressing symptoms, but never to hasten death. Even when a patient asked to be killed, it was always understood to be a cry for relief from suffering—physical, emotional, or spiritual—and not as permission to take a life.

Today, permanent sedation and the withholding of nutrition and hydration are often done with the intention that the patient die. This practise is known by various terms: “terminal sedation,” “palliative sedation,” “total sedation,” “permanent sedation,” “comfort sedation,” and “deep continuous sedation.” Authentic terminal sedation is used to relieve “terminal agitation” or restlessness at the end of life. It is never appropriately used as a first line of therapy. Permanent sedation is properly used when pain is so extreme that absolutely no other means have been effective.

Sedation has a legitimate place in end-of-life care but must be used only when absolutely necessary. When palliative sedation is misused to cause death, the patient is placed in a medically induced coma and nutrition and hydration is withheld. When this happens, circulatory collapse occurs from fluid volume deficit within a few days to a few weeks, depending on the patient's condition. This is an excruciating process for the patient and for those who must keep watch at the bedside.

Dr. William Burke, a St. Louis neurologist, describes what happens to patients as they undergo death from dehydration: "They will go into seizures. Their skin cracks, their tongue cracks, their lips crack. They may have nosebleeds because of the drying of the mucus membranes, and heaving and vomiting might ensue because of the drying out of the stomach lining. . . . It is an extremely agonizing death." 6 Even if patients are sedated, how could we be certain that they would feel no pain, thirst, or hunger?

Many in the field of hospice and palliative care—medical and nursing directors, nurses, social workers, and chaplains—as well as physicians across the country, confirm that there is a clear trend toward hastening deaths of patients. Oncologists and primary care practitioners are shocked when their patients, who have chronic or terminal illnesses but are not in the active phase of dying and are not expected to die suddenly, die within days or weeks of entering hospice. Internationally known hospice and palliative care leaders confirm these reports.7 These professionals cannot all be wrong or ignorant.

Confirmation

Fifteen years ago, Dr. Joanne Lynn, a foremost authority in modern palliative care, was quoted in the New York Times: "When a patient is ready to die, I can stop nutrition and hydration, I can stop insulin and ventilation. I can sedate them." 8 This is intended death, not death from any terminal illness. Dr. Timothy E. Quill, palliative care specialist and physician-assisted suicide advocate, and Dr. Ira R. Byock, prominent hospice and palliative care physician, suggest that when patients request that death be hastened, terminal sedation and voluntary refusal of hydration and nutrition can "substantially increase patients' choices at this inherently challenging time." 9

Thus, many hospice and palliative care physicians are urging, and actually performing, euthanasia by stealth. They administer sedatives that in themselves do not cause immediate death, but knowingly cause the conditions that result in death. This misuse of terminal sedation with intent to end life is properly termed "stealth euthanasia"—it is not active euthanasia or passive euthanasia, but a combination of both.10

It strikes people as wrong to withdraw food and fluids from patients who are not in the end-stage active phase of dying. O'Reilly, perhaps unintentionally, exposes this fact: "New developments in end-of-life care—aggressive pain and symptom management (even to the point of unconsciousness), along with a greater willingness to withdraw advanced, life-sustaining treatments such as mechanical ventilation, dialysis, and artificial hydration and nutrition—still strike many people as wrong." 11 It is horrifying that health care professionals—those to whom we entrust our lives—intentionally hasten death while pretending to be providing appropriate end-of-life care. That this is a pretense is becoming more and more evident to patients and families.

Although Medicare guidelines require patients to have a terminal diagnosis in order to be enrolled in hospice, patients who are not terminal are fraudulently admitted.12 Sometimes patients with chronic conditions such as Alzheimer's disease or brain damage were admitted to hospice, and then they died from dehydration.13

The Catechism of the Catholic Church states that "an act or omission which, of itself or by intention, causes death in order to eliminate suffering constitutes a murder." 14 Therefore, omission of nutrition and hydration that causes or hastens a patient's death must be rejected. Physicians who seek to continue providing food and fluids are often pressured not to do so. This results in patient deaths and terrible anguish for physicians.

Secular bioethical arguments are used to "justify" stealth euthanasia: for example, "poor quality of life," suggesting that the patient is "better off dead," or "respect for patient autonomy," even though many of these patients are not requesting death.

Expectations versus Reality

Traumatized families are reporting the hastened deaths of loved ones, and hospice and palliative care providers are warning that euthanasia and stealth euthanasia are sometimes being performed in end-of-life care settings. This is not surprising considering who leads the hospice and palliative care industry today. The National Hospice and Palliative Care Organization (NHPCO), the leading trade organization for this industry, is the actual legal and corporate successor to the Euthanasia Society of America.15 The Euthanasia Society of America was successively known as the Society for the Right to Die, Choice in Dying, Partnership for Caring, and Last Acts Partnership before finally being absorbed into the NHPCO. This explains the contradiction between the publicly stated hospice mission and the reality in too manyclinical settings. It appears that the NHPCO is intent on quietly subverting that life-affirming mission.

The September 2000 declaration of the World Federation of Right-to-Die Societies, states in part,

We wish to draw public attention to the practise of "terminal sedation" or "slow euthanasia" which is performed extensively today throughout the world in hospitals, nursing homes, hospices, and in private homes. . . . A physician may lawfully administer increasing dosages of regular analgesic and sedative drugs that can hasten someone's death as long as the declared intention is to ease pain and suffering. . . . Compassionate physicians, without publicly declaring the true intention of their actions, often speed up the dying process in this way. 16

Indeed, the culture of death has deeply infiltrated the hospice and palliative care industry! Despite this, some health care professionals courageously remain faithful to the original mission of providing care until the natural end of life of a patient. Faithful professionals, who have a reverence for life, need support and encouragement as they serve extremely vulnerable patients.

The difficulty facing patients and their families is that they do not know how to discern which health care providers can be trusted to care and to never kill. The first question to ask when looking for a pro-life hospice or a palliative care programme is does every physician and nurse reject all justifications for intentionally causing the deaths of patients? Authentic hospice involves adding resources to uphold the dignity of the patient and the sanctity of life. Yet because the average person is uneducated about their rights at the end of life, they often do not question the advice, orders, or actions of their health care professionals.

Discerning True Values

Patients who are in pain need pain relief that is safely administered and poses little or no risk of hastening death. They do not need (nor do most want) death. The culture of life promotes ethical principles that guide the appropriate and judicious use of sedatives and opioids. Practise has shown such use prolongs overall patient survival in end-of-life care settings.

On the other hand, in the culture of death, unethical practises—overdosing with opioids and "permanent sedation" with dehydration—are surreptitiously employed to deliberately end lives prematurely. Those involved maintain that their only intent is to do good (i.e., "relieve pain"). At best, they are deceiving themselves; at worst, they are lying to others. They may say, "We're letting him go," "His quality of life is very poor," or "It's her time."

Pope John Paul II stated that "there is need to develop a deep critical sense capable of discerning true values and authentic needs." 17 What is at stake in the struggle between the culture of life and the culture of death is our very ability to discern true values. The needs of the most vulnerable among us cannot be truly understood or met without first recognizing the sanctity of human life. What is at stake affects not only patients but also the medical profession and the whole of society. Whether practises that are knowingly used to impose death are "justified" by principles of secular bioethics or the misuse of the principle of double effect, they are always unethical. 18

The American Medical Association's position is that "the societal risks of involving physicians in medical interventions to cause patients' deaths are too great in this culture to condone euthanasia or physician-assisted suicide at this time." 19 The British Medical Association is also officially opposed to euthanasia. However, the influential BMJ—a journal that is supposedly independent of the British Medical Association yet is often cited as its official voice—has taken a position in favor of euthanasia.20 An editorial and two articles were published in BMJ supporting the purportedly "neutral" stance of health care professionals not to oppose any efforts to legalize euthanasia. However, one of the two articles, by Dr. Raymond Tallis, an emeritus professor of geriatrics, was titled "Our Professional Bodies Should Stop Opposing Assisted Dying." 21 This makes the American Medical Association's qualification "at this time" profoundly troubling.

Stealth euthanasia methods avoid the readily identifiable labels "euthanasia" and "assisted suicide." Nevertheless, physicians who use their medical skills to impose death by stealth defy the American Medical Association's official policy and are dishonest with their patients and the public.

They have been edging closer and closer to open euthanasia, but they are not there yet. In a few years, not too many, we will hear, "Everybody knows that we've been hastening death. Since we're doing it anyway, let's make it more 'humane'—let's legalize direct euthanasia through lethal injection." Unless there is a major change in the health care system and in society, this is guaranteed.

About the Authors

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End Notes:

1 Kevin B. O'Reilly, "End-of-Life Care: Pain Control Carries Risk of Being Called a Killer," amednews.com, April 16, 2012.

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Week 6

Hard Cases Make Bad Euthanasia Laws

by Paul Russell

April 3, 2014 (MercatorNet) - The pro-euthanasia lobby often promotes media reports of people facing difficult prognoses who wish to end their lives rather than face inevitable deterioration. Such persons often become, for a short while, celebrities for a macabre cause. The media attention can even become addictive and provide, a distraction from their suffering or a raison d'etre.

But are these stories really a substantive reason for changing the law? I would argue, no.

In a debate in Launceston, Tasmania, a few years back a delightful woman on the other side of the debate told the story of her husband who had motor neurone disease and took his own life rather than face the trajectory of deterioration. She described the understood trajectory of MND in some detail. I imagine that she was describing a worst-case scenario.

One could easily understand the anguish of what her late husband was facing: he was a fascinating person with great achievements. When I met his wife and son I got the sense that he would have been a wonderful person to have met. I imagine the audience that night must have felt the same.

Yet, at the close of the evening when the audience had a chance to speak, a woman rose from the back of the auditorium and said that her husband had recently passed away after suffering with MND. She told the audience that his death was, "nothing like that", referring, clearly to the earlier description.

More recently I received an email from a gentleman questioning how I could hold my opposition to euthanasia and describing the recent loss of his own mother. He said that she had been bereft of consciousness for the better part of seven years and that her passing was not dignified.

My mother-in-law had been similarly lacking consciousness for much longer than that, as I relayed by return email. Yet Mum had a very dignified passing. My conclusion was simply that his unfortunate experience was not, therefore, an argument for euthanasia at all.

Readers will recall the celebrated pleas of Englishman Tony Nicklinson a few years back which were played out in the British Courts over his wish to die. Nicklinson had locked-in syndrome. Yet at the same time a young man with the same condition told the media that while his life had significant limitations, he had a good life. He wanted to let people know that not all locked-in syndrome sufferers were like Nicklinson.

One can easily understand what might have been the young man's concerns. If people think that all locked-in sufferers are desperate to die, then perhaps he won't get the kind of care he would need to live if there were ever a medical emergency. Perhaps he simply wanted people to know that he wasn't down in the dumps about his accident.

His motivation for speaking out was unclear but nonetheless poignant and timely. I doubt that people like Nicklinson would have considered the effect that their public cause would have on others with the same condition. Their focus is essentially on themselves. Understandable given the circumstances; but nevertheless, not the complete picture.

It is not the illness or the prognosis that is the driver for euthanasia in any of these cases. It has more to do with the person themselves and how they decide to cope with their pending or existing situation. It really is about their choices.

A few months back, another MND sufferer, Paul Chamberlain, became a cause celebre for the assisted suicide campaign in the UK. He was interviewed repeatedly on British media including a joint interview with Dr Kevin Fitzpatrick from the Euthanasia Prevention Coalition – Europe. Once again we find the counter position put by other MND sufferers including former Springbok Rugby player, Joost van der Westhuizen.

"It's been a rollercoaster from day one and I know I'm on a deathbed from now on. I've had my highs and I have had my lows, but no more... It's only when you go through what I am going through that you understand that life is generous."

Then there's the story of Alistair Banks. Throughout his MND and up unto his death he wrote inspiring messages of hope. He said:

"Everyone I know with MND is trying to do positive things, otherwise they would sink into despair. It's a coping mechanism. Doing things means that you can pull in friends and family to share something both fun and rewarding."

I have no doubt that some people die better than others, just as people deal with the dying and death of a loved one in many different ways. But these are not arguments for euthanasia. Rather, they suggest that we need to continue to learn better ways of caring and to make sure that quality care is universally available.

Autonomy is a good thing, but should we burden society with a euthanasia or assisted suicide law because some people – probably only a handful in any disease cohort – wish to choose another path? We may have decriminalised suicide, but we should never endorse it. All of humanity is diminished by a law that tells us that some people's lives are less worthy of life than others. No man is an island.

The heart-wrenching stories of a few are compelling. But as arguments they are false.

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The Fatal Flaws of Assisted Suicide

By Catherine Glenn Foster

In 2014, there were 2,626,418 deaths in the United States.[1] Of these, 44,193 were attributed to intentional self-harm: suicide.[2] Suicide is currently the tenth leading cause of death in the country, and one of only three leading causes that are on the rise.[3] Lawmakers recognize the "significant medical and non-medical costs" of suicide and its "physical, emotional, and psychological damage" to patients and their families and friends.[4] Yet even as this epidemic increasingly threatens our society, some lawmakers are proposing and enacting legislation that perversely escalates rather than resolves America's suicide crisis. This dissonance is illustrated by two high-profile suicides that occurred in 2014.

Robin Williams' cultural influence on generations of Americans would be hard to overstate. But even as he brought joy to millions, he was facing very serious personal challenges. In addition to a long-term struggle with substance abuse and depression, Williams had been diagnosed with Parkinson's disease and, according to his wife, was experiencing symptoms of what an autopsy revealed to be Lewy body dementia when he killed himself in August 2014. What Americans mourned in the wake of Williams' passing wasn't only the heart-breaking loss of an admired actor and contemporary comedic hero, but also the perniciousness of suicide itself.

Not quite three months later, a young California woman who wanted to take her own life was in the headlines. Earlier that year, Brittany Maynard had been diagnosed with terminal brain cancer.[5] Realizing that the coming months would likely bring bodily deterioration and physical disability, she decided to seek physician-assisted suicide.[6] Since in 2014 it was not legal in California, Maynard moved to Oregon—which had legalized assisted suicide in 1997—where she received a prescription for life-ending drugs and died in November 2014.[7]

While many might assume that the mainstream media would take a similar approach to these two deaths, nothing could be further from the truth. The headlines labelled Robin Williams a "sad clown," and referred to his death with language such as "slashed wrist," "hanged," "tortured," "failed," "despair," "agony," "driven by demons," "tragic," and "way too soon."[8] In stark contrast, Brittany Maynard's death was described with phrases such as "choice," "dignity," "option," and "inspiration"; news reports said she died "on her own terms" with "zero regrets" and "reignited debate."[9]

Robin Williams and Brittany Maynard each faced a terminal illness; each chose to take control over the time and place of the death. However, when an authority figure such as a doctor sanctions a deliberate death, when death is medicalized and presented as a "treatment," people may start to feel differently—more deferentially—about the circumstances surrounding the person's demise. Rather than seeing physician-assisted suicide as a specific category of suicide, some will validate and even defend the decision to end one's own life, recasting it as a death "with dignity."

Speaking to the false distinction between such deaths, Dr. Kevin Fitzpatrick, former Director of Hope Ireland, wrote, "When non-disabled people say they despair of their future, suicide prevention is the default service we must provide. Disabled people, by contrast, feel the seductive, easy arm of the few, supposedly trusted medical professionals, around their shoulder; someone who says 'Well you've done enough. No-one could blame you.'"[10]

Suicide, in all its forms, is an attack on the inherent value and true dignity of every human life. Yet while suicide generally and assisted suicide specifically, having been so prevalent in the public eye, might seem novel, society has long struggled with these issues and with fringe efforts to push assisted suicide and euthanasia into the mainstream as viable options.

The contemporary debate on assisted suicide and euthanasia is in fact the latest manifestation of a campaign that began in the late 19th century, when proponents started promoting legislation that would legalize one or both of these practices. Initially, such legislation was largely rejected due to the wide criticism and controversy that attended the topic. However, in 1942 Switzerland became the first country to decriminalize assisted suicide where no "selfish motives" existed.[11] Today, Switzerland is a destination for suicide tourism, a phenomenon that draws people to the country for the sole reason of killing themselves.[12]

The next major changes in the law came in the mid-1990s, when Australia briefly legalized assisted suicide in the Northern Territory[13]—and quickly be- came the first and only place to repeal it—and courts in Colombia ruled that euthanasia on demand was legal, but passed no substantive law on the matter. In the 2000s, activists continued to see some modest success as the Netherlands and Belgium legalized euthanasia in 2002, as did Luxembourg seven years later.[14] In 2015, Colombia enacted a law legalizing euthanasia on demand; Canada legalized it in 2016.[15] But numerous legislative and legal efforts to promote assisted suicide/euthanasia around the world have largely failed—today it is legal in only four of the fifty European nations, and only a handful of countries and jurisdictions internationally.

Several such jurisdictions are in the United States.[16] While no federal law has been enacted on the subject, assisted suicide is now legal in California,[17] Colorado,[18] the District of Columbia,[19] Oregon,[20] Vermont,[21] and Washington;[22] it will go into effect in Hawaii on January 1, 2019.[23] Generally, these laws have an application process that, upon completion, allows a person with a medical prognosis of six or fewer months to live to obtain a prescription for lethal drugs. This process typically includes a written request form which requires the signatures of two witnesses.[24] While the current legislation provides that one of the two witnesses must be unrelated to the patient and must not receive any benefits upon his or her death,[25] no requirements are in place for the second witness to be disinterested in any way—the two witnesses could be an heir and his cousin or an heir and his best friend. Once the drug is dispensed, there is no follow-up supervision. No requirement exists that the death be witnessed by neutral, disinterested parties, or by anyone at all. Furthermore, there are no requirements that the individual who was prescribed the drug be the one to ingest it, leaving ample room for abuse of the system.

The vast majority of states, however, have enacted laws to prohibit assisted suicide. Even Oregon and Washington have such bans in place; their legislators simply decided to carve out an exception for one profession to assist in suicides. While assisted-suicide activists have attempted to argue that such bans were never meant to apply to medical professionals, legislative histories demonstrate that many of them were enacted in the 1990s as a protective measure in the wake of the Kevorkian scandal. And in the years since Oregon legalized assisted suicide, more states have affirmatively enacted laws to ban the practice than have passed laws to legalize it; about 200 assisted-suicide bills have failed in more than half the states.

The legislative efforts to protect vulnerable populations from assisted suicide have been almost universally supported by the courts. The U.S. Supreme Court, in particular, has consistently found that for "over 700 years, the Anglo- American common law tradition has punished or otherwise disapproved of both suicide and assisting suicide."[26] The first two Supreme Court decisions on the subject, Washington v. Glucksberg[27] and Vacco v. Quill,[28] declared that nothing in the U.S. Constitution provides for a fundamental right to assisted suicide and continue to protect Americans today. Moreover, the Court has repeatedly held that the preservation and protection of life is a legitimate and valuable state interest, and that while all lives have intrinsic value, society's most vulnerable members—elderly adults and those with disabilities—are particularly in need of protection. The Court affirmed that bans on assisted suicide further compel- ling state interests such as the preservation of human life and protection from medical malpractice, coercion, financial pressure, and psychological complications.[29] The Court has said that were it to declare assisted suicide a constitutionally protected right, it would be the first step down the path to voluntary and perhaps involuntary euthanasia.

The Supreme Court's concerns have proven valid. Research has shown that for the most part the reason individuals choose to commit suicide has nothing to do with pain, or even the fear of pain. Ezekiel Emanuel, a prominent bioethicist, has written that "[p]atients themselves say that the primary motive is not to es- cape physical pain but psychological distress; the main drivers are depression, hopelessness and fear of loss of autonomy and control In this light, assisted suicide looks less like a good death in the face of unremitting pain and more like plain old suicide."[30] And the top reasons cited for assisted suicide in Oregon are fear of losing autonomy (91.5 percent), of being less able to engage in activities (88.7 percent), and loss of dignity (79.3 percent).[31]

One study in that state specifically cites depression as an overlooked factor in requests for assisted suicide.[32] Yet even in light of this vulnerability, patients are entrusted with the decision of whether or not to take their own life. Many of them may be considering assisted suicide because of financial duress, pressure from family members, loneliness, or because they are feeling like a burden to someone else. Yet the legislation that is being proposed has no psychological- screening requirement, only a circular requirement that the attending physician refer the patient for counseling if he or she believes the individual needs it. Counseling referrals are not as common as they should be. In 2014 only three patients of the 155 who requested doctor-prescribed suicide in Oregon were referred for a psychological evaluation.[32] In 2013, only two of the 71 patients who actually committed doctor-prescribed suicide in that state were referred for counseling.[33] In one particularly clear-cut case, a man with a 43-year-his- tory of suicide attempts, paranoia, and depression was deemed not to require counseling prior to receiving a lethal prescription.[34] In one study, 94 percent of non-psychiatric physicians indicated that they could not determine whether a psychiatric disorder was impairing the judgment of a patient who requested assisted suicide.[35]

Tragically, the decision to commit assisted suicide may often be influenced by misdiagnosis. Current studies show that "experts put the [misdiagnosis] rate at around 40%."[36] There are reported cases of individuals who have been killed without having any underlying symptoms, where the doctor had simply made an "error."[37] Prognoses are often wrong, as well—at least 17 percent of patients in one recent study were misinformed.[38] Harvard professor of sociology and medicine Nicholas Christakis agrees that doctors often get terminality wrong in determining eligibility for hospice care.[39] In recognition of this fact, Arthur Caplan, director of the Center for Bioethics at the University of Pennsylvania, has declared that six months is an arbitrary figure.[40] And real-world stories sup- port the claims made by experts in the field.

Aside from the obvious flaws, there are endless loopholes that exist in state laws legalizing assisted suicide. Too often, those seeking to end their lives with medical help "doctor shop," whether from doctor to doctor, or from state to state as Brittany Maynard did. Even if a doctor refers for counseling, the purpose of such evaluations is to determine competence, not to treat the patient's underlying issues. Once competence is established, the patient has the ability to request life-ending drugs—which are not tracked after delivery and thus can easily be appropriated by others or otherwise misused.[41] As no witnesses are required at the time of actual ingestion, there is no assurance that the act itself was truly voluntary, or even self-administered. And, in fact, in the bills proposed thus far, there is no requirement that "only" the person who receives the prescription may administer the dose. Rather, "self-administer" is defined as the patient's "act of ingesting"; in Washington, for example, the assisted-suicide act states: "'Self-administer' means a qualified patient's act of ingesting medication to end his or her life " There is grim irony in the prospect of mainstreaming

assisted suicide in the name of individual autonomy and liberty, when such legalization simultaneously introduces new ways to compromise that autonomy and potentially coerce and oppress vulnerable individuals, for example, through elder exploitation and the abuse of individuals with disabilities.

When a person has decided to commit assisted suicide, she must take one of two kinds of barbiturates—precisely the same kind that have led to furor over instances of botched capital punishment. These can take anywhere between three and 48 hours to actually take effect and bring about death. Side effects such as vomiting are common, and some patients regain consciousness after taking the drugs. Incredibly, one in five patients does not even die from taking these drugs.[42] In pursuit of the abstract goal of dignity, and having engaged in the precise planning of the details of their death, many will find themselves in excruciating and potentially humiliating situations.

It is both strange and puzzling that as Americans enjoy prosperity and continuing international influence and power, more of us are nonetheless clamoring for new ways to die. This mystery might be solved, at least in part, by understanding a phenomenon called "suicide contagion," scientifically known as the Werther Effect.[43] There is empirical evidence that media coverage of suicide inspires others to commit suicide.[44] One study, which incorporates assisted-suicide statistics, demonstrates that legalizing assisted suicide in certain states has led to a rise in overall suicide rates—assisted and unassisted—in those states.[45] The study's key findings show that after accounting for demographic, socio economic, and other state-specific factors, physician-assisted suicide is associated with a 6.3 percent increase in overall suicide rates.[46] These effects are even greater for individuals older than 65 years of age—14 percent increase.[47]

Journalism students are taught to adhere to strict reporting guidelines concerning suicide due to the increasing pervasiveness of the Werther Effect. Celebrity suicides, such as those this year of Kate Spade and Anthony Bourdain, also serve to inspire more suicides—some people have even killed themselves at celebrity funerals.[48] Following the media attention surrounding Saddam Hussein's execution by hanging, the rate of suicide increased sharply; specifically, the number of young men who hanged themselves rose.[49] Suicide prevention experts have criticized assisted-suicide advertising campaigns, writing that a billboard proclaiming "My Life My Death My Choice," which provided a website address, was "irresponsible and downright dangerous; it is the equivalent of handing a gun to someone who is suicidal."[50]

Unfortunately, it gets worse. There have been numerous instances in which voluntary death leads to involuntary euthanasia. Dr. Peter Saunders has observed that "in practice the boundaries are continually migrating and the nation's moral conscience is shifting year on year. Call it incremental extension, mission creep, or slippery slope—whatever—it is strongly in evidence in Belgium."[51] In that country, one-third of the people being euthanized are in fact being killed involuntarily—without any explicit request from the individual.[52] A written request for euthanasia in Belgium was absent in 87.7 percent of unreported cases from June 1, 2007, to November 30, 2007.[53] Indeed, nearly half of all cases of euthanasia in that country are not even reported, allowing for an unknowable amount of abuse within the system.[54] This expansion of assisted suicide and euthanasia is not exclusive to Europe. A pro-assisted-suicide lawmaker has introduced legislation to expand the prognosis window for assisted suicide in Oregon. Barbara Coombs Lee, president of Compassion & Choices—formerly known as the Hemlock Society—told USA Today: "It's not as simple as pain. Everyone gets to identify their own definition of suffering."[55] And the Oregon Health Authority recently admitted: "The question is: should the disease be allowed to take its course, absent further treatment, is the patient likely to die within six months?

. . . I think you could also argue that even if the treatment/medication could actually cure the disease, and the patient cannot pay for the treatment, then the disease remains incurable."[56] Simply put, this is neither autonomy nor choice. Meanwhile, physicians tend to be rightly concerned about assisted suicide as a threat to the integrity of their profession and to their conscience. Assisted-suicide laws and proposed bills contain, at best, only the most limited conscience protections to avoid coercive or mandatory participation in these deaths by doctors—the same healing professionals who have sworn to "first do no harm."[57] Most contemporary versions of the Hippocratic Oath require physicians to swear that they "will give no deadly drug to anybody who asked for it, nor . . . make a suggestion to this effect."[58] Assisted suicide negates a core tenet of the curative, healing, and caring professional role of the physician.

The Supreme Court has stated that "[t]he government undoubtedly 'has an interest in protecting the integrity and ethics of the medical profession.'"[59] Accordingly, Justice Scalia wrote: "Virtually every relevant source of authoritative meaning confirms that the phrase 'legitimate medical purpose' does not include intentionally assisting suicide. 'Medicine' refers to '[t]he science and art dealing with the prevention, cure, or alleviation of disease' [T]he AMA has determined that '[p]hysician-assisted suicide is fundamentally incompatible with the physician's role as healer.'"[60]

This is even true in Switzerland, the suicide tourism capital of the world. One study found that although most of the doctors polled approved of assisted suicide, most were themselves unwilling to intentionally cause death.[61] However, some American medical associations traditionally opposed to assisted suicide are now considering not only taking neutral positions but even forcing doctors to refer patients for assisted suicide.

Likewise, some American pharmacists are concerned about the impact that legal assisted suicide may have on their businesses. Pharmacies keep in stock only a small percentage of drugs at any given time due to the number of avail- able drugs on the market and often-limited shelf life. However, there have been a number of lawsuits relating to contraception and abortion drugs in which the government has demanded that pharmacies stock specific medications, al- though a patient could simply go to another nearby pharmacy that stocks the drug. As it relates to assisted suicide, if a pharmacy manager decides not to stock life-ending medications, the state could opt to intervene and mandate the presence and availability of death-hastening drugs throughout every community in the state.

Coroners, similarly, are being compelled to facilitate assisted suicide by essentially falsifying death certificates, listing the patient's disease, not the drugs ingested, as the cause of death. In states where assisted suicide has been legalized, physician-assisted suicide cannot be termed a suicide. Accordingly, the then-president of the California State Coroners Association, Rocky Shaw, ex- pressed concerns about how to classify such a death. After the bill legalizing physician-assisted suicide passed in California, Shaw probed: "[W]hat should we do if a guy takes life-ending drugs and then goes to sit in a park to die, and we find him there?"[62] And if the death certificate lists a disease, not suicide, as the cause of death, it could create a legal inability to prosecute criminal behavior and affect civil suits.

While many proponents of assisted suicide claim that adequate safeguards exist to protect individuals, Paul Russell, founder of Hope: Preventing Euthanasia and Assisted Suicide, articulated it well when he wrote, "I have never come across a 'safeguard' that could guarantee safety for vulnerable people.[After all,] unless we describe, in the law, every possible illness and every possible remedy, what possibility is there that we can ensure safety? The variables are infinite. What the supposed 'safeguards' do well is to protect doctors. They are provided with an immunity from prosecution for homicide or assisting in suicide if they comply with a set of procedures."[63] In simpler, more direct, and unfortunately cruder terms, assisted suicide endorses the right of doctors to give some Americans the means to fatally overdose.

Yet assisted-suicide activists continue to agitate for its legalization in legislatures and courts. They are pushing radical cultural shifts through documentaries like How to Die in Oregon and more mainstream movies like Youth in Oregon and You Before Me. And they are engaging in the political process more than ever before.

Recent media coverage has led some advocates to declare premature victory: describing assisted suicide as having "reached a threshold where it is unstoppable." But legalization bills are seeing significant pushback. In fact, even in the socially liberal state of Connecticut, assisted-suicide bills have been proposed in five of the last six years but have failed to get a single vote despite advocates having spent well over $500,000. Compassion & Choices has publicly admit- ted that in Connecticut, they "were concerned that if the votes weren't there to come out of committee, that a vote in the negative would set back this issue for several years."[64]

And just as, thanks to recent Supreme Court developments, we may have in- creased hope on issues concerning the beginning of the life spectrum, so too can we have hope on the other end. Justice Gorsuch wrote a pivotal book on assisted suicide, The Future of Assisted Suicide and Euthanasia.[65] And Justice Kavanaugh has publicly stated his admiration for former Chief Justice Rehnquist, and especially of his Glucksberg analysis, which conducted appropriate substantive due process analysis by asking whether a right to commit suicide with the aid of a doctor was longstanding and well-established in common law and tradition. In the end whatever the circumstances and catchphrases employed, assisted suicide is not about "choice" or "dignity," it is government-endorsed suicide, guided by a trusted medical professional. Assisted suicide is dangerous for all involved and indeed for all Americans. Our hope, however, lies in the fact that there have been a number of victories in this realm of the law as many states have continued to reject proposed assisted-suicide legislation and organizations nationwide vigorously oppose the mainstreaming of intentional death and affirm historic and life-affirming practices in both medicine and law.

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Anglicans FOR LIFE

Position on Euthanasia and Assisted Suicide

Scripture References

"It is not without significance, that in no passage of the holy canonical books there can be found either divine precept or permission to take away our own life, whether for the sake of entering on the enjoyment of immortality, or of shunning or ridding ourselves of anything whatever. Nay, the law, rightly interpreted, even prohibits suicide, where it says, "Thou shalt not kill." This we affirm, this we maintain, this we pronounce as in every way to be right, that no one ought to inflict on himself voluntary death, for this is to escape the ills of time by plunging into those of eternity..." St. Augustine, City of God (1.20, 26)

"What makes a person master of himself is having free will. He may accordingly fashion his life in respect of all things that go to make up his life, and this is the province of his free will. The passage from this life to a more blessed one is, however, not matter subject to human free will, but to God's power. A person may not, therefore, kill himself in order to escape from any of his miseries of this life…So to inflict death on oneself in order to escape from the miseries of this life is to take on a greater evil in order to avoid a lesser." St. Thomas Aquinas, Summa Theologiae (2a2ae. 64, 5)

"God hath created nothing simply for itself, but each thing, in all things and of every thing, each part in another hath such interest that in the whole world nothing is found whereunto any thing created can say, I need thee not." Richard Hooker, A Learned Sermon of the Nature of Pride

Anglicans for Life Official Position

Scripture and Tradition forbid intentional killing. For two thousand years, the Christian Church has forbidden suicide and other intentional taking of innocent human life. This prohibition stems from the clear witness of Scripture, following St. Augustine's interpretation of the Sixth Commandment of the Decalogue, "Thou shalt not kill." This command, as St. Thomas and Richard Hooker tell us, speaks to the fundamental value of human life as made in God's image (Gen. 1:27, 9:6), endowed with God-like capacities such as free-will, called to friendship with God, and limited by God's sovereign power over life and death. Most importantly, this command condemns any act as intrinsically evil where an innocent human life in intentionally taken either through omission, i.e. willfully refusing to provide available aid and treatment when truly need, or commission, i.e. willfully engaging in a direct, lethal act on another life.

What is, and what is not, Euthanasia? Given the clarity of this prohibition, Christians must never practise euthanasia, defined by the *Journal of the American Medical Association* as "the medical administration of a lethal agent to a patient," for this would disobey God's command through an act of commission. Christians also must never take actions which intentionally seek to end life by withdrawing and withholding effective medical treatment, sometimes known as "passive" euthanasia, for this would disobey God's command through an act of omission. These prohibitions are to be distinguished from actions which are outwardly similar, but fundamentally different: the administration of palliative care that has the foreseen, but unintended, effect of shortening the patient's life; and the withholding or withdrawing of treatment that would effectively worsen the patient's condition.

What is, and what is not Assisted Suicide? Christians must also never practise Physician Assisted Suicide, defined by the *Journal of the American Medical Association* as the "facilitation of a patient's death by providing the necessary means and/or information to enable the patient to perform a life-ending act." While some may argue that assisted suicide is a moral alternative to euthanasia, since here the physician is not actually doing the killing, but merely respecting a patient's autonomous wishes, this still violates the Sixth Commandment through an act of commission. For there is no way for the physician to say that he or she does not somehow intend the patient's death by prescribing medication that has the death of the patient as its goal. This prohibition is to be distinguished from the advice a physician gives concerning withdrawing or withholding medical treatment that does not have death as its goal.

What is, and what is not, intentional killing? To say that the Sixth Commandment prohibits intentional killing is to use the word, *intentional*, in a precise way. Intentional signifies a crucial component of human action. Intentions are different from desires, which see something as attractive or unattractive, and from motivations, which provide the end or underlying emotion that our actions may fulfill. Intentions, by contrast, describe the willful choice of a reasonable plan, or the "game plan," so to speak, of means and ends that each of us chooses in pursuing any deliberate course of action. The game plans that compose intentions are often described by one word, such as "offend", which describes a game plan that results in wounding another's feelings, or "murder". Intentions are *reasonable* to the extent that they match the reality of our actions—we cannot say that our intention is to run faster than the speed of light. Intentions are moral to the extent that the game plan we choose performs an action that is good and avoids actions that are evil—we cannot say that we do not intend to kill if the action we choose is one where killing, rather than say relieving pain, is our game plan.

To speak of intention, then, is to identify what is at stake in the crucial distinction between directly killing and merely allowing someone to die. For two thousand years, the Christian tradition has disallowed any direct killing, but has allowed that in certain situations persons may cause a death, called *indirect* killing, that they do not intend, but only permit or cause out of self-defense. In every case where these permissible deaths occur, the game plan is not one of killing, but one where persons are trying to protect their neighbors, or themselves, from harm. Thus the Christian tradition understands these certain actions as having death as *foreseen, but not* intended, effect. In terms of medical ethics, this would mean that a physician may intentionally administer palliative care to address pain or may intentionally withhold unproductive treatment. These actions may lead to a death the physician foresees, but does not intend, and a test of this game plan is this: *should the patient survive, the physician does not consider his or her aims frustrated.*

While some might see the concept of intention as obsolete, it forms the backbone of most of our moral considerations surrounding life and death. In the legal system, for example, the difference between First Degree Murder and Second Degree Murder is that the former is a killing that is deliberate and premeditated, i.e. intentional, while the latter is killing that is only motivated by malice. More significantly, on June 26, 1997, the U.S. Supreme Court decided that the distinction between directly killing and indirectly allowing dying "comports with fundamental legal principles." Chief Justice Rehnquist contrasted the physician who intends only to treat pain or to withdraw burdensome treatment and the physician who assists a suicide or practises euthanasia:

"A doctor, who assists a suicide, however, must necessarily and indubitably, intend primarily that the patient be made dead. Similarly, a patient who commits suicide with a doctor's aid necessarily has the specific intent to end his or her own life, while a patient who refuses or discontinues treatment may not. The law *has long used actor's intent or purpose to distinguish two acts that may have the same result."*

Other considerations regarding euthanasia and assisted suicide. While Anglicans for Life prefers to argue against euthanasia and assisted suicide from the perspective of Scriptural and Christian tradition, there are many arguments and studies that argue against these practises from the perspective of common sense. If studies have shown that there is great potential for the practises of euthanasia and assisted suicide and if they are widely accepted by our society, we will suffer severe repercussions—manipulation of vulnerable persons, such as women, the poor, the disabled, the elderly, and those who suffer from depression and other mental illnesses.

This has certainly been the case in the Netherlands, where assisted suicide and euthanasia are legal. A study published in the *Journal of the American Medical Association* (June 4, 1997) found that "the Netherlands has moved from considering assisted suicide" alone, "to giving legal sanction to both assisted suicide and euthanasia to nonvoluntary and involuntary euthanasia." There is also potential for ruining the integrity of the medical profession and the bond of trust that develops in patient-doctor relationships. As the *New York State Task Force on Life and the Law* notes, many physicians believe that, "Medicine is devoted to healing and the promotion of human wholeness; to use medical techniques in order to achieve death violates its fundamental values…allowing physician to act as 'beneficent executioners' would undermine patients' trust, and change the way that both the public and physicians view medicine."

Official Church Positions

The Episcopal Church has not passed a resolution officially acknowledging Euthanasia. At the 1998 Lambeth Conference a resolution affirming "that life is God-given and has intrinsic sanctity, significance and worth; resolved that Euthanasia is neither compatible with the Christian faith nor should be permitted in civil legislation."

Anglicans for Life
promotes the Biblical view of the sanctity of human life
at every stage of biological development
and seeks to influence our Church and culture
to embrace this Biblical attitude
morally, legally and in practise.
Anglicans for Life and its chapters reach out
to protect life and offer compassion
in communities across the nation.

Additional Information about Euthanasia and Assisted Suicide

History

- 1938 - The Euthanasia Society of America (ESA) was founded to promote legalization of euthanasia, both voluntary and involuntary.

- 1967 - ESA established the Euthanasia Educational Council (EEC) which introduced the Living Will, a document to help promote discussion of Euthanasia to gain acceptance of euthanasia. The Living Will contained standard language that expressed a person's right to refuse certain types of medical treatment. Many people who were concerned about the very real issue of overtreatment and denial of a patient's rights saw the Living Will as the way to prevent them from being subjected to procedures and equipment they found frightening, cruel, or unnecessary. The greatest stimulus for acceptance of the Living Will was the publicity given by journalist "Dear Abby." Abigail "Abby" Van Buren was a member of the Euthanasia Educational Council!

- 1975 - ESA changed its name to the Society for the Right to Die (SRD).

- 1979 - EEC changed its name to Concern for Dying (CFD) and split from SRD.

- 1980 - The Hemlock Society (HS), formed to promote death-on demand, was named after the poison used in ancient Greece for executions and state approved suicides.

- 1991 - SRD and CFD—having merged in 1990—became Choice in Dying.

- 1993-94 - Compassion in Dying (CID), an HS spin-off, was created to provide information and assistance to sick people who want to die and to promote "aid in-dying" laws.

    - The Death with Dignity National Center (DDNC) was established in Washington D.C. to work to replicate the new voter-approved Oregon "physician-assisted suicide" (PAS) law in other states.

    - Together, CID and DDNC have relentlessly led campaign after campaign attempting to legalize physician-assisted suicide throughout the U.S.

- 1997 - Last Acts, a coalition of more than 100 prominent organizations, funded by the Robert Wood Johnson Foundation, was established purportedly to improve the quality of end-of-life care. ("Improving care" is often code for hastening death.)

- 1999 - Choice in Dying became Partnership for Caring (PFC). PFC managed the Last Acts programme.

- 2003 - HS started End of Life Choices, a political action committee, in Denver.

- 2004 - Final Exit Network (FEN) was started by disgruntled former HS and End of Life Choices members, including HS founder Derek Humphrey. FEN counsels people on ending their lives with helium and plastic bags. "Exit guides" attend suicides.

- PFC merged with Last Acts to form Last Acts Partnership, which folded soon thereafter. Some Last Acts Partnership leaders moved on to positions of influence in the realm of hospice and palliative care.

- 2005 - Compassion in Dying and End of Life Choices joined to form Compassion& Choices (C&C).C&C describes itself as "working to improve care and expand choice at the end of life," but its actual efforts have been directed at only one "choice"—suicide. Since 1997, CID/C&C have facilitated most of the physician-assisted suicides in Oregon as well as numerous deaths elsewhere. C&C, along with DDNC, has led campaigns to legalize PAS throughout the U.S.

Additional Definitions of Terms

Euthanasia - Definition:

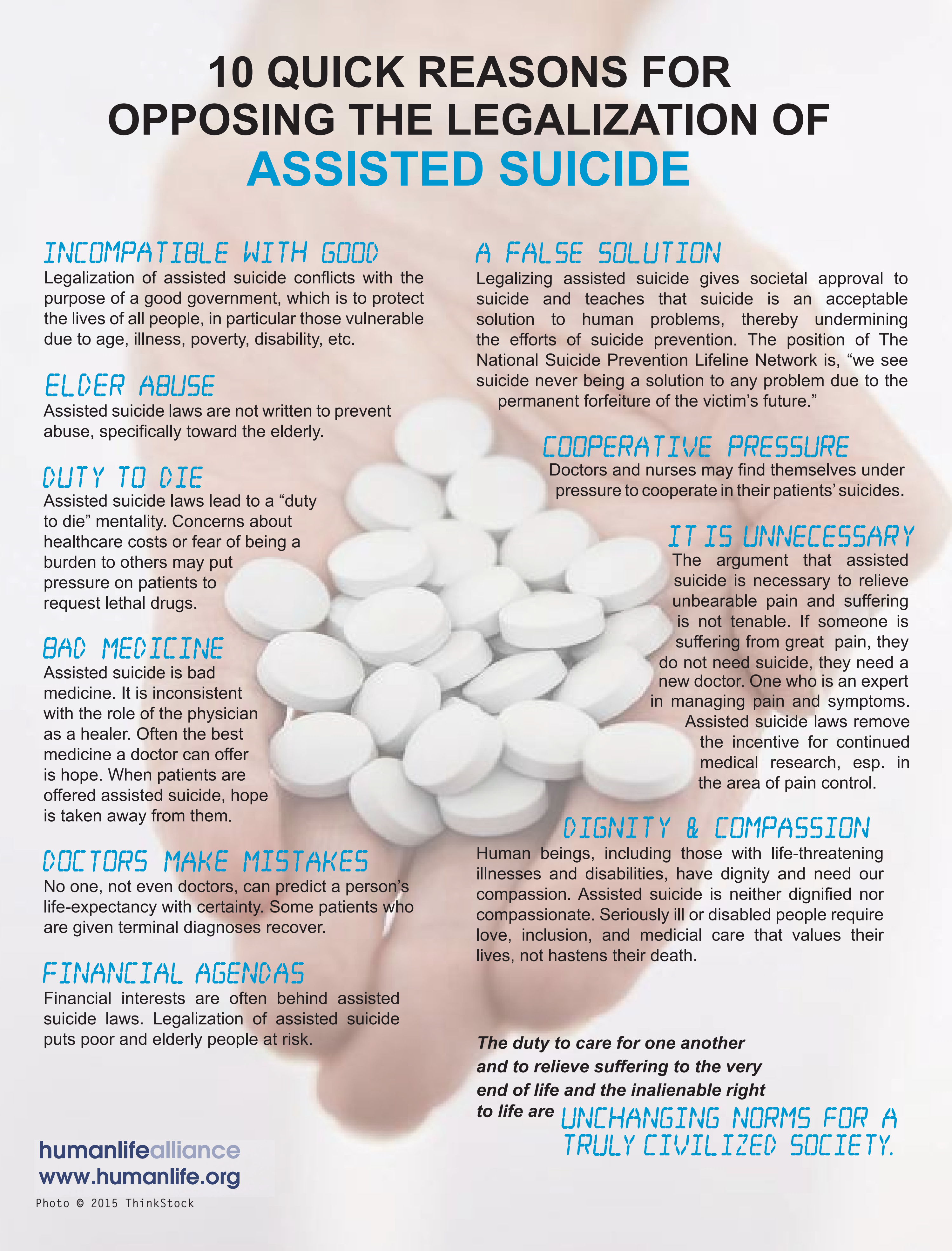
- Euthanasia is an action intentionally done to cause death of a person for the purpose of relieving suffering. This can be an act of omission by intentionally withdrawing basic medical care with the intent of directly causing the death of the person who is not otherwise dying, most commonly food and fluids, because food and fluids are now categorized as medical treatment. Terri Schiavo is an example of a person who was not dying – she had a cognitive disability, a somewhat non-responsive state. But because she had no additional life support beyond food and fluids, she dehydrated and died when they removed the medical treatment.
- Euthanasia only differs from murder in its motivation, which is to relieve suffering. It's a form of homicide in that it directly and intentionally causes death.
- It is usually done by lethal injection. But it can be done in many ways. Euthanasia is sometimes referred to as Mercy Killing.

What Euthanasia is not:

- Withholding or withdrawing medical treatment that is useless burdensome or extra-ordinary. You have the right to say no to medical treatment, we are not opposed to someone accepting the limits of life. However, nobody should have the right to kill you.
- The proper use of large doses of pain killing drugs to relieve suffering is NOT Euthanasia. Abuse of pain medicine can be used for Euthanasia.
- The proper use of sedating a person with a regimen of drugs is to relieve the suffering of a person. No one is opposing sedation, only sedating them to kill them.
- The proper uses of analgesics and sedation techniques are not Euthanasia. The abuse of analgesics and sedation may be a form of Euthanasia.

Assisted Suicide - Definition

- Assisted suicide is not "Aid in Dying," palliative care is aid in dying.
- Assisted suicide is when one person is directly and intentionally **<u>involved</u>** with ending the life of another person—to aid, encourage, or counsel for suicide.
- What's the difference between euthanasia and assisted suicide? Assisted Suicide can be performed by yourself with the help of another person. Euthanasia is done by another person to you. In Euthanasia, a lethal injection could be given to you without your knowledge. In Assisted Suicide, the doctor writes a prescription for a lethal dose, knowing your intention to take that lethal dose yourself.
- Euthanasia and Assisted Suicide are very similar and are hard to separate because once you have the prescribed lethal dose of medicine, who's to know if you take it yourself or if some one gave it to you. Often the medicine is mixed with applesauce and given to the patient, so it may be euthanasia.



10 QUICK REASONS FOR OPPOSING THE LEGALIZATION OF ASSISTED SUICIDE

INCOMPATIBLE WITH GOOD

Legalization of assisted suicide conflicts with the purpose of a good government, which is to protect the lives of all people, in particular those vulnerable due to age, illness, poverty, disability, etc.

ELDER ABUSE

Assisted suicide laws are not written to prevent abuse, specifically toward the elderly.

DUTY TO DIE

Assisted suicide laws lead to a "duty to die" mentality. Concerns about healthcare costs or fear of being a burden to others may put pressure on patients to request lethal drugs.

BAD MEDICINE

Assisted suicide is bad medicine. It is inconsistent with the role of the physician as a healer. Often the best medicine a doctor can offer is hope. When patients are offered assisted suicide, hope is taken away from them.

DOCTORS MAKE MISTAKES

No one, not even doctors, can predict a person's life-expectancy with certainty. Some patients who are given terminal diagnoses recover.

FINANCIAL AGENDAS

Financial interests are often behind assisted suicide laws. Legalization of assisted suicide puts poor and elderly people at risk.

A FALSE SOLUTION

Legalizing assisted suicide gives societal approval to suicide and teaches that suicide is an acceptable solution to human problems, thereby undermining the efforts of suicide prevention. The position of The National Suicide Prevention Lifeline Network is, "we see suicide never being a solution to any problem due to the permanent forfeiture of the victim's future."

COOPERATIVE PRESSURE

Doctors and nurses may find themselves under pressure to cooperate in their patients' suicides.

IT IS UNNECESSARY

The argument that assisted suicide is necessary to relieve unbearable pain and suffering is not tenable. If someone is suffering from great pain, they do not need suicide, they need a new doctor. One who is an expert in managing pain and symptoms. Assisted suicide laws remove the incentive for continued medical research, esp. in the area of pain control.

DIGNITY & COMPASSION

Human beings, including those with life-threatening illnesses and disabilities, have dignity and need our compassion. Assisted suicide is neither dignified nor compassionate. Seriously ill or disabled people require love, inclusion, and medicial care that values their lives, not hastens their death.

The duty to care for one another and to relieve suffering to the very end of life and the inalienable right to life are UNCHANGING NORMS FOR A TRULY CIVILIZED SOCIETY.

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We Support

√ Physicians assisting patients to live as fully and normally as possible until death occurs from natural causes;

√ Better training for physicians and nurses in appropriate management of pain and other distressing symptoms, e.g., the judicious use of opioids and sedatives with no intention to hasten or cause death;

√ Provision of food and water, whether by mouth or medically assisted, as basic, ordinary care which is never withheld or withdrawn to hasten or cause death;

√ Authentic compassion that seeks to alleviate patients' suffering and attend to their individual needs;

√ Enabling disabled persons to participate in all areas of society by providing the social programmes and support they need to achieve their goal;

√ The same quality of care for all patients, i.e., no rationing or discrimination based on age, physical or mental condition, or ability to contribute;

√ Educating people to protect and nurture those who are sick, disabled, and otherwise may be in danger of neglect, abuse, or imposed death;

√ The right of every person, particularly those unable to defend themselves, to full protection under the law, from the first moment they are created, throughout life, until true death from natural causes.

In short we promote a climate of public opinion that recognizes the right of every human being to life, respect, compassionate care, appropriate medical treatment, and equality under the law.

Why So-Called Safeguards Don’t Work: Physician Assisted Suicide

Background:

Looking at both legal analysis of doctor prescribed suicide laws and the experience in Oregon and Washington, there is evidence that any so-called safeguards that might come attached to the proposals do not work.

So Called Safeguard: **“The patient must be competent”**

Why this does not work:

There is nothing in the law to protect those with mental illness:

- It is a well-established psychological fact that nearly every terminally ill patient who desires death is suffering from a treatable mental disorder .[1]
- There is no requirement that the patient be given a psychiatric evaluation. Over nearly a decade and a half, Oregon Department of Health statistics show that only 6.7% of patients were referred for an evaluation.[2]
- A major state paper, *The Oregonian*, has documented that many patients suffering from depression and dementia are receiving doctor prescribed suicide.[3]

There is no requirement for a witness at the time of death:

- It is unknown if the person is still competent at the time she or he actually ingests the lethal prescription.
- The range of time between the first request and death is 15 -1009 days (nearly 3 years).[4] A lot can happen in that time. Did the person’s mental state deteriorate? Did caregivers tire of caring for a sick relative?

There is no requirement that the doctor has any knowledge of or relationship with the patient:

- ”Doctor shopping” is common. A network of doctor prescribed death proponents ensures that patients will receive lethal prescriptions[5], even when their family doctor knows their desire for death is transient and could be alleviated.

So Called Safeguard: **“The patient must be terminally ill”**

Why this does not work:

- Terminal illness is often difficult to predict. Further, there is evidence that many non-terminally ill patients receive the lethal prescriptions. The Oregon Department of Health reports that the range of time between the first request and death has been as long as almost 3 years. [6]

- The definition of terminal illness includes a person with an incurable irreversible disease that will...produce death within six months”. Looking at one example under this definition, insulin reliant diabetics who stop taking their medication could qualify, even though they could live decades with treatment.

ROBERT POWELL CENTER for MEDICAL ETHICS
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So Called Safeguard: **"The request must be voluntary"**
Why this does not work:

- There is no language in the law prohibiting anyone from pressuring the patient to accede to doctor prescribed suicide. The Oregon Health Plan notified state health insurance recipients Barbara Wagner and Randy Stroup that the treatment they needed to survive would not be covered, but informed them that doctor prescribed death was available and would be covered.[7]

- There is insufficient protection from the improper motives of family or friends who apply pressure. In new proposals, an heir can actually serve as a witness for the request for doctor prescribed death.[8]

- In Oregon, studies and official reports show that people are regularly requesting doctor prescribed suicide because they fear becoming a burden on family and friends.[9,10]

- Although the law states doctors must give patients "feasible alternatives" to assisted suicide – like pain control, and hospice, there is no requirement these are covered under insurance.

So Called Safeguard: **"The patient must self-administer"**, so it is not euthanasia
Why this does not work:

- Although the statute claims to allow only those who can "self-administer" to request the lethal prescription, many legal observers argue that this is one court challenge away from being overruled. If, for example, there was a person with disabilities who could not swallow, there is an official legal opinion from the Oregon Attorney General's office stating that this is unconstitutionally discriminatory.[11] This means that lethal injection might be one legal challenge away. This could be the case in any state that legalized the practice of doctor prescribed death.

So Called Safeguard: **"The state can punish violations"**
Why this does not work:

- The doctor prescribing death is held only to a "good faith standard" which is far lower than the malpractice standard applied to other health providers.[12]

- There is no mechanism to ensure doctors report (they self-report) or comply.

- The underlying reported data in OR and WA is destroyed by the state yearly.[13]

- In OR and WA, the death certificates are falsified by statute, listing only the underlying illness as the cause of death, making the real number of suicides unknowable.[14]

ENDNOTES:

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[3] Erin Barnett, "A family struggle: Is Mom capable of choosing to die?" *Oregonian*, Oct. 17, 1999.

[4] Oregon Public Health Division, *2011 Report on Oregon's Death with Dignity Act,* released 3/6/12.

[5] Erin Barnett, "A family struggle: Is Mom capable of choosing to die?" *Oregonian*, Oct. 17, 1999.

[6] Under the law, a patient is supposed to have 6 months to live or less. However, patients are holding on to lethal prescriptions for nearly 3 years. Oregon Public Health Division, *2011 Report on Oregon's Death with Dignity Act,* released 3/6/12.

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[14] See both statutory language available at: http://public.health.oregon.gov/ProviderPartnerResources/EvaluationResearch/DeathwithDignityAct/Pages/ors.aspx and the Oregon Health Department Press release at: http://www.oregon.gov/DHS/news/2005news/2005-0304a.shtml which states "The state law authorizing physician-assisted suicide neither requires nor authorizes investigations by DHS, said Barry S. Kast, DHS assistant director for health services."

Assisted Suicide Turned Homicide? Doing in the Dutch
by John Stonestreet, Colson Center

Officially, the Netherlands is a safer country to live in than the United States. Its gun homicide rate is about 4 percent that of the United States, and its official murder rate is less than one-fourth that of the United States.

The key word in that statement is “official.” Because, as a recent report in the Guardian tells us, there’s a lot of killing going on in the Netherlands that doesn’t involve a gun and isn’t classified as murder, although it should be.

An article in the January 18 edition of Britain’s Guardian newspaper asked the question “Death on demand: has euthanasia gone too far?”

Now to be clear, the Guardian is the British Left’s paper of record. It’s a far more liberal publication than any mainstream American newspaper. So for the Guardian to ask whether euthanasia has “gone too far” suggests that things could be a lot worse than the public has been led to believe. And the area of focus for the piece was The Netherlands.

The Guardian found that in 2017 “well over a quarter of all deaths… in the Netherlands were induced.” “Induced” means that the person died at his or someone else’s hand, instead of by illness or accident.

By way of comparison, during the same period in the United States approximately 65,000 deaths out of more than 2.7 million were “induced.” This includes approximately 17,000 homicides, 45,000 suicides, and 1,300 deaths via physician-assisted suicide. That’s only 2.5 percent.

So, which one is the more dangerous country again?

As I noted, the Netherlands official homicide rate is one-fifth that of the United States, and its suicide rate is about a third lower. So, who’s “inducing” all these deaths? The troubling answer is… doctors.

We’ve talked a lot on BreakPoint about the ever-expanding euthanasia-industrial complex. We have told you about how the so-called “right to die” eventually becomes, in effect, the “duty to die.” We’ve also told the stories of doctors so eager to end life that it isn’t clear in some instances if it was what the patient actually wanted.

Still, even in the context of all of those realities, what the Guardian found was shocking. For example, Dutch doctors commonly practise what’s known as “terminal sedation.” This is “a slow-motion euthanasia wherein patients not in the active stage of dying are put into artificial comas and denied all sustenance until they dehydrate to death.”

This is different from “palliative sedation,” which is “a rarely required procedure in which patients near death are sedated to control pain or other symptoms such as severe agitation or air hunger that cannot be alleviated in any other manner.”

While approximately 6,600 Dutch were officially euthanized and another 1,950 people killed themselves in 2017, the Guardian found that “the number of people who died under palliative sedation – in theory, succumbing to their illness while cocooned from physical discomfort, but in practise often dying of dehydration while unconscious [that is, terminal sedation] – hit an astonishing 32,000.”

Add it all up, and in 2017 more than 40,000 of the 150,000 deaths in the Netherlands were induced.

While the Guardian was astonished, Wesley J. Smith wasn’t. He’s among those telling anyone who will listen that in places like the Netherlands the line between palliative sedation and terminal sedation has been blurred for some time.

As he wrote in the National Review, “Since euthanasia was first decriminalized in the Netherlands, the country’s doctors have traveled a very dark road.” The category of people deemed candidates for induced death has steadily grown. And while a theoretical line has been crossed, Dutch officials do nothing.

It could hardly be otherwise. As Smith put it, the Dutch aren’t “horrible, ghoulish people.” But they are logical. Once they “accepted the premise that killing is an acceptable answer to suffering,” they’re now simply taking “that belief precisely where it leads.”

Which makes the Netherlands a lot more dangerous than official stats suggest. And which makes me ask, “Americans, is this what we really want?”

Week 7

The Death of a Parent Affects Even Grown Children Psychologically and Physically

by Joshua A. Krisch

Grief is both real and measurable. Scientists now know that the death or your father or mother will forever alter your brain chemistry and may also have physical effects.

Losing a parent is the closest thing humanity has to a universal emotional experience. But universality doesn't dampen the trauma of the event, which tends to inform and affect the rest of peoples' lives. Even under the best circumstances, studies suggest that losing a parent changes an adult both psychologically and biologically. Under more trying circumstances, those changes can become pathological.

"In the best case scenario, the death of a parent is anticipated and there is time for families to prepare for the loss, say their goodbyes, and surround themselves with support," Dr. Nikole Benders-Hadi, a psychiatrist with Doctor On Demand told Fatherly. "In cases where a death is unexpected, such as with an acute illness or traumatic accident, adult children may remain in the denial and anger phases of the loss for extended periods of time…[leading to] diagnosis of Major Depressive Disorder or even PTSD, if trauma is involved."

No number of brain imaging studies or psychological trend analyses can truly capture the unique experience of grief. But there are a handful of constants in the scientific literature because all fully developed human brains are wired to respond to emotional pain with the same basic pathways.

Studies have implicated the posterior cingulate cortex, frontal cortex, and cerebellum brain regions in grief processing. These regions are involved in retrieving memories and dwelling on the past — but, in a cruel twist of neuroanatomy, they're also involved in regulating sleep and appetite. "This might provide some explanation for the different and unique responses to grief and loss," Jumoke Omojola, a clinical social worker in Omaha, Nebraska, told Fatherly. "Physiological changes might include headaches, stomach aches, dizziness, tightness in the chest too much sleep, too little sleep, overeating, or lack of appetite."

In the short term, neurology assures us that loss will trigger physical distress. In the long-term, grief puts the entire body at risk. A handful of studies have found links between unresolved grief and hypertension, cardiac events, immune disorders, and even cancer. It is unclear why grief would trigger such dire physical conditions, but one theory is that a perpetually activated sympathetic nervous system (fight or flight response) can cause long-term genetic changes. These changes — less pre-programmemed cell death, dampened immune responses — may be ideal when a bear is chasing you through the forest and you need all the healthy cells you can get. But this sort of cellular dysregulation is also how cancerous cells metastasize, unchecked.

While the physical symptoms are relatively consistent, the psychological impacts are all but unpredictable. In the twelve months following the loss of a parent, the American Psychological Association's Diagnostic and Statistical Manual of Mental Disorders considers it healthy for adults who have lost their parents to experience a range of contradictory emotions, including sadness, anger, rage, anxiety, numbness, emptiness, guilt, remorse, and regret. It is normal to withdraw from friends and activities; it is normal to throw oneself into work.

As ever, context matters. Sudden, violent death puts survivors at higher risk of developing a grief disorder, and when an adult child has a fractured relationship with a parent, the death can be doubly painful — even if the bereaved shuts down and pretends not to feel the loss. "Coping is less stressful when adult children have time to anticipate parental death," Omojola says. "Not been able to say goodbye contributes to feeling depressed and angry." This may explain why studies have shown that young adults are more affected by parental loss than middle-aged adults. Presumably, their parents died unexpectedly, or at least earlier than average.

Gender, of both the parent and child, can especially influence the contours of the grief response.

Studies suggest that daughters have more intense grief responses than sons, but men who lose their parents may be slower to move on. "Males tend to show emotions less and compartmentalize more," Carla Marie Manly, a clinical psychologist and author, told Fatherly.

"These factors do affect the ability to accept and process grief." Studies have also shown that loss of a father is more associated with the loss of personal mastery — purpose, vision, belief, commitment, and knowing oneself. Losing a mother, on the other hand, elicits a more raw response. "Many people report feeling a greater sense of loss when a mother dies," Manly says."This can be attributed to the often close, nurturing nature of the mother-child relationship."

At the same time, the differences between losing a father and a mother represent relatively weak trends. "Complicated bereavement can exist no matter which parent is lost," Benders-Hadi says. "More often, it is dependent on the relationship and bond that existed with the parent."

Grief becomes pathological, according to the DSM, when the bereaved are so overcome that they are unable to carry on with their lives. Preliminary studies suggest this occurs in about 1 percent of the healthy population, and about 10 percent of the population that had previously been diagnosed with a stress disorder. "A diagnosis of Adjustment Disorder is made within three months of the death if there is a 'persistence of grief reactions' exceeding what's normal for the culture and the religion," Omojola says. "In this situation, the grieving adult has severe challenges meeting social, occupational, and other expected, important life functions." Even adults who are able to go to work and put on a brave face may be suffering a clinical condition if they remain preoccupied with the death, deny that their parent has died, or actively avoid reminders of their parents, indefinitely. This condition, known as Persistent Complex Bereavement Disorder, is a trickier diagnosis to pin down (the DSM labeled it a "condition for further study").

Elisabeth Goldberg works with grieving adults as a relationship therapist in New York City, and she has seen the toll that long-term grieving can take on a marriage. Specifically, Goldberg suggests a (somewhat Freudian) link between losing a parent and cheating on a spouse. "I see many affairs as manifestations of unresolved grief about losing a parent," Goldberg says. "The adult child stays in a state of disbelief, and rejects reality in many ways in order to feed the delusion that the parent is still alive. The grieving child needs a new attachment figure, that's the psyche trying to reconcile the denial and grief. So rather than say, 'my mother died,' the grieving child can say, 'while mommy's away, I will play with someone other than my spouse.'"

In more concrete — and dire — terms, unresolved grief can spiral into anxiety and depression. This is especially true when the parent dies by suicide, according to Lyn Morris, a licensed therapist and VP at Didi Hirsch Mental Health Services. "Adults who lose a parent to suicide often struggle with complex emotions such as guilt, anger, and feelings of abandonment and vulnerability," she told Fatherly. Indeed a 2010 study out of Johns Hopkins University confirmed that losing a parent to suicide makes children more likely to die by suicide themselves.

How to cope in a healthy way remains an active area of scientific inquiry. Ross Grossman, a licensed therapist who specializes in adult grief, has identified several "main distorted thoughts" that infect our minds when we face adversity. Two of the most prominent are "I should be perfect" and "they should have treated me better" — and they tug in opposite directions. "These distorted thoughts can easily arise in the wake of a loved one's death," Grossman says.

When a son or daughter reflects on how he or she should have treated a deceased parent, "I should be perfect" thoughts tend to rise to the surface. Grossman's patients often feel that they should have done more and, "because they didn't do any or all these things, they are low-down, dirty, awful, terrible human beings," he says. "These kinds of thoughts, if left undisputed, usually result in a feeling of low self-worth, low self-esteem, shame, self-judgment, self-condemnation."

On the opposite extreme, patients sometimes blame their deceased parents for not treating them properly, and never making amends. This is similarly unhealthy. “The usual result of this is deep resentment, anger, rage,” Grossman says. “They may have genuine, legitimate reasons to feel mistreated or abused. In these situations, it’s not always the death of the parent but the death of the possibility of reconciliation, of rapprochement and apology from the offending parent.”

“The possibility has died along with the person.”

In extreme cases, therapy may be the only way to get a grieving son or daughter back on his or her feet. But time, and an understanding spouse, can go a long way toward helping adults get through this unpleasant, yet ubiquitous, chapter in their lives. “Husbands can best support their wives by listening,” Manly says. “Men often feel helpless in the face of their wives’ emotions, and they want to fix the situation. A husband can do far more good by sitting with his wife, listening to her, holding her hand, taking her for walks, and — if she desires — visiting the burial site.”

HELLO

Ten Grief Conversation Starters for Children

Rick Bergh, M.Div., CT, NT

Grief Conversations for Families

Here are things that you can do with your family to engage them in healthy conversations. Here are some ideas:

1. Visit a Cemetery

Take time to visit a cemetery. Walk through it together. Look at the names. Notice the birth and death dates. How were old were the people when they died? What words are written on their headstones? Ask about other pictures or symbols on the headstones and what that might say about this person. If it's someone your family knows, ask, "What do you miss about this person?" If it's a family member, tell a story about the importance of them in your life.

2. Use Nature as a Tool

Whether you are at the lake, in the mountains or the prairies, nature in its vastness is all around you. And it's full of life and death all the time. Nature's life cycle of re-creation and death easily leads to a deeper conversation and understanding of death, dying and bereavement. Enter into these teachable moments.

3. Visit at a Long-Term Care Facility or Auxiliary Hospital

Teach your young ones about aging, illness and empathy. Help them to become comfortable with a body that is physically or mentally aging. Wait for curious questions that may emerge and conversations that may continue as you leave the facility.

4. Be Bold and Share at a Family Reunion

Whether it's at a big family reunion or a weekend family get-together, why not invite those in attendance to come prepared to share something about the person who is no longer present this year. Say, "Let's take just a few minutes to remember . What do you remember that was special about this person to you?"

5. Photo Remembering

Pull out a photo album or your computer and look at pictures together. Stop and talk about what you miss that you no longer have that used to be part of your life: a person, a pet, a home or a friend, etc. Check in with your child or grandchild. You could start with the statement "Do you remember when…?"

6. Watch a Movie Together

A great way to segue into a conversation about death, dying and grief is through a movie. There are lots of films for each age group (We Bought a Zoo, The Bucket List, The Lion King, Frozen, Bambi, Inside Out, etc.) each with scenes that will lead to great conversations. Ask, "What made you sad?" "What made you happy?" "What made you mad?" "What did you like most about the movie?" "What did you not like?" This is a great way to teach emotional intelligence.

7. Bring a Family Member Closer

If someone special has died and you are really missing that person, one of the best ways to bring him or her closer is to ask this very simple but important question:

"What do you think would say to you if she/he were here today?"

8. Ritual Building

The summer is a great time to think, reflect and build rituals that will help you to continue to remember that person who has died and is no longer physically present in our lives. Is there a summer ritual that you want to keep going that was part of your mom's, dad's or grandparent's summer tradition? Perhaps it's a family reunion, a camping trip or a favourite picnic spot? Honour them by keeping it going.

9. Attend a Funeral or Memorial Service

Kids and grandkids have school off. If someone dies that you know, ask the kids if they would like to attend the service with you. When can you teach them if they don't experience a funeral? Ask them the following question after the service, "What did you think about the funeral today?" Invite the children to be curious.

10. Cloud Gazing

Lie on your back on your yard, in a park or on your chaise longue and look up into the sky. Notice the clouds. Ask, "Do you ever wonder where heaven is and where people go after they die?"

Make a commitment this summer to begin teaching your children about death, dying and bereavement. And get ready to be taught by your little ones too!!

Rick Bergh (M. Div., CT, NT) is a thanatolgist, narrative therapist, ordained minister, bereavement educator and keynote speaker. He is a best-selling author and leads workshops to equip and train volunteers and professionals who are involved in a grief and bereavement vocation. You can connect with him at www.rickbergh.com.

Week 8

Alzheimer’s, Human Dignity, & a Church that’s Truly Pro-Life

by Todd E. Brady

You can tell a lot about people by watching how they treat those who can’t articulate, defend, drive, bathe themselves, or even comb their hair.

I’ve never seen a more pro-life group of people than those at a West Tennessee church down on Main Street. No one from the church went to Washington, D.C., for the March for Life Rally. They don’t picket outside abortion clinics. They don’t preach and write proclamations about the evils of abortion. They believe babies should be born, but for them, that’s not the whole picture of being pro-life. One way they demonstrate this is in how they love Frank.

Frank, a 75-year-old man, has been a member of the church for about 10 years, along with his wife. Several years ago, he started showing signs of Alzheimer’s disease, and it’s been mostly downhill ever since. He is one of more than five million Americans living with the disease. With each passing day, Frank knows and remembers less. He’s slowly slipping away from everyone. Like Nancy Reagan once said, it’s like experiencing a long goodbye.

Frank consistently makes his rounds on Sunday mornings during the service’s greeting time. He says, “Good morning,” “Glad you’re here,” and “God bless you.” It’s obvious that he’s glad to be there and see everyone. He remembers which pew is his, but he can’t remember his phone number or how to get home after church. When he talks, he doesn’t make sense. He says words, but they aren’t related to each other; they’re strung together in a series of meaningless jabber.

Once a month, the men gather for a prayer breakfast. And Frank is always there. Everyone is kind to him. One week, as the men were sharing, Frank spoke up and said, “I’ve got something to say.” He stood, looked at the group, and started talking. Nothing he said made sense. As he does when he’s talking to someone one-on-one, Frank started putting unrelated words together; it was just meaningless chatter.

The men around the table leaned in. They looked at Frank in the eyes. It was hard to listen, but everyone listened well. No one tried to stop him. He probably only spoke for a minute or two, but it seemed like an eternity. After he finished, the other men around the table immediately started affirming Frank. They spoke of how thankful they were for him. They told him he was a good man. They talked about how the church wouldn’t be the church that it was if it weren’t for him. They told him they loved him.

Valuing a human being

It was a powerful moment. It was the church being the church. It was the church being pro-life, valuing a human being regardless of what he could bring to the table. The people in that church recognize that all people have inherent value because they have been created in the image of God (Gen. 1:27). They treat Frank with dignity and respect, not because of any ability he has— he’s losing his abilities—but because he is a human being.

The number of people in America who have Alzheimer’s disease is expected to triple to over 16 million people by 2050. Church communities are not immune to this disease, and it’s only going to become more prominent in our churches. This means that the church must be ready to minister to those with Alzheimer’s and their families.

The Southern Baptist Convention unanimously approved a resolution in 2016 titled “On Alzheimer’s Disease And Dementia, Caregiving, And The Church.” The resolution acknowledges this issue and that there is no cure. Southern Baptists collectively said,

God calls us to care for the most vulnerable among us, including those who are unable to remember or speak for themselves (Isa. 58:1-14; Zech. 7:8-10; James 1:27); and . . . All people are created in the image of God (Gen. 1:26-27) and this status as image bearers does not depend upon cognitive or intellectual ability, because all people, including those with Alzheimer's and dementia, have value and are loved by God.

My favorite line of the resolution is when Southern Baptists state, "RESOLVED, That we urge our churches to treat people with Alzheimer's and dementia with dignity and continue to invite them into the life of the church, rehearsing the good news of the Gospel together, singing familiar songs and hymns, reading Scripture together, and praying together, including well-known prayers, such as the Lord's Prayer."

The way we treat those with Alzheimer's is about the mission of the church. Alzheimer's disease is yet another evidence of the fact that we live in a world that is fallen. A day is coming when Jesus will make all things new, and this horrific disease will be a thing of the past. Until then, we work and love and proclaim the gospel until he comes. "Beloved, we are God's children now, and what we will be has not yet appeared; but we know that when he appears we shall be like him, because we shall see him as he is" (1 John 3:2).

People will continue to gather at that West Tennessee church every Sunday. Everyone will worship again. There will be the time in the service for greeting one another. Frank will be there. He will wander through the crowd during the Sunday morning worship service and tell folks, "Good morning," and, "Glad you're here," and, "God bless you." He will have conversations with people that make no sense, yet they will be kind to him. They will love him. They will value him—because their commitment to one another and to being pro-life will show in the way they treat Frank.

The Retirement Reformation Manifesto
Purpose, not Pastime by John Stonestreet, Colson Center

America is getting older. In 1950, near the beginning of the Baby Boom era, the average life expectancy of Americans was 68. Today, it is 79. By the year 2040, one in five Americans will be over the traditional retirement age of 65.

With so many facing life at or beyond retirement age, a new group of Christian leaders based in Colorado Springs is asking us to engage in some non-traditional, but thoroughly biblical, thinking about retirement itself.

This group says that age 65 isn't the age to retire. It's an age to re-fire, re-boot, and re-focus on your calling, influence, and ministry. It's a time to pursue purpose, not pastime.

To focus their commitment, this group has produced a Retirement Reformation Manifesto, which begins: "Reforming retirement requires a reframing of our thinking, allowing us to shine a light into the purposeless retirement void and finding freedom from unending leisure, indulgence, and self-gratification."

The group is led by Bruce Bruinsma, a 77-year-old entrepreneur and financial planner still active in business. Bruinsma says the Bible teaches that Christians are "called to bear fruit in every season of life." That's why the Manifesto aims to inspire "a movement where every Christ follower is confident in God's plan for a lifetime of faithful service and committed to helping the Body of Christ reform its understanding of retirement."

Bruinsma said: "As Christians, we are to remain faithful for a lifetime. My hope is that the Retirement Reformation Manifesto will inspire many, many people to believe God still has more for them in their later years."

According to a statement released by Bruinsma and the other drafters of the document, "the 10-point manifesto challenges signatories to overturn traditional attitudes toward senior years as merely a time of relaxation and leisure. Instead, they are urged to embrace their 'final quarter' of life as time to find spiritual fulfillment and meaning in using their life experiences and resources to serve and enrich others."

Among the commitments those who sign the manifesto make are to:

- challenge society's typical view of retirement
- exercise wise physical and financial stewardship to ensure making the most of what could be as many as 30 years of post-work
- build intergenerational community

The topic of retirement is one we care about at the Colson Center, in large part because Chuck Colson himself talked about it often in the last years of his life. He swore he'd never spend his final years "chasing a little white ball around." Older Christians, he firmly believed, should be actively pouring their lives into other, younger people who could carry on Kingdom work.

In fact, the Colson Center owes its current vitality in part to Chuck's belief that Christians should always die with "our boots on." Chuck modeled that for us when, at 80 years old during The Colson Center's 2012 Wilberforce Weekend, he collapsed on-stage mid-speech and had to be helped into a waiting ambulance. He died just a few weeks later.

In that speech and in many others, Chuck said that senior-citizen Christians might give up their 9 to 5 jobs, but they should never retire from Kingdom work. Deuteronomy says that teaching our "children and our children's children" to love and fear the Lord is a part of the Christian's job description. The Apostle Paul praised Lois, Timothy's grandmother, for discipling her grandson in the faith.

Bruinsma and the Retirement Reformation team is taking up that message. "We believe that the Retirement Reformation Manifesto has the potential to be history-making," said Bruinsma. "Imagine what might happen if millions of seniors are inspired and equipped to approach their retirement radically differently, finding meaning and satisfaction through helping extend God's kingdom, as they pursue purpose rather than just pastimes."

I can imagine it. Come to BreakPoint.org, click on this commentary, and we'll link you to the Retirement Reformation Manifesto. or visit https://retirementreformation.org/manifesto

Notes

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Notes

Embrace the Journey **Participant Evaluation**

Thank you for participating in the **Embrace the Journey** *series. We are praying that this series will improve people's attitudes about aging and dying. Your feedback on this short evaluation will help us improve future* **Embrace the Journey** *series.*

Please rank your response to the following questions:

1 = Strongly Disagree 6 = Strongly Agree

1. I feel better informed about aging and dying.
1 (Strongly Disagree) 2 3 4 5 6 (Strongly Agree)

2. The information presented in **Embrace the Journey** was helpful and relevant.
1 (Strongly Disagree) 2 3 4 5 6 (Strongly Agree)

3. I have a deeper understanding of the biblical reasons that Christians need not fear death.
1 (Strongly Disagree) 2 3 4 5 6 (Strongly Agree)

4. After going through **Embrace the Journey**, I feel better prepared to help myself and others navigate end-of-life issues.
1 (Strongly Disagree) 2 3 4 5 6 (Strongly Agree)

5. The Participant Guide was a helpful tool for me throughout the **Embrace the Journey** series.
1 (Strongly Disagree) 2 3 4 5 6 (Strongly Agree)

6. The **Embrace the Journey** series was well organized.
1 (Strongly Disagree) 2 3 4 5 6 (Strongly Agree)

7. After going through **Embrace the Journey**, I have strategies for to help me prepare for aging and dying.
1 (Strongly Disagree) 2 3 4 5 6 (Strongly Agree)

Please rank your response to the following components of Embrace the Journey on an OVERALL basis:

1 = Not Helpful At All 6 = Extremely Helpful

1. The Opening Prayer & Activity Sections
1 (Not Helpful At All) 2 3 4 5 6 (Extremely Helpful)

2. The DVD segments
1 (Not Helpful At All) 2 3 4 5 6 (Extremely Helpful)

3. The group discussions
1 (Not Helpful At All) 2 3 4 5 6 (Extremely Helpful)

4. The Closing Thoughts and Prayers sections
1 (Not Helpful At All) 2 3 4 5 6 (Extremely Helpful)

5. The Personal Study and Reflection exercises
1 (Not Helpful At All) 2 3 4 5 6 (Extremely Helpful)

4. The Participant Guide as an aid to learning
1 (Not Helpful At All) 2 3 4 5 6 (Extremely Helpful)

Please share your thoughts on these questions:

1. What did you find most helpful about **Embrace the Journey**?

2. What will you do related to aging and dying because of going through **Embrace the Journey**?

3. What would you improve about **Embrace the Journey**?

4. Would you recommend **Embrace the Journey** to others?

5. Other Comments:

Embrace the Journey **Leader's Evaluation**

Thank you for coordinating this **Embrace the Journey** series. We are praying that this series will *improve people's attitudes about aging and dying.* Your feedback on this short evaluation will help us improve future **Embrace the Journey** series.

Please rank your response to the following statements:
1 = Strongly Disagree 6 = Strongly Agree

1. The **Embrace the Journey** series helped our people become more committed to helping the aging and dying in our parish.
1 (Strongly Disagree) 2 3 4 5 6 (Strongly Agree)

2. Because of **Embrace the Journey**, our church or group is becoming more active in reaching out to the elderly in our community.
1 (Strongly Disagree) 2 3 4 5 6 (Strongly Agree)

3. **Embrace the Journey** was a setting where people had fruitful discussions.
1 (Strongly Disagree) 2 3 4 5 6 (Strongly Agree)

4. The group atmosphere was positive and productive in **Embrace the Journey**.
1 (Strongly Disagree) 2 3 4 5 6 (Strongly Agree)

5. The DVD segments helped people understand aging and dying issues better.
1 (Strongly Disagree) 2 3 4 5 6 (Strongly Agree)

6. The Leader's Guide was helpful in the planning of **Embrace the Journey**.
1 (Strongly Disagree) 2 3 4 5 6 (Strongly Agree)

Please rank your response to the following components of Embrace the Journey:
1 = Not Helpful At All 6 = Extremely Helpful

1. The DVD segments
1 (Not Helpful At All) 2 3 4 5 6 (Extremely Helpful)

2. The Group Discussions
1 (Not Helpful At All) 2 3 4 5 6 (Extremely Helpful)

3. The Participant Guide as an aid to learning
1 (Not Helpful At All) 2 3 4 5 6 (Extremely Helpful)

4. The Personal Study and Reflection exercises
1 (Not Helpful At All) 2 3 4 5 6 (Extremely Helpful)

5. The overview of the major responsibilities for coordinators in the Leader's Guide
1 (Not Helpful At All) 2 3 4 5 6 (Extremely Helpful)

6. The checklist in the Leader's Guide
1 (Not Helpful At All) 2 3 4 5 6 (Extremely Helpful)

7. The publicity help for **Embrace the Journey** that was available from Anglicans for Life
1 (Not Helpful At All) 2 3 4 5 6 (Extremely Helpful)

Please share your thoughts on these questions:

1. How do you think the **Embrace the Journey** series has influenced your group?

2. What did you find helpful in the Leader's Guide?

3. What would you improve or add to the Leader's Guide?

4. What other support could you have used as the Leader?

5. What advice would you give to other Leaders of the **Embrace the Journey** series?

6. Other comments:

Please share your thoughts on these questions:

1. What did you find most helpful about **Embrace the Journey**?

2. What are you going to do related to aging and dying after going through **Embrace the Journey**?

3. What would you improve about **Embrace the Journey**?

4. Other Comments:

Please send evaluation forms to:

Anglicans for Life
100 Leetsdale Industrial Drive, Bldg 80, Suite 301
Leetsdale, PA 15056

Thank You!

Anglicans
FOR LIFE

We Thank You!

Here at Anglicans for Life, we see the Sanctity of Life as the basis for all we do, think, and say.

Words cannot express how grateful we are that you have honored God, the Creator of all Life, with the gift of your time by coordinating and leading this Adult Education series.

We will never know, on this side of Heaven, how your willingness to serve has impacted lives for eternity.

We are so grateful for your commitment to lead ***Embrace the Journey****, and we praise God for you!*

For His glory,

Georgette

Deacon Georgette Forney
President, Anglicans for Life

Anglicans FOR LIFE

the only global Anglican ministry dedicated to inspiring the Anglican Church to understand and compassionately apply God's Word when addressing abortion, abstinence, adoption, euthanasia, and embryonic stem cell research.

Our purpose is to be a life-affirming ministry in the worldwide Anglican Communion.
Our mission is to: advocate for the sanctity of human life, from conception to natural death, in the Church and society.
Our vision is to stand for the value of every human life as revealed in Scripture and to equip people to develop a biblical response to issues that threaten human life.

We are a fellowship of Anglican Christians who believe:

- God values each human life and gives it purpose.
- God ordains marriage and family for the creation and nurturing of human life.
- God desires that we respect and love each person, especially the poor, the weak, and the vulnerable.
- God calls us to minister to people in ways that affirm the sanctity of human life.

Declaration of Life Statement

God, and not man, is the creator of human life. Therefore, from conception to natural death we will protect and respect the sanctity of every human life. Furthermore, we recognize that the unjustified taking of life is sinful, but God gives absolution to those who ask for His forgiveness.

Anglicans for Life encourages individuals, churches, and groups to adopt this declaration so that others will know where they stand.

Prayer for Life

Lord God, thank You for creating human life in Your image.
Thank You for my life and the lives of those I love.
Thank You for teaching us through Scripture the value You place on life.
Help me to uphold the sanctity of life in my church and community.
Give me the strength to stand up to those forces that seek to destroy the lives of those most vulnerable, the unborn, the infirm, and the elderly.
Today I commit myself to never being silent, never being passive,
and never being forgetful of respecting life. I commit myself to protecting and defending
the sacredness of life according to Your will, through Christ our Lord. *Amen.*

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