

# HOW TO HAVE "the talk" PLANNING YOUR LAST CHAPTER WELL

## How to have THE TALK with yourself:

### THE ELEPHANT IN THE ROOM : FEAR

Most of us fear at least one aspect of death: physical pain, psychological suffering, the unknown, possible regret, or losing control. Often we avoid or deny the subject to lessen the full impact of an otherwise painful experience, or we only address it in bite-sized pieces to process it at a more manageable rate. (1st Corinthians 3:2).

But remember that not all fears are negative - they can be a springboard for action and reflection. Acknowledging and naming your fears reduces their power over you, giving you room to make clearer, more informed, and less rushed decisions. The resulting refresh can cause a pivot in how you approach life altogether, setting the stage for focusing on what matters most while readjusting your focus on important tasks with a clear mind. Fear - and hope - change as our situation and health evolves. Ask yourself:



- What are you most afraid of?
- What reduces fear in your life? What gives you comfort?
- What might offer you peace of mind as you face the end of your life?
- What are your fears regarding the end of life?

### DEATH EDUCATION

The first step is to take ownership of our mortality and our relationship with death. Ask yourself these questions and reflect:

- When did you first learn about death and dying?
- Where were you and whom were you with?
- How old were you when you first began to develop an understanding of death?
- Who/what was your teacher?
- What was your take-home message from this experience?
- What did death mean to you then?
- What does death mean to you now?

**PUT IT IN ACTION:** Discuss your answers and the emotions they evoke with those closest to you. This not only demonstrates and exemplifies more openness about this important topic, but it helps you explore your position, too. In doing so, you'll begin to take ownership of living until you die.



## YOUR LIVING WILL APPLIED

Think of it as an insurance policy. You wouldn't drive without one, and you probably wouldn't even ride in a car without utilizing a seatbelt. This is no different. And though it can seem like an enormously daunting task, it is possible to both take things one step at a time and also allow room for changing your opinion, mind, or plan.

For example, if you are reflecting on plans for a "a good death," what can you decide now - in your current state, knowing what you know - while anticipating how things may evolve? It's impossible to know the exact situation in which any of us will face our last chapter - but if you could plan, what would you prefer? Would you prefer to die at home, in a facility, or in a hospital? Or do you not have a preference?

Don't let perfection prevent you from progress. Ask yourself of your ideal: **is good enough for now and is it safe enough to try?** "Good enough for now" means that - given your circumstances right now - your ideal is possible. "Safe enough to try" simply means that your ideal settles well enough or that you feel content with it. When a statement you make about your end-of-life wishes is good enough for now and safe enough to try, it means you have found a workable means of moving forward.

**PUT IT IN ACTION:** Select three of your end-of-life wishes, write them down and look at them. Notice how this feels; what sensations you feel in your body, and what's running through your mind. If any of them don't feel safe enough to be written down in this way, amend them so that they do. Sift through all options until one feels safe enough to commit down on paper, then sit with it. Revise as necessary.

## A GOOD LIFE / A GOOD DEATH

- How would you define a good life for yourself? For others?
- What is essential to continue your defined quality of life?
- Do you have any particular goals for the future, and if so, what are they?
- How satisfied are you with what you have achieved in your life?
- What do you most value about your physical or mental well-being?
  - For example, do you most love to be outdoors? To be able to read or listen to music? To be aware of your surroundings and those in your presence? Seeing, tasting, touching?
- Name the top 3 things that make life worth living for you.
- What are you most proud of? How would you describe your legacy?
- How would you sum up your life?
- What do you think might make a day good for you, even as you are dying?
- What challenges have you overcome in the past? How can you use the same skills or resources to help face the challenge of dying?
- If you could plan it today, what would the last day or week of your life be like?
  - Where would you be? What would your environment be like? Who would be present? What would you be doing? What would you eat if you could eat? What would be your final words or last acts?
- If you could choose the setting for your last days, where would you prefer to die?
  - Who would you want in your company?
  - What kind of atmosphere would you prefer?
  - Do you prefer silence, music, or conversation?
  - Are there any kinds of music or smells would you like to your space?
  - Would you want to be sedated if it were necessary to control your pain, even if it makes you drowsy or puts you to sleep much of the time?
  - Would you want to be bathed often and your lips kept moist?
  - Are there any passages or poems you'd like read to you?
- What would be important to you at the end of your life?
  - Ideally, where would you like to die?
  - Who would you like by your side?
- What plans need to be in place to allow you to die in a way that reflects how you lived your life?

## YOUR HEALTH:

- How would you describe your current state of health? Do you have any health issues that affect you, your work, your family, or your ability to function on a day-to-day basis?
- How do you feel about your health issues; what would you like others to know about it?
- What might your future health challenges be?
- What kind of care do you think you might want or need?
- If you are ill or in pain, how can your symptoms be controlled and your death be peaceful? What are your thoughts on balancing pain versus alertness?
- If your current physical or mental health gets worse, how would you feel about your dependence on someone else for your care needs versus your ability to be self-sufficient?
- Do you want to live as long as possible, no matter what?
- When you consider nearing the end of your life, do you feel the quality of the time you have left is more important than the quantity?
  - If you knew you'd had a stroke, and your ability to move and speak would be compromised, would you want to receive treatment if you contracted an infection?
  - Imagine you've had a heart attack right now, would you want to be resuscitated?
  - If you knew you had a terminal illness, would you want to receive antibiotics if you contracted pneumonia?
- How might potential illness or disability affect where you currently live? Would a nursing home or other residential facility be acceptable to you, or not?
- Do you want your doctors'/health care team's decisions to be respected over and above how your family feels - or how you feel regarding your plan of care? Does the thought of being a burden to your family trouble you and, if so, what would you like to have happen to lessen that?

## YOUR PEOPLE:

- What role do family and friends play in your life, and how important are they to you?
- How do you expect friends, family, and others to support your decisions regarding any medical treatment you may need now or in the future?
- Are there people to whom you want to write a letter or for whom you want to prepare a taped message, perhaps marked for opening at a future time?
- Who would you trust to care for you or make decisions on your behalf? (DPOA)
- Do you have any unfinished business that you need to address before you die? What is it and what steps can you take to resolve it?
- Is there anyone whom you don't want around you toward the end? Though it may take courage to admit this - let alone write down their name(s) - this is your chance to put yourself first. It's your moment, after all!

## YOUR FAITH

- How would you describe your spiritual or religious life?
- What gives your life its purpose and meaning? What was it all for?
- What is important for others to know about the spiritual or religious part of your life?
- How do your beliefs affect your feelings toward serious, chronic, or terminal illness?
- Given your beliefs, what is important to you about your end-of-life care?
- What do you need for comfort and support as you journey near death?
  - For example, to meet with your pastor? Would you like to be prayed for by others, have religious texts read to you, or have music playing?

# How to have THE TALK with others:

## WHO NEEDS TO HEAR IT

Think about who in your life needs to hear your thoughts on your end-of-life planning. Also consider the most ideal context/setting for the talk (while on the phone, in person while on a walk or when driving, etc?). Which of the bullet points above are most important for you to say - maybe start with just three.

## CONVERSATION STARTERS

<p><b>Warm them up.</b> Often setting the stage or agenda helps others feel less caught off guard.</p>	<p>“I’ve been thinking about some things I want you to know about my future healthcare decisions. I’m hoping we can talk about it sometime this week — maybe during our planned [call/walk]?”</p>
<p><b>Start simple and check assumptions.</b> Starting with your understanding of the other person’s opinion gives them room to share it and also ensures you’ve got it correct. Be sure you understand what your person is okay with you sharing (or not) with others about their health.</p>	<p>“If [example] happened, here’s what I think you’d want _____. Is that OK with you?”</p> <p>“By the way - who is your DPOA? Have you told them about your wishes recently? We want to make sure they are up-to-date.”</p> <p>“Are you comfortable with me making decisions if you can’t speak for yourself? Is there someone else you want to make decisions?”</p> <p>“I remember you once said that when it comes to receiving medical treatment, you want the ‘whole enchilada.’ What exactly did you mean by that?”</p>
<p><b>Explain why this is important to you.</b> Be straightforward but empathetic and patient. Emphasize the benefits of conversations and the clarity they can provide. Don’t focus on negative or scary stories or worries about what could happen.</p>	<p>“I know you have no intention of dying anytime soon, and you know I want you to be around for a very long time. But because I love you and because I want to care for you (or, inversely, allow you to participate in my care), there are some questions I need to ask you.”</p> <p>“I love you and I want you to live your best life until the very end. What should I know and what can I do to ensure that?”</p>
<p><b>Include a shared memory.</b> Talk together about a time when someone you love went through a health episode where decisions had to be made. What was it like? Were the person’s wishes known and respected?</p>	<p>“Remember that movie/show we watched the other day? That scene made me think about why it’s important to share what’s on my heart/values/what matters most to me...”</p> <p>“I need a sounding board - do you remember when ___ died? What would you have done? Have you ever imagined yourself in a similar situation?”</p>

# How to have THE TALK with others:

## CONVERSATION STARTERS (CONTINUED)

### Learn from someone else's

**experience.** Include some details and open-ended questions to continue the conversation. If you are the listener, avoid imposing your wishes on them.

"I was reading this article/listening to an interview/saw this Facebook post...and it made me realize I'm not entirely clear on what your wishes would be if you get really sick..."

"Since \_\_\_ died, I've been thinking about life and death a lot. How do you feel about it?"

"Did you hear about [news event]? I wonder what happened and what is happening now. I think if I were in that situation, I would \_\_\_\_\_. You?"

**Focus on your values.** Explain that you want to talk about what's important to you, in life and in your health care, in case you can't speak for yourself. This can be about how you want to live your life through the end — not a focus on death and dying.

"Is there a particular milestones you're looking forward to?"

"I know you've had some health concerns lately. How have they affected what you think about living a long life?"

"I was just talking with my pastor about what matters most to us if we get really sick. Have you thought about that?"

**Summarize & Clarify.** Point how the consequences of not discussing things now - regret later on, misunderstandings, feelings of guilt, etc. Explore your own stake in the conversation: you want to know their wishes so you can better manage your own stress and grief in the future. Many people don't want to talk about their own death, but even fewer want to be a burden on their loved ones.

"I've been reviewing the advance directive we talked about last year and realized I have some updates and wanted to be sure you knew..."

"I remember you once said that when it comes to receiving medical treatment, you want the 'whole enchilada.' What exactly did you mean by that?"

"I know you and I talked about what quality of life means to you, has anything changed given all that is happening right now?"

"I think I've heard you say XYZ, is that right? Anything else you'd want me to know?"

**Lead by example.** Show that YOU have had conversations about what matters for you and your health. Doing it yourself can encourage your person(s) to join you — and it can help you have empathy when you're on the other side of these conversations.

"I've been asked some questions about how I'd like the end of my life to be. I'd love to process this with you and hear your thoughts for yourself, too."

"By the way, I wanted to let you know that I've spoken with \_\_\_ about being my DPOA should I need it. Do you have one?"

## How to have THE TALK with others:

### PREPARE FOR RESISTANCE

<p><i>"I don't see what good it does to talk about such things. It's all in God's hands anyway."</i></p> <p><b>Response:</b> Be firm and straightforward.</p>	<p><i>"Yes, death is in God's hands, but how we live until that moment is in our hands, and that's what I need to talk to you about."</i></p> <p><i>"I have faith that everything will be alright, but in the off chance that something happens to me, here's what I want you to know..."</i></p>
<p><i>"I don't know about you, but I shall live forever. No need to even think about it. We can wait and handle things as they come up."</i></p> <p><b>Response:</b> Be realistic yet patient. Remind them your answers aren't set in stone.</p>	<p><i>"I know this makes you feel uncomfortable, but I need you to listen, to hear what I have to say. It's very important to me."</i></p> <p><i>"You make decisions every day about your life and your healthcare. I've seen how independent you've always been, how you have operated on your own for so long. That's why I want to understand your wishes to make sure that you maintain your independence as long as possible. Why leave really important decisions to chance?"</i></p>
<p><i>"I need to get my affairs/trust/ paperwork in order before I can talk about this."</i></p> <p><b>Response:</b> Point out the possible consequences of not talking now.</p>	<p><i>"If we don't talk about this now, we could both end up in a situation that is even more uncomfortable. I'd really like to avoid that if I could."</i></p> <p>If they seem calm enough, you might try exploring why they reacted so strongly. Or you can redirect to something that might seem less scary and vague, such as <i>"What would you want in a hospital stay?"</i></p>
<p><i>"We will do everything the doctors tell us and will never have to face a single decision with them at the wheel."</i></p> <p><b>Response:</b> Remind them of the burden of decisions without direction or informed DPOA.</p>	<p><i>"Though your doctor will help, she or he will still turn to us (your family) to make the choices for you. It will be very difficult for us to know what to do if you haven't talked about your wishes. And, it puts a real burden on all of us to have to make decisions on your behalf when we aren't sure what you would want."</i></p>
<p><i>"Why hasten death talk? We'll jinx it - talking about it makes it more likely to happen."</i></p> <p><b>Response:</b> Involve your DPOA or find a mediator to initiate and lead the discussion with other family members or your doctor. This may make your job of explaining, clarifying, and answering questions easier.</p>	<p><i>"I understand you don't like talking about this. Are you comfortable with me making decisions if you can't speak for yourself? Is there someone else you want to make decisions? I want to make sure your wishes are honored."</i></p> <p><i>"I'd love to fill you in on what [DPOA's name] and I spoke about in terms of my own health plan."</i></p>

## How to have THE TALK with others:

### PREPARE FOR RESISTANCE (CONTINUED)

<p><i>“This is a sad topic I’d rather not think about...”</i></p> <p><b>Response:</b> Remind them that it’s life-giving to talk about death.</p>	<p><i>“While it can be hard to talk about, it’s very important for our family. If we have to guess what you would like, we will feel anxious about making the right decision. And, we may disagree and not know what to do. Talking about this now will be a wonderful gift you can give to me and all of us who love you. Let’s see how it goes.”</i></p>
<p><i>Your loved one ghosts you.</i></p> <p><b>Response:</b> Be patient and not defensive. Many people are open to these conversations, but if your person isn’t, be sensitive and listen well. Try again at another time. Remember, you don’t need to solve everything with one conversation. You can try to revisit in the future or accept that it might not be a high priority for them at this time. Your person also might be interested in the materials but not in talking about it with you. That’s okay.</p>	<p><i>“I’m so sorry if this conversation made you feel uncomfortable, and I also know that I want to honor you. Can we try again later?”</i></p> <p><i>“Sounds like you don’t want to talk about this right now. I’m going to respect that.”</i></p> <p><i>“If it is too overwhelming for you right now, I understand. But let’s make an appointment for a specific time to sit down together to discuss this. All right? This is important to me because I love you.”</i></p> <p><i>“I just want you to know that I’m here for you and want to be sure your wishes are honored. If you’re up for it another time, I am really eager to understand your wishes. For example, you could send an email to me later, pick someone else to talk to, or bring a note to talk about with your doctor.”</i></p>
<p><i>“I can’t/don’t want to be part of this conversation.”</i></p> <p><b>Response:</b> Inform your chosen DPOA of your wishes, then follow up with your family. Find a good support for <i>yourself</i>. Be sure to find other people to lean on and ways to be kind to yourself.</p>	<p><i>“I want you to know that I chose [name] to serve as my proxy. That means they will make health care decisions for me if I am unable to speak for myself. We talked and they know what matters to me and my wishes. I want you to be able to focus fully on our time together, rather than on health care decisions that may cause you stress.”</i></p>

#### Based on insight found in:

- *Before I Go: The Essential Guide to Creating a Good End-of-Life Plan.* by Jane Duncan Rogers, Findhorn Press, 2018.
- *Talking About Death Won’t Kill You: The Essential Guide to End-of-Life Conversations.* by Dr. Kathy Kortez-Miller, ECW Press, 2018.
- *The Art of Dying Well: A Practical Guide to a Good End of Life.* by Katy Butler, Scribner, Simon & Schuster, Inc, 2019.
- *How not to say the wrong thing* by Susan Silk and Barry Goldman. [LA Times](#) opinion piece, April 7, 2013.

# How to have THE TALK with your DPOA:

## PREPARE TOGETHER

These questions can help you and your DPOA discuss various topics that may influence the process and result of healthcare decision-making. The discussion items are open-minded statements and can be completed at whatever level of self-disclosure you wish.



With each question, decide who will be the first to speak and who will be the first to listen. The first speaker will complete the phrase in 2-3 sentences, then the first listener will paraphrase what the first speaker said. Once the first speaker is satisfied that they have accurately been heard, switch roles and readdress the question. Repeat the process. Remember listening well is essential to good communication. Though you are encouraged to answer the questions in order and to not skip ahead, you may decline to complete the phrase as the speaker, but the other person still will have a chance to express their answer. Either partner can stop the conversation if uncomfortable or anxious at any time. When done, communicate your level of confidentiality with both your and their answers.

- My name is, and the reason I am here is...
- When I enter a room full of people I don't know, I usually feel...
- When I have something to say...
- The person who influenced me most is...
- From that person, I learned...
- It is fun to...
- People think of me as...
- Values are...
- If I could not make my healthcare wishes known, my greatest concern would be...
- The most important person in my life is...
- My most significant quality is...
- Right now, I'm feeling...
- The part of me that most makes me human is...
- The value I place above all others is...
- For me, doing good is...
- Something I like about myself is...
- The thing I like best about you is...
- I think quality of life is...
- Dying is...
- The most important decision I've ever made is...
- The most important decision I'll ever make is...
- What I think you need to know about me is...
- Listening check: "What I hear you saying is..."
- Right now, I'm feeling...
- I believe in...
- I really fear...
- I am happiest when...
- I am happy for my friends when...