

ENGAGE WITH GRACE

DISCUSSION GUIDE • QUESTION 1

On a scale of 1 to 5, where do you fall on this continuum?

Not the most fun question to answer, is it? But having frank discussions about your end-of-life preferences allows you to end your life in the way it was lived – with intent. And it will help ensure your family and loved ones feel empowered to support your wishes as well.

Here are some things to think about as you consider where you fall on the spectrum:

- What do you think is important to know about the end of life?
- How do I judge quality of life- being able to move on my own? Eat on my own? Think for myself?
- How do the needs of my loved ones factor into what medical treatment I would undergo? For example - if I had a young child, am I more interested in continuing medical treatment than if my child was an adult?
- Are there any “bucket list” items- things I would ideally like to do before passing away? Do I need to find closure with a relative? Visit the ocean? Spend a last night in my bed with my partner? Will accomplishing that item affect the way you think about how you spend your last days?
- How do my religious or spiritual philosophies impact the type of end of life care I want to receive?
- Will money have any role in my end of life care decisions?
- Am I willing to try a new drug or medical treatment if my chances of survival are slim?
- Would I want life support if it was unlikely that I would wake up? What if I could potentially wake up if kept on life support, but would likely have severe brain damage?

Here are some things to think about as you consider how your loved ones would answer this question for you:

- How will the needs of my loved ones impact their preferences for my end of life experience?
- Is there someone who could become your caretaker if you would prefer not to be at home without medical assistance?
- What impact will the cost of my care have on my family?

It may be helpful to compare your wishes with some hypothetical examples:

If you answer 1, you might be like Michael: Michael is a 20 year old young man at home with his family. Recently diagnosed with terminal brain cancer and given just a few months to live, Michael doesn't want any type of traditional medical intervention and has refused all forms of treatment that doctors have offered. He believes on healing will occur through prayer. He passes away after 3 months, at home and surrounded by his family, and without any medical intervention.

If you answer 2, you might be like Veronica: Veronica is a 78 year old Alzheimer's patient, who has just been diagnosed with leukemia and lives in a nursing home. Her husband died two years ago and the only living relative is Helen (her daughter), who serves as her health advocate. Ten years ago, Veronica put together a living will that indicated she would prefer to be comfortable when she died. The treatment for leukemia may hasten Veronica's death and will be physically uncomfortable. Although Veronica is alive, she is not lucid enough to make a decision about whether or not to undergo chemotherapy. Helen would like Veronica to

remain alive for as long as possible, so she would prefer for her mother to agree to treatment. Based on the living will and her previous discussions with Veronica, however, Helen decides against chemotherapy and remains her mother's strong advocate throughout the process. Helen is with Veronica when she passes away two months later, in her daughter's home, surrounded by pictures of the glorious life she lived, with soft music playing, and her daughter holding strongly to her hand and whispering to her how much she loves her.

If you answer 3, you might be like Sonia: Sonia is a 32 year old mother, who recently was diagnosed with late stage breast cancer. The doctors embark on the recommended course of treatment, which is not effective. She is offered access to an experimental procedure that has a small chance of working, but also has uncomfortable side effects. After suffering through the chemotherapy, Sonia decides that she would prefer to spend her remaining 6 months with family and asks to be released from the hospital. She passes away seven months later, surrounded by her large and loving family, and her dearest friends. They are reading to her from her favorite book, *The Great Gatsby*, and taking turns holding her hand and stroking her arms and face.

If you answer 4, you might be like Bill: Bill is a 45 year old male who was in a near-fatal car crash. An active man his whole life, Bill has been placed on life support and the doctors do not think his chances of returning to a normal life are high. He is married to Heather, and has two children, Ally (8) and Greg (12). Heather decides to continue life sustaining treatments, with the hope that they allow her husband to regain consciousness, and ultimately see his children grow up into adults. He is kept on life support for 12 months, until doctors say that there is virtually no chance that he will ever regain consciousness, and he passes away in the hospital – which was the wish of his family, since they were worried they could not care for him adequately at home.

If you answer 5, you might be like Jim: Jim is a 46 year old man who gets diagnosed with a rare form of cancer. After several unsuccessful rounds of chemotherapy, Jim enters a clinical trial of an unproven drug. He takes the drug, which has a limited impact. He eventually loses all mobility and needs a feeding tube. His family agrees to a final round of chemotherapy while he is on the feeding tube, which fails to improve his medical situation. Jim passes away in the hospital, by choice, surrounded by his loving family, and supported by the staff that have cared for him so well through his illness.

To think through how you would respond in specific end of life experiences, check out this survey:

Specific Medical Treatments: <http://www.mycarecommunity.org/MakingDecisions/AdvancePlanningToolKit/HealthcarePlanning/tabid/520/Default.aspx#will>