



Preparing for the Journey: Ethical Challenges and Decisions at End of Life

Goals of Care Questions for Reflection & Discussion

- What about your life is most important to you?
 - Examples: Being able to make your own decisions, care for yourself physically, live in your own home, communicate with those you love, being comfortable, being mobile, being able to eat the foods you enjoy, hobbies and passions, etc.
 - If your ability to engage in any of these aspects of life is lost due to illness or medical treatment, is this something you would be willing to compromise on or would it be intolerable for you?
- If you were to get very ill, what would be your biggest worries or fears?
- If you were diagnosed with a life-limiting illness, what types of treatment would you prefer? Are there any you do not want (CPR, ventilator, feeding tube)?
- How do you feel about being in the hospital for an extended period of time?
- If your health condition became terminal, when would it be OK with you to shift from trying to cure an illness to trying to enjoy the end of life as much as possible?
- When you look ahead to the future, are there important events or dates you hope you're there for?
- What would you like your final days and hours of your life to look like? Where would you prefer to die? Who would you want there?
- Are there any cultural or spiritual beliefs, rituals, or traditions that are important for people to know about when it comes to your medical care and/or end-of-life experience?
- What do you need to address to feel more prepared for death (examples: finances, property, legal documents, relationships, health care situations)?
- Who would you like to make health care decisions for you if you couldn't speak for yourself? Is there anyone you would not want involved?
- What can I do to best support you and your choices?

Tips for having the Conversation with Loved Ones

- When & Where
 - Pick a time when those you would want to support your decisions are there such as a family get together. Do not pick a stressful time as this topic can be hard

enough for most people. Pick a spot that is quiet, private, and calm where you can avoid distractions.

- Mindset and approach
 - Normalize the conversation. If you're anxious, they will be too.
 - If you can't help but be a little nervous, that's ok. Give permission for all to have a bit of a hard time with it.
 - Be prepared to really listen, with all your senses.
 - Ask for permission for the conversation to take place: "It's really important for me to understand what healthcare decisions you would like made if you were ever in a position where you couldn't tell us, is that ok?"
 - Talk about your own wishes – vulnerability invites vulnerability
- How to introduce the topic
 - Mention a book you read or movie you watched that got you to start thinking about your wishes.
 - Share a recent experience of someone you love living with chronic or terminal illness.
 - Share a recent personal experience: "That last hospitalization seemed to be really rough on you, do you want to keep going back and forth into the hospital when things come up? We can explore other options."
 - Just say it, "Kids, I want to take a minute to talk about something that is very important to me..."
- Document it
 - Optional, while can be very helpful down the road
 - Take notes or record (audio or video) the conversation
- Use tools to guide the conversation
 - Watch a documentary together: Netflix documentaries Extremis and End Game review professional end-of-life care and options
 - Use a card deck with conversation starters: The Death Deck

Talking with your Medical Provider

Talk about your goals, values, and wishes now. Don't wait for them to bring this up. You don't have to be facing a challenging decision to start the conversation.

Questions to ask

- Can I review my healthcare directive with you?
- Can we talk about CPR?
- Will you be straightforward with me and my loved ones right away if I have a serious or terminal illness?
 - Will you refer me to a palliative care or hospice team that can help me live as well as possible in the time I have left?
- Will you be clear about the risks and benefits of treatments and let us know when treatment is not or has stopped helping?

Questions to ask related to your diagnosis, prognosis, and treatment from The Conversation Project

- Can you tell me what I can expect from this illness?
- What is my life likely to look like 6 months from now, 1 year from now, and 5 years from now?
- What can I expect about my ability to function independently?
- What are some possible big changes in my health that I should be prepared for?"
- What costs should I expect with this plan?
- Can I expect to get better if I choose this treatment? What are common side effects? What are my other choices?
- What can I expect if I decide to do nothing? What will my quality of life be like?

Documents & Tasks to Complete

- Healthcare Directive (or living will) listing healthcare agents and written guidance for your wishes
- Providers Orders for Life Sustaining Treatment if chronically or terminally ill
 - Great video that describes the POLST in detail: <https://polst.org/about/>
- Financial Power of Attorney
 - <https://www.ag.state.mn.us/consumer/handbooks/probate/PowerOfAtty.pdf>
- A will and/or trust to be completed with your trusted estate planning attorney
- Funeral planning

Be sure to put these and other important documents in a secure place that the necessary people in your life know how to access.

Treatments to Research

Use trusted online resources such as WebMD or Mayo Clinic to learn more about these treatments. Always talk with your trusted medical provider about any questions that arise.

- CPR
- Artificial hydration and nutrition
- Dialysis
- Ventilators and other breathing support interventions
- Antibiotics
- Hospice and palliative care

Trusted Resources for Advance Care Planning

- <https://theconversationproject.org/>

- <https://www.acpdecisions.org/patients/>
- <https://www.caringinfo.org/>
- <https://prepareforyourcare.org>
- <https://honoringchoices.org/>

Educational Resources for Other Ethical End-of-Life Issues

Voluntarily Stopping Eating & Drinking

- <https://vsedresources.com/>

Medical Aid in Dying

- <https://www.aadm.org/patientinfo>