



## Discussing Death

As you consider your values and wishes for end-of-life care, you need to convey this information to your loved ones and healthcare surrogate. This is especially true if you would consider hastening your death if you were faced with a future that you deemed unacceptable. This can be an awkward conversation to initiate, but it is necessary to get past any squeamishness you have about discussing life's uncomfortable realities. Do not let anyone else's squeamishness derail you either. Be prepared to express how important this conversation is to you, in case a loved one tries to deflect the discussion with, "You're doing fine right now..." or "Don't be so morbid..."

Do not wait. The closer to death one gets by age or debility, the more emotionally laden these discussions may become. Once you have laid the groundwork, the discussions don't have to be long or drawn-out, but have them regularly. Do not presume that because you had an in-depth talk five years ago, your loved ones still remember and feel comfortable with your values and wishes. If your family is accustomed to you raising the subject of your death, it will be easier to tackle end-of-life issues when those issues shift from distant and theoretical to immediate and practical.

This is particularly important if you might consider hastening your death. It is not the same thing to share your wish not to live if your quality of life becomes unacceptable as it is to share that you would consider actively ending your life. Callers to Final Exit Network, when asked if they have told their loved ones that they are considering self-deliverance, frequently say something like, "Oh, they won't be surprised; they know my values." In our experience, that is not a valid assumption. They may well be surprised or shocked by the emotional reality of it, and the sooner you explicitly raise the possibility, the more time they will have to consider and get comfortable with the idea.

It can be helpful to break this sensitive topic into multiple conversations. It is asking a lot of loved ones to expect them to shift their understanding in a single discussion from business-as-usual to hastened-death. Start with an initial discussion about your values as they pertain to your quality of life and your current condition. Be frank and matter-of-fact about your condition; it will help your loved ones understand where you are coming from. Once your loved ones understand your values and your condition, then broach the possibility of hastening your death. After they have had a chance to get comfortable with the theoretical idea, then start to talk about it as a concrete possibility.

Give them time to internalize and emotionally grapple with the options you are considering and the choices you might make, and don't be discouraged if their initial reaction seems negative or oppositional. Not infrequently, people come around after they have had some time to digest and think about what you have shared.

In broaching your end-of-life wishes, let your loved ones know that you have thought deeply about these issues and considered them over time. Keep in mind that you are not seeking their approval or their permission. You are seeking their:

- understanding and respect for your values, your priorities, and your wishes,
- support when you are able to express or execute your choices yourself, and
- representation of your wishes when you are unable to express or execute your choices yourself.

Be careful if you bring money into the discussion. While you may abhor the idea of money being spent to prolong your suffering or indignity, the focus should be on your personal values. Telling loved ones that your choices will save them money is asking them to tell you how much they love you and that cost is no object. If preserving financial resources is important to you, emphasize the values you envision those resources going toward and contrast that with the use of those resources to prolong your life in a condition you consider unacceptable.

Likewise, be careful if explaining that you do not want to be a burden. While this may be true, this reasoning also invites protests from your loved ones that they would be happy to care for you and that it would not be burdensome. Clarify that you do not want to BE a burden, which is different from not wanting to burden THEM. It is not about them; it is about you and what you want for yourself.

It can be helpful to acknowledge the seemingly contradictory emotions that often swirl around death, and a hastened death in particular. A loved one can simultaneously not want to lose you, and also support you in ending your life. A loved one can both disagree with your decision, for whatever reason, and also respect your right to choose. Life is messy; death is no different.

Finally, take what is useful here and ignore the rest. You know your loved ones and where they are coming from. There are many ways to broach and explore this topic, and if you approach it with patience and an open heart, you will find your way.

## Possible Talking Points

These intimate conversations must come from you and reflect your unique history and personality. The following example talking points express values we frequently hear from those who seek our services and might help you as you consider what matters most to you and how you might share that with those close to you.

- We all die; it is not a question of if but when. For me, choosing to end my life before I lose my autonomy is an act of self-compassion. It is a choice that reflects my values and allows me to close my final chapter before my quality of life becomes unacceptable to me.
- It is not that there is nothing left that I enjoy, but the pleasures are fading and the pain and daily effort are growing. I have reached a point where the fatigue and burdens of life outweigh the pleasures. My death must come, and I feel ready. I do not want to wait until I am trapped in a future I cannot control.

- I have had a good, fulfilling life, but I can no longer do many of the things I used to enjoy and that isn't going to improve.
- Life is, for the most part, uncertain, but one thing is sure, we all must die. I have reached a point where the possibility of a sudden, debilitating fall or heart attack or stroke could leave me physically trapped or with brain damage. I do not want to live as a shell of my former self. I have had a long and interesting life and am ready to say goodbye. It is more important to me to maintain my autonomy than it is to live as long as physically possible.
- Since this diagnosis, I have thought a great deal about what matters to me and what I want my death to be. I would prefer to have a slightly shorter life and avoid the final stages of this disease. I want to exit while I am still comfortable and able to control my own destiny.
- For me, my mind is the essence of who I am. Dementia is eating away at my very essence, slowly, but surely. Yes, I am doing okay right now, but already I am less sharp than I once was. If I wish to avoid a future that I consider abhorrent, I must act while I still have the mental capacity and resolve to make this difficult choice.
- I am choosing to end my life in order to avoid a fate that I consider worse than death. I am not suggesting this is the right choice for anyone else, but it is the right choice for me.

January 2021