



HOW TO TALK TO YOUR FAMILY ABOUT END OF LIFE

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MOST PEOPLE DO NOT WISH TO TAKE TIME OUT OF THEIR DAY TO TALK ABOUT END OF LIFE ISSUES.

It's not fun. But, since we are all going to die someday, it is in our best interests to make decisions about how we wish to die. Rather than letting the medical industry, lawyers and strangers decide for you, you can take control of the end of your life just as you have been taking control of your earlier years.

So, I'd like to help you by giving you some advice on how to talk to your family about your wishes. My information is mostly from experience, and I hope it gives you something practical and positive to think about.

1) WHY SHOULD YOU TALK ABOUT HOW YOU WANT TO EXPERIENCE THE END OF YOUR LIFE.

Whether you are conscious of it or not, you probably have feelings about how you wish to die. You most likely have opinions of what you can live with and what you cannot. For example, Steven Hawking had no abilities - he could not walk, talk, move, or eat without the help of machinery and assistance from others. However, his brain worked fine. He could still be a productive member of society. On the other hand, John had Alzheimer's and knew that ultimately his brain would no longer function. It would be a slow death of his brain. He knew he would not be a contributing member of society.

Steven Hawking chose to live with his disability while my husband chose not to live.

Thus, thinking about these issues and talking about what your wishes are helps you to determine how you wish to live and die on your own terms.

2) WHEN SHOULD YOU TALK ABOUT YOUR END OF LIFE WISHES?

I don't believe there is a concrete answer to this, but I do believe as an adult one should take responsibility for their adult decisions. It is never too soon to have philosophical discussions with the people who care about you. For example, are you okay with spending your life in a wheelchair?

John and I were married for 41 years. Because I watched my mom suffer with early onset Alzheimer's, I had some idea of what this brutal disease was like. This experience motivated me to talk about whether or not I wanted to live in a vegetative state with my husband. We both agreed that neither one of us wanted that kind of end of life. We started discussing this early on in our marriage. First casually, then later on more seriously. We understood each other's wishes and why we made these choices.

3) HOW DO YOU TALK TO YOUR LOVED ONES ABOUT YOUR END OF LIFE WISHES?

Actually, the answer here is the simplest. Talk honestly and freely. It is your life and you should have some agency in creating a plan for your last chapter. Once you start the discussion, it gets easier and it is helpful for members of your family to discuss it together. You can learn from each other. You can listen to different perspectives and try out in your mind how you feel about certain opinions. There is no right or wrong answer to this end of life question.

4) WHO SHOULD YOU DISCUSS YOUR END OF LIFE VIEWS WITH?

In early stages of your discussion, when you are young and healthy, this kind of discussion can occur like any other topic with friends and family. This is a more casual, conceptual conversation. When you reach an age when mortality starts to reach your consciousness, then discussing your options with your spouse, partner and immediate family is appropriate. I like to think about it as concentric circles - the people who are closest to you and who will be most affected by your choices should be the inner circle. Then as the circles go further out, those are people who you want to know what your beliefs are but are not necessarily personally impacted.

5) HOW DO YOU MANAGE NEGATIVE REACTIONS TO YOUR DECISIONS?

First of all, remember this is your life and your right to choose. Listen to the objections. Try to explain your point of view, but do not allow pressure to force you to not follow your heart and mind.

When John decided he wanted to participate in assisted suicide, we told only those who needed to know (our adult children) and those who were closest to us. (siblings). As we drew nearer to the date he would die, we told a few very close friends. We told our outer circle on the day we flew to Switzerland for his assisted suicide. The rationale for keeping such secrets was A) it would be difficult for a person with a brain disease to defend his choice and B) it was our personal choice and we were trying to not add tension to our lives.

6) WHICH OUTSIDE RESOURCES SHOULD YOU USE AS REFERENCES?

- A) Find out what the laws in your state are for MAID - medical aid in dying and assisted suicide.
- B) Talk to your doctors about your wishes to learn their perspective.
- C) Talk to your religious leaders to ensure you are comfortable with your own choices.
- D) Learn about hospice care in your area. What are the costs? What is the availability of space? Are there at home options?

NOTE: MAID is not legal in the US for people with dementia. The law states that two doctors must say the patient has six months to live and can demonstrate mental capacity to make this decision. Doctors cannot predict how long a dementia patient will live and if the patient were to be six months from dying, he definitely would not have mental capacity. These two criteria eliminate dementia patients.

7) WHAT ELSE SHOULD YOU CONSIDER?

Make sure you have medical directives in your Will and/or Trust. Identify the person in your life you want as your medical power of attorney. This person should be ready to support you and ensure your wishes are carried out at the end of your life. Know that you can always change your mind. What you think at 50 years old may not be what you think at 80 years old. I like to frame the question as "What are you willing to live with and what are you not?"

8) WHY IS THIS SO HARD?

I believe this is difficult because in our western culture we do not accept death as part of life. We do not like to talk about dying. Instead of treating death as an accepted part of our life cycle we act like it is abnormal and strange.

A second reason is we are afraid to die. We don't know if it will be painful and we don't know what happens after we die. Certainly it is much more difficult to accept the death of a young person than of an older one, but while we know we are all going to die, we treat death as though we all will live forever.

This is why these conversations matter so much. The more we are willing to talk openly about death, dying, and the choices we have along the way, the more power we reclaim over our own lives, and the lives of the people we love the most. You have a right to make decisions about your life, and about how you care for your loved ones.

I learned this in the hardest way possible, walking beside John through his dementia and, ultimately, through his choice to die on his own terms. I wrote *How To Live With Your Spouse With Dementia (And Not Lose Your Mind)* to share what that journey taught me, not because I have all the answers but because I wished, every single day, that someone had walked the path ahead of me first.

If you are on this challenging journey yourself, or simply want to understand it better before you have to, pick up a copy of my book on [enter release date]. You don't have to walk through this alone.