

RESOURCES FOR NORTHAMPTON

NEIGHBORHOOD NETWORKS

Introduction

Following are references with annotations and suggestions you might find useful in *TAKING CHARGE* of your end of life planning. My e-book *YOUR LIFE, YOUR DEATH, YOUR CHOICE: How to Have Your Voice to the End of Your Life* provides many more references (links) and suggestions on how to have conversations about the information in the links. It also provides downloadable forms.

You can watch the three videos in my presentation with your family as helpful tools in beginning conversations with your family.

1. Kiernan, Steven, author of *LAST RIGHTS: Rescuing End of Life from the Medical Profession*, demonstrates what it is like to be put under pressure when medical decisions have to be made...

Watch this with people special to you and discuss the issue of the fear of dying and how you can overcome or cope with this fear if there is an accident or a serious diagnosis.

Notice that this video has to do with Hospice and folks fear of it. Did you know that Hospice can actually extend and improve the quality of life? This is especially true if one choses Hospice earlier in one's illness.

CLICK ON THE LINK BELOW TO WATCH THIS VIDEO.

<https://www.youtube.com/watch?v=sPlkqYpRN3g>

2. Bernhagen, Michael and Kuldhudal, Terry Consider the Conversation. You can learn more about this film at the following link: <https://considertheconversation.org/>

Consider the Conversation has won 22 awards and an Emmy nomination as a documentary about the importance of having serious conversations about end of life choices.

This extraordinary 2 minute trailer conveys many essential concerns of doctors: (1) the lack of honesty between patients and doctors, (2) the unintended consequences of powerful technology which can keep a body going, but with little quality of life, (3) the high likelihood that a patients choices will be ignored if they don't have an ombudsman who knows what they want, (4) the fierce attacks on doctors who broach the possibility that a loved one might not survive, and (5) the urgency doctors see in promoting serious and deep conversations.

Here is a place for a conversation both with your doctor and your family. It has to do with how much treatment you want, and whether your doctor can be “on board” with your choices. (Some doctors are very uncomfortable talking about dying.) S/he should also be able to help with your thinking through your choices.

CLICK ON THE LINK BELOW TO WATCH THIS VIDEO.

https://www.youtube.com/watch?v=5R8kavgev_o&feature=youtu.be

3. Williams, Brian 30 Rock A dying man makes his plans for his end of life.

This 8 minute video shows what happens when one engages in end of life planning at a Wisconsin hospital. It conveys the courage and strength of those who choose to anticipate and plan for death. It also emphasizes how *TAKING CHARGE* is a gift to one's children.

Watch this with your family. Notice the questions that are asked. How would you answer these questions? Notice how the two different families respond to knowing that there is a plan in place.

Start a conversation about what each family member would want if they lapsed into a coma and doctors said there was little or no hope of regaining consciousness.

CLICK ON THE LINK BELOW TO WATCH THIS VIDEO

Here is the link: <https://youtu.be/s6NTxUJpfW8>

4. Goodman, Ellen Ted Talk on “Having the Conversation” (We did not watch this video due to time constraints.

Ellen Goodman, a noted journalist, explains the reason for the book I wrote. Particularly poignant is her description of how difficult it was to

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make decisions regarding her mother's health without having talked with having talked with her mother about her wishes.

Goodman has a web site with information, forms, and scripts for having difficult conversations with your family and/or doctor. Of special note is that the Conversation Project has produced an online "Conversation Starter Kit" to help you organize your thoughts and begin talking about your wishes. To view the kit or print a copy go the following link.

<http://theconversationproject.org/starter-kit/intro/>

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CLICK ON THE LINK BELOW FOR Goodman's 12.46 MINUTE TED TALK.

<https://www.youtube.com/watch?v=xbWcLYOniWU>

5. **Extremis** A Netflix Documentary September 2016. (About 22 minutes)

This is a short compelling film about the struggle to make treatment decisions for patients who are gravely and likely terminally ill. The struggle is illustrated by both the doctors trying to find out what a patient wants and attempting to help the family sort through the best decision when there are few good options. Poignantly, Dr. Zitter, the lead physician in this film struggles with the notion that providing *more* interventions can extend life, enhance suffering, and provide little benefit. It is an elegant display of caring physicians and other health care providers.

A review of this film in the Journal of the American Medical Association (Jan 17, 2017, volume 317, number 3) states the following: "... many Americans will encounter end of life decision making – not as

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an active choice but, passively, with little or no opportunity to influence the decision or the outcome.” (pg 241).

Extremis is a testimony to the importance of deciding what you want and “having the conversation” with your family, doctor, and health care agent (Medical Proxy). It illustrates how hard the choices are when there have not been adequate conversations.

A lot of this film focuses on breathing machines and two patients who end up with different decisions. After you watch this, try to decide what would be your choice if you were one of these patients. Then show the film to your loved ones and proxy and have a conversation with them starting with asking them what *they* would choose for treatment followed by sharing what *you* would choose.

6. Go to a Compassion and Choices website to learn about Covid-19 and the importance of considering choices.

While the article you will see was published prior to a vaccine being available, pages 4 and 5 have information about two life support responses which you must understand and discuss with your family: CPR and Ventilation.

Here is the link.

<https://compassionandchoices.org/resource/covid-19-understanding-your-options/>

7. GENERAL SUGGESTIONS FOR STARTING A CONVERSATION

If you have difficulty initiating the conversation, ask others what they would want if they were in an irreversible coma. Then share your thoughts.

Watch movies like “Still Alice” and ask what each of you would want if you were Alice and facing Alzheimer’s Disease. Share your own thoughts.

Talk about someone who has passed away who was known to all (a grandparent, uncle, close neighbor, young friend, etc.). Ask what they thought about their passing. Was it good? Or not so good? Than ask what they would want in that situation. Share your own perspective.

Identify a story in the news about someone who is being kept alive without much hope of recovery. Ask what others would want, then share your thoughts.

Encourage, your relatives to have conversations about this topic. They may be asked to make decisions for you.

Download the script from the Conversation Project and use it to help start a conversation.