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Making Meaningful and Financially Appropriate Decisions at the End of Life

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What Do People Want?

Mr. A's Story

Sections of Quality-of-Life Statement

- 1. Types of illnesses where this advance directive would apply
- 2. What is important to me? What makes my life worth living?
- 3. What conditions would I find horrible to live with long term? What would be a fate worse than death?
- 4. What would be an acceptable level of better? I wouldn't like it but I would be willing to live with _____.
- 5. CPR, ventilator and feeding tube preferences
- 6. What would be important to me as I die? What is a good death in my opinion?
- 7. What do I want the doctors to know about honoring my religious/cultural beliefs both while I am sick and/or dying?
- 8. Reassurances for my decision maker(s)
- 9. Additional guidance for the doctor

Section 1: Types of illnesses where this directive would apply

- **How his document failed him:** “If I am in a persistent vegetative state or dying,” but it didn’t directly address other injury/illness
- His words were taken literally
- He meant to express a certain level of functioning that he would hate, not the reason he got that way

How I Solved This...

- *I can never list every type of disease that might make me begin to lose my mental capacity but the list might include, and is not limited to: all types of dementias, stroke, brain injury, mental illness, anoxic event, etc. I don't have to be completely out of it, like being in a persistent vegetative state, coma, or minimally conscious state, for this document to go into affect. And I don't have to be terminal. The point is that I don't want to have my life prolonged/sustained if my brain no longer works well enough to enjoy what is important to me.*

Section 2: What is important to me? What makes my life worth living?

- **How his document failed him:** It said, “If I am not enjoying life then...”
- It didn't define what made his life enjoyable
- Unfortunately, this vague statement was misinterpreted by the doctors and court

How I Solved This ...

- *To make a difference in the world. To be able to communicate with those I love. To receive the joy that comes from personal relationships. To have some independence. To be able to give love, not just receive people's kindness. To not be a burden on my family or friends - financially, emotionally or physically.*

Section 3: What conditions would I find horrible to live with long term?

What would be a fate worse than death?

- **How his document failed him:** He didn't say what types of conditions would be horrible to live with or how long to give him to recover enough to "enjoy life."
- The only guidance offered was, "If I am dying."
 - Having a terminal illness (days to years)
 - Actively dying (within the next 24-48 hours)
 - Qualifying for hospice (6 months or less)

How I Solved This ...

- *Please give me the chance to recover if recovery is possible, but if I am not recovering to a level of functioning that I would think is worthwhile, whether terminal or not, then choose comfort care and hospice which I understand will lead to my death.*
- *All of the following conditions do not have to be present at the same time for the decision to be made to allow me to die from my illness or injury. Any one of these conditions may be sufficient enough to change my course of treatment from prolonging my life to comfort care and allowing a natural death.*

- **What I have listed:**
- *Not being able to communicate by voice, computer, sign language or gestures.*
- *I couldn't bear for my husband, Ed, to visit me in a dementia unit and see me becoming violent, or not recognizing him, or hitting on another man because I am so confused. That would be a fate worse than death.*
- *And, don't park me in a SNF hallway and tell me that this a good quality of life. It is not.*
- **Others have told me:**
- I would say suffering
- Paralyzed with no means of communication with my caretakers. Of course, with all the sewing and knitting I do, just losing a hand would kill me.

Section 4: What Would Be an Acceptable Level of Better? I wouldn't like it but I would be willing to live with...

- **A client wrote:** I think a fate worse than death would be if my brain could no longer register love, if I could no longer connect in any way with those I loved. Losing my speech, mobility, or independence would be horrible, but I don't think that would be a fate worse than death. There are so many ways to connect without those things.“
- Goal of sections 2, 3 and 4 is to clarify boundaries
- Put simply: Here is what I would **like**. Here is what I would **hate**. Here is what I could **live with**.

Better Information = Better Decisions

- When asked what patients might want if they were in advanced dementia state in a skilled nursing facility:
 - 50% comfort care
 - 21% everything done
 - 18% some interventions
 - 11% unsure
- After being shown a 2-minute video of a patient with advanced dementia being cared for in a SNF:
 - 89% comfort care
 - 0% everything done
 - 11% some interventions or unsure
 - Differences regarding race, ethnicity and education level disappeared

Steps to Improve the CPR Conversation

- 1. Ask the patient/family what they know about CPR.
- 2. Explain what really happens during CPR.
 - Most patients think it only includes chest compressions, mouth to mouth resuscitation, and some realize it includes paddles to shock the heart
- 2. Explain that in real life, CPR does not work like they see on television
 - On TV, it works 75% of the time
 - Overall CPR survival is 15-17%
 - Metastatic cancer or multi-organ system failure is 0-1%

- 4. Patients don't understand that they may come back to life in a worse condition than they were in before, both mentally and physically. Explain the risks involved.
 - Leaving the hospital with your brain back to where it was before the code – 7%
 - Rib fractures – up to 97% of the time
 - Breastbone fractures – up to 43% of the time
 - Bruising of chest – 59%
 - Defibrillator burns – 30%
 - Bleeding in chest; damage to trachea, esophagus and/or abdominal organs; lung damage; and damage to lips and teeth
- **5. Patients don't understand that the type of death they are choosing**

Unexpected Costs at the End of Life

- *Make sure that the treatments being offered have a chance of achieving the patient's quality-of-life goals*
- Other costs:
- Medications that are life prolonging
- 24 hour care if needed
- Frequent ambulance rides because patients tend to have multiple hospitalizations as they near death
- One more trip to the hospital to have the pacemaker removed or turned off
- Supplies such as Depends, bed pads, etc.
- Family missing work to stay home with loved one
- Flying family in for one more visit and/or for the funeral

Resources

- **Go Wish Cards** www.gowish.org (English and Spanish)
- **Consider the Conversation** – documentary www.considertheconversation.org
- **Insider's Guide to Filling Out Your Advance Directive and Questions to Ask When Making Medical Decisions** www.TheCaregiversPath.com resource page – book excerpts
- **Thinking Ahead Project** <http://www.coalitionccc.org> (English, Spanish, Korean, Chinese)
- **Well Spouse Association:** A wonderful website, chat room, and support system for spouses and significant others.
- **How to Say It To Seniors** by David Solie

More Resources

- **The Cards I've Been Dealt** – Needs Assessment cards to help the patient and/or family review the patient's abilities and needs www.thecardsivebeendealt.com
- **The Caregiver's Path to Compassionate Decision Making: Making Choices for Those Who Can't** by Viki Kind
- **New Book - Resource Workbook, Visual Conversation Guide and Visual Toolkit** by Viki Kind (8 ½ x 11) Full size so you can easily make copies of the worksheets and articles for your client
- **DVD – How the Healthcare Directive Fails in the Hospital and How to Fix It** by Viki Kind (includes 80 minute video and 13 document templates)