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Why the Healthcare Directive Might Not Work In the Hospital

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	Great Family	Difficult Family	No Family or Friends
Great Advance Directive			
Poor Advance Directive			
No Advance Directive			

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His Document Didn't Sound Like Him

- "If I am ever in a wheelchair, just shoot me."
- He didn't want to be disabled in any way
- *Legal language vs. Medical language vs. Human language*
- Nothing personal or meaningful in directive

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Sections of Quality-of-Life Statement

- 1. Types of illnesses where this advance directive would apply. Do you want this statement to apply only when you are dying or should it also apply when you will continue living with limited mental capacity from diseases like dementia, stroke, or other brain injuries?
- 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?

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- 4. What would be an acceptable level of better? I wouldn't like it but I would be willing to live with ____.
- 5. What would be important to me as I die? What is a good death in my opinion?
- 6. My preferences regarding cardiopulmonary resuscitation (CPR), being on a ventilator (breathing machine), and/or feeding tubes. (*Talk to your doctor about your specific health situation before making these medical decisions.*) Would I be willing to be on a ventilator and/or have a feeding tube for a *short period* of time so I can recover from my illness/injury? Would I be willing to be on a ventilator and/or have a feeding tube for the *rest of my life*?

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- 7. Reassurances for my decision maker(s). Imagine the person who will be making the decisions for you is sitting beside your hospital bed. What would you want to say to help him/her feel more comfortable and confident that he/she is making the right medical decisions for you?
- 8. What I want the doctors to know about honoring my religious/cultural beliefs both while I am sick and/or dying?
- 9. Additional guidance for the doctor.

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Types of Illnesses Where Directive Would Apply (When Dying and/or Cognitively Impaired and Ill)

- **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

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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.*

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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

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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.*

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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 (1) what types of conditions would be horrible to live with or (2) 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)
 - Qualifying for hospice (6 months or less)
 - Actively dying (within the next 24-48 hours)

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How I Solved This – Regarding Timing

- *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.*

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Viki's Fate Worse Than Death

- *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 skilled nursing facility hallway and tell me that this a good quality of life. It is not.*

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An Acceptable Level of Better – I Wouldn't Like It But I Would Be Willing to Live With...

My friend's statement: *"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."*

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Others Have Told Me

- *It would be okay if I couldn't recognize people because every day I would make new friends.*
- *I would say suffering. (Explain what suffering means to you. Physical suffering, emotional suffering, spiritual suffering, etc.)*
- *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.*

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When You are Home Sick in Bed, Do You Want Your Feet Tucked In?



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Go Wish Cards



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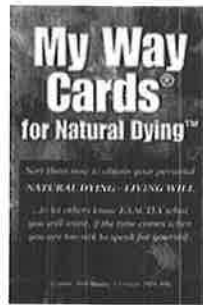
**Create a Personalized
“Care Preferences” List
(Not a Legal Document)**

- Don't assume your family knows your day-to-day preferences
- Create a list of care preferences for when you can no longer communicate
- If you are the caregiver, write down the person's preferences for the those who may be caring for him/her in the future

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My Way Cards



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Dementia Advance Directives - VSED Voluntarily Stopping Eating & Drinking

- **Dementia Advance Directives for Oral Foods/Fluids**
 - Stanley Terman, MD. <https://caringadvocates.org/>
 - Dementia Directive and "My Way Cards"
 - End of Life Choices New York: "Advanced Directive for Receiving Oral Foods and Fluids in dementia."
 - End of Life Washington: "My Instructions for Oral Feeding and Drinking"
 - thaddeuspope.com/hasteneddeath/vsed.html

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You Are Mrs. B's Decision Maker

(You haven't seen or talked to her in years.)

What Will You Choose?

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Chemotherapy or Hospice

- Her advance directive says, “Yes to having CPR.”
- She doesn’t need CPR. She needs chemotherapy.
- Chemotherapy isn’t addressed in her document.
- Should we treat the cancer? Put her on hospice?

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What If Mrs. B Has No Family or Friends?

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Can’t Use “Emergency Consent” for Chemotherapy

- Emergent vs. Urgent vs. Important
- Emergency = Loss of life or limb – *It is not necessary to secure a court order in an emergency case in which health care is required for the alleviation of severe pain or the patient’s condition, if not immediately diagnosed and treated will lead to serious disability or death. (Cal. Probate Code)*

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**Can We Achieve Mrs. B's
Meaningful/Worthwhile Goals?**

What About Her Suffering?
*What will it feel like and be like for
Mrs. B to experience this decision?*

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Will _____ Be Futile?

- Don't use "futile" – Use **Medically Ineffective, Medically Non-beneficial, or Medically Inappropriate** (Probate codes in your state?)
- 1. *Will _____ Treatment Work? (physiologically)*
Physician determines what are valid medical options to offer.
- 2. *Will _____ Achieve a Worthwhile Goal?*
Quality-of-life goal is determined by the patient or the decision maker using the patient's values.

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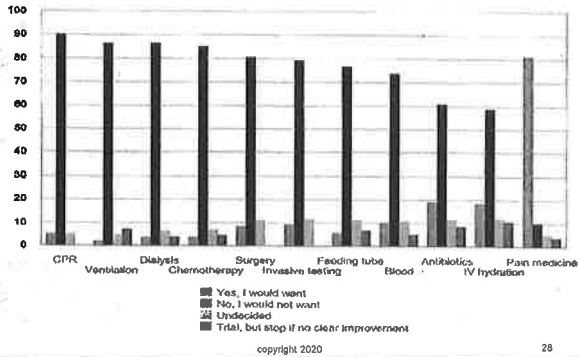


**Will CPR Work? Is CPR
Worthwhile for This Patient?**

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How Doctors Die – Dr. Ken Murray



End-of-Life Videos

- Link to excellent research article: <https://dash.harvard.edu/handle/1/4662006>
- Link to end-of-life videos: <https://www.acpdecisions.org/products/videos/>
- Article about videos being used in Hawaii: <http://www.npr.org/sections/health-shots/2015/03/29/394087394/videos-on-end-of-life-choices-ease-tough-conversation>

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CPR vs. DNAR/AND Decision

- What do you know about CPR?
 - Chest compressions, medication, defibrillator, intubation, ventilation
- CPR does not work like on television
 - On TV, it works 75% of the time
 - Overall CPR survival is 15-17%
 - 1% of people with late stages of cancer live after CPR
 - 5% of people who are in a nursing home live after CPR, even if they have CPR in a hospital
 - 2% of people with dementia live after CPR

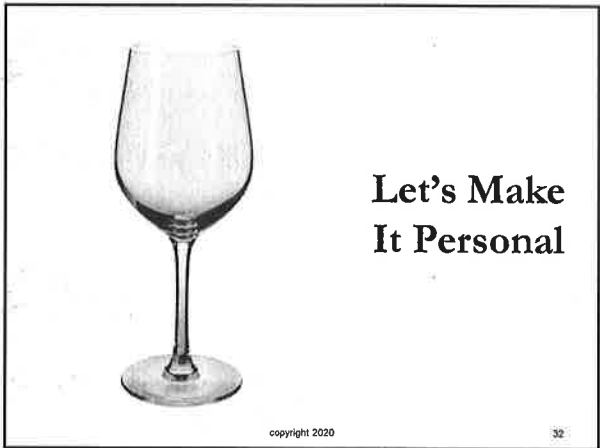
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- You may come back to life in a worse condition both mentally and physically. (CoalitionCCC.org)
 - 50% will have brain damage that never gets better
 - 97% will have rib fractures
 - 43% will have breastbone fractures
 - 59% will have bruising to the chest
 - 30% will get burns on the skin from shocks
 - Bleeding in chest; damage to trachea, esophagus and/or abdominal organs; lung damage; and damage to lips and teeth
- Dying during CPR – It may not be how you imagined the last minutes of your life

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- ### Alzheimer's and Feeding Tubes
- Best option before final stage: Assisted oral feedings to provide nutrition and human touch and contact (takes more time but better for person)
 - Patients live equally as long with hand feeding vs. feeding tubes
 - Social interaction of hand feeding creates higher quality of life
 - CaPOLST.org – two types of informational flyers about feeding tubes – high and low literacy
 - Alzheimer's Association statement on Feeding Tubes

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- Final stage of Alzheimer's: Unable to swallow even with assistance or have lost all interest in eating and drinking
- Feeding tube DOES NOT:
 - Improve nutritional status
 - Prevent or lower incidence of pneumonia
 - Reduce skin breakdown
 - Increase longevity

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- Feeding tubes DO:
 - Increase diarrhea and related discomfort
 - Increase use of physical restraints
 - Increase chance of agitation and discomfort
- 12% will have diarrhea or cramping
- 10% will have nausea or vomiting
- 4% will have leaking of the tube
- 1% to 4% will have infections of the skin
- 1% will have bleeding

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What Does it Feel Like to Live With A Feeding Tube?

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Katie Lunsford Age 25

**Endometriosis, fibromyalgia, and
now chronic pancreatitis**

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“I completely underestimated how difficult it would be to adjust with getting all my nutrition through a tube. I struggled with the reality that there was a tube sticking out of me. I felt deformed, I felt weird, I felt like something other than myself. I struggled daily with getting enough calories into my body. It hurt at first and it was uncomfortable to pump formula into my intestines. I would wake up sick in the middle of the night because I wasn't on the right formula. I dealt with clogs, pain and some infections from the new hole in my body. At times, I didn't know how I could get through the week. What was I doing? How did I get to this point? My body was failing me and I had no control over it. I felt lost, but luckily I made it through the rough patches.”

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“I'm slowly starting to be able to participate in life again. I will start grad school in the fall and hopefully pick up a part time job. I'm still me. I'm not broken, I am just different. I'm not going to lie, it is difficult to try to get back in the dating world. If I try to tell a potential date about it, things get awkward. I just like to consider myself as a cheap date because I don't eat at restaurants

I still struggle at times being self-conscious about my tube, getting all my calories, or even struggle at times with avoiding food. But, my tube is beginning to be a new normal for me. I'm a tubie and my tube is letting me get back to life. I feel like myself -- tube and all!”

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Gratitude

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Resources

- **Low Literacy Decision Guides** – Ventilator, CPR, feeding tubes <http://coalitionccc.org/tools-resources/decision-guides>
- **Go Wish Cards** www.gowish.org (English/Spanish)
- **The Cards I've Been Dealt** – *Needs Assessment* cards and *Values and Wishes* www.thecardsivebeendealt.com
- **Thinking Ahead Project** www.coalitionccc.org (English, Spanish, Korean, Chinese)
- **Consider the Conversation 1 and 2** – Documentaries about making the decisions meaningful www.considertheconversation.org
- **Expert in health law** <http://thaddeuspope.com/>

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Some of Viki's Favorite Resources

- **www.KindEthics.com** Resource page for templates
- **Virtual Dementia Kit** https://www.youtube.com/watch?v=LL_Gq7Shc-Y
- **They're My Parents Too** by Francine Russo
- **The Lost Art of Listening – How learning to listen can improve relationships** by Michael P. Nichols Ph.D.
- **How to Say it to Seniors – Closing the communication gap with our elders** by David Solie, MS, PA
- **My Stroke of Insight: A Brain Scientist's Personal Journey** by Dr. Jill Bolte Taylor
- **The Caregiver's Path to Compassionate Decision Making: Making Choices for Those Who Can't** by Viki Kind

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