

Viki's Quality-of-Life Statement

Reminder: Use these Questions for Your Quality-of-Life Statement

- 1. 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? (If you are uncertain how to answer this question, you can skip this question.)*
- 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. 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. (You should ask more questions about these medical treatments and 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?*
- 7. Reassurances for my decision maker(s). Imagine the person who will be making your decisions 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 do 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.*

The following example is my personal quality-of-life statement. It sounds like me and represents my values. When you write yours, it should sound like you and represent your values. In the section before this, I have given you a template you can use to create your own quality-of-life statement. I have attached my completed document to the Advance Directive that works in my state.

Types of illnesses where this advance directive would apply whether I am terminal or not terminal.

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 effect. 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.

What is important to me? What makes my life worth living? [The loss of any of these might be enough for my decision maker(s) to implement my wishes documented in this advance directive.]

- 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/friends—financially, emotionally or physically.
- To have a good death as defined by me (see below).

What conditions would I find horrible to live with long term? What would be a fate worse than death?

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/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. This list of "Conditions I would not want to live with" includes and is not limited to:

- Not recognizing my loved ones. I couldn't bear for my husband, Ed, to visit me in the 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.
- Not being able to communicate by voice, computer, sign language or gestures.
- Wandering around aimlessly.
- Suffering that isn't necessarily pain related.
- Significant pain that can't be controlled, that 1% of intractable, unmanageable pain. (However, for the 99% of pain situations that are manageable, control it and fix it.)
- Significant pain that requires so much medicine that I am sleeping all the time.
- Don't park me in a SNF hallway and tell me that this is a good quality of life. It is not. Having to live in a skilled nursing facility or sub-acute facility permanently with my cognitive impairment. Nursing homes create such a sadness in me every time I visit or have stayed overnight with a loved one. I am too empathetic and take in people's suffering too easily to be in that environment. It would destroy me long term. I would rather die. A short-term stay in a SNF/ rehab/sub-acute is okay, if I can recover to a life that I would consider worth living. (I understand that with certain types of traumatic brain injuries, it may take a longer period of time to evaluate

whether recovery is possible or not.) But if it looks like I am not recovering, then no thank you.

What would be an acceptable level of better? I wouldn't like it but I would be willing to live with _____.

I could accept being in a wheelchair or on a ventilator, as long as I have my cognitive abilities. The reason I could tolerate a bad physical condition is because I could still be able to make a difference by talking and laughing with my family and friends, writing articles and supporting others in need. But once my cognitive abilities are damaged to a certain level, then there is no acceptable level of better.

Okay, now the CPR, ventilator and feeding tube conversation.

My overall guideline is that if CPR, ventilator support or a feeding tube can return me to what I would consider to be a meaningful existence (what is important to me), then please give me CPR, ventilator support and/or a feeding tube. But there has to be value in these medical options and any other medical treatment choices that are being considered. Don't do things, including and not limited to, antibiotics, etc., that are just to sustain my poor condition. (It would be qualitatively futile to do treatments that can't achieve my personal goals.)

I am not opposed to living with a feeding tube, if it gives me many years of being able to enjoy what is important to me. But if the feeding tube is just to sustain my miserable condition (what I would consider horrible), then don't put it in or give me feedings through it; and please take the feeding tube out if it is already in. (Okay, if I am on hospice and the feeding tube gives you access for administering the pain and suffering meds I need, then you can leave it in. But don't put food or additional liquids in it.) The feeding tube, like all medical decisions, needs to create value in my life, not just sustain my life.

If I am still healthy and can still experience lots of the things that are important to me, then give me CPR. But as my health declines and CPR becomes less statistically successful, then make me a DNR. Just like many doctors and nurses, I don't want to die by CPR. I want to die peacefully

without life-prolonging medical interventions. [Doctor, please ask yourself the surprise question: Would I be surprised if Viki died during this hospitalization or died in the next 6 months? If the answer is "No, I wouldn't be surprised," then talk to my decision maker(s) about end-of-life choices, including putting me on hospice.]

Reassurances for my decision maker(s)

You are allowed to make the best decisions you can based on the circumstances and what you know at the time. You do not need to know for certain or absolutely that you have all the answers. The decision doesn't have to be perfect. Use your heart and your head.

I trust you to do the best you can. (Ed, you don't have to go into super-perfectionist mode.)

I believe love does not obligate a person to sacrifice themselves to be the caregiver for another. The damage done to the caregiver, emotionally, physically and mentally is too costly. I do not expect someone to give up their mental, emotional and physical health for me. Look at the MetLife studies. Caregiving sucks. And I love my decision makers and alternates too much to impose such a burden on them. (Ed, if you need some time to make peace with what has happened, then you can take the time you need. I don't want the decision to feel rushed or uninformed, which would cause you a lifetime of regret.)

For you doctor, your role is to give my decision maker(s) as much information as you can so he/she can make an informed decision. I encourage you to share your wisdom, guidance and experience but ultimately, it is my decision as expressed through my decision maker(s) and this document. Remember, this document is an act of autonomy and should not be ignored by my decision maker(s), other family members, doctors or worst case, the courts. (I will definitely come back and haunt a judge who isn't respecting my wishes.)

Writhing in pain is not acceptable. My husband, Ed, who is an inpatient pharmacist, explained the nuances of pain control so I could explain it to you. I realize it may take a little while to find the appropriate med and dose to alleviate my pain. When initiating or adjusting my pain meds, pain levels

more than 6 are acceptable for 4 hours. But any pain above 6 for more than 4 hours is unacceptable. My caregivers and decision makers will help you monitor and keep abreast of my levels and management, as I would expect them to.

What is a good death in my opinion?

I would prefer to die at home but I realize that sometimes, a person needs to die somewhere else so I accept that. I would like to have my family/friends with me which includes and is limited to those I interact with on a regular basis.

Because I like control over my life, I would like to be able to clean up my desk and to get my financial information updated. I would like to be able to write love letters, record messages and to say my goodbyes. I have also written down and attached my Go Wish Card's answers. (The Go Wish Cards are another way to further document your end-of-life preferences. GoWish.org)

I would like to die with reasonable pain control. For the days leading up to my death, I would be willing to tolerate a small amount of pain if that allowed me to have meaningful time with family/friends. But at the end, there had better be no pain and definitely, no air hunger. (So don't put me on a ventilator; instead manage my air hunger with medications.)

And you better not be force feeding me by mouth, by IV or by tube as that would increase my suffering. (And that includes you at the skilled nursing facility, sub-acute facility or other care community if I happen to be dying there. I know you have your regulations but I also know you can't assault someone with food if the person has said, "No," when the patient had capacity.) That's it for now.

Viki Kind _____ Date: May 2018