

## **Viki's Quality-of-Life Statement**

The goal of writing a quality-of-life (QOL) statement is to have it express your personal preferences and to have it sound like you. The problem with most of the legal/medical forms is that they all sound alike and they don't allow your voice to be heard. I encourage you to use the questions I have listed below to express what you would want people to know about you if you were too sick to speak for yourself. You can use some of my language from my document below if you would like but my goal is for you to make it personal and meaningful to you. You will know you have gotten it right when people read it and say, "Yes, this sounds like what he/she would say." By explaining what is important to you and making it very personal, you will help your doctors and family/friends feel more confident that they are truly honoring your wishes.

### **Sections of QOL Statement to Include in Your Advance Directive/Living Will:**

- Types of illnesses where this advance directive would apply.
- What is important to me? What makes my life worth living?
- What conditions would I find horrible to live with long term? What would be a fate worse than death?
- What would be an acceptable level of better? I wouldn't like it, but I would be willing to live with \_\_\_\_\_.
- What would be important to me as I die? What is a good death in my opinion?
- My preferences regarding CPR, being on a ventilator and/or feeding tubes.
- Reassurances for my decision maker(s).
- What do I want the doctors to know about honoring my religious/cultural beliefs both while I am sick and/or dying?
- 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, yours should sound like you and represent your values. [I would encourage you to do what I did. I attached my quality-of-life statement to an advance healthcare directive (living will) from 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 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.

## **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 not 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, they 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 not 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, 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. But any pain above 6 for more than 4 hours is unacceptable. When initiating or adjusting my pain meds, pain levels more than 6 are acceptable for 4 hours. 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 done my Go Wish Cards. (See attachment)

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. (That doesn't mean ventilator support; it means 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: January 19, 2014

## **Guidance for My Decision Maker(s)**

### **I have picked you because ...**

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### **What I will need you to do for me:**

- Go to the hospital to see me with your own eyes. If you can't get there, ask the hospital to use a webcam or skype so you can see how I am doing. Or text a cell phone picture daily. If that isn't possible, make sure you call and talk to the doctor, nurse or social worker every day to find out how I am doing.
  - Give the doctor, nurse or social worker a copy of my advance healthcare directive, durable power of attorney for healthcare and any other healthcare documents I have given to you in this packet of information.
  - Tell the doctor, nurse or social worker the names of my regular doctors and the hospital that I usually go to when I am sick.
  - Ask the doctors for information about my disease/injury, treatment options and what the consequences of each option would be.
  - Ask lots of questions until you know enough to make a good decision. You can use the list of *Questions to Ask When Making Medical Decisions* I have included in your packet, on pages 29-35.
  - I know that this may be a really stressful time for you. I encourage you to use the *Crisis Worksheet*, on pages 7-14, that is also part of the packet of information I have given you.
  - Other things I will need you to do for me while I am sick: (Feel free to add more pages to this list.)
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### **Please use Substituted Judgment when making the decisions for me.**

Substituted Judgment means you are supposed to ask yourself, "What would \_\_\_\_\_ be telling us if he or she were able to speak

*right now?"* And then tell the doctor what I would be saying if I could. Begin by thinking about everything you know about me.

–What are my values, religion and culture?

–What have I said to you in the past about my health?

–What would I say is important for you to consider when thinking about this decision?

*If you aren't sure or don't know, then now is the time to have this conversation with me, while I can still talk to you.*

Another way you can think about these decisions is to ask yourself:

What will the benefits be from choosing this option?

What will the possible risks and side effects that may come from choosing this option?

What will it *feel like* and *be like* for \_\_\_\_\_ to experience this decision?

Will there be any suffering?

What can the doctor do to help make it easier for \_\_\_\_\_ to go through these treatments?

What kind of condition will \_\_\_\_\_ be in months from now?

Would that be a condition that \_\_\_\_\_ would want?

**Reassurances for my decision maker(s):**

I know it may be difficult for you to make these medical and end-of-life decisions for me. But I want you to know that ...

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***If you do not think you will be able to do what I have asked, please let me know now so I can choose someone else who would be willing to be my decision maker.***

**Print and Sign:** \_\_\_\_\_

**Date:** \_\_\_\_\_