

Stroke and Dementia: Nemeses of a Good Death

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When I speak around the country I get more questions on stroke and dementia than on terminal illnesses. These conditions are particularly frightening because of the fear of loss of personhood and choice; we worry that we will no longer be able to do the things we value that allow us to be in control and independent. Especially vivid is our concern that we no longer will be mentally or physically able to end our lives when we feel the quality has irreparably and unacceptably diminished. These disorders, rather than resulting in death, leave us where we could linger indefinitely in a state where we need 24 hour care, are limited in our communications, and will only get worse.

The two disorders are quite different in that dementia usually occurs gradually thus, in some cases, providing a chance to make preparations. Stroke often occurs suddenly although there are often warning signs such as Transient Ischemic Attacks (TIAs) or small strokes that may occur before a large stroke. Also, dementia is essentially unpreventable and treatments serve only to delay the symptoms and are not cures. In stroke there are known antecedents like high blood pressure which can be treated. After a stroke there are treatments available, especially in the area of physical therapy and rehabilitation, which can restore functioning. Kirk Douglas is an example of a person who experienced almost complete recovery from a severe stroke.

Here I want to talk about five things you can keep in mind, and discuss with your loved ones, your doctor, and the person(s) you designate as your health care proxy(s) should you want to hasten dying in these situations:

1. Refusing food and hydration. You should let your loved ones know that you may choose this option if you fear a life of debilitation and helplessness caused by a stroke or dementia. Even patients with severe Alzheimer's have sometimes been able to stop taking food and fluids and have died peacefully. In advance, caregivers should know that if there is no hope for your recovery and you are going downhill you may not choose to eat and drink and you do not want to be force fed, enticed to eat, or have any tubes inserted to provide artificial food or hydration. You want them to know that if you take this route you want to be made as comfortable as possible, that you want hospice to help you with the process, and you want adequate nursing and medical care so that your symptoms will be treated while this is happening. You do not want to be hospitalized and, if you are in a nursing home, you want your proxy to have this information on file to ensure that the nursing home is not liable for elder abuse or any kind of mistreatment if they don't force feed you. In most cases death will occur relatively peacefully in 5 to 21 days, depending on your physical condition.
2. Terminal sedation. Under the same circumstances you should let it be known that you would want to be rendered unconscious and not fed or given fluids while in you are in coma.. Some doctors are doing this for severe, intractable stroke. If

you have any indications that you may be in this situation you should discuss this with your neurologist and indicate that you would want this done, or find a doctor willing to do it. With terminal sedation (or total or palliative sedation) your suffering will be relieved by a pharmacologically induced coma. Death is foreseeable and will be a result of the underlying disease, dehydration, or the large amount of medication necessary to maintain the coma. It is acceptable ethically since the intent is to relieve pain and/or suffering. Again, your health care proxy may have to be your strong advocate so it is important that s/he know that would be your wish.

3. Preemptive action. Either through the use of the methods described in *Final Exit* or through our Caring Friends program, a person could plan to hasten their dying if they knew that severe debilitation and unacceptable suffering were to inevitably follow given their present condition. This means that it needs to be done while one still can, though one might not be ready to die since it is not legal for someone to help. This is what happens even with the Oregon law, and it is what Janet Adkins did when she sought help to die from Jack Kevorkian when she felt that her Alzheimer's disease would get too advanced for her to take any action. This would be done by the ingestion of medication, if it were available, or the use of the helium method – both are detailed in *Final Exit*.
4. Advance directive. There is a document, *My Last Wishes*, that describes some of these situations and, though not completely legal, is a way of discussing what your wishes might be with those who care about you. When your wishes are not discussed loved ones often feel compelled – out of love and/or guilt – to do everything to perpetuate life. This document requests help in dying if you cannot do such things as recognize the people you love, or are in a situation where you need 24 hour care and have little cognitive functioning. Of course, that is not yet a legal option but it may prevent a prolonged dying process.
5. Specify wishes. These are the things you might want to make sure you specify if you are unacceptably and irreparably mentally or physically impaired and in a progressive and declining situation:

- No breathing machine
- No artificial food or hydration
- No dialysis
- No antibiotics
- No hospitalization
- No cardiopulmonary resuscitation
- No invasive diagnostic procedures
- As much medication as possible to ensure comfort
- Hospice care
- Allow natural death
- Terminal sedation

Failing to make the transition from life-sustaining and curative care to comfort care can result in disastrous consequences for the patient and the family. This is discussed in Dr. Sidney Wanzer's excellent book, *The End of Life: How to Deal with the System*. The most important thing is to talk about your wishes with everyone involved before these situations arise. We also have a *Do Not Consent Card* that can be hung on a door or over the bed to make sure your wishes are known.