

Roger H. Strube, M.D. (retired)

## GOOD LIFE – GOOD DEATH

The Baby Boomers are turning sixty five and will swell the ranks of those covered by Medicare. This is the generation for which the possibilities were limitless. We embraced Winston Churchill's statement, "...we shall never surrender!" Most of us lived the American Dream while the middle class flourished. Most of us lived the good life...or at least the adequate life.

We grew up with the philosophy not to trust anyone over thirty. Then we turned thirty. Many of us obsessed with the culture of youth, developed delusions and ego defense mechanisms to suppress our anxiety about aging. Forty became the "new thirty." Fifty became the "new forty." Seventy is becoming the "new Fifty."

The evidence of America's obsession with the vain attempt to hold on to youth is all around us. Billions of dollars are spent on advertising youth restoring snake oil to what is now the tsunami of Baby Boomers. Many more billions are spent purchasing this snake oil and chasing the myth of perpetual youth. The art of growing old gracefully seems to be lost.

I don't want this to sound like an [Andy Rooney](#) rant, as I believe an individual should be concerned with health, wellness and prevention. We should do what we can to make each day we have on this mortal coil as pleasant and enjoyable for ourselves and all those around us. However, our obsession with youth has become pathological and counterproductive. Our focus on living in the moment while obsessed with youth provides instantaneous gratification and is not, in itself, destructive as long as we have prepared for the future.

There are two important futures for which we all need to prepare. I have observed the majority of Americans have prepared poorly for one and remain in a state of denial of the other. These futures are both end of life realities. Unless you are among the unfortunate who die young or early, neither can be avoided.

The first is retirement. Retirement is the art of living the "Good Life" after your full time working career ends. Unless we die or become disabled prematurely, most of us will retire at about the age of 65. Retirement is a lot like dying for some folks. They may be leaving their only interest in life behind. For others, retirement may be a transition to a better, more enjoyable life.

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Retirement can be like reincarnation to a different life. With some preparation, this reincarnation can be much better. The good life after retirement can be very fulfilling for the person and trouble free for relatives and friends. No news is good news. Without preparation, it can be much worse. The individual may become a burden to relatives and society and a pariah to old friends.

For whatever reason or whatever age retirement comes, a great deal of long term planning should precede the milestone. Some of us planned well ahead for this reality. Most did not. By preparing physically, emotionally and financially, retirement can be a real joy. I retired at 57 years old. Kathy and I moved aboard our cruising catamaran and sailed the islands for several years. These adventures are on my personal web site: [www.wingsailor.com](http://www.wingsailor.com)

This level of activity and comfort in retirement is not possible if your life is overspent in the moment, hoping to live on Social Security “assistance” when you are too old or disabled to work. Aesop’s fable of [The Ant and the Grasshopper](#) seems directly applicable.

The second, and equally important future is the “Good Death.” The vast majority of Americans live in a state of denial regarding this absolute and final reality. We joke about it. “The only sure things in life are death and taxes.” Some hope for the end to be quick and without awareness. Many do not prepare for the end.

### Advance Directive

Everyone should make reasoned decisions about their health care while they are rational. People of driving age may check the “donor” box on their license application so they may give the gift of life to someone if they die suddenly. This is a type of instruction about what should be done with your body in advance of your death. The term *advance directive* describes two types of legal documents that enable you to plan for and make known your end-of-life wishes in the event that you are unable to communicate. For example, if you suffer a major global head injury or stroke and suffer [brain death](#) or fall into a [persistent vegetative state](#), your family and care givers might have to continue extraordinary means of life support if you have not communicated your wishes. By executing a [living will](#) and [medical power of attorney](#) the power to terminate artificial life support is given to the close

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relative or other person of your choice. Ideally, these documents should be completed and on file with your physician well before they are needed.

The [Terri Schiavo](#) case was the result of a battle between relatives that could have been avoided if there had been an advanced directive. This was an ongoing seven year battle between her husband and her parents regarding removal of her feeding tube. Common sense prevailed but not without a firestorm between the political right and left.

We have not heard the end of this battle. The then governor of the State of Florida, [Jeb Bush](#), put himself in the middle of the fight. The [Palm Sunday Compromise](#), a political tactic put together by Jeb and congressional Republicans, transferred the case to the federal courts. At the same time the notorious [Schiavo Memo](#) surfaced. This document suggested the Schiavo case offered "a great political issue" that would appeal to the party's [religious base](#). It was felt the issue could be used against Senator [Bill Nelson](#), because he had refused to cosponsor the bill. It didn't work as Senator Nelson was elected with 60% of the vote. But what of the future? Do you think the issue of state and federal interference with very personal family decisions will surface if Jeb decides to run for president in 2012?

It appears Terri Schiavo died very slowly (between 1990 and 2005) for lack of an advanced directive. Fortunately, her prolonged death was painless in her persistent vegetative state. Most deaths are neither quick nor painless. For many folks knowledge of an incurable terminal condition may precede death by months to years. For many of these folks medical science may offer treatments that prolong life while life is worth living. Unfortunately, many physicians continue to prescribe these treatments and patients (or their families) continue to request them after their effectiveness to prolong life or lessen suffering ends. Such care does not accommodate the "Good Death."

The highest American mortality rate seems to be caused by hospital beds. Fewer people die peacefully at home, surrounded by family and friends. More of us expire in hospital "expensive scare" units hooked up to machines with tubes and needles everywhere. For the few, with reasonable hope of recovery, such interventions may be appropriate and a reasonable use of health care resources. For those truly at the end of life, such an exit is not a "good death."

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### The Good Death and Dying with Dignity

My book, *Discovering the Cause and the Cure for America's Health Care Crisis*, contains long passages devoted to this topic. For the healthy individual, [death and dying](#) are existential, but distant realities. As [Andy Rooney](#) said, "Death is a distant rumor to the young." Some keep anxiety about the subject at bay through dark humor. Using humor is a good way to deal with this disturbing ultimate reality until a close friend or relative is found to have a terminal condition. We then either observe, or participate in, the [five stages of grief](#) with the individual.

The five stages are: Denial; Anger; Bargaining; Depression; and, finally, Acceptance. Unless we are among the fortunate few who have a sudden, painless exit, we will have to deal with our own mortality. How well individual negotiates the five stages depends on the individual's ability to perceive reality. Each individual has their own demons that may cause them to stall in one of the stages until the end. The goal should be to get to Acceptance as quickly as our rational minds can carry us there. It is impossible to experience a Good Death, or to Die with Dignity, if you remain fixated in Anger or Depression.

At some point standard medical care fails to defeat or mitigate a potentially deadly or incurable disease. The Good Death and Dying with Dignity require us to make hard choices. Those folks psychologically unable to work through the five stages of grief may choose to fight on with ineffective standard therapies, hoping for a miracle. The individual or their families may insist on continuation of extraordinary means of life support beyond a reasonable expectation of improvement or recovery. This decision is between the patient, the family and the physician. The government and insurance companies may facilitate decision making but the final determination must be made by the patient and family. Frequently, because some or all these folks remain in Denial, Anger or Bargaining, a decision supporting a Good Death is not made.

Being fixated at Bargaining may lead to the suggestion of experimental therapy. Providing experimental therapy is ethical, provided the patient is given the information facilitating "Informed Consent." The information must include all the medical and financial information necessary to make a proper decision to submit to human experimentation.

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Health care financing (insurance) companies, including publicly funded Medicare and Medicaid private claims processors, have contractual exclusions for experimental medical care. Insurance companies do not fund medical research through claims adjudication. The definition of “experimental care,” who makes this determination, and the rationale for denying benefit payment is presented in detail in my book.

For those patient, families and physicians who have worked through the five stages and reached Acceptance, support is available. Virtually every community has hospice services available to those who qualify. All insurance companies, including Medicare and Medicaid cover hospice benefits. You will need to read your insurance documents to get the specific details, including the qualifying criteria, for your health care plan. Many modern health plans allow continuation of the terminal disease specific therapy while hospice benefits are in place.

The [American Society of Clinical Oncology](#) web site has publications available to help patients and their families through this difficult time. Many folks will find [Advanced Cancer Care Planning](#) helpful. [Closure](#) is an organization dedicated to “Raising expectations and empowering the community to want and demand a different health care experience.”

Grass roots organizations that encourage us to take control of our lives, especially concerning final arrangements in preparation for our death, are springing up across the country.

### Hospice

Hospice provides additional medical goods and social services that are not part of traditional health care insurance policies. Over the counter (OTC) medications and disposable supplies may be part of the program. Assistance with activities of daily living may be covered. Hospice is designed to provide comfort and support to those choosing the “Good Death.”

Accessing Hospice benefits requires that the patient meet several qualifying criteria. Perhaps the most important and difficult to accept is the expectation of death within six months. The physician must make this critical judgment and communicate it to the patient. Both must agree that this is reality and decide

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hospice is the most appropriate care. The insurance or HMO carrier is notified of the patient and physician decision and the benefit starts.

For some terminal illnesses, the choice of Hospice or early [Palliative Care](#) will result in a longer survival, with less anxiety and less pain, than aggressive therapy for a terminal illness. The August 19, 2010 article in the New England Journal of Medicine documents this fact for metastatic non-small-cell lung cancer:

<http://www.nejm.org/doi/full/10.1056/NEJMoa1000678>

There are several other loose ends that need to be tied up at the beginning of hospice care. The acceptance of the Good Death directly effects the decisions regarding medical care during the final months of life. Treatment of unrelated injury or illness is not withheld. Standard health care continues. However, if the patient takes a sudden turn for the worse, suffering an immediate life threatening medical problem, directives regarding management must be in place. These "Advance Directive" instructions are the request of the patient that the physician withhold extraordinary means to support life. At one point we called these, "Do Not Resuscitate Orders." They also direct artificial means of life support is discontinued should the patient's medical condition deteriorate beyond a reasonable expectation for recovery.

There are many ethical nonprofit organizations managing the delivery of hospice benefits. They are supported by direct claims payment and donations from individuals and family trusts. If you are an HMO member or Medicare Advantage enrollee, the hospice organizations in your network provider directory will have been vetted and credentialed. The [Robert Wood Johnson Foundation](#) provides grants to organizations determined to be the best of the best and the most deserving.

### The Robert Wood Johnson Foundation

The Robert Wood Johnson Foundation is a reliable, unbiased source of information about the American Medical-Industrial Complex. They publish unbiased position papers on major health care issues of our time. Information published by RWJF is well researched and accurate. Positions taken by RWJF are not influenced by politics or profit.

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The Robert Wood Johnson Foundation provides grants to organizations that study health issues, health care quality and health care delivery. Grant requests undergo a thorough vetting process. RWJF evaluates the management operations and quality of health care delivered by organizations it funds. You may trust such organizations to deliver quality, ethical health care goods and services.

The RWJF Mission Statement:

The mission of the Robert Wood Johnson Foundation is to improve the health and health care of all Americans. Our goal is clear: To help Americans lead healthier lives and get the care they need.

<http://www.rwjf.org/>

The following organization received a grant from the  
Robert Wood Johnson Foundation:

The National Hospice and Palliative Care Organization

<http://www.nhpco.org/templates/1/homepage.cfm>

ADVANCE DIRECTIVE  
Download State Forms

<http://www.caringinfo.org/stateaddownload>

OTHER HOSPICE FOUNDATIONS AND ORGANIZATIONS  
(May not be funded by RWJF)

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The Hospice Foundation of America

<http://www.hospicefoundation.org/>

The American Hospice Foundation

<http://www.americanhospice.org/>

Compassion and Choices  
(The Hemlock Society)

History: [http://en.wikipedia.org/wiki/Hemlock\\_Society](http://en.wikipedia.org/wiki/Hemlock_Society)

This right to die organization promotes information about end of life decisions and the value of Advance Directives. Their web sites provide free down loads of the necessary documents to assure your final decisions are known.

<http://www.compassionandchoices.org/hemlock>

<http://www.hemlockflorida.org/index.htm>

The World Right to Die Society

<http://www.worldrtd.net/news>

The American Society of Clinical Oncology

The web site for the [American Society of Clinical Oncology](#) (cancer treatment specialists) offers oncologist approved information and publications about cancer and your choices of therapy. One of their very helpful documents, [Advanced Cancer Care Planning](#), offers sound advice to patients and their families. They also suggest resources for folks faced with end of life decisions:

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American Cancer Society - [www.cancer.org](http://www.cancer.org) - 800-227-2345

American Hospice Foundation - [www.americanhospice.org](http://www.americanhospice.org) - 800-347-1413

CancerCare - [www.cancer.org](http://www.cancer.org) - 800-813-4673

Caring Connections from the National Hospice and Palliative Care Organization  
[www.caringinfo.org](http://www.caringinfo.org) - 800-658-8898 / 877-658-8896 (*multilingual line*)

Center to Advance Palliative Care - [www.GetPalliativeCare.org](http://www.GetPalliativeCare.org) - 212-201-2670

International Association for Hospice and Palliative Care (IAHPC)  
[www.hospicecare.com](http://www.hospicecare.com) - 866-374-2472

Jack and Jill Late Stage Cancer Foundation - <http://jajf.org/home/> - 404-537-5253

Medicare - [www.medicare.gov](http://www.medicare.gov) - 800-633-4227

National Association for Home Care - [www.nahc.org](http://www.nahc.org) - 202-547-7424

National Cancer Institute - [www.cancer.gov](http://www.cancer.gov) - 800-422-6237

National Family Caregivers Association - [www.nfcares.org](http://www.nfcares.org) - 800-896-3650

### Final Exit Network

Some folks take believe they should be in control of their final exit or death. A group of these individuals have organized a not-for-profit, 501c3 organization called the "Final Exit Network." This organization was formed to provide information to people of sound mind suffering intolerable disability or pain from terminal illness. Although many members of this group are advocates of assisted suicide, they do not recommend anyone choose to end their life. They do believe this choice is a right and the decision must be based on the individual's moral and religious beliefs. Neither the organization, nor its members provide any direct recommendations or material assistance to the mentally competent individual choosing to end their suffering.

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More information about the Final Exit Network may be found on the following web sites:

<http://www.youtube.com/watch?v=z1evoiPMHA>

[http://en.wikipedia.org/wiki/Final\\_Exit\\_Network](http://en.wikipedia.org/wiki/Final_Exit_Network)

<http://www.finalexitnetwork.org/>

### Cremation Services

You have come this far. Consider going all the way. Determine what should be done with your body when (not if) you die. Take the burden of what to do off your children's or other relative's shoulders. My preference for final funeral arrangements is cremation. Ever since I learned about [continental drift](#) and [plate tectonics](#), I realized everybody buried in North America will ultimately be cremated as our North American Plate is recycled into the Earth's core. It may take a couple of hundred million years but time has no meaning to the dead. Why wait? The most efficient and least costly final arrangement is cremation. We have purchased the services of the Neptune Society. Their web site follows:

<http://www.neptunesociety.com/>

For a few dollars more, this organization will cast your ashes into cement forms that become part of the underwater Neptune Memorial Reef off the eastern shore of Key Biscayne, Florida. Relatives visit this reef by boat or snorkel charter.

<http://www.nmreef.com/>

I want my ashes spread on the waters of Boca Grande at the mouth of Charlotte Harbor on an outgoing tide at sunset. My wife, Kathy, wants to have her ashes spread in my daughter's garden. In reality, our son and daughter can do anything they determine is best. Once we are gone, it matters little.

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### Epilogue

All we have in life that is of any real value is time. Spending time wisely may result in a Good Life. Understanding and accepting the cycle of life may allow us to choose to have a Good Death. How much time do you have left? How will you spend the time you have?

My brother-in-law is older than I but continues to work after his initial, official retirement. He works with a group of younger men, all in their 20's and 30's. As Andy Rooney said, "Death is a distant rumor to the young." Most were not preparing financially for retirement, and none give serious thought to end of life issues.

After work one day, as the boys were having a beer, he laid an eight foot tape measure on the floor. An eight foot tape measures 96 inches. He gave each one a pencil. He placed his pencil at seventy two inches. He asked each of the boys to place their pencil at the inch mark representing their age. I would have placed mine at sixty eight inches. As they looked at the tape, he asked them how much time they felt they had left.

Such a demonstration does tend to put a lot of things into perspective. Think about where your pencil would be placed. Have you lived a Good Life? How much time do you think you have left? How will you spend it? Have you prepared financially and emotionally for retirement? When the time comes, are you ready to experience a Good Death?