

**Caring for Persons with Dementia at the End of Life  
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***“...dying is no longer something that happens to you but something you do.”***

*Margaret Pabst-Battin in Physician Assisted Suicide: Safe, Legal, Rare? 1998.<sup>1</sup>*

Knowing how to approach end of life decision-making is difficult enough when a person is cognitively intact. It is even more challenging when a person no longer has decision-making capacity. Spouses, adult children, other family members, friends, conservators, and health care professionals are in the difficult position of discerning “what is the right thing to do” in providing care, especially at the end of life. This workshop and syllabus provide some concepts and frameworks to navigate both the ethical and legal aspects of end of life decision making as well as the care of persons with moderate to severe dementia.

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## **Part I: Aging and End of Life--Dying is no longer something that happens to you but something that you do.**

### ***Demographics of an aging society-The numbers are staggering.***

#### ***American society is graying.<sup>2</sup>***

- In 2003 36 million people age 65 and over lived in the US accounting for 12 percent of the total population
- During the 20<sup>th</sup> century, the older population grew from 3 million to 35 million and is projected to grow to almost 87 million by 2050.
- In 1900, life expectancy at age 65 was almost 12 years, and at age 85 it was 4 years. By 2001 life expectancy at age 65 had increased to more than 19 years for women and about 16 years for men. At age 85 it was 7 years for women and 6 years for men.
- The fastest growing cohort over the last decade had been 85 and older.

#### ***Alzheimer's disease becomes clinically symptomatic with age.<sup>3</sup>***

- The incidence of Alzheimer's disease doubles every 5 years after age 65. By age 85 approximately 30 to 50% of persons have mild, moderate or severe Alzheimer's disease.
- There are currently 5.1 million Americans diagnosed and living with Alzheimer's disease. By 2030 this number is expected to grow to 16 million.
  - Age 65-74: 2 percent 300,000 people
  - Age 75-84: 19 percent 2,400,000 people
  - Age 85+: 42 percent 2,200,000 people

#### ***The direct costs for care and the unpaid caregiver costs are enormous and complex.***

- There were 186,614 relatives and friends who provided unpaid care to Minnesota Alzheimer's patients in 2005.<sup>4</sup>
  - The number of unpaid hours of care is estimated to be 161 million hours per year.
  - The estimated economic impact is \$1.58 billion dollars.
- Nationally unpaid caregivers provided the nation with an economic asset worth almost \$83 billion in 2005, based on their hours of care.<sup>3</sup>
- The average daily cost for a private room in a nursing home was \$206 in 2006, or \$75,190 a year.
- The average monthly cost for a private, one-bedroom unit in an assisted living facility was \$2,968, or \$35,616 a year in 2006. (Assisted living facilities that provide specialized dementia care often charge additional fees ranging from \$750 to \$2,200 monthly for that care.)
- An estimated 70 percent of all nursing home residents have some degree of cognitive impairment. About 47 percent of nursing home residents have a diagnosis of Alzheimer's or another dementia in their medical record.
- The health of the patient's family caregiver is put at risk, especially for elderly patients and their spouses.

*Cause of Death and Patterns of Dying in America*

**Dying Past and Present<sup>5</sup>**

<b>Causes of Death Comparison</b>				
<b>Rank</b>	<b>Cause of Death in 1900</b>	<b>Percentage</b>	<b>Cause of death 1994</b>	<b>Percentage</b>
<b>1</b>	Influenza, pneumonia	11.8%	Heart disease	25.7%
<b>2</b>	Tuberculosis	11.3%	Cancer	20%
<b>3</b>	Gastritis, Enteritis	8.8%	Strokes	6%
<b>4</b>	Heart disease	8.0%	Chronic Pulmonary Obstructive Disease	4.5%
<b>5</b>	Strokes	6.2%	Accidents/trauma	3.4%
	All others		All others	

Sources: [Lerner](#) M. When, why and where people die. IN: E. Sneiderman, ed. Death, Current Perspectives. 1976, Mayfield: Palo Alto.  
Deaths: Preliminary Data for 2000, vol. 49. 2001, National Center for Health Statistics.

***Causes of Death and Patterns of Dying***

Less than 10% of persons die a sudden death from illnesses such as a heart attack or an accident. The vast majority of Americans now die from a chronic illness. Typical of cancer deaths is a steady decline and a short terminal phase. For some cancer patients the illness can last years, e.g. breast cancer. For other chronic illnesses the pattern of decline is slow with periodic crises, emergency room visits, hospitalizations and then sudden death. This is true of heart disease, chronic obstructive lung disease and dementia. The significance of the causes of death is that most of us will know how we will die and will have many choices along the journey to influence the pattern of living with and dying from that illness.

***Advances in life sustaining and life prolonging medical technologies***

The discovery of penicillin and the ability to manufacture it large quantities over 50 years ago marked the shift from dying as something that happens to you to a treatment option requiring a personal choice. The rapid growth of medical technology ushered in an era of choices beyond antibiotics for the treatment of bacterial infections to the treatment of viral infections, chronic illnesses

and organ failure through the administration of new drugs, the development of innovative surgeries, and advances in life sustaining technologies, and organ transplantation. Concurrently with the ability to extend life and postpone dying there have been unfortunate examples of technology used for unintended purposes. Most life sustaining treatments were originally intended as bridging treatments that would allow individuals who suffered from a sudden injury or illness to recover and be weaned from the technology.

Unfortunately, in some situations life sustaining treatments have continued for an indefinite period of time prolonging individual suffering and extending unnecessarily the dying process. The wisdom of when and with whom as well as when not to use life sustaining and prolonging medical technologies has had difficulty in keeping pace with the increasing number and variability of options. A number of high profile Supreme Court constitutional law cases and contributions from bioethics over the past several decades are beginning to provide resources for patients, families and professionals to make better choices regarding when and with whom to use life sustaining and life prolonging treatments. The centerpiece of this literature has been “respecting persons”, individual autonomy and self-regarding choices.

### ***Self-regarding choices at the end of life***

The societal debate regarding what choices, control and assistance an individual should have regarding the timing, place and manner of one’s dying, although, not new or recent, has reemerged and intensified in the past 60 years due to the advances in medical technology and the graying of societies world-wide. In Greek society Plato, Aristotle, and Hippocrates all weighed in on this issue. The Stoics advocated dying on one’s own terms consistent with living on one’s own terms whereas Hippocrates and the Pythagoreans were opposed to what they considered the cult of suicide.<sup>6</sup> The more recent US national debate, sparked by the Supreme Court decisions in the 1990s and the legalization and implementation of physician-assisted suicide in Oregon in 1997, will continue well on through the 21<sup>st</sup> century due to what has been described as the tsunami of 76 million baby boomers who begin turning 65 in 2011. The changing demographics of American society and the advances in medical technology will present major financial, psychological, moral and political issues to be addressed.

### ***The near term future—an epidemic of acting on behalf of and choosing for others.***

These numbers suggest that individuals, families, health care professionals, and policy makers will have steep learning curves on what is possible and what is desirable as individuals age, live longer with illness and face end of life choices. Person with dementia present unique challenges as they become ill as they cannot fully participate in decisions or make their wishes known as the illness unfolds. This workshop will present some concepts and approaches that may be useful in navigating the medical and care giving arenas as well as developing a person-centered authoring of the last act of one’s life.

**Part II: Case I: A face in the wall--Illness, Worlds and World Reconstruction**

*When called upon to do something a person can't do, a person will do what they can, if they do anything at all*

Pete Ossorio, *The Behavior of Persons*<sup>7</sup>

As I was walking up the stair,  
I met a man who was not there.  
He was not there again today.  
Oh, how I wish he'd go away.

Pauline Boss, *Ambiguous Loss*<sup>8</sup>

*I feel abandoned by a health care system that commits resources and rewards to rescuing the injured and ill but then consigns such patients and their families to the black of hole of chronic custodial care.*

Carol Levine, *The loneliness of the long term care giver*<sup>9</sup>

**Persons develop concepts** from the earliest years of infancy throughout life. Concepts are the tools that distinguish various ways that an individual's world can be one way or another. As you view this slide what do you see and how would act upon what you see?



*Write down what you see. It can be more than one thing.*

**If you didn't have a concept** of an animal, map, or face you couldn't see it. This seems obvious. However, for most individuals, families, and even professional end of life concepts are not explored, understood and in most instances are avoided in day to day living. The Terry Schiavo case served as a reminder of the expansion of end of life options due to modern technology that can run amok. Much of this workshop will explore clinical, legal and ethical concepts regarding end of life.

**Faces don't ordinarily appear** in walls. Imagine for a moment that you see a face appearing in a wall. Other facts about the experience include you have not been drinking, there are no hidden plasma screens, or rear projectors, and everyone else can also see the face in the wall. It is not a delusion.

How would a face in the wall experience affect you?  
How would you react?  
How would such an experience change the way you experience the world, how you would think about your world? What actions might you take?

***Thinking the unthinkable—“You have cancer and only six months to live.”<sup>10</sup>***

**Consider how a person would react** when a physician says to a patient, “You have cancer and only six months to live.” That individual’s experience could be likened to a “face in the wall experience” where everything is turned upside down. Hearing such troubling and threatening information leads individuals to experience a whole range of intense emotions from fear, panic, sadness, depression, and anger. Actions taken may range from constructive action to seek information and treatment to avoidance, withdrawal, and self-medication through alcohol and drugs. Similarly, a person’s world is turned upside down when a physician says, “You have Alzheimer’s disease.”

***Persons, worlds, chronic illness and terminal illness***

**The use of the World Concept** in this workshop is a short hand locution to describe the totality of one’s experience. “It is the psychological environment within which one conducts one’s life.”<sup>10</sup> Worlds can be constructed, deconstructed and re-constructed. Illness has a profound impact on a person’s world, experience and possibilities. The illness threatens or impairs a person’s ability to act in the world to which he or she is accustomed; it can paralyze individuals and families or it can bring about strategies to respond to the illness in order to minimize its impact on ways of living. One important strategy is to engage the health care system and health care professionals to respond to the threats represented by the illness and to seek remedies. Alzheimer’s disease and other dementias are particularly cruel in that over time they rob persons of their ability to act and to be actors or players in their own worlds.

**Terminal illness may bring about a crisis** of a different sort—facing the end of any world in which one can act or be a player. A terminal illness is often accompanied by physical, psychological and spiritual suffering for the individual person, his family, friends and colleagues. Dementia is again

somewhat unique in its insidious impact where a social death may occur months or years prior to the actual death.

**Nancy Cruzan Grave Marker**

Born: July 20, 1957  
Departed: January 11, 1983  
At Peace: December 26, 1990

**A Case Narrative of Dementia in five acts<sup>1</sup>**

***Act I: Personal Relationships—I and Thou and loving relationships***

Harry met Sally many years ago in a psychology class at the University of Colorado in Boulder. They both noticed each other immediately. Their relationship evolved from strangers to fellow students and possible friends to possible lovers to actual friends and lovers. They eventually married, raised several children and flourished in their lives and relationships. Early in the marriage they developed a profound appreciation for each other’s perspectives on many issues and regularly would debrief each other on how their day went. They were committed to creating and maintaining a relationship unlike the families in which they were raised. They discussed fair sharing of household chores, how to share child care and career as family became a reality. The years went by with the usual ups and downs of family life, children growing up, going to college and leaving the nest to create their own lives.

How would you describe this marriage?  
What are the core key concepts that describe a good marriage?

One way to describe the relationship between Harry and Sally as an I and Thou relationship where both individuals have high esteem for each other, value each other’s contributions to the relationship and demonstrate a high level of mutuality.<sup>11</sup> The history of their relationship and their family is one of mutual creation and contribution. Other characteristics to describe successful marital relationships include concern for the well-being of the other, authenticity, intimacy, sexual desire, romantic love, friendship and partnership.<sup>12</sup>

<sup>1</sup> Thanks to Peggy Trezona for collaborating in the creation of this case scenario.

***Act II: Patient-Physician Relationships and A face in the wall experience***

***When my journey began, no one told me what to expect. There is no process of informed consent for family care givers.***

Carol Levine, *“The loneliness of the long term care giver.”*<sup>9</sup>

Harry and Sally are now in their late 50’s and beginning to contemplate some changes in their work life as they recognized that they are now at a point when they could work less and pursue some of their interests in more depth. Unfortunately, Harry is finding himself—for no apparent reason-- not enjoying his work like he usually does. Sally has noticed that he is becoming irritable and short-tempered-- very uncharacteristic for him. Over the last 6 months, Harry noticed that he was having some word finding problems and forgetting names. He became more worried when one day after work he couldn’t remember how to drive home. For some period of time, both knew something was different, but couldn’t act on what they were experiencing. Harry’s irritability has now progressed to occasional rages over seemingly insignificant issues. Sally finds herself becoming more vigilant-- censoring what she is going to say, trying to keep things going smoothly, and this is resulting in more emotional distance from Harry. Sally has been seeing a therapist for about a year—initially independent of this situation with Harry- and through talking with her, begins to be able to face that there are real changes going on with Harry, and consequent changes in how she is relating to him. She recognizes that she has actively resisted the possibility that Harry could have some major thing wrong with him ....She had a vision of what their growing old together would be like and a long experience with a spouse who has been a respectful, full partner. Sally has obviously been aware of these changes in her husband—the truth about the growing unpredictability of Harry’s behavior, but has not been prepared to act on this ‘truth’—she has not wanted to make the changes ‘real.’ With the therapist’s help, Sally has begun acting on her lived experience and takes Harry to his primary care physician who does blood work, finds nothing abnormal until he does a mini-mental status examination. The primary care physician is surprised when Harry only scores a 20 out of 30 possible points. He suggests a consultation with a neurologist, orders some brain imaging tests that Harry will bring to the neurologist for review.

The neurologist examines the patient, and reviews the brain imaging studies. He informs the Harry and Sally that the diagnosis is early Alzheimer’s disease. He is sorry to have to tell them this. He let’s them know that he will send a report to the patient’s primary care physician.

How do you think Harry and Sally would react to this news and the way the neurologist informed them?

What do you think the neurologist and the primary care physician should do to be helpful to Harry and Sally?

Reflecting *on* the face in the wall image and experience, one would hope that physicians and in particular neurologists would do some of the following. They would recognize what everyone in the room experiences with the locution “you have Alzheimer’s disease”—a face in the wall experience, a confirmation of a profound threat to the individual’s world as well as his or her continuing existence as a person.

Ideally the neurologist would put words to the experience, acknowledge the impact of the new information and the change the information portends for the person, the marriage and the family. The neurologist and/or physician would also define his or her relationship as a guide to help them navigate the new world they were entering. He or she might say something like the following, “The next few days and weeks will be a period of uncertainty and confusion. I will give you some information on educational resources, on treatment options and will be available to you at any time for questions or concerns. I would like to set up an appointment for a neuropsychological evaluation to confirm the diagnosis as well as follow-up appointment to see how you both are doing. I will also send a copy of my evaluation to your primary care physician with my recommendations. I know we have covered a lot of things today. I would like to call you tomorrow to check in with you regarding any questions you might have.” He would then ask if there are any questions or things they like to have addressed.

For some time after the visit both Harry and Sally find it hard to accept the diagnosis. They know it is true that some things are different, but it doesn’t seem real, where “real is defined as being prepared to act on the new information or perspective. This is a common reaction to threats and trauma, for a while what is true is not real for the person or the relationship.

### ***ACT III: Care giving as a strategy to preserve a marital relationship***

***In addition to holding a full-time job, I manage all my husband’s care and daily activities. Being a care manager requires grit and persistence.***

Carol Levine, *The Loneliness of the long term care giver.*<sup>9</sup>

Sally senses the relationship is changing—feels ‘close yet distant.’ She has no way of thinking about what is happening to the relationship. She wants to be a spouse, but is becoming a caregiver. Harry seems like her husband yet he doesn’t. When he is verbally aggressive and abusive towards her, she feels he is not himself at all. When they have a nice evening together with friends, she finds herself wanting to believe that maybe this isn’t going to get worse. As time goes on, and Harry is no longer able to be by himself at all, asks her the same questions over and over all day, and sometimes even asks her who she is, she has greater difficulty feeling like a wife.

Sally is losing herself in the care of Harry. She notices that she doesn’t even feel like she inhabits her own body, she feels ‘genderless.’ It is very difficult to eat a good diet—her IBS symptoms are out of control, yet no time to see a doctor, much less go thru what it takes to make an appointment. She hasn’t seen her friends—if it weren’t for her daughter, she would be lost. Her own writing has suffered—it is impossible to have any time at the computer, because Harry seeks her out whenever she leaves his side and begins talking to her, asking the same questions over and over. She gives up and goes to be with him. Sally’s therapist counsels her to find respite care, but Sally feels overwhelmed with the idea of making calls, and interviewing people. Besides, she feels she should do as much as possible by herself. After all, she doesn’t have the time she thought they’d have together as they age,

so each day with Harry seems precious to her. Sally tries a few home health aides, none of whom are reliable and she is never able to trust them to care for Harry properly.

One day, Sally is trying to get Harry into the shower and he falls, entangling her on the way down. As she struggles to get Harry upright, she realizes that the demands of caring for him are more than she can handle alone. For the past several months the list of things Sally does for Harry has consumed most of her day and include: managing his incontinence, maintaining his hygiene, finding and putting in order objects that disappear around the house, and maintaining other aspects of a routine household (shopping, cooking, cleaning, etc.). She is exhausted.

What therapeutic advice do you have for Sally? For Harry?  
When is care giving a strategy to maintain a marital relationship and when does it become incompatible with a marital relationship?

Changes within relationships can occur quickly or glacially slowly. The change may be barely perceptible as persons are quite adaptable. However, some behaviors are incompatible with the nature of historical relationship and invite a re-description of the current relationship. The following notational device is a useful way to clarify the high level view of the relationship and how it changes.

Relationship change formula.<sup>7</sup>

*If* A has a given relationship, R, to P

*And*

The behavior of A with respect to P violates R, and the behavior of A with respect to P is an expression of another relationship, R1, which is incompatible with R

*Then* The relationship changes from being R toward being R1.

In the case of Harry and Sally, the enduring marital relationship has been characterized by mutuality, reciprocity, shared world creation, and equal status assigners (contributors) in the conduct of their lives and relationship. With the impairments of dementia Sally has engaged in the social practice of “care giving” as a strategy to maintain their marital relationship. However, the increasing care giving demands become incompatible with the historical marital relationship. Describing the change to the well spouse is often quite helpful as a first step in allowing her to reflect upon her own well being as well as beginning some advance care planning for the long run.

The historical relationship R = marriage defined by mutually, reciprocity, etc...

Care giving needs become enormous, are one-sided, are 24/7 and become incompatible with the previous relationship R and move it to

R1 in this case becomes a care taking relationship of a care giver to patient which is becoming incompatible with the nature of their historical relationship.

### ***A person of uncertain status and a relationship of uncertain status***

Sally began with the social practice of care giving which is something she did not need a reason to do—as with any intrinsic social practice, that’s just what loving wives do is care for their ill husbands. However, the degree of Sally’s care giving has taken her out of the spousal domain into more of what a professional caregiver would do—all of the activities of daily living. Until Sally had a ‘good enough reason not to’ engage in care giving, she wasn’t able to stop. Sally had assumed the status of a caregiver, and was no longer just giving care as a common social practice in her culture.

As the caregiver moves along the care giving continuum, doing more and more for the spouse, the concept of preserving the spousal domain of the marriage can be helpful in persuading the well spouse to obtain respite care sooner rather than later. In this way, the aspects of the spousal relationship can be preserved as long as possible. This is particularly important in chronic illnesses where the ill person’s cognitive status is not significantly changed. Thus, if all your time is not taken up in maintaining activities of daily living you and your spouse can have time to share a meal, watch a movie together, talk about the days events.

### ***ACT IV: Ambivalent Loss and Grieving***

***During my nine-year odyssey, I stopped being a wife and became a family care giver. In the anxious weeks when my husband was in the intensive care unit, I was still a wife.... (at time of discharge) At that point, I was important only as the manager and, it was expected, the hand-on provider of my husband’s care... (at the rehab center)... a place I now think of as a boot camp for care givers.***

Carol Levine, *The Loneliness of the long term care giver.*<sup>9</sup>

Sally knows in the back of her mind that some day Harry will have to live in a care center and yet she finds herself unable to think logically about that at all. What things would be happening to make that decision clear? Wouldn’t his going to a care center mean she had failed to provide the care he needs? Once he leaves, he will never come back. They will never be able to share the same bed again.

Harry has gotten much worse and finally had to go into a memory care unit at a local seniors living complex. She knows it is a good place and feels lucky about that part, but who is Harry now? She is having trouble figuring this out. She visits every day for two months despite how sad each visit leaves her feeling. Harry doesn’t know she is Sally, doesn’t know they are married, yet he says, “I love you.”

He talks in gibberish much of the time, but can suddenly quote paragraphs of the poetry he used to teach. Harry is not the same person. Who is he now? Who is she to him?

***Ambiguous Loss*<sup>8</sup>**

Pauline Boss has studied and written about ambiguous losses. She refers to such losses as frozen grief. Such losses can occur from any number of circumstances where a family member is lost, missing in action, or even a common loss that occurs through a divorce. Dementias also provide the circumstances that can create an ambiguous loss. As Harry’s dementia progresses his embodiment is relatively unchanged. He looks like the person he always used to be. However, his disposition, powers and capacities are profoundly different. He demonstrates little interest in activities, hobbies, and family members. He is unable to perform the many activities of daily living or self-care that characterizes healthy adults. He withdraws from social interaction, is irritable and cannot carry on a normal conversation. For Sally, this is devastating. She no longer experiences him as her husband, yet she knows that he is.

***Grieving: two images*<sup>7</sup>**

Peter Ossorio describes two forms of grievous loss captured with an image of a pruned tree and an image of a unique production of Hamlet. In the first image of a tree that is pruned, the tree suffers a grievous loss yet will grow back to be an intact tree. The tree has the capacity to recover, grow and flourish. The second image is that of a troupe of Shakespearian actors. In this small troupe there is only one actor who can play Hamlet. This actor has gone missing. The troupe decides nonetheless to put on the play without any actor playing Hamlet. What kind of production would this be and how would it affect the interactions among the remaining actors as well as the relationship to the audience? Trying to mount the production without the key actor, as if nothing had changed, would certainly lead to a unique if not unrecognizable performance.

The two images suggest a way of thinking about grief as a process of grievous loss requiring acknowledgement of the loss, experiencing the sorrow and accompanying suffering and slowly reconstructing a fulfilling, vibrant personal world. The second image captures how grief can be frozen, can go wrong, and performances fail because of the failure to experience and adapt to grievous loss.

Sally’s grievous loss is the marital relationship and the community of two that she and Harry created throughout their marriage. She is struggling with the incompatibility of her developing status as a full time care giver and having an “I and Thou” relationship with her husband.

Relationship Characteristics	I and Thou	Care giver
Significance or purpose	Romance, Friendship, Partnership	Nurture, Protect and preserve world
Normative relationship	I-Thou	I-Thou and I-It
Observer perspectives	Reciprocity	Monitor and scan
Evaluation perspectives	Respect	Diagnose how things go wrong
	Intimacy	Prescribe remedies
	Sexuality	Maintain safe environment
Ways things go wrong	I-It	Exhausted care giver

## ***Dementia, Death and Dying: Goals of Care and Caring***

Spouses and families struggle mightily with defining positive treatment goals in dealing with the dementia and its impact on personal and family functioning. Later in the workshop we will address the following questions:

- What goals of care are possible for persons with dementia?
- What are concepts of goals of care at the end of life? For patients with dementia?
- What concepts make sense of dementia and dementia patients with symptoms?
- What is the status of a person with end-stage dementia?
  - Former president, former governor, former baseball player
  - Historical person?
  - How to decide what such a person would want—ethics of withholding or withdrawing treatments?

### **Act V: World Reconstruction<sup>10, 13</sup>**

Sally has begun the process of declaring bankruptcy as she prepares to pay off her house so she can further spend down her assets. She feels very strange as she acts on this new reality—no longer trying to save money for a shared future, but spending money so that she can qualify for government subsidy for the care her husband will continue to need. Sally realizes she will need to get a job at some point. She had been reluctant to change the household arrangements—wanting to leave it just like it looked when her husband lived with her, even finding herself unable to sleep on his side of the bed. However, she is beginning to reclaim her home as hers, finding some momentary pleasure in cleaning out the clutter that had accumulated over the last year and re-arranging furniture. She has found a religious community to be part of and has plans to get involved in their social justice work. She hasn't yet returned to her own writing but at least now has that as a goal. She is seeing a therapist and the concept of 'world reconstruction' is helping her see that this rebuilding process is necessary and even good. Sally continues to grieve as her husband declines, but now has a handhold in her own life.

Summary of Case: Creating a narrative that achieves understanding of an unthinkable, unimaginable, and tragic experience

- Personal Relationships
- Thinking the unthinkable
- Relation formula and relationship change formula
- What is a person and what changes with chronic illness? With dementing illness?
- Concepts of care giving
- Grief, loss and world reconstruction

### **Part III: Two Cases: Navigating Multiple Worlds—what is the right thing to do?**

#### ***Goals of Care at the end of life<sup>5</sup>***

We are about to observe a short interview between a hospital physician and a patient's wife. The patient is in the hospital because of a change in his condition and mental status. He was transferred from a nursing home where he is a resident with end stage dementia. He is incontinent of bowel and bladder, has been bed bound for over a year and does not recognize his wife when she visits. As you observe the short interview note the following:

1. The actions of the interviewer and the sequence of the interview.
2. What the interviewer does well.
3. Is there anything that you would have done differently if you were the interviewer?

**NOTES:**

#### ***Goals of Care for patients with dementia***

Individuals frequently don't reflect on the goals of care when they go to see a physician. It is usually straightforward—prevention of illness, a treatment to alleviate discomfort for a cold, an antibiotic to cure a bacterial infection, a surgery to take out an inflamed appendix, etc. The goals of care most often are to maintain function or restore function. If a sudden injury or acute illness causes organ failure bridging technologies can sustain life until the person's own body recovers to function on its own. At any time both the person and the health care professional can discuss the goals of treatment ensuring that the patient's wishes are respected.

Unfortunately, the usual goals of care are less relevant to slowly progressing degenerative illnesses, particularly with dementias. Discussion of the goals of treatments as well as the wishes of the patient is further compromised by the ill patient's inability to participate meaningfully due to changes in cognition and abilities. Family members or other decision-makers are challenged to do "what the patient would have wanted." If restoring or maintaining function is no longer an option, what should the proxy decision-maker or health care agent do? How should they think about what is the right thing to do? What if they don't know the person well or there are no advance directives to guide the decision-makers? What if there is conflict among family members on what to do? How is one to know if a life-sustaining technology is prolonging suffering and dying rather than maintain quality of life? What are reasonable goals of care that families and decision-makers can hope for?

#### ***Navigating a world of multiple perspectives***

Patients with end stage dementia often require nursing home or other residential placement at the end of their illness. As a patient's condition changes the goals of care discussions can be extremely

complex and involve the nursing home or residential staff, the primary care physician, family members, as well as hospice staff. Not infrequently a patient care conference is scheduled especially when a patient is newly admitted to a facility, when there is a change in condition or when there are serious conflicts about the goals of care among the staff and family members involved with the patient. Care conferences are important venues and opportunities to get everyone on the same page, clarify goals of care and resolve conflicts. However, professional care givers and health care clinicians receive little guidance or training on how to conduct such conferences. The following grid can be useful in understanding and planning for such conferences.

<i>Participants</i>			<i>Perspectives</i>			
	Medical	Psychosocial Cultural	Legal	Ethical	Spiritual Religious	Public Policy
Person						
Family						
Caregiver						
Medical Team						
Hospice						
Legislatures Executives						

The left hand column lists the various participants or actors who may attend the conference or whose influence is strongly felt at the care conference, e.g. legislative acts and statutes that come into play such as vulnerable adults, or recently as in the 2005 Terry Schiavo case where state and national players intervened. The Perspectives row reflects various professional and non-professional community concepts, practices, standards and decision-making principles that are relevant to a given individual that may also guide and influence decision-making.

Consider the following patient situation which led to a care conference.

*A 75 year old widowed patient suffered a number debilitating strokes, decline in self-cares and an expressive aphasia, requiring a nursing home placement. She has two adult daughters who both have power of attorney for health care decisions. The patient has difficulty swallowing, frequently chokes and coughs when she eats, yet enjoys eating. On a previous admission to a psychiatry unit because of behavioral problems an advance directive was noted in the medical record which stated that she did not want to have a feeding tube. The patient is now in hospice and there has been a decline in her ability to swallow solids and liquids. A nursing from the nursing home calls hospice as well as the daughters because she notes that the patient is very uncomfortable and is pointing to her stomach. The nurse worries aloud that the patient is starving. The two daughters are very concerned about their mother's suffering. However, they cannot agree on what to do. One daughter thinks that the patient is starving and wants a feeding tube put in right away. The other daughter refers to the advance directives and states to the nurse that she is clear that her mother would never want this done, but isn't sure on how to approach her mother's discomfort.*

1. Using the above grid, in small groups, review the relevant perspectives to this patient's circumstances.
2. What could account for the patient's discomfort?
3. How would you proceed to facilitate this care conference—who should be present, how would you structure the discussion?

**NOTES:**

### **The importance of a care conference**

- Creating a mutually defined understanding of the person, family, nursing caregivers, medical professionals and organizational circumstances and reality
  - Respecting everyone's attempts at doing the right thing, and doing it right
  - Honoring patient/parent/spouses wishes
  - Avoid unnecessary suffering
- Responding and resolving conflicts in goals of care:
  - Autonomy (withdrawing treatment) versus beneficence
  - Prolonging life versus prolonging suffering (do no harm)
  - Prolonging life versus futility (justice)

- Developing a consensus on a plan of care and how to proceed

### **Prior to the care conference**

- Make sure that all the key people can attend
- Invite some representatives from the administrative and clinical leadership of the nursing home or facility when there are significant disagreements among the staff on how to proceed
- Make sure there is up to date medical information on the patient's medical status prior to the conference

### **Facilitator first moves: Set the stage and "Seek first to understand"**

- Begin with introductions: roles, relationships, and accountabilities
- State the purpose of the care conference or meeting and desired outcome
- Recognize current stresses
- Honor everyone in attempting to do what they think is the right thing to do and to do it right
- Review the facts of the person's illness, the up to date medical information, nursing staff reports, or other documented observations on the patient's condition, the goals of the care conference.
- Do a check in by having everyone report on how each is viewing the patient's current situation
- Begin with a narrative of how the illness unfolded and created the current circumstances
- Summarize what the family member, nursing staff, or other participants have said and verify that you have understood their view of the current situation

### **Reframing the Understanding of the Current Situation: Creating a Shared Reality**

- "There comes a point where the treatments may be prolonging the patient's suffering and process of dying rather than returning to the previous quality of life or level of comfort. I think we are getting close to that threshold in light of what we are all observing today...."
- "Sometimes there is a difficult choice between alertness and suffering versus some mild sedation and control of the patient's symptoms and level of comfort..."

### **Ending the meeting**

- Summarize everyone's understanding of the current situation, the current goals of care and the agreed upon next steps.
- Thank everyone for their participation and effort to achieve agreed upon goals of care and treatment interventions.
- Discuss communication follow-up on the outcome of the treatment interventions and next meeting if needed.

### **Goals of Care for patients with end stage dementia: the importance of context**

- How goals change at the end of life
  - Major focus on comfort
  - Stabilizing function is no longer a prominent goal
  - Focus on quality of life rather than prolonging life
- Addressing suffering versus prolonging suffering

- Prolonging biological life versus a lived life
- Hospice goals
  - Self-determined end of life closure
  - Safe dying
  - Comfortable dying
  - Effective bereavement

***What are we doing by doing that?—feeding tubes in dementia patients***

Despite everyone’s best efforts at the care conference the two adult daughters could not agree upon the use of a feeding tube with their mother. Both daughters were focused on the comfort of the mother. One daughter believed that her mother would never want to continue living in her current circumstances and that a feeding tube would only prolong her suffering and dying. The other daughter knew how much her mother enjoyed eating and could not get the comment made by one of the nurses that her mother was starving. She believed that the feeding tube would be a comfort measure. The hospice medical director who was present at the conference explained that a feeding tube would not prevent continued aspiration due to her dysphagia, that there were associated side effects with feeding tubes including infection, perforation, poor tolerance of the chemical nutrients, bloating, diarrhea, and possible hastening of the patient’s dying. Nonetheless the one daughter still insisted on a feeding tube.

You are at the end of the meeting and the conflict is not resolved. How would you proceed?  
 What do you do when there is no consensus on the goals of care or how to proceed?  
 How would you justify your decision on what to do next?  
**NOTES:**

**When in doubt...**

- Work to achieve a consensus -- Families will remember the process for a life time
- Propose Time-limited treatments trial to answer a question
  - Will Medically Provided Hydration and Nutrition (MPHN) achieve goals of care?
  - Will MPHN increase burdens in order to provide a benefit?
  - Will MPHN increase the patient’s ability to meaningfully participate in relationships and intentional living?

**Remember...**

- Advance Directives have their limitations and persons can change their minds
- Incompetent patients may have the ability to express their preferences
- An unresolved family conflict regarding decision-making can last a lifetime and beyond
- Honor everyone’s intentions to do the right thing, framing the disagreement as a conflict among views of what the right thing is to do!

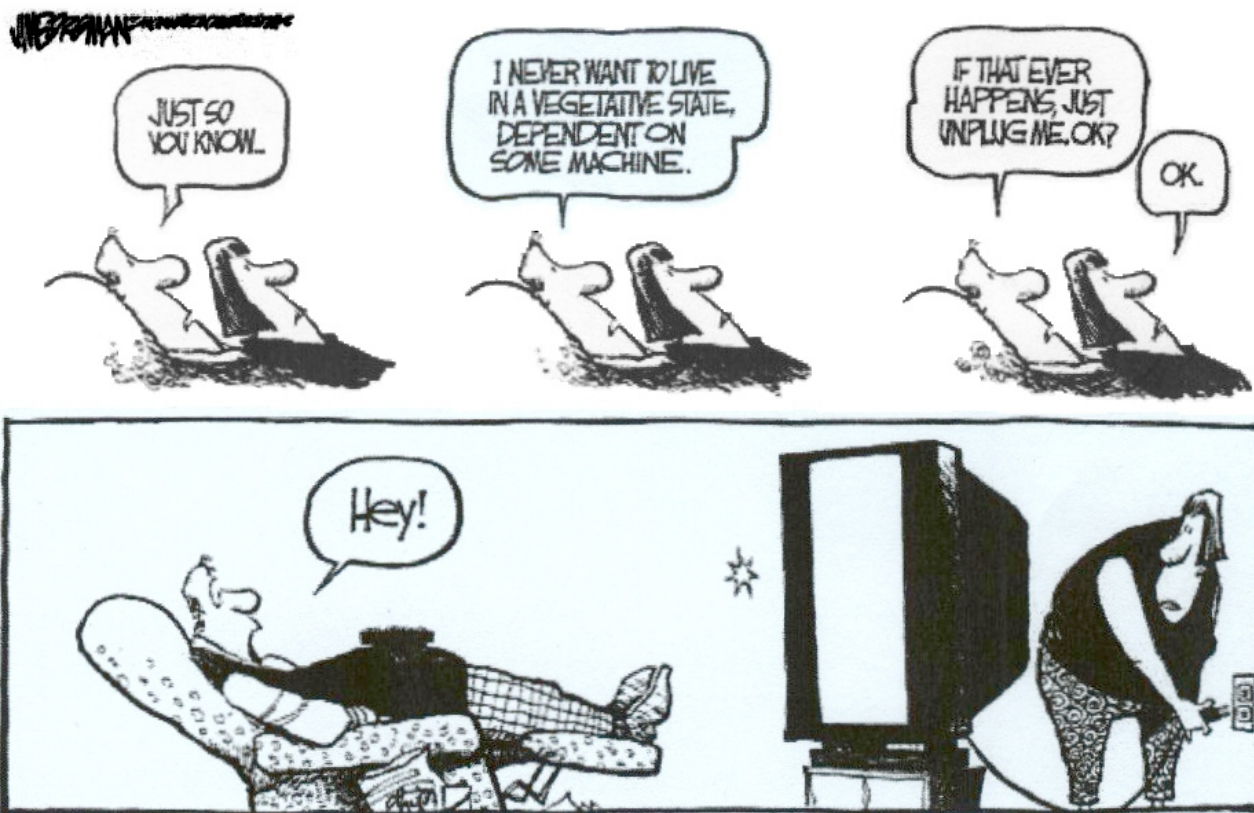
### Some other ways to explore goals of care

- Will the treatment achieve meaningful quality of life or prolonging suffering and dying
- What would the person want if he or she had a moment of lucidity –would they want to continue living this way?
- What would you want for your family if you were in this situation?

### Part IV: Respecting Persons, Advance Directives, Ethics and Medical Decision Making at the End of Life 1

#### Advance Directives Lunch Assignment

Over the lunch break take some time to complete your advance directives. You can use the Five Wishes format or any other format that you wish. Choose a proxy decision-maker who can act on your behalf if you are unable to speak for yourself.



## The Five Wishes

How did you react to this assignment?  
How did you react to filling out the Five Wishes?  
What was difficult about completing the exercise?  
Who did you think about naming as a proxy decision-maker?  
What would you do with the completed form?

### Types of Advance Directives: A Glossary

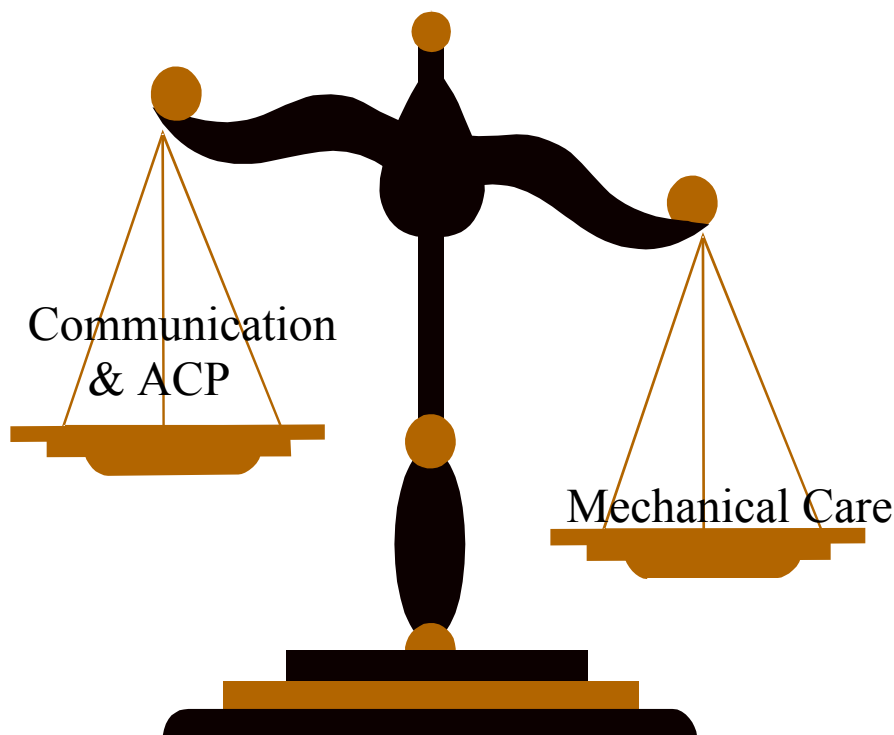
Each state has its own laws regulating advance directives. Prior to August 1, 1998 Minnesota law recognized 3 types of advance directives:

- Living will
- Durable health care powers of attorney
- Mental health declaration

The law changed in 1998 and the Health Care Directive replaced both the living will and DPOA. The Mental Health declaration still exists.

- A Durable Power of Attorney is a legal document where a person names a proxy to act on his or her behalf if he or she is unable to speak due to a variety of temporary or permanent conditions. It does not require a terminal condition and it is durable because it is effective upon incapacity or incompetence.
- A guardianship is a court appointed person or entity who delegated the responsibility to make decision for an incapacitated person's care or financial matters or both.
- A conservator is a person appointed by the court to make limited decisions for an incapacitated person's care or financial matters or both.
- In Minnesota the MN Health Care Directive law required the following 6 minimal requirements to create a valid health care directive:
  1. Be in writing
  2. State the patient's name
  3. Be dated
  4. Be executed by a person with capacity to do so.
  5. Verified by a notary or two witnesses. Only one witness may be a health care provider or employee.
  6. Include either health care instruction or health care power of attorney/agent or both.

## Restoring the Balance: The Importance of Advance Care Planning (ACP)



### **Advance Directives and Advance Care Planning**

Nancy Cruzan was tragically injured on January 11, 1983 when a pick-up truck she was driving rolled over causing significant brain injuries.<sup>14</sup> The injuries eventually led to a persistent vegetative state. At the time of the injury the medical practice was to keep such persons alive indefinitely. Nancy Cruzan's family believed that she would never recover and she would never have wanted her body to be alive with only the prospect of a steady, progressive deterioration in a persistent comatose state. The family went to court in the State of Missouri to sue for the right to terminate the life sustaining treatment. The case eventually was reviewed by the Supreme Court of the United States.<sup>15</sup> The holding of the case was based upon common law precedents of bodily integrity; every person has the right to control what is done to them, including the right to refuse or discontinue treatment. However, the States were also sustained in their ability to set the evidentiary standards for determining the wishes, values, and information needed to clarify what the person's decision would have been if he or she could speak for him or herself. The evidentiary standard for the State of Missouri at that time was "clear and convincing" versus preponderance or circumstantial evidence, which is a very stringent standard.

Because of the inherent difficulty is determining what a person would have wanted if they couldn't speak for themselves, the Supreme Court also urged the Congress and the States to develop statutes to encourage individuals to provide information on their health care wishes and values. Congress passed the Patient Self-determination Act in 1992 which required that any facility receiving Medicare financing must provide an opportunity for patients or residents to express their health care wishes in the form of advance directives.<sup>16</sup> Over the past decade States have created a variety of legal vehicles to

document and patients' end of life wishes: living wills, durable power of attorney for health care, health care agents, and guardianships. In addition to having written advance directives, individuals are encouraged to identify a proxy or surrogate decision-maker that can act on behalf of the person if they are unconscious or lose decisional-capacity.

***The The Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments (SUPPORT) : JAMA, 1994, 272:1839-1844.***<sup>17</sup>

In the wake of Patient Self-Determination Act, the Support Study was undertaken to evaluate ways to improve patient self-determination. It was a large, multi-center collaborative study involving 9000 patients funded by the Robert Wood Johnson Foundation to improve the care of seriously ill patients at the end of life, and to facilitate physician's understanding of patient's choices about end of life care. The first phase of the trial studied how patients died in the hospital. The second phase involved a randomized controlled study of a nurse based intervention with 2500 subjects in each group. The disappointing results suggested that despite the nurse intervention to make physicians aware of patients' preferences 53% of the physicians did not understand that patients wanted to avoid CPR. Thirty-eight percent of patients endured prolonged suffering 10 or more days in the ICU, in coma or on a ventilator. About a half of the patients experienced moderate or severe pain at least half the time within their last few days. Other findings from the study were that 34% of the patients needed significant amount of care giving, 31% lost most of their savings, 29% lost a major source of their income, 20% had a major life change for a family member and 12% had another family experience illness from the stress. The conclusions of the study authors was that site of death was predicted by the number of hospital beds, hospice spending, % patients in nursing home, expenditures on long term care and diagnostic category. Patient preferences were found to be irrelevant.

Despite a number of efforts by physicians, health agencies and others only about 30% of Americans have written advance directives or named surrogate decision-makers.<sup>18</sup> An additional problem with advance directives is the lack of information systems that can make the information available when and where it is needed.<sup>19</sup> A third difficulty with advance directives is the inherent limitations of a written document which may be drafted at a point in time without being able to anticipate the medical circumstances that will occur in the future.

Over time electronic medical records will communicate with each other and will provide medical information including advance directives in all venues of care.<sup>19</sup> This will solve the problem of availability, but not content or specificity. What should be in an advance directive necessarily will change over time as individuals have more information on the illnesses that will be specific to their life circumstances. More importantly, advance directives should not be viewed as a document to complete. They are more appropriately thought of as an element of an advance care planning process that should be reviewed yearly with the designated decision-maker, family, friends and physicians. Five wishes, available from the Aging with Dignity Web Site, <http://www.agingwithdignity.org/>, provides an excellent step wise approach to thinking about end of life decision-making and how to have conversations with family, friends and possible surrogate decision-makers. Just as taxes and tax planning is a yearly process, so should advance care planning.

### **Quality of Life—*political, social and individual morality/philosophy***

In the wake of Terry Schiavo—if ever there was a case of a family conflict!!!

*An 87 year old man is on a respirator. He suffers from chronic lung disease and had a recent pneumonia that led to a respiratory failure. He is cognitively intact. This is his second hospital admission in 3 months. You have been asked to talk with the patient and family about advance directives as well as possibly stopping the respirator. You have heard the staff say that this patient has no quality of life and should be referred to hospice and extubated. How would you approach the discussion with the patient and family?*

There is an interesting debate among philosophers regarding quality of life. Some writers, objective value theorists, assert that there are objective qualities of life that are recognized across many cultures and therefore qualify for “universality”. Other theorists assert that quality of life is ultimately within the eyes of beholder. A more nuanced approach might be that there are insider and outsider views of quality of life and sometimes they line up and other times they are in disagreement.

**If we assume for the moment that there are objective qualities of life**, across cultures and possible candidates for universally agreed upon values that make life worthwhile what would they be?

1. List as many as you can think of....
2. What values or qualities could you not live without?
3. How would you decide if the 87 year old patient on the respirator had quality of life?
4. What would you recommend to the medical staff who are requesting a consult on getting advance directives, e.g. stopping all aggressive treatments and referral to hospice?

If quality of life was objective then a given individual could be mistaken about his or her own judgment of quality of life. Although hard to imagine that someone would know better than I would about the quality of my experience, we all have been in situations where friends, family or colleagues may say this is “good for you”, “this builds character”, “you will be the better for this experience”, “you are doing fine”. In health care there is a tendency of professionals to make judgments about the quality of patient’s life, or even the worth of an individual’s life. Obviously there are other issues that are in play in these situations, e.g. values of social worth, psychological reactions to watching patients and families suffer, etc. Even if there were a list of values that made quality of life worthwhile or not, how many of the values would be required to have enough quality to make life worthwhile? Who could make such judgment for any given individual? What type of consensus could be achieved on the weighting of any individual value in contributing to a person’s perceived quality of life?

John Finnis, in *Natural Law and Natural Rights*, focused on seven of what he calls intrinsically valuable basic goods:<sup>20</sup>

Life  
Knowledge  
Play  
Aesthetic Experience (Beauty)  
Sociability (Friendship)  
Practical Reasonableness  
Religion.

However, in his latter works these have been partially reworked. He states that these basic goods are self-evidently "good" and cannot be deduced from other premises; they are incommensurable with one another. The incommensurability of these goods means that one cannot rationally measure one against another. Their supposed incommensurability also leads Finnis to state that people should pursue all the 'goods' and should not ignore any one of them. People may individually choose to emphasize one good over another, but none should be entirely excluded.

(from Wikipedia on John Finnis)

Consider the context of quality of life within various political systems. In liberal democratic constitutional societies, liberty, equality and justice preclude a privileged position of a "good life". Liberalism allows maximal choice on values, wishes, and conception of the good as long as there are no harms to other persons. Individual persons have a negative liberty right or a right to be left alone in conducting their lives without the state or others interfering or requiring conformity to religiously inspired law. In societies with this type of governance and political philosophy, self-regarding behaviors are in the purview of the individual; individual morality trumps social morality.

In contrast to liberal constitutional democracies consider the relationship of individual and social morality in a theocratic society such as Iran where the political philosophy is a religiously based morality. In such societies, and with most religiously based communities, social morality trumps individual morality in the conduct of ones' life, one's wishes and personal projects. The concept of good emanates from the community inspired revelations from God and interpretations of the received laws.

With these considerations in mind, let's turn to our 87 year old man on the respirator. Let's look at the list of possible values that contribute to quality of life and challenge ourselves with a determination of the patient's quality of life.

From an insider perspective the patient may still be capable of .....

From an outsider (in this case the health care professionals caring for the patient) the patient's quality of life is .....

Therefore the life sustaining treatment is ..... justified? .....Futile?

Life  
Knowledge  
Play  
Aesthetic Experience (or Beauty)  
Sociability (or Friendship)  
Practical Reasonableness  
Religion.

What do you think?

The concept of futility creates a mine field for health professionals because of the tension between an individual's perspective on the good and a collective view of the good regarding wise use of resources and stewardship. We will return to this issue and how clinicians can respond to issues of futility by understanding such conflicts as conflicts in goals of care that can be addressed in different ways by focusing on underlying important values.

## **What is a person?**

Patients with diseases that affect mood, memory, language, thinking, desire, personality, and intentional action challenge families, professionals, and surrogate decision makers to figure out what is the right thing to do in terms of end of life decision-making. As in the case of the 75 year old woman in hospice with a terminal diagnosis of stroke, difficulties swallowing led to a discussion regarding the use of a feeding tube. Too often such discussions start with the benefits and burdens regarding the technical aspects of such life sustaining treatments. The focus on the medical aspects of the treatment channels the discussion to physiology rather than function, to calories in and calories out rather than what would this treatment enable the person to do as well as how might this meet the person's own goals, if he or she could speak for her or himself.

Implicit in end of life discussions about patients who are severely impaired cognitively, is the personhood of the person. Who we are as persons changes dramatically across the life cycle from infancy, childhood, adolescence, young adulthood, middle adulthood, young old age, middle old age and old-old age. Yet as long as one is cognitively intact and an individual is able to author his or her life, and personhood is not questioned. Intact persons can make medical decisions based upon their evaluations of the benefits and burdens of a particular treatment or treatments and the quality it brings to their lives. This is no longer the case for severely cognitively impaired persons with end stage dementia and other end stage illnesses.

Central to our sense of who we are is the authorship of our lives. Each individual authors his or her own life. It is reflected in the distinction between a biographical versus a biological life. The concept of a biographical life is the deliberation and intentionality with which individuals over a life time author their lives, creating a narrative in many acts. The tragedy of illnesses that rob individuals of their intentionality is that they cannot author the last act of life. In such circumstances spouses, adult children, health care professionals and sometimes court appointed surrogate decision-makers do their best to make decisions that are consistent with the patient's whole life narrative.

Imagine you are facilitating an end of life discussion with a family member of a patient with end stage dementia. The physicians are requesting guidance on how vigorous they should be in treating the patient's pneumonia, or other change in condition. How would you help the spouse or adult child make a decision regarding treatment?

How do you understand biographic versus a biological life and how might you use these concepts to help a family member make a decision regarding life-sustaining treatment?

Without wading into the tendentious discussions regarding sanctity of life, all religions recognize that everyone dies sooner or later. Many religions bring to medical decision-making the concept of weighing the benefits and burdens of initiating or terminating treatments as well as what is permissible and impermissible for end of life choices. The key determinant in many of the end of life situations is the ability of a person to participate in significant relationships, or engage in meaningful activities or be kept comfortable. Costs are also relevant considerations though not determinative. Often the most helpful question to facilitate decisions is, "If this person were lucid for a moment and he or she could evaluate his or her circumstances, would they want to continue living this way?" "Would they want any further treatment that would prolong their living this way or would they want the physicians to focus on comfort?" Note that the discussions should always discuss goals of treatment rather than treatment versus no treatment. The goal is to provide the appropriate treatment that is consistent with the wishes of the person. The difficult determination often is will the selected treatment prolong suffering, prolong dying, or will the treatment return the person to some meaningfully quality of life?

## Memory and Person Impairments in Dementia

The popular understanding of memory is often limited to "memories" or what is called event memory. A fuller understanding of memory and it may be impaired can guide family members and professionals in helping persons with dementia. Although the progressive pathology in various dementing illness can affect specific brain circuitry in somewhat different patterns, it is helpful to understand how higher levels of memory eventually can be impaired and how such impairments affect thinking, emotions, acting, and behaving. With this understanding care givers can anticipate the type of situations that will present problems for patients as well as provide safe environments and appropriate interventions to maintain patient's dignity and ability to participate as a person.

There are four, somewhat distinct types of memory that are critical to being a person and maintaining personhood.<sup>21</sup>

- Event memory
- Semantic memory
- Procedural memory
- Working memory

Event memory is what most people commonly think of when thinking of Alzheimer's dementia. It is the ability to **remember events**, circumstances and contexts of lived experience. For older persons

almost everyone can remember where they were when John Kennedy was assassinated. For younger persons it might be 9/11. Intense experiences are often remembered with vivid details: place, time, social circumstances, weather, and so forth. Less intense experiences with less detail, but with help can be called forth as when reminiscing with friends.

Semantic memory is the ability to **remember the significance or meaning** of a particular symbol, word, interpersonal or physical environment. When approaching an intersection and observing a yellow pole supporting a box with three colored lights, most people easily recognize this as a stop light that regulates traffic; red means stop, green means go, and yellow means be careful as the flow of traffic will be soon changing. Significance is vital for understanding and recognizing potentially dangerous situations, threats, or what is called for in everyday typical situations, e.g. what a spoon is, how it differs from a fork, and when and how it is used to eat what type of foods.

Procedural memory is the ability to **remember key sequences** to accomplish a task. Washing the dishes involves taking the dishes from the table, aligning them properly in the dishwasher (glassware and plastics on top; silverware in the silverware holder, and plates on the bottom rack), filling the soap dispenser, and pushing the on button. Checking the weather on the internet involves turning the computer on, signing in with the appropriate username and password, clicking on the explorer or foxfire icon, activating the bookmarks and clicking on weather.com. As most of us have experienced forgetting one of our many passwords, a whole sequence is aborted if you the person can't remember any one of the key steps.

Working memory is perhaps the most noted impairment as Alzheimer's disease progresses. Analogous to RAM memory in a computer, this is where **currently needed information** to accomplish any task is lodged during the time it takes to complete the task. In reading this particular paragraph the reader keeps in working memory the concept of working memory and how it is described in subsequent sentences. Working memory is vital for all social interactions of any complexity as it allows the sequencing of any interpersonal communication, transactions, collaborative actions, etc.

Given the progressive impairment in event, semantic, procedural and working memory what would you predict the impact would be on a person and how would it affect their social-interpersonal world?

What type of symptoms might occur for each type of memory and how might that guide therapeutic interventions?

## “The Ethics” in End of Life Decision Making: Respecting Choices

***“It is not who is right but rather who has the right to decide.”***

*Paraphrase from Aulisio, Arnold, & Younger, (Eds) Ethics Consultation: From Theory to Practice, 2003.<sup>22</sup>*

### ***Medical, Ethical and Legal Approaches to end of Life Decision-making***

A 59 year old woman with advanced, wide spread cancer who has recently been told by her oncologist at the Mayo Clinic that there are no more treatments to help her. She currently has a feeding tube and is receiving intravenous fluids. The patient wants no more treatments and would like the supportive treatments stopped. Her husband wants more time and wants her treated vigorously with a blood transfusions, hyperalimentation and continued IV fluids. She has been referred to hospice because of her end stage illness, continuing diarrhea, nausea and pain. The medical team believes that the diarrhea and nausea are due to the feeding tube nutrients which can no longer be absorbed because of the patient’s debilitated condition.

An 81 year woman on renal dialysis is referred to hospice. She also has heart failure and a progressing dementia. She isn’t quite certain why she is in hospice and doesn’t understand why she would want to stop dialysis. Her daughter has durable power of attorney for health care and has been told that the dialysis treatments are no longer working and should be stopped.

In the above two medical vignettes the medical treatments are less and less effective, presenting the clinicians, patients and family members with a dilemma regarding continuing treatments, changing goals of care and confronting end of life issues. Informed decision-making involves medical, ethical and legal considerations. Medical practice provides a framework for what is clinically possible and what is ***medically indicated*** for treatment of diseases and symptoms. Ethics looks at intentions and actions that are ***morally permissible and not permissible***. Case law provides a societal consensus at a point in time on what is ***legally permissible and not permissible***.

### ***The doctor patient relationship: Informed Choices, Informed Decision-Making***

Although advance care planning does not require involvement of a physician, it is critical at some point to involve physicians in such planning. There is an inherent asymmetry in the doctor patient relationship that affects medical decision-making. Physicians and health care professionals have a wealth of information about illness, treatments, and the likely medical benefits and burdens of individual treatments. Persons as patients have direct and private knowledge of their values, wishes, hopes, beliefs and life projects. Neither the physician nor the person as patient can make an informed decision or choice without important sharing of information. This seems to be an obvious truism, but frequently missed in practice as physicians are under pressure to make decisions quickly and persons as patients are often stressed and overwhelmed by medical crises and information that is life threatening.

A number of models of the relationship between physician and patient recognize this asymmetry of information, the inherent uncertainty about planning, and the important role played by physicians. Emmanuel and Emanuel suggest four models that reflects the various roles that can be played by physicians in the physician-patient relationship: paternalistic, informative, interpretive, and

deliberative.<sup>23</sup> A **paternalistic relationship** suggests that the physician knows best what is in the patient's best interest and can make the appropriate decision for the patient. At times a patient may request such a role, especially when there is an enduring, long standing good prior relationship. The patient may truly not know what to do and he or she might request for the physician to recommend the best choice. An **informative relationship** is modeled more on a **customer-consumer** approach where the physician provides the information and leaves it up to the patient to sort out the best alternative. The **interpretive approach** is modeled on a counseling model of helping the patient understand the choices within the context of his or her health related values. Finally, the **deliberative approach** is modeled on a mutually interactive search to discover the patient's health related values and choices in an inherently difficult and unknowable future.

In any doctor-patient relationship that endures, physicians relate in any or all of the ways described in the four models depending on the individual patient and his or her needs. Unfortunately at the end of life and the specialist model of modern medicine, patients frequently are dealing with a medical crisis and a variety of specialists each attending to a different organ rather than the person in which the organs reside. What is also missed in the focus on managing an immediate crisis is the larger context of end of life issues which might be quality of life versus quantity of life.

### *Ethics Facilitation*<sup>22</sup>

Ethics facilitation and consultation in the medical world has developed in response to value conflicts among patients, families, health care professionals, administrators and surrogate decision-makers as they confront changing goals of care and end of life options. The underlying value conflicts are frequently under-appreciated by the various persons involved and exacerbated by hospital settings or other crises that frequently need immediate decisions to be made and actions to be taken. As noted in the section on the importance of care conferences, until all of the key persons involved in making and implementing health care decisions sit down together, each participant may have limited information or misinformation on the current circumstances of the patient as well as each other's views of what is important in caring for the patient. Ethical perspectives, ethics consultation/facilitation can help clarify the value conflicts that need to be addressed and ultimately who has the right to make the medical decision. This type of clarification has had an important impact on the culture of medicine especially on the doctor patient relationship.

Ausilio presents a case that illustrates the importance of value clarification as well as who gets to decide in the chapter on Meeting the Need, Chapter 1 in Ethics Consultation.<sup>22</sup> A woman is brought to the emergency room after a motorcycle accident. The physician tells the patient that her leg can be saved if a vein is transplanted from her wrist leaving her with a minor wrist deformity. She chooses to have her leg amputated. This makes no sense to the physician until he discovers that the patient is a pianist.

From the physician's perspective the value of maximizing physical functioning by saving a leg versus a minor wrist deformity is a no brainer. However, from the patient's perspective her definition of self and ability to continue working as a pianist would be much less compromised by having a leg amputated.

In the previous section we took a high level view of the various roles a physician can play in the doctor patient relationship. In this section and the next one we review the emerging consensus on the ethical perspectives that guide what is permissible and impermissible decision-making in the relationship. Although autonomy is consistently an important value to be respected in the doctor-patient relationship there are some limits to what is permissible. Physicians have duties to provide evidence based care that is indicated for a condition. More often than not patients and physicians have similar goals and conflicts in values are not at issue. However, at the end of life there can be conflicts on what the patient judges to be in his or her best interest versus what the physician or family may want on behalf of their view of the patient's best interest. One of the best known and widely used ethical perspectives on how to approach such value conflicts is known as the principled approach.

Childers and Beauchamp in their well known Principles of Biomedical Ethics outline their perspective and approach, sometimes referred to as principlism or the four principles.<sup>24</sup> The four principles are autonomy (respecting persons), beneficence (the good of the person), non-maleficence (do no harm) and justice (fair and equitable health care). At the end of life the most ethically difficult situations are conflicts between respecting patient autonomy and beneficence. When patients choose to terminate life sustaining treatment or refuse treatment for an acute or reversible illness, physicians often are concerned that such treatment refusals are not in the patient's best interest and that they have a duty to convince the patient and family to reverse their decision.

### **Key Questions**

Under what circumstances may one stop life sustaining treatment (LST)?

Must LST be continued unto death?

What role should the patient's wishes play?

Is withholding or withdrawing LST a form of homicide or suicide?

What role should a physician play in responding to requests for hastening death?

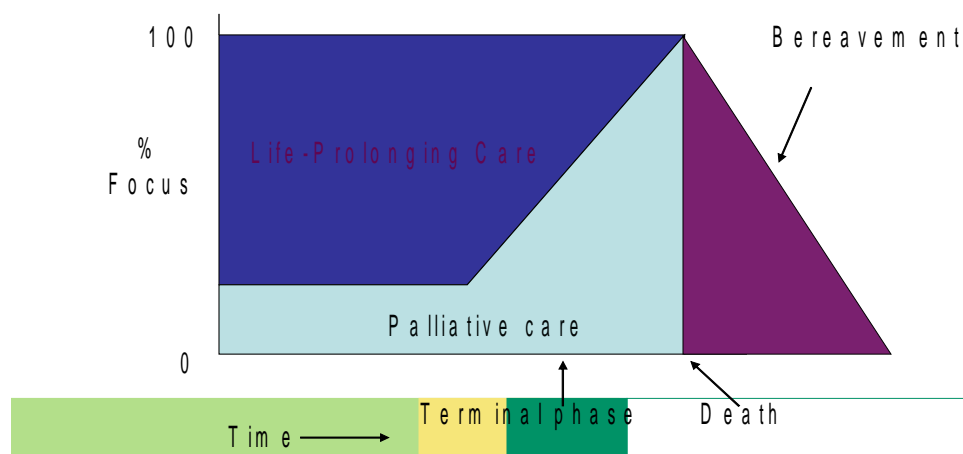
### **Refusing Treatments versus Requesting Aid in Dying**

The case law over the past 50 years has reinforced the ethical emphasis on respecting persons and choices even when such decisions may lead to a hastened death. Patients who have intact decisional capacity or surrogates acting on behalf of incompetent patients have an almost absolute right to refuse any and all treatments including antibiotics, surgery, intubation, nutrition, and medications. This includes discontinuing any treatments as well. However, the negative right to refuse treatments does not extend to a positive right, claim, duty or ethical obligation on the part of physicians to provide or initiate any and all treatments. Patients have a reasonable expectation to receive appropriate, evidence-based treatments from their physicians. However, they don't have a right or a claim on physicians to provide treatments which are not indicated such as receiving an antibiotic for a viral infection, or a chemotherapy treatment that is not effective for particular cancer. An additional limit on what patients can claim from their physicians has to do with rights of conscience where a physician might find a

particular treatment request morally repugnant or contrary to deeply held person values. Examples at the end of life are physicians in Oregon who would decline to participate in physician assisted dying.

## Part V: Palliative and Hospice Care—ethics and medical decision making at the end of life II

### Model of Care Transitions



#### *Hospice is a concept of Care*

Dame Cicely Saunders, a British physician founded the modern hospice movement. Witnessing the immense amount of suffering among patients with inadequately treated pain, she pioneered new more vigorous and effective end of life treatments. She also inspired the founding of the first residential based hospice where patients could receive adequate management of their symptoms. In the United States the Hospice movement developed as concept of caring allowing patients choice and the ability to receive care in their own homes. Hospice is a concept of caring involves the following elements:

- A treatment focus on comfort, control of symptoms, and quality of life; not on cure or remission of the underlying disease.
- Hospice care attends to the physical, psychological, spiritual and interpersonal aspects of the person.
- The unit of care involving that includes the patient but spouse, family and significant others
- A team-based approach to providing care that includes a medical hospice physician, nurse case manager, hospice social worker, chaplain, home health aid, volunteers and a bereavement counselor.
- A Plan of Care where the treatment goals of care determined by the patient and family
- A Medicare benefit covering medications, durable medical equipment and care team visits related to the terminal diagnosis.

The Medicare benefit is available to any person 65 years or older or any person who is receiving social security disability. The admission criteria for hospice services requires that a two physicians determine that the patient has a terminal diagnosis or life limiting illness of approximately 6 months or less.

Palliative care forms the core of the hospice medical treatment approach. However, the specialty of palliative care has come of age with a research base as well as evidence based medicine and is applicable to any person with a chronic illness. The major problem is providing palliative care as part of a team has been the lack of a business model to support such care. Various insurers are now experimenting with palliative care benefits which do not require a 6 month or less life limiting illness to be eligible for such care.

### ***The Current Medical-Legal-Ethical Framework for End of Life Decision-making***

#### **Reminder ---**

- Ethics looks at intentions and actions that are permissible and not permissible
- Case Law provides a societal consensus and sets a floor for what is permissible and not permissible
- Medicine provides a framework for what is clinically possible and what is medically indicated for treatment of diseases and symptoms

#### **The Sources of the current framework are:**

- Constitutional Law
- Administrative Law (e.g. FDA or EPA)
- Presidential Commissions on Bioethics
- Case Law (created by judges' rulings in common law)
- State Law (Legislatures and Statues)
- Medical Professional Societies and Practices (Oaths and codes of ethics)
- Applied Ethics

The health care professions have a unique role and status within society to promote health care values. Yet the most contentious issues that aren't resolved in the patient-physician relationship often make their way into the courts or legislatures for resolution (abortion, physician assisted dying).

#### **Legal Framework for EOL Care Decision Making (Constitutional and Case Law [judges])**

- Schloendorff v Society of New York Hospital 1914<sup>25</sup>
- Re Quinlan, 70 N.J. 10, 355 A.2d 647 (1976)<sup>26</sup>
- Cruzan v Director, Mo Dept of Health 1990<sup>15</sup>
- Vacco v Quill 1997<sup>27</sup>
- Washington v Glucksberg 1997<sup>28</sup>
- Terri Schiavo 1990 - 2005<sup>29</sup>

## **Basic Elements<sup>30</sup>**

- Competent patients have a common law and a constitutional right to refuse medical treatment, even if that treatment is necessary to sustain life
- Incompetent patients have the same rights as competent patients; however the manner in which these rights are exercised is different

## **Venue of Decision-making**

- The decision-making process should generally occur in the clinical setting without recourse to the courts.

## **Decision-making of incompetent patients<sup>31</sup>**

- In making decisions for incompetent patients, surrogate decision-makers should apply the following standards, in descending order of preference:
  - Subjective standard (the patient's own living will or durable power of attorney for health care)
  - Substituted judgment (do what you infer the patient would have wanted)
  - Best interests (do what is best, most reasonable for the patient).

## **Withholding or Withdrawing Treatments<sup>32</sup>**

- There is no ethical difference between withholding or withdrawing life-sustaining medical treatment.
- Artificial nutrition and hydration is a medical treatment and may be withheld or withdrawn under the same conditions as any other form of medical treatment

## **The right to refuse treatment<sup>32</sup>**

- The right to refuse life-sustaining medical treatment does not depend on the patient's life expectancy or being "terminally ill."

## **The Rule of Double Effect<sup>33</sup>**

- It is acceptable to provide pain medication sufficient to control a patient's pain even if it is foreseen that it may hasten the patient's death.
- Active euthanasia and assisted suicide are morally and legally distinct from forgoing life-sustaining treatment.

## **Central Point of the Framework is that it is Patient Centered**

- It is centered on the notion that the individual has a right to determine what kind of medical care he or she receives, at any time during their lives, including when they are terminally ill or critically ill.
- People have a right to control what is done to their own bodies.
- People have a right to control the use of life-sustaining medical technologies and machines in accordance with their own preferences, beliefs, and values.

## ***Physician Assisted Dying, Euthanasia, Palliative Sedation and the Rule of Double Effect*<sup>6, 34-36</sup>**

Hospice care has been critical in improving end of life care and addressing suffering at the end of life. The need for Physician assisted dying or euthanasia has certainly been lessened as hospice care has become a standard and a choice for end of life care. Only in the state of Oregon is physician assisted dying a legal option. Euthanasia is not a legal option anywhere in the United States, but is an end of life option in the Netherlands. For a small percentage of patients whose suffering cannot be addressed through palliative care, palliative sedation is an option. Palliative sedation is the induction of a deep sleep state in a terminally ill patient to address intractable symptoms and suffering.

### **Rule of Double Effect Dan Sulmasy, OFM, MD, PH.D.<sup>2 37</sup>**

- Doctrine
- Principle: very fundamental rule
- Rule: concrete prescription for action
- Meta-rule: when two rules clash then use the rule of double effect
  - Comfort (beneficence) versus non-maleficence (do no harm)
  - Relieving air hunger versus suppressing respiratory drive

**When beneficence and non-maleficence are in conflict use the rule of double effect**

### **Outcomes and Agency Matter**

- outcomes only matter – (utilitarianism) end suffering by hastening death
- If agency (intentions) only matter – (deontology) never harm a patient
- We give medications to patients all the time that have side effects. Our intention is to lower blood pressure, not to create dizziness, falls, or hip fractures
- We do surgeries to save lives, not create scar tissue, cause pain or other discomfort

### **RDE: Definition**

- One action, 2 effects
  - One is good
  - One is bad
- Act is not intrinsically evil or bad
- Intent is good, foresee the bad outcome, but the agent does not intend the bad outcome
- The bad action is not the cause of the good (hastening death to treat the suffering)
- Act is proportionate
  - The good is greater than the bad (morphine to relieve hunger or pain, is greater than the suppression of respiratory drive or sedation from level of medication to relieve the pain)
  - Means fit the end

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<sup>2</sup> Notes from Dan Sulmasy lecture at May Clinic Course on Ethics in Geriatric Practice. May, 2006

## *Balancing individual, family, medical, legal and ethical perspectives*

### **Provide a Healing Presence**

- Non-possessive Warmth
- Accurate Empathy
- Genuineness
- Patience
- Listening & Communication Skills
- Capacity to approach each person as unique individual

### **Help individuals and families ask and discuss the difficult questions:**

1. What's the goal of medical care for this person at this time & in this phase of her/his illness/injury & life?
2. What does the patient want?
3. What's in the best interest of the patient & patients (the "common good") ?
4. What's the prognosis & probable consequence of treatments (risks & benefits)?
5. Can I let go & let it be?

### ***Part VI: From Soloist to Ensemble Player***<sup>3</sup>

- End of life caring takes place in homes (including your own), nursing homes, hospitals, assisted-living, clinics, shelters and other venues outside the "office"!
- You have unique skills that can be helpful in all of these venues as well as with your family, friends, colleagues and patients!
- Let's continue talking and discussing as we change end of life care in America....

**When we honestly ask ourselves which persons in our lives mean the most to us, we often find that it is those who, instead of giving much advice, solutions or cures, have chosen rather to share our pain and touch our wounds with a gentle hand. The friend who can be silent with us in a moment of despair or confusion, who can stay with us in an hour of grief...who can tolerate not knowing, not curing, not healing and face with us the reality of our powerlessness, that is the friend who cares."**

*Henri Nouwen*<sup>4</sup>

<sup>3</sup> From CJ Peek on Collaborative Care

<sup>4</sup> <http://www.henrinouwen.org/> internationally He was a renowned priest and author, respected professor and beloved pastor Henri Nouwen who wrote over 40 books on the spiritual life.

## References and Bibliography

## A Few Selected Resources

### Some starter readings and resources in end of life care

#### Online Learning Resources

The Stanford University End of Life on-line Curriculum

Web Address: [http://endoflife.stanford.edu/M00\\_overview/def\\_pall.html](http://endoflife.stanford.edu/M00_overview/def_pall.html)

Full course on end of life care based upon the Educating Physicians End of Life Curriculum.

#### End of Life Online Curriculum - Modules

[Overview of Palliative Care](#)

[Dyspnea](#)

[Home Hospice](#)

[Opioid Conversion](#)

[Prognostication](#)

[Transition to Death](#)

[Palliative Sedation](#)

[Communication](#)

[Bereavement](#)

The Medical College of Wisconsin sponsors the End of Life and Palliative Education Resource Centers which is a treasure trove of information and links to resources.

Web site: <http://www.eperc.mcw.edu>



#### Overview of Medical Legal Ethical Framework

The Colby and Quill books are excellent overview of end of life care issues. Colby captures the emotions and lived experience of the cases that made end of life care what it is today. Quill, similarly is be through the major changes in increasing options at end of life for the past 30 years.

Colby WH. *Long Goodbye: The Deaths of Nancy Cruzan*. Carlsbad: Hay House Inc.; 2002.

Colby WH. *Unplugged: Reclaiming our Right to Die in America*. New York: American Management Association; 2006.

Quill, Timothy, *Caring for Patients At the End of Life*. Oxford University Press

Facing an Uncertain Future Together

Timothy E. Quill

