

# Case study on dementia: end of life decisions



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Ms. Long has been admitted to a skilled nursing home after four months in the hospital, and has been assigned a public guardian since she is no longer able to make life decisions on her own. The end-of-life decision needs to address the ethical concerns of beneficence, human dignity, informed consent, integrity and totality of the individual. The guardian is faced with the problem of deciding whether maintaining/sustaining life-giving care or palliative/hospice care is appropriate for their charge. Given the prognosis of the medical team, and a personal assessment, the apparent choice would be to exercise the palliative/hospice route. Comfort care at this stage becomes the basic concern. The palliative care plan should be the consideration for the do-not-resuscitate (DNR) provision. The guardian should also consider the alternatives of artificial nutrition and hydration, as well as cardiopulmonary resuscitation and the option to sustain life.

The concept of an appointed guardian to be the voice and advocate for someone who is cognitively impaired is a much needed tool. Unfortunately, there are barriers to good guardianship as this service is rife with fraud. Since guardianship can remove the basic rights of an individual, making them totally dependent on their advocate, the goal to protect the well-being of their charge can be lost.

This case study will present the proposal that palliative care is the course of choice, and that it is the responsibility of the guardian to develop an implementation plan that provides continued patient assessment of quality of life, and human dignity in the totality of the patient's need requirements.

Overview and Background

The End- of- Life Decision Making case study presents a problem where a public guardian has been appointed for Ms. Long, and is seeing her for the first time to compose an assessment, and make several determinations. One of those determinations is whether Ms. Long is terminally ill. Upon seeing her, the guardian takes note of the facts. Ms. Long has just been transferred from a four month stay in the hospital to a skilled nursing facility. Ms. Long's medical history states that she suffers with severe dementia, diabetes that impairs her vision, poor kidney function, has recent recurrent pneumonia and prior strokes. The challenge the guardian faces are, what decisions should be made that provide the quality of care and dignity Ms. Long deserves?

Today, the guardian sees that Ms. Long is very thin, and has a large necrotic pressure sore on her sacrum. She has an IV of running fluids in her left arm and her right arm is limp. Sometimes she is able to track the movement of the nurse, and sometimes not. She does not give answers to questions, either verbally or with nods, and is not able to concentrate on the person asking the questions. The speech therapist tries to get her to smile, but she doesn't respond. When Ms. Long is moved, she grimaces and cries out in pain. When offered a straw she accepts it, but does not suck on the straw. She is offered ice cream but after two spoonfuls, she has had enough and pushes it away, indicating with a slap that she is done.

The case study does not state whether Ms. Long is terminally ill, which is what the physician would be responsible for deciding, as presented in the prognosis of the patient. " When further intervention to prolong the life of a patient becomes futile, physicians have an obligation to shift the intent of care toward comfort and closure" (AMA, 2010). Given Ms. Long's severe

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dementia, deterioration of her kidney function, diabetes and her recurrent pneumonia, we are assuming the doctor's prognosis is that she is terminal. Terminal illness has been defined by the American Medical Association (AMA), as having a life expectancy of six months or less. Dementia can affect every patient differently in duration, and eventually the patient requires complete care. The question the guardian must answer is whether Ms. Long is at the stage of needing palliative services or hospice services? Determining life expectancy in a patient can be difficult.

### Background

As one approaches end-of-life, there are certain ethical concerns the patient should be concerned about. These would include the principles of beneficence, human dignity, informed consent, and integrity and totality (Ascension Health, 2009). The charge of this guardian is to assure that the principles outlined above are adhered to for Ms. Long.

The principle of beneficence is considered the first principle of morality, and applies to doing good while avoiding evil. This would especially be true in an end-of-life situation, and the role the public guardian plays in the decision making for the patient. The goal here would be to assure that Ms. Long is receiving the best care possible to meet her specific need requirements. These goals should be focused on employing the necessary life sustaining measures, or providing the best dignity of death provisions possible. The key concern of the guardian is being able to differentiate what is appropriate to the given situation.

The principle of human dignity assumes that every human being should be acknowledged as an inherently valuable member of the human community, and as a unique expression of life. Ms. Long has the right to life, the right to death, and the right to health care. In an end-of-life decision making, the guardian is challenged to see that Ms. Long receives the best possible care, whether it is the maintenance of life or the preparation for death.

The principle of informed consent is very appropriate in end-of-life situations. The patient must have all the facts available to them so that a cogent decision of care may be made, be free to evaluate this information without duress, be able to comprehend the extent of the information provided, and be competent to make a decision. Because these criteria cannot be met, it is the charge of the public guardian to intervene on the best behalf of Ms. Long.

The principles of integrity and totality apply to the well being of the whole person, and determining the best course of treatment for the patient. Each patient has a unique set of circumstances that they are dealing with, and the health care team needs to assess the patient's needs, and develop a care plan accordingly. The public guardian must be capable of inferring what Ms. Long's desires would be, given that she is incapable of doing it herself.

## Problem Identification & Analysis

### Problem Identification

The decision the guardian is faced with is, at what stage of the life/death process is Ms. Long? Once this is determined, then the decision as to

whether or not the guardian should support the health care team in maintaining/sustaining life, or supporting a transition to death can be made. Given the advances in technology, patients can be maintained for an extended period of time. Here is where one needs to understand where in the process the patient is.

Key indicators established by the medical community available to the guardian for their decision making, can be derived by asking the following questions (WebMD, 2008):

Does the patient show excessive sleepiness and weakness?

Are there marked changes in the patient's breathing?

Are there changes in the patient's visual and hearing capability?

Is there a decrease in appetite and ability to swallow?

Are there changes in urinary and bowel habits?

Are there changes in body temperature?

Are there emotional changes and lack of awareness in the patient's surroundings?

Ms. Long meets at least four of these criteria, so the preliminary decision would indicate that preparation for the death process is more appropriate than following a maintain/sustain regime. For this decision, the guardian must work with the health care team to determine what level of palliative and/or hospice care is required, and make the determination of whether do-

not-resuscitate (DNR) or cardiopulmonary resuscitation is required. Palliative Care

Dementia describes symptoms related to changes in cognition, personality, and behavior (Peterson, 2010). It is very clear that Ms. Long's leading symptom is that of dementia. The challenge to the guardian is to be able to assess what Ms. Long truly desires, given her inability to cogently communicate their real desires. Ms. Long is listless and without focus. One could easily infer that her action of swatting away a food offering by the speech therapist had an immediate, " I don't want this food" action, or a longer term, " I don't want to live" response.

Sadly, dementia is not typically considered a terminal disease in itself (Sachs, et. al., 2004), but rather, an incapability of the patient to assess or communicate for themselves their condition and/or preference of treatment. This will often result in the patient not receiving the comfort care they require, and can in some instances, hasten their demise. The health care team needs feedback from the patient so that they may assess the effectiveness of the health care being provided. Bed sores, such as what Ms. Long has, is a perfect indication of the inability of the patient to make the health care team aware of a problem. This, in turn can lead to gangrene or other complications. Comfort care is the basic tenant of palliative care giving.

In Ms. Long's case, it is crucial that she is on the most appropriate pain medication regime, and she is in the best apparatus to preclude the occurrence or progression of her bed sores. Palliative care also requires that

the guardian is capable of interacting with the health care team as Ms. Long's advocate. This requires that the guardian possess some knowledge of medical procedures and processes, as well as knowing what alternatives is available to the patient through the hospital administration or the court system. Both can be very daunting and fraught with impasse that is not in the patient's best interest. The guardian must be able to cut through the road blocks to assure that Ms. Long's needs are met, and also participate in the decision making as to when Ms. Long is transferred from a nursing care, to hospice care environment.

Do-not-resuscitate (DNR).

DNR is self explanatory when referring to a medical patient, but also has a legal implication. DNR naturally follows in end-of-life scenarios where the decision must be made as whether life should be maintained. A legal paper called a DNR informs medical professionals of the patient's decision to decline CPR, or other life saving measures if they go into cardiac arrest or cease breathing. The law requires that any place that offers medical care must execute CPR, unless a patient has signed a DNR (ASCO, 2009). Ms. Long, being unable to do so, the guardian will have to see that a DNR is in place, allowing a natural death to occur.

Commonly, physicians approach a patient that has reached the end of treatment that was not effective, and if the patient is suffering, or if the patient has no quality of life left, to offer an option of a natural death (ASCO, 2009). This is not an option for Ms. Long since her dementia has progressed to the point where her cognitive skills are almost non-existent. This leaves



the choice to a guardian to act on her behalf, using the information given by the physician.

### Cardiopulmonary Resuscitation

If Ms. Long was to stop breathing, or her heart was to stop pumping and CPR was performed, one would only be delaying the inevitable. Ms. Long is terminally ill and her quality of life has drastically declined. She is unable to move on her own, speak for herself, she is in obvious pain, and she has shown no desire to sustain herself through food. These are all things that a guardian should take into account when trying to make the best end-of-life decision on behalf of Ms. Long.

### Statement of Key Problems/Issues

The key issues the public guardian must take into consideration should assess the ethical principles associated with end-of life decisions required for Ms. Long. It is apparent that the quality of life Ms. Long has is substandard, as she is barely conscious and capable of interacting with her surroundings. Ms. Long's human dignity would indicate that even though she has a right to life with all other things possible to sustain that life, she also has the right to death where no undue measures are enacted to prevent this. Ms. Long must be considered in her totality and given that she is incapable to act on her own accord, the public guardian must provide for her informed consent.

### Alternative Solutions

#### Artificial Nutrition and Hydration

When making decisions about nutrition for patients in the end-of-life phase, family members usually tend to think that if the patient is no longer eating and taking nourishment, it is best to begin them on IV fluids and a feeding tube immediately. However, this is not always the best step. When making this kind of a health decision, the family member or, in Ms. Long's case, the guardian must first consider her level of bodily dilapidation, and whether nourishment can actually bring her back to health. If the answer is "no", then a different nutrition plan is needed. Allowing the patient to decide whether or not to forego nutrition and hydration when their quality of life is gone, is a very hard decision for a caregiver to make. At this point, medical personnel will introduce the thought, but usually not advocate the possibility of artificial nutrition and hydration (Schultz, 2009).

The caregiver, or guardian, must consider the quality of life that Ms. Long will have after the insertion of a feeding tube and/or intravenous fluids. This process and application can sometimes be quite painful for the recipient. A majority of doctors would also agree that by introducing this kind of nourishment into a patient's diet can make the patient more uncomfortable. These types of nourishment have been known to cause bloating, swelling, cramps, and shortness of breath in elderly patients (Caring Connections, 2006). It can be better to let the patient have as little or as much food as they want, when they want it, until such a time when they can no longer take nourishment for themselves. After a certain period of time in this condition, it is the responsibility of the guardian or the family caregiver to decide when the artificial nutrition is deemed to be an "extraordinary means" for prolonging the life of an elderly patient. Extraordinary in this case means

that the administration of nutrition and fluids is contrary to the body's natural desire to go into permanent shutdown. It has been observed by the medical community that when nutrition and fluids are withdrawn, the patient becomes euphoric from the added ketones that the body produces. The glycerin "lollypop" the nurses use, slightly dipped into water is all the patient desire; just enough to moisten the tongue and lips. After great consideration, they may decide to discontinue all nourishment and allow the patient to die peacefully (Lamers, 2010). This could be what Ms. Long was demonstrating when she swatted the speech therapist's hand away, when trying to feed her.

### Cardiopulmonary Resuscitation (CPR)

CPR is a life sustaining measure and stands for cardiopulmonary resuscitation. CPR is the procedure used to prompt someone to start breathing, or for their heart to start pumping after either has ceased. The process is carried out by chest compressions, mouth to mouth breathing, placing a tube through the throat, electric paddles placed on their chest, or medications given directly into their veins (FCA, 2009).

This life saving technique is primarily beneficial to people who are involved in accidents, have had a heart attack, or experienced some sort of trauma. CPR is much less effective to people who are afflicted with a chronic or terminal illness. When a terminally ill patient is given CPR, few will recuperate enough to go home (ASCO, 2009). The act of CPR itself can be damaging, causing broken ribs, liver damage, or pain to the person it is being performed on (FCA, 2009). Two very serious complications can arise

from CPR being given to a terminally ill patient. The first problem that may occur is harm to the brain from a deficiency in oxygen, leaving them in a vegetative state. The second complication that must be considered is that the patient may never breathe on their own again, possibly putting them on life support (ASCO, 2009). For Ms. Long, one would likely be extending her life only to see her not recover, possibly leaving her on life support permanently.

### Barrier to Good Guardianship

Guardianship often removes the basic rights from the individual, such as the right to make health care decisions, make gifts, marry, decide where to live, and to sell property. When the court appoints a guardian to make decisions for another person, the guardian owes that person a special duty of care and accountability. Guardianship should only be used as a last resort. However, a judge may determine that a guardianship is the only way to protect the assets, and provide safety for an adult with diminished capacity. Ensuring good guardianship depends on the quality and dedication of the guardian, as well as the oversight of the Court (Aging Network, n. d.). Ms. Long, who is without family, has been appointed a guardian by the court to protect and provide for her.

A drawback to an alternative guardianship lies in the fact that guardians are subject to court supervision, where agents acting under the power of attorney are not. Even with supervision though, an agent may misuse and abuse their powers making it imperative that care is taken in selecting an agent (Aging Network, n. d.).

The Center for Social Gerontology, Inc (TCSG), established in 1972, is a non-profit research, training, and social policy organization in Ann Arbor, MI, whose purpose is to promote the independence of older persons and advancing their well-being. TCSG has conducted a number of studies to analyze the different aspects of the guardianship issue. They studied how the guardianship system is handled in the courts, the use of mediation in guardianship cases, and examined how to improve the quality of guardianship service providers (TCSG, 2004).

In 1988, the Michigan Legislature enacted the Michigan Guardianship Reform Act to cover the appointing of guardians for legally incapacitated individuals. This act safeguards individuals that are facing guardianship to the right of counsel, independent evaluations, and a hearing or a jury trial. A legal preference was stipulated that partial guardianships be used for specific decisions, rather than full guardianship over all possible life decisions. It also specified that guardianship be used only as necessary in order to promote and protect the well-being of the individual (TCSG, 2004). For this case study, the guardian sphere of responsibility is limited to Ms. Long's end-of-life decisions.

A TCSG report was highlighted in a Detroit Free Press article on a Michigan state audit. This audit of five probate courts stated that the guardians, family members, court appointed as well as professionals (lawyers), abused their charges by paying bills late, not accounting for how they spent money, borrowed interest free money from their charges to buy things for themselves, and consistently filed inaccurate accountings, all without being held responsible and rarely sanctioned. This resulted in the Michigan

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Supreme Court creating the Task Force on Guardianships and Conservatorships in 1996 (TCSG, 2004).

Guardianship has gone from total control the public guardians had over the life choices of individuals, to mediating other alternatives that provide for the individual's need of help, assistance and support. Rather than think in terms of incompetence, new legislation is replacing it with assisted competence, to include a range of supports that will enable individuals with cognitive disabilities, to receive assistance in decision-making that also preserves their rights (Aging Network, n. d.). For the reasons pointed out above, the court approved the petition to provide a guardian for Ms. Long.

#### Decisions & Recommendations

The guardian decides that Ms. Long is terminally ill given the fact that she has a history of pneumonia [possibly the aspirating kind that precedes death], is receiving artificial nutrition and hydration, cannot eat or swallow, is listless and non-responsive, and has bed sores that indicate total incapability of ambulation or movement. The guardian determines that palliative care is required, and will recommend to the health care team that hospice care be considered. The guardian makes these decisions based on Ms. Long's quality of life potential, inability to provide informed consent, assessment of the whole person to insure she has the highest dignity possible as she faces her final troughs with life.

#### Implementation and Monitoring Plan

The guardian has the responsibility of evaluating Ms. Long's condition quickly, and developing an affirmative action plan that provides the best quality of life possible for the given situation, while retaining the highest human dignity and compassionate care possible. Questions to ask as being responsible for an incapacitated person as they apply to this scenario include, (FGA, 2000):

What is the update in prognosis or change in diagnosis?

What are the inputs from the hospital ethics committee or other social agency that can help sort through options for care decisions?

What guidance is the court providing to the public guardian? How do they affect the patient?

What are the patient's financial assets and ability for extended care? Does this preclude certain health care services?

Do they have Medicare, medical or long-term care insurance, or other specialized insurance plans for hospital or hospice coverage? Are they eligible for Medicaid?

As the guardian develops the implementation plan, they should include periodic conferences with the health care team, physician, nurses, therapist(s), and others that include both the frequency of review, and provisions for patient care plan adjustments. The implementation plan should be flexible enough to cover contingencies that may be encountered with the patient; deterioration or improvement in medical condition. This

frequency could be as little as weekly or bi-weekly, or as often as daily, depending on the status and urgency of the medical care plan.

The assumption when one enters hospice, is they are on the final path of living; that of death. Circumstances may change in the patient's condition that may allow for the patient to contribute to their healthcare decisions. Ms. Long's capacity, having advanced dementia, would make this possibility highly remote.

The guardian should always be questioning themselves to make sure they are meeting their ethical responsibilities of their patient's needs including assuring the whole patient is provided the highest quality and dignity of care in their dying moments. The whole being is what is important.