A Continuum of Care Case With Commentaries

An 81-year-old single female with her one sibling (a brother) as her legal representative was admitted to the ECF two years prior with a diagnosis of schizophrenia, major depression, psychosis, short term memory loss, CVA, history of respiratory failure with tracheotomy insertion and gastrostomy tube for nutrition and multiple other conditions. The tracheotomy and gastrostomy tube had been removed after extensive therapy and repeated resident dislodging of the tubes. Code status was changed from full resuscitation to DNR CC arrest after her legal representative found her living will. The resident's living will clearly stated that she did not want a feeding tube. When the living will was created, the resident was alert and aware of her decisions. She had attached studies and articles related to unsuccessful resuscitation efforts.

The resident's psychosis increased despite intervention with medications. The medications resulted in auditory hallucinations commanding her not to eat under threat of death. The resident stopped eating, resulting in significant weight loss and a deteriorating general condition. After a discussion with her legal- representative, medical, and psychiatric staff, the brother agreed to transfer her to the hospital for shock therapy and medication management for major depression and psychosis.

While at the psychiatric hospital, the legal-representative was approached about inserting a gastrostomy tube for nutrition during treatment to assist with recovery and changing the code status due to hospital policy. All patients admitted for shock therapy have their DNR's rescinded during treatment due to the risk of the treatment and full resuscitation efforts would be made in the event a person's heart stopped. Both forms of treatment resulted in minimal response.

The resident returned from the hospital to the ECF with a gastrostomy tube and a full code order due to the psychiatric hospital's policy. While the patient was receiving treatment, her legal representative reported an early diagnosis of Alzheimer's disease and no longer felt comfortable making decisions. Consequently, he petitioned the court for a legal guardian to be appointed. The guardian continued all treatments with the exception of the code status which was changed to a DNR CC Arrest. The resident's brother stopped visiting due to his own compromised state and the resident continued not to take nourishment orally and occasionally dislodged the gastrostomy tube.

(Editor's note: This is an actual case. However, we are not identifying the source for reasons of confidentiality).

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Commentaries on Care Case

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This resident has many health issues, which frequently makes it difficult for the legal representative to make decisions regarding medical treatment and be sure they are fulfilling the wishes of the person. Ethical issues identified in this case include:

- The need to identify the benefits and burdens of this treatment (ECT) on the resident, particularly in light of her directive that she does not want a gastrostomy tube, and the need to change her resuscitation status.
- ECT is usually a choice of treatment when medication is not effective, and often requires hospitalization. The effect on the resident of relocation to another campus and the impact of the potential side effects of ECT on her other medical conditions should be assessed to determine possible negative outcomes.
- The brother is a major stakeholder and is alone. What support was given to him to help him sort out the issues to make an informed decision regarding treatment? Was the brother overburdened with having to make this decision?
- At what stage is the resident with regard to chronic disease management? It seems that she has multiple conditions, in addition to the mental health diagnosis, that may be contributing to her declining health status. Does she meet the criteria to be evaluated for palliative care?
- There was minimal response to the treatment, yet the court-appointed guardian has agreed to continuation of all treatment, including repeated reinsertion of the gastrostomy tube when the resident dislodges it. Should the treatment be continued?
- This person may not be deemed terminally ill with her individual diagnoses, but is she in a terminal state due to multiple chronic diseases?

Long term care organizations have a great opportunity to help assist residents and family members/surrogate decision makers to prepare for potential chronic disease changes through the care plan process. The goal is to assist residents and family members/surrogate decision makers to begin thinking about and asking questions related to ongoing changes in health status. As the resident's health status declines, it is beneficial to include the primary care physician in the meeting to answer questions and explain the changes that may need to be addressed in the near future. Residents and family members/surrogate decision makers often find it difficult to discuss the unknown.

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Addressing these concerns regularly in the care planning process can decrease the number of crisis decisions that residents, family members/surrogate decision makers may have to make.

This case also brings up the question of when to address whether treatments may not be providing sufficient benefit and should perhaps be discontinued. A court appointed guardian may or may not discuss treatment decisions with the family, but in this case the brother had withdrawn from participation. Therefore, it is important that a staff person establish a relationship with the guardian to keep him/her informed of the resident's response to treatment as well as her overall condition. Also, the guardian is sometimes limited if the resident's living will or health care directive is not directly related to the current situation by definition, such as if she were in a terminal state.

An ethics consultation with the guardian regarding continuing treatment would be beneficial. It would provide the guardian support and foster decision-making that would be consistent with the resident's values and directives.

This case presents many questions related to multiple chronic disease issues and how to make treatment decisions in such cases. Including the care plan team as active members of the organization's Ethics Committee better prepares the staff to recognize situations that may arise requiring complicated decisions to be made. The case demonstrates the challenges that decision makers have in determining if it is possible to reverse a resident's declining health status, in assessing the burdens of treatment, and in judging how long before the treatment needs to be re-initiated.

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This case study is rich with clinical information and reveals layers of issues surrounding the palliative care that ought to have been organized for this 81 year-old resident of an Extended Care Facility (ECF, seemingly on a downward trajectory resulting from her multi-factorial chronic illnesses. We are provided extensive medical and social history, telling the story of baseline physical and psychiatric diagnoses accompanied by many complications. We are also made aware of a changing cast of caregiving characters.

At the end of a reading of the case, though, we need to sift through the abundance of data to see if there is a way to justifiably simplify the ethics issues. What we have is the story, very typical, of an elderly person whose capacity changes over time—in this case, due to progressive mental illness— and who, also over time, undergoes progressive physical deterioration and debilitation.

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What is not typical in this case is the fact that the Living Will created by this woman not only clearly articulates her wishes, but was drawn up with a complete explication of why she made the choices that she specified. The research studies and articles she had included with her advance directive ought to have made it so stand out from what staff usually sees that there should not have been any confusion or misinterpretation of the decisions this resident had made.

The progression of this person's mental illness results in a hospitalization for treatment that calls for the temporary suspension of her DNR. Further, the gastrostomy tube that was discontinued at the ECF, because she repeatedly pulled it out, is reinserted while she is hospitalized, with her health care proxy's consent, to enhance her recovery. Upon completion of the hospital treatment, she is returned to her ECF, having shown no improvement in her clinical status.

As happens all too often in the course of residents'/patients' movement from one facility to another, the temporary suspension of her DNR was never reversed upon her return to the ECF, and the reinserted feeding tube was left in place. Both were in direct violation of her clearly articulated Living Will. The document ought to have been part of her chart. It is very problematic that the advance directive not only was not with the resident's chart upon readmission, but also that it was not actively sought and replaced on the chart when she arrived back at the ECF. Given the atypical thoroughness with which the document was completed by the resident, with its attending documentation, it is even more problematic that no one apparently made the connection with the name or appearance of the resident and her very unusual living will.

The rationale for advance directives is well known and supported by clinical providers, clinical institutions and healthcare policymakers. Advance directives are meant to allow and protect the autonomy of individuals to make informed decisions about their healthcare in advance, so that those decisions can be known at the time that patients/residents do not have the capacity to articulate their wishes.

Pertinent to the ethics issues is the fact that a woman with capacity prepared an advance directive that spelled out her desire to be DNR CC – arrest and not to have a feeding tube placed. She also designated a health care proxy.

The question presented to us at the end of the detailed story is whether any or all of the intervening factors—the hospitalization and treatment, the continued downward progression of her psychiatric and physical illnesses, and the capacity-limiting diagnosis of her designated health care proxy requiring the appointment of a new proxy in the person of a court-appointed legal guardian—constitute justifiable reasons for ignoring the prior and fairly immutable fact that a person with full capacity had articulated and documented an advance directive

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which was a clear and also well-documented presentation of the patient's wishes, and which certainly indicated sound reasoning.

This case study depicts two major breaches in the fiduciary relationship that LTC staff are meant to honor with their residents/patients: the honoring of an advance directive and the careful transmission of patient wishes, as well as they can be known, when residents/patients are transferred from and re-admitted to the long-term care setting. As a matter of record, the failure here rests on both institutions. It is clear that the hospital knew about the Living Will since they had to obtain the proxy's permission to write orders that would countermand the advance directive.

Were that fiduciary relationship to be honored and were this patient's autonomy to be protected and implemented, not only would the DNR status be restored to what it was before the hospitalization, but also the feeding tube, declined in advance by the person with capacity, shown to be ineffective in restoring good nutritional status, not an intervention that would correct the underlying disease pathologies that the resident suffers, and furthermore, a potential source of problems like infection with the resident's repeatedly dislodging it, would be discontinued.

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