

**Commentary:**

**What Edward Taught Us About Healthcare Decision-Making Before and at End of Life: Why We All Must Listen**

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As the former regional director and executive director of residential providers of services to people with intellectual, developmental, and/or psychiatric disabilities, I have received the phone calls that most of us in those positions dread. One of mine started something like this:

Staff: We're taking Edward to the hospital emergency room because his skin and eyes are yellow.

Me: Okay, sounds like the right thing to do; is he alert and aware of what's going on?

Staff: Yes, just annoyed that we have to go to the ER.

Me: Par for the course; let me know what the ER says.

Okay, so as phone calls go, that one was not earth shattering. In fact, it was pretty mundane. What ensued during subsequent conversations, and over the next few years, however, was not mundane and helped reinforce for me my belief that we need to do advance care planning with people who use our services.

“Advance care planning” is the language used by the community of people who work in palliative and end-of-life care. It is the process of identifying one's wishes about healthcare treatment and care at end of life (usually through a living will); and identifying a surrogate decision maker, usually known as a Healthcare Agent, Healthcare Proxy, or Durable Medical or Healthcare Power of Attorney.<sup>1</sup> It is possible to only have a Healthcare Power of Attorney and not a living will; but it is generally recommended that one have both a living will (the document that spells out one's wishes) and a Healthcare Power of Attorney (the surrogate decision maker). Legally, an Advance Directive can include either or both of these elements, but again, the recommendation is usually that a person has both. For purposes of this article, we will use the language of “Healthcare Power of Attorney,” and when we say “Advance Directive” we mean the two elements combined: the living will and the Healthcare Power of Attorney.

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<sup>1</sup> Different states use different language for this role as surrogate decision maker. They all refer to the same person; that is, the person designated to act on the individual's behalf for healthcare decisions, when the individual is unable to do so

**Having That Critical Conversation.** Much like our historical approach to intimacy and sex, we rarely have conversations with the people who use our services with the intent of advance care planning around healthcare wishes and, if need be, care at end of life. We are doing a disservice to the people we support and ourselves as providers of those supports when we fail to identify surrogate decision makers and acknowledge people's preferences about their own care.

There are several reasons why we need to be doing advance care planning with people who use our services:

- The notions of autonomy and self-direction do not only apply when people are healthy, though given our lack of planning in the past it would be easy to think this was the case. Self-direction and being in charge of one's life is a right we all deserve and that right does not change when one develops a critical, chronic, or terminal illness.
- Too often, people with developmental and intellectual disabilities are excluded from medical decision-making because they are presumed to be incompetent and/or not capable by the sheer virtue of their DD/ID label. By failing to plan ahead, we further reinforce this notion because we are ill prepared to demonstrate why and how we know someone is capable (aside from just saying something to the effect of "but he makes all his own decisions" or worse, "it's his choice").
- Trying to gather information and plan at the eleventh hour when a critical decision is staring us in the face makes no sense, is immensely difficult, is fraught with emotion that often leads to poor judgment, and is a poor response on our part as a system.

**Edward's Surgery.** So, how was the original phone call connected to the need for advance planning? Let me continue with the story.

***Issue 1): Too often people are presumed to be incompetent and/or not capable because they have the label of intellectual disability (still known in the medical and legal community as the clinical diagnosis of "mental retardation").***

Within a few hours of that phone call, I learned that Edward needed to have his gallbladder removed. Again, not earth shattering. Edward was a very capable man and was certainly able to consent for surgery. That was until the surgeon read one of Edward's old psychological evaluations wherein the evaluator indicated that "Edward has the mental capacity of a seven- year-old" (paraphrasing). The next conversation then went something like this:

Surgeon: "Seven-year-olds cannot consent for surgery. Who is this man's Guardian or Power of Attorney?"

Me: “He is not seven, he is 68; and he is his own Guardian. He doesn’t have a Power of Attorney; he is capable of consenting on his own.”

Surgeon: “No, he’s not capable of consenting. He is \_\_\_\_\_ (the “R” word) and I am not operating on him unless someone else consents.”

Given the urgent nature of the situation, we did not have time to get on our advocacy soap box and explain why we were clinically convinced Edward had the capacity<sup>2</sup> to consent for surgery. We therefore chose the path of least resistance and speed, which was to quickly prepare (with Edward) an emergency Healthcare Power of Attorney specific to that event. While it would have been helpful to have had plans in place before this crisis, Edward was fortunately both medically and legally capable of making the choices required to execute a Healthcare Power of Attorney.

With that detail completed, Edward and his Healthcare Power of Attorney discussed the issues surrounding the surgery (risks, benefits, etc) and the Healthcare Power of Attorney consented to the surgery (Edward agreed, too).

***Issue 2): Self-direction and autonomy do not stop as one gets older and/or develops a critical, chronic, or terminal illness.***

**Healthcare Power of Attorney & Advanced Directive in Action.** Several months later, I left my position as director of the agency that supported Edward. But Edward was very important to me and I chose to stay somewhat connected to him and his life. As he grew older, I became more and more concerned about who would be present in his life to help him make decisions, healthcare included, as he had only one elderly sister living and she was 3,000 miles away. I eventually met with Edward and his team and discussed putting in place a more detailed Advance Directive. This Advance Directive would not only name the person whom Edward wanted to act on his behalf in healthcare matters, but it would also ensure we all understood his wishes about the healthcare – and particularly end-of-life care – that he did and did not want, and allow his Healthcare Power of Attorney to make sure those wishes were honored. Edward was always very clear about his wishes and he liked the idea of having someone he trusted to help him. Edward chose me as his Healthcare Power of Attorney (which he was capable of doing) and for many years, my role was pretty limited.

Now, fast forward six years; and the phone call goes something like this:

Doc: “Edward is hospitalized for aspiration pneumonia; he failed his swallowing study miserably; and we need your permission to put in a feeding tube.”

Me: “Does this need to be done immediately... as in the next few hours, or sometime today?”

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<sup>2</sup> A clinical assessment of a person’s ability to make a decision free of coercion, based on a set of criteria including the person’s understanding of the options, the risks and benefits, the rationale for the decision and the person’s values. Respecting Choices Advance Care Planning Curriculum, 2002; Applebaum, P. (2007). “Assessment of Patients’ Capacity to Consent for Treatment”.

Doc: "No, we can do an NG (nasogastric) tube for about 48 hours."

Me: "I am several hours away today and am not willing to make this decision without talking with Edward. I can be there in the morning. If he is okay with the NG tube, you can try that until I can get there. If he is not okay with it, let me know so we can figure out what our options are."

In the six years since the original gallbladder surgery, Edward's physical and mental health had deteriorated significantly and it was doubtful he would have had the capacity at that point to make the decision about the feeding tube. Clearly the hospital felt he did not have the capacity as they were already expecting me to make the decision.

If Edward had had no Advance Directive already in place, things would not have been so clear. Because of his mental confusion and his decreased psychiatric health, Edward would not have been seen as having the medical and legal capacity to complete an Advance Directive (the document he had completed before); and I would not have been seen as having the authority to make the requested decisions.

**What Could Have Happened.** If we had not done advance care planning with Edward several years earlier, and I had not been the Healthcare Power of Attorney, one of three options would have likely been suggested:

1) Once again, go through the "emergency Healthcare Power of Attorney" process. The problem with this is that for an individual to name his/her Power of Attorney he/she must have the capacity to do so and there must be someone willing to step into that role (someone who is not a paid healthcare provider as most staff is considered to be). As mentioned above, given Edward's confusion it is highly unlikely he would have had the capacity to name a surrogate.

2) Go to court and request to have a Guardian appointed immediately. Even given the urgency, this would have likely taken several days at best; and in the meantime, Edward was miserable, all the while pulling out the NG tube repeatedly, complaining of being hungry and thirsty and becoming more and more agitated and cantankerous. Additionally, his physicians were quite concerned about his physical condition and they were anxious to move ahead on improving his nutritional status. Waiting several more days really was not an option.

3) Look to "the system" for a decision. Depending upon where one lives, it is possible that without an identified surrogate decision-maker, the decision would bounce to the local director of administrative services or beyond. I do not know about you, but I, for one, do not want someone making life and death decisions about me or someone I care about when he/she doesn't know me (or the person); may have never even met me (or the person); and certainly does not know my values (or the person's), what is important to me and what I expect from my healthcare. I also do not want to be the administrator being asked to make such decisions under those same circumstances. It is bad planning and poor policy either way, especially knowing that we have other

legitimate options. Last resort effectiveness maybe, but certainly neither person-centered nor based on any semblance of self-direction.<sup>3</sup>

Ultimately we decided not to do the feeding tube for several reasons; not the least of which was that Edward did quite well on a second swallowing study; and one of the things we knew that was immensely important to him was eating a meal, preferably a big southern meal! We also learned that his swallowing difficulties were directly correlated to how he was feeling both physically and mentally. The decision was not to do the feeding tube, but to put in place protocols for how to support him during meals so as to minimize the chances of him aspirating again.

Having an authorized decision-maker who knew Edward, his preferences and his capacities, eliminated the need for an uncomfortable feeding tube procedure and allowed him to continue eating foods he enjoyed with appropriate supports. This not only valued his personal preferences, but also helped his medical and psychological recuperation and avoided the potential infections that can often accompany any invasive procedure.

Within a week it was time for Edward to be discharged, but he was still in poor shape physically, so when he left the acute care hospital he was moved temporarily to a nursing facility for short term rehabilitation.

**The Dreaded Phone Call.** Then it happened. The 1:00 a.m. phone call we really do dread:

Doc: "Edward had a heart attack at the nursing home and was found unconscious. They do not know how long he was without oxygen. He is on life support but is completely unresponsive and has no brain activity. We need to know what you want to do."

Me: "I need to come to the hospital and see him and talk with his doctors and friends before making decisions."

***Issue 3) Eleventh-hour planning is not planning; it is an ineffectual response to our lack of process for thinking ahead.***

What started out as a relatively simple issue around needing someone to consent for gallbladder surgery, over time lead us down a path of supporting Edward in the best way we knew how all the way to the very, very end of his life; using all the tools and skills of good person-centered practices we knew to use, including advance care planning. Edward was fortunate to have a plan in place, as was I as his Healthcare Power of Attorney, so that we were not trying to make life and death decisions in the absence of information about what was important to him and what his values were.

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<sup>3</sup> North Carolina is one of 41 states with a surrogate decision making law. Another option would have been to look to the statute for direction which in this case would have dictated calling Edward's sister. There may be other options based on surrogate decision making statutes; that information is not detailed here but will be in a series of articles mentioned at the end of this article.

Like it or not, death is the one great equalizer. It *will* happen to all of us, including the people we support. As systems of support, we have championed self-direction and person-centeredness; but if we cannot help someone maintain positive control during a critical illness or at the end of his/her life; and if we cannot try and ensure that someone's final wishes are honored, we are out of time. We do not get to submit a "plan revision" on this one.

**Need for Advanced Directive Planning Training.** Statistically, it is estimated that only 18% to 36% of Americans have an Advance Directive<sup>4</sup>. Anecdotally, for people with intellectual and developmental disabilities who have capacity to assist in creating an Advance Directive, we know that figure is significantly lower.

This is not to say that no one is trying to address the issue. In North Carolina for example, on our state's mandated person-centered plan format we include the statements "I have a living will" and "I have a Healthcare Power of Attorney" (owner of plan or plan writer checks yes or no for each statement) and beside each one, there is a place to check off, "if no, I would like one". Unfortunately, most of the plans I have looked at have a "no" and "no" response; and recently a Medicaid auditor shared that she, too, has never seen a plan on which someone indicated they were interested or would like more information.

Planners truly have no idea how to answer these questions. At a recent training on "People Planning Ahead",<sup>5</sup> out of 25 participants, only one person worked in the developmental disability/mental health services system, even though marketing for the workshop was targeted to those providers. Administrators and planners do not know what they do not know, and they really do not realize how much information and skills they're lacking.

People with disabilities are dying in places and in ways they would never wish (and we would never wish for them) because we are not having these conversations ahead of time, when it is not an urgent situation. The professionals who would in most cases have these conversations (Qualified Developmental Disabilities Professionals (QDDPs)', Case Managers, Social Workers, Nurses, etc.) do not know how. We are not teaching them and are not setting the expectation; and they are not doing it because they do not know how and do not understand the ramifications.

**Edward's Passing.** In Edward's case, after much conversation with his physicians and others who knew and loved him; and after many of his friends came to visit, we made the decision to remove the ventilator. Based on previous conversations with Edward and in accord with his Advance Directive, we believed this is what he would have

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<sup>4</sup> Advance Directives and Advance Care Planning. Report to Congress. (2008). Can be downloaded from: <http://aspe.hhs.gov/daltcp/reports/2008/ADCongRpt.pdf>

<sup>5</sup> Kingsbury, Leigh Ann Creaney (2008). A planning guide and accompanying training for using person centered practices to support healthcare decision making and care at end of life wishes. Available through [www.aaid.org](http://www.aaid.org) and/or the author.

wanted. We presumed he would pass away, but no one really knew for certain. As it turned out, there were five of us there, all former staff and/or friends holding hands with each other and with Edward as he passed away a few minutes later.

If heaven exists and Edward and I are lucky enough to meet there someday, I expect he will read me the riot act for letting the situation reach the point that it did. Edward loathed hospitals and he really did not want to be connected “to a bunch of tubes” (as he once described it). He was not wearing clothes he liked when he died and he probably would have been somewhat embarrassed by how he looked. But if he had not had a Healthcare Power of Attorney, his care would have been very different. He would have had a feeding tube months earlier and he would have likely been utterly miserable for the remainder of his life. He would have had very different care – without a full examination of the options.

If Edward had not had a Healthcare Power of Attorney, two physicians (possibly after consulting the hospital ethics committee and his elderly sister) would have made the decision to turn off the respirator; and Edward, the grumpy old man with crystal blue eyes and a great laugh, who loved nothing more than a big ole’ Southern meal, playing the harmonica, and everything Elvis probably would have died alone.

Dying alone in a hospital and in particular, dying in a way that does not honor our wishes, is not what the majority of Americans say they want when “their time comes.” Why then would it ever be okay for people who use our services, and why then are we not doing whatever we can to avoid it?

Right after Edward died, his attending ICU nurse commented to me “Wow, he must have been a really important man for all of you to be here.” If she only knew.....

For additional information:

- Please feel free to contact the author at [lakingsbury@suddenlink.net](mailto:lakingsbury@suddenlink.net) or 910-297-3510.
- The AAIDD is co-sponsoring a series of webinars on aging and end of life care. Check [www.aaidd.org](http://www.aaidd.org) for upcoming topics and speakers.
- Leigh Ann Creaney Kingsbury and Mindy Morrell will be producing a small series of articles on alternatives to guardianship (including information on surrogate decision-making), healthcare decision-making, and care at end-of-life to be distributed through The University of Delaware’s National Leadership Consortium on Developmental Disabilities in 2010.