

Imagine My Surprise: A Controversial Advance Directive Scenario

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“... To everything there is a season, and a time for every purpose under the heaven.”

—Ecclesiastes 3:1

HARRY WAS AN 86-YEAR-OLD MAN who had survived the Holocaust. He had been in pretty good shape until a year earlier, living alone in his apartment in San Francisco. He tried to keep himself healthy, ate reasonably well, exercised, and saw his doctors regularly.

Yes, he had some heart failure, some kidney problems. Sure, he forgot things sometimes, and woke up each morning with aches and pains that changed from day to day. His ex-wife was still his good friend, but she had significant cognitive impairment and they did not share a lot in the past few years. His only living relative was a niece who lived outside of Chicago, who had her own health issues and had recently cared for her dying husband.

Essentially, Harry was alone in the world.

When Harry and his wife were married and were both mentally “competent” he had written an advance directive that stated that he wanted “everything” done to keep him alive. This is common in the community of Holocaust survivors. The concept of choosing “not to prolong life” seems viscerally antithetical, when one’s entire existence has been a testament to the human ability to maintain and prolong life against all odds.

Over the past year, Harry showed up at the emergency room of his hospital more frequently: a fall, a bout of pneumonia, an exacerbation of his chronic heart failure. Each time, the nurses who treated him noticed he was a bit more confused. He no longer followed up with his physicians when he left the hospital, and he became more of a recluse. Finally in August, his heart failure became extreme, and he began the long, slippery downhill slide that elders can face at this stage of the game: heart failure, renal failure, multi-organ failure, advancing dementia. He was unable to care for himself or make sound medical decisions.

I have the privilege of being the Director of the Palliative and End of Life Care Program of Seniors-At-Home, the senior services division of Jewish Family and Children’s Services of the San Francisco Bay Area. Seniors-At-Home offers a comprehensive range of award-

winning programs to help seniors live safer, healthier, more independent lives in their own homes. Seniors-At-Home also maintains a Conservatorship Program. This means that through the Probate Court in the State of California, our agency can petition for and be granted conservatorship of clients who have been deemed incapacitated to make decisions for themselves. Since we have a contract for conservatorship cases with the hospital where Harry was a patient, he was referred to us for an assessment.

Harry ended up in critical care. He was intubated, his veins flooded with intravenous drips, and he had a feeding tube, which he proceeded to pull out five times. After 3 weeks of this, he actually improved and was put back on a med-surg unit.

Remember, this is an 86-year-old man, with advancing dementia and multi-organ failure. He had not seen his regular doctor in over a year. During a previous hospitalization, he had told the doctor that he still “wanted everything done,” but this was before his systems completely crashed. There had been no follow-up conversations since then to discuss his on-going health-care wishes. The hospital staff was working hard to keep Harry alive, knowing that if he did survive this hospitalization, he would need to be transferred to a skilled nursing facility for the duration of his life.

Our agency was in process of becoming Harry’s conservator, when he “coded” and was brought back to the intensive care unit, and once again intubated. At this point, the hospital staff called a meeting of their bioethics committee and invited our conservatorship care manager and our palliative care team to the meeting. The physician was able to contact Harry’s niece, Sally, in Chicago and have her included on a conference call for the meeting. She was audibly tearful and appreciative of our reaching out to her, even though she was also clear that she was not the decision-maker and did not wish to be. She stated that she had spoken with her uncle over the past year, while she was caring for her own dying husband, and that her uncle had stated clearly that he felt he had lived a full life and that he would not ever want to be kept alive “artificially.” When his condition was described to her by the physician, including the fact that he continued to pull out his feeding tubes and intravenous lines and would now need to be physically restrained, she said that she felt this was a clear message that he no longer wanted any of these treatments.

Harry was, after all, a Holocaust survivor. The idea of tying him down so that we could continue to administer

medications and treatments that might prolong his existence but certainly not his quality of life, seemed abhorrent to Sally and to most of us at the bioethics meeting. The conversation that afternoon was long and involved, examining Harry's previously stated wishes—which were to attempt resuscitation and be a “full code”—as well as his current medical, emotional, and spiritual status. We all left the meeting feeling a sense of sadness and confusion. If only Harry had changed his advance directive in the past year, to reflect his current status. If only he had named his niece to be his agent. Ah yes, if only we had crystal balls and could foresee the future.

Three nights later, Harry extubated himself. He pulled out his endotracheal tube and screamed for help. Since Jewish Family and Children's Services only had temporary conservatorship status at that point, the court ordered that he be reintubated and kept alive, until they could do more research. This meant at least “chemically restraining” Harry, so that he could not extubate himself again. Our care manager spoke with lawyers daily, waiting to see if we would be granted full authority to make decisions.

This was where the learning curve came in for me: the gray, murky area between law and medicine. I am a palliative care/hospice nurse, with years of experience in oncology and critical care. I teach people about the importance of advance directives, assist patients/clients in creating personal and appropriate forms, and always point out the advantages to having these documents in place. I talk about the need to update one's documents and have critical conversations with one's agents and loved ones. But what if you no longer have “agents” who are able to make decisions? What if you never updated your documents, and now the court looks at the only official statement you ever made concerning end-of-life wishes, and it reads, “I want to prolong my life under any circumstances?”

This is the “letter of the law.” This is the legal document. It does not take into account the changes in one's life since the signing of the form, or the medical condition that a person may experience at a new juncture in their life. Courts and lawyers must follow the law. At the same time, doctors and nurses must follow the ethics of a profession that mandates us to “First, do no harm,” but the meaning of that is not always crystal clear or agreed upon by all practitioners.

The doctors and nurses in this case did come to the decision that to continue to resuscitate and intubate Harry felt medically futile and unethical. Given all his serious medical conditions, it would only serve to prolong his suffering, not his life. They witnessed Harry's blank stares, heard his gasps for air, and medicated him regularly for confusion, agitation, and pain. As his temporary conservator, our agency team felt similarly. But we were all under the jurisdiction of the courts, and they were not convinced that Harry's original wishes to “do everything” no longer applied.

Having little experience with legal decisions like this, I was surprised that the deliberations of a hospital ethics committee in conjunction with a patient's only living relative, did not seem to hold enough weight to balance the scales of justice. I was also greatly dismayed to have such a clear example of an advance directive that could not accomplish the appropriate level of care at the end of a life. People and circumstances change constantly. Documents only change when we rewrite them.

After many days of research and questioning, the court decided that if Harry's heart actually stopped again, and he stopped breathing, he did not need to be brought back to life.

Harry clearly had a strong will. He lived for 2 weeks after his self-extubation. He was on a med-surg unit, in and out of consciousness, appropriately medicated and seemingly comfortable most of the time. He was no longer force-fed with tubes. The rabbi from our agency visited him several times to say prayers, and he seemed to respond positively. Our palliative care volunteers held a vigil, visiting Harry in the hospital regularly, so that he would not be alone. On a Saturday afternoon, Valerie—a volunteer—was sitting at Harry's bedside. She noticed a flowery card on the bedside table, and not knowing whether anyone had read it to Harry, she picked it up and read the kind and emotional words that Sally had written to her uncle, telling him how much he had influenced her life, how important he had been to her and her family, and how much she loved him.

Harry did not respond, but Valerie believed that he heard Sally's gentle words. Valerie put the card back on his bedside table and left the hospital.

Harry died quietly several hours later, finally beyond resuscitation, beyond the laws of this world, and hopefully at peace with the laws of the universe.

I will be adding a section to my advance directive workshops, on “Updating Your Wishes and Your Agents as You Age and Change!” Thank you, Harry, for yet another valuable lesson in health care—the kind that can only be learned by being present for each situation. These are the things that we do not learn in school.

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