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## 'I Thought I Was Prepared To Be My Mother's Healthcare Proxy But I Was Not'

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**I thought I was prepared to be my mother's healthcare proxy, but I was not.**

A year before she died, I got a call from an endocrinologist who had just examined my mother and believed that she should have surgery for a thyroid condition that had gotten worse over the previous year. My mother had just turned 100 and had a year or so earlier reaffirmed her desire never to go to a hospital — except for fracture care — and never to have surgery that required inpatient care. I told the endocrinologist that my mother had an advance directive not to have surgery. The doctor was not happy with **my decision and pressured me a bit, but I insisted on respecting my mother's wishes.**

Later, I discussed my decision **with my mother's primary healthcare provider at the life care community where she lived.** She agreed with my decision even though we both **believed that it would probably lead to my mother's death sooner rather than later.**

But I was uneasy about our decision. The facility did not believe that my mother had capacity to make medical decisions because she had a form of dementia that severely limited her memory. They cleared all significant medical decisions with me as her healthcare proxy. I, however, believed that my mother had some decision-making capacity even though she could not remember her decisions. For example, even though I had power of attorney, I consulted with her about major financial decisions such as large gifts to her great grandchildren and heirs.

So I was uncomfortable about making this decision for her, even though her healthcare provider and I had met with her some months earlier to reaffirm her advance directives and to have her sign a new form that consolidated her directives. She had reiterated at that meeting what she had told me years before when she was fully competent, that she

did not want treatment just to extend her life. She wanted to avoid suffering but not to fight death when treatment would rob her of functional ability, when she had, in essence, reached a natural end to her life.

But I remained uncomfortable even after consulting with the alternate healthcare proxy — my younger brother — who fully agreed with the decision not to permit surgery.

Pretty clearly I was emotionally distressed to let my mother die without a fight to preserve her life. My distress probably should not have surprised me, but I come from an insistent rational family, which had been open about the inevitability of death at least since I was 12 when my grandfather died. My parents had wills prepared before they were 40, had identified healthcare proxies, and had made arrangements to contribute their bodies to science. Over the years I had met with them several times to clarify their wishes regarding end of life care, the disposition of their bodies, and funeral arrangements. After my father died, I continued to check in with my mother on occasion in case she had changed her mind.

I could not have been more prepared, I thought. But now that it was real, I was finding it very painful to let my mother die.

In addition, I felt ethically uncertain about my moral authority to make this decision on **my mother's behalf. I tried to find literature regarding the ethics of being a healthcare proxy and did not find any. I talked with a friend who was studying medical ethics, who didn't know of any literature either. Finally, I talked with a friend who is a retired surgeon, who thought that the ethics were clear. I had no authority unless my mother was unable to make a decision and then I was bound by her advance directives.**

No authority unless my mother was incapable of making a decision — how obvious is that? But it had eluded me because of the general assumption that I would make decisions for my mother and because of my own emotional distress.

**I told my mother's doctor I believed that my mother had decision-**making capacity and that I wanted the decision about thyroid surgery to be hers. We met with her, and once again she said that she never wanted to have surgery. Though I was unhappy about the imminence of her death, I was immensely relieved not to be the person deciding that she should die without treatment.

But that is not the end of the story. Several months later I again got a call from my **mother's endocrinologist, to** whom she had been taken for a routine follow-up visit **because of a clerical error. The endocrinologist was very distressed about my mother's** condition because the goiter she had developed was now so large that it was beginning to limit her ability to swallow **and to breathe. My mother's doctor and I were aware of her** condition and had called in hospice care believing that she would die relatively soon. But the endocrinologist was very insistent that she see a surgeon and threatening when I repeated that my **mother did not want surgery. Finally, I said to her, "Did you ask my mother?" "Yes," she responded. "What did she say?" I asked. "When I told her that the growth would reduce the quality of her life unless she had surgery, she said, 'Well, I guess I will have to do it.'**"

That changed everything. If my mother was now open to having surgery, we were, I believed, ethically bound to explore it. I immediately arranged to meet with my mother and her doctor so that we could ask her if she wanted to see a surgeon.

**It was a very difficult meeting, which lasted about 20 minutes, longer than my mother's** usual memory span. But she stuck with it. I reminded her that the endocrinologist thought she should see a surgeon, which she had no memory of, that she had previously insisted that she did not want surgery, and that her doctor, who was with us, believed that surgery was ill-advised if not impossible because of the risks. What, I **asked, did she want to do? "I won't decide now," she answered several times, leaving** us, I believed, no choice but to schedule an appointment with a surgeon.

We could, I suppose, have decided that my mother really was not competent to make a decision and continued with palliative care. But it seemed clear to me, and I think to her doctor as well, that she could not bring herself to say that she was ready to die — indeed, that she wanted to live. Perhaps she had changed her mind about living as long as possible. Perhaps her advance directives were null and void.

**My mother's "companion," a staff member** from the facility, brought her to the appointment with the surgeon. **My wife and I joined them in the waiting room. "Why am I here?" my mother asked. I explained it was to see a surgeon about the massive growth on her neck. "But I don't want surgery," she said. A minute or two later she asked again,**

**“Why am I here?” I explained again. “But I don’t want surgery” she repeated. She asked again and then again and then again, as usual because of her impaired memory.**

I considered leaving since she was so insistent that she did not want surgery but decided that we should know whether the surgeon thought that surgery was advisable if even possible.

I was worried, of course, that he would be one of those surgeons who thinks that surgery is almost always worth the risk, a doctor — like the endocrinologist — who opposed the palliative care approach that we were pursuing with my mother.

Quite the contrary as it turned out. He gently examined my mother, and he talked with her about her condition and her wishes with great respect. Surgery he thought was absolutely ill-advised, but draining the growth might give her some temporary relief and a little extra time without additional suffering.

That was what he recommended. That is what was done. It gave her a few extra days or perhaps weeks. About two months later she died — without pain, in her own bed, after visits from all of the family who mattered to her on the last day she showed any signs of consciousness. There was a particularly poignant exchange between her and her 4-month-old great granddaughter just before she lapsed into unconsciousness.

It had been a painful and confusing journey for me as her healthcare proxy. Even near the end when the hospice team made decisions that moved her closer and closer to death, particularly by withholding food and water, I questioned whether I should intervene and insist that she be given more care. I controlled myself and let the process play out — let my mother die. It was, I think, the right decision. But it was far from easy.

**As I said at the beginning, I thought I was ready to be my mother’s healthcare proxy, but I was not. I was not prepared for my own emotions. I was not prepared for the ethical questions. And I was not prepared for the difference between the idea of death and its concrete reality.**