

How to be a strong advocate for your elderly parents



It was close to midnight. I was worried, tired and cold. Why are emergency rooms always so cold? A few hours earlier I had brought my 91-year-old father to the hospital because he had a bad infection. I was my father's health care proxy, designated to make health care decisions on his behalf.

A surgeon came into the room in scrubs. He was young and very aggressive.

"We're going to operate tonight," he said.

I was stunned. Surgery hadn't crossed my mind as an option. And who thought it was a good idea to put a 91-year-old man with dementia under anesthesia?

"I don't want him to have surgery," I said.

Now it was the surgeon's turn to be stunned.

"You don't want him to get better?" he asked me.

“What are other options?” I replied.

The surgeon shook his head and went to check on some lab results. While I waited for him, I started to question myself. Maybe surgery was necessary. But by the time he returned, I was resolved. I knew my father best and I knew surgery and a prolonged hospital stay would be disorienting and disruptive for him. I told the surgeon he could not operate and asked him to send the ER doctor in to discuss alternatives.

Being a health care proxy for a loved one can be a tough role. It means advocating for an elderly parent when your parent cannot do it for themselves. To help prepare you to be a strong advocate, here are my three tips, vetted by experts.

1. Do your homework

Being a strong and effective advocate starts with knowing your parent’s desires and goals before they need you to advocate on their behalf. That night in the hospital, I wasn’t just making a decision based on my opinion; my father and I had discussed his wishes and I knew he would not have wanted surgery either. Especially helpful, is to have your parent complete an advance directive. This is a form they complete with a doctor that outlines just how much medical intervention they want in different scenarios. For example, would they want to use a ventilator to aid in breathing.

Being a strong advocate, however, means more than just understanding your parent’s medical preferences. Tim Murray, the CEO and co-founder of Aware Senior Care, an in-home care agency in North Carolina, and who cared for his own mother, likens advocating for your parents to flying a plane.

“When you want to fly a plane, you need to know its status from head to toe,” he says. “Similarly, when you want to help care for your parent and advocate for them, you must consider them and their wishes holistically. It’s not just understanding the medical condition or financial situation of mom or dad. It’s about understanding their medical and financial wishes but also expanding that understanding to include their social, spiritual, physical and mental health. You can’t do this if you just fly in occasionally.”

2. Remember the paperwork

“Make sure you are legally able to speak to your parents’ doctors and nurse,” says Vivian Young, a content manager who advocated for her now deceased father and grandmother and is currently caring for her 90-year-old mother. “The Health Insurance Portability and Accountability Act of 1996, commonly known as HIPAA, has a privacy rule which protects patients’ health information.”

Without a signed form, called a health care proxy, which establishes you as someone who can legally speak to the doctors and make decisions on your parent’s behalf, you will not be able to receive updates on your parent’s health, nor will you be able to provide input on their treatment.

And just as you will want to have paperwork to give to your parent's medical team, you will want to request copies of paperwork from them, as well.

"Ask for both digital and paper copies of test results, diagnoses and other pertinent medical information," says Young. "Don't expect [your parent] to remember cholesterol levels or blood pressure results. These will be forgotten by the time they leave the examination room."

3. Trust your gut

Most importantly, in order to be a strong advocate for your parents, you have to trust yourself. That night in the ER with my father, I had done my homework and I had my paperwork in order, but I started to doubt what I knew to be true when the surgeon recommended operating with such authority. But I was an authority, too. I was the expert on my father and I reminded myself that I was an important part of his care team. I knew his wishes. I knew how he reacted to hospital stays. I knew we had to find another alternative.

Gael Chiarella Alba, a holistic counselor and certified caregiving consultant, learned to trust her instincts when her then 23-year-old son suffered a severe traumatic injury in a ski accident and was sent to a trauma unit.

"After surviving the initial stages of life support and physical repair, the medical team began pressing for an experimental pharmacological cocktail to hasten his waking state," says Alba. But when a nurse presented the consent form to Alba for her signature, she hesitated.

"My instinct pulled back," she says. "I looked up to see the male nurse saying the words 'sign here' while shaking his head no. It was then I realized I was never informed that my signature was a choice, not a mandate. I felt the darkness in that room and wondered how anyone could receive waking cues with no natural light. I handed back the unsigned papers and requested a room change instead, one with a window. The next morning, the team physician on rotation was aghast but did comply with my request. Twenty-four hours later, my son opened his eyes."

Alba says it's irrelevant how old the person you are caring for is.

"When peace has arrived in your decision-making, you're onto something good," she says.