



## HEALTH

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# On a Mission to My Dad's Remission

5 ways grown children can navigate the health care system for their parents

By [Meredith Oppenheim](#)

January 17, 2020

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Meredith Oppenheim and her father

*Credit: Meredith Oppenheim*

“Your father is very sick.” This is not what you want to hear from your parent’s oncologist, but precisely why I was by my father’s side at his appointments. The coldest days of winter 2017 were also the darkest days, as I was living in fear my father, Richard Oppenheim, could die.

At the age of 72, my father — a financial adviser for executives and athletes — was diagnosed with the rare blood disease, amyloidosis. This disease is often defined as “difficult and deadly.” With neither a full diagnosis of my dad’s situation nor any medical training of my own, I told my father after his first appointment: “I will do everything possible to save your life and will not let you down.”

The amyloidosis diagnosis was terrifying, but the robust testing he had didn’t yield any indication of organ malfunction, the gravest risk to his life. The numbness in his hands and feet were not necessarily caused by this disease. So, we took a wait-and-see approach.

## What the Support Groups Taught Me

Though my dad appeared to be diagnosed with one of the worst diseases, at that time, he had one of its best cases possible. I joined amyloidosis [support groups online](#) and it seemed my father’s situation was either very different from others or had not progressed to the point of many who were struggling with this disease.

**She said: “I am starting to worry about your father.” We all were.**

But over the next six months, my father’s health declined, and his bloodwork indicated he had lymphoma and [leukemia](#). He grew increasingly exhausted and developed a cough his pulmonologist could not resolve. After an appointment when my father walked out of the exam room coughing and with an unsteady gait, his oncologist and I had a private moment. She said: “I am starting to worry about your father.” We all were.

## Researching My Father’s Condition and Treatment Options

This motivated me to begin digging through his medical records. I’d requested them in anticipation of his ultimately being unable to travel the 45 minutes from his New Jersey home to New York City to see his specialists.

I’ve spent decades as a senior-housing executive and only had high school-level science courses. So, I relied on my Harvard Business School MBA training to devise a plan for my father and make medical decisions for him with incomplete information. This meant tapping into physicians, nurses and other health care experts in my network for answers to lots of questions about test results and treatment options.

After great hesitation and contemplation, we all agreed my dad should begin chemotherapy under the supervision of a local oncologist/hematologist.

This outpatient office, however, required over an hour wait for a few minutes with a physician for clearance to get my dad hooked up in a public infusion room. Sadly, when my father was sick, being around other sick people made him feel sicker.

## **The Caregiving Toll on My Mother**

As he grew weaker from the medications, often sleeping the entire day, my mom Ronnie — his primary caretaker — became depressed. I then had to not only worry about my dad's physical health, but also my mother's mental well-being.

I helped my mom engage in the local community and together we found classes to distract her from the caregiver grind. The caregiving duties became particularly challenging once my dad's nephrologist insisted that he go on a no-salt diet to help address his fluid retention. Suddenly, my mom was not just my father's nurse and driver, but chef.

During chemotherapy, my dad's legs and feet swelled to a point where he could barely walk. His cough intensified, so he could barely breathe. And his heart, which was not in great shape, became a problem. He was eventually hospitalized locally.

## **Time for a New Approach**

During my visits there, I got to meet the hospital's Chief Operating Officer, explaining that we had to find a different approach and needed a new doctor in the area.

A few days later, we received a call from the hospital and were told that a local oncologist/hematologist would be relocating to the cancer center and my dad could see her after he was discharged.

When we arrived for the appointment, after just a few minutes wait, a very personable doctor came into the waiting room to introduce herself and escorted us to the exam room. She took one look at my father, who lacked the strength to stay awake, and said he shouldn't be this sick on chemo. She suspended all his treatments and medications.

## **Saving My Father's Life**

This doctor was already thinking through a less conventional approach. She saved my father's life.

After my dad's blood work came back, the new doctor said he should start the [immunotherapy](#) drug Ibrutinib, something none of his other doctors ever mentioned.

When I started researching the drug, I discovered in an article from UCLA that when combined with the IV drug Retuxin, which my dad tolerated well, the effectiveness of Ibrutinib dramatically increased. But Medicare didn't quickly approve Ibrutinib for my father.

I asked his doctor if my dad could take Retuxin alone while we waited for Medicare, since he was getting weaker by the day. She thought this was a great plan, so he did. My father continued taking Retuxin after Medicare finally approved Ibrutinib.

## Remission!

Dad loved his first day at the new cancer center where he had a private room, a catered lunch and a view of the water. In less than a month on Ibrutinib and Retuxin, he was in [remission](#).

As the weather warmed, he shed his shroud of fear and anxiety and slowly started living again. He even got on a bike and rode with my daughter Brielle who was 6 at the time — he hadn't been on a bicycle in a decade. He later bought Brielle a bike that could last her for five years, since my dad planned to be around to enjoy it with her.

His doctor continued monitoring him and, as he became healthier, ultimately tapered him off some of his other drugs. My mother and father bonded with this physician. When they went to see her after my dad was in remission, my father would talk about the places my mom wanted to travel and his concerns about going. She'd tell him to stop complaining and start living, which is something he continues to do.

## My 5 Tips for Others

Stanford University's Clinical Excellence Research Center refer to women like me as "conscientious daughters." My experience has taught me that conscientious daughters — and sons — need to do five things:

**1. Advocate for our loved ones by thinking ahead, every step of the way.** During this journey, we met countless administrative staff, doctors and nurses. Every chance I had, I introduced myself and made sure they knew I was paying close attention to my dad's

health. A tip: showing up with treats is helpful to build a rapport, especially when you visit often.

**2. Ask lots of questions to get as clear of an understanding as possible of diagnoses and treatment options.** Until I started reviewing my father's records, I didn't know he had lymphoma or leukemia; no physician had mentioned that to us. Once I knew this, we were able to ask more informed questions and make better decisions.

**3. Get lots of medical opinions. In our case, that required visits to multiple hospitals.** We found several New York City specialists for my father's amyloidosis disease, yet only one whose bedside manner (with actual handholding) worked for us.

**4. Search for the best solutions within your network of contacts.** With limited scientific knowledge, I tapped into others' experiences and insights. I emailed a wide network of friends who have: had sick relatives with blood-related diseases, invested in biotechnology companies, reported on the pharmaceutical industry or worked in health care.

**5. Join support groups.** Googling amyloidosis was a terrifying experience until my search yielded the woman who leads the nation's largest amyloidosis support group. She was an incredible resource, always willing to recommend physicians, share research and provide connections via a Facebook community.

## My New Goal

When my dad was sick, I couldn't speak with him on the phone, because he was unable to engage in a conversation. I know he is better now, since he asks me every time we speak: "What are you doing now that you no longer have to fight for my life?"

After witnessing the dire consequences of diseases and accomplishing my mission to my dad's remission, I've realized the tremendous toll illness takes on patients, families and our economy. That's why I'm parlaying my 30 years of experience working with older people to create an online and offline community called Vitality Society™. The goal is to build affinity around a vitality philosophy of eight guiding principles.

Now, I'm on a mission to bring vitality to fruition.

By [Meredith Oppenheim](#)

*Meredith Oppenheim is the founder of Vitality Society™, a new online and offline community for people 60 and better to be at their best. She has a 30-year track record serving older people,*

*including nearly two decades as an executive in the senior housing industry. She recently authored "A New Look at an Aging Industry" published by the American Senior Housing Association. Oppenheim earned a U.S. Congressional Award for her work and served on Mayor Bloomberg's Age-Friendly NYC Commission and the NYC Department for the Aging not-for-profit board.*

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