Becoming an informal caregiver (unpaid family, friends, and neighbors) is not a job most people ask for, but it quickly can become the most mentally and emotionally challenging, and requires a lot of time and effort on behalf of both patient and caregiver.

Woefully unprepared, my father and I became my mother’s caretakers, from her original lumpectomy for breast cancer, to rehabilitation from brain cancer, to her demise despite the efforts of some of the best doctors in the country nearly 12 years after the original diagnosis. I hope that by sharing this cathartic article, I can educate and empower caregivers while helping other young adults to learn from my experiences.

1) You are not alone.

My mom was first diagnosed with breast cancer when I was 12 years old. This was before pink ribbons adorned every car on the road and the NFL wore fuchsia for the entire month of October. I was shocked and scared, but I had faith that my mom’s doctors unequivocally knew what they were doing…. we’ll get back to that thought in a moment. Because I was relatively young when I first got exposure to the wonderful world of breast cancer, it simply became a part of my life. Not surprisingly, it’s a part of many others’ lives as well.

There are almost 30 million family caregivers of people with chronic disease or disability in the United States as of 2010. This number is expected to exponentially increase as baby boomers get older and chronic disease explodes. The person most likely to assume care giving for an older person is an adult child. Surprisingly, 18% of the adult caregiver population is between 18 and 25 years old, and they have been largely ignored as a group in chronic need of emotional and mental support. A study published by International Journal of Behavioral Development postulates that more than four out of 10 young adult caregivers show signs of major depression. Deleterious mental health is not just found in young adult caregivers either: Across the general adult caregiver population, up to 50% are chronically depressed, their rates of prescription psychotropic drug use are higher than noncaregivers, and their mortality risk is increased compared with that of the general population!

Speaking from personal experience, I do not believe caregivers are doomed to remain unhappy and depressed. I went through the five stages of grief (denial, anger, bargaining, depression and acceptance), and then invented about 47 more. It’s all about a positive attitude, personal growth, finding time for yourself, and getting support. There are many professional and volunteer services that can help a caregiver from anything from delivering meals, professional home care, free transportation to and from appointments, and advocates to help navigate insurance or provide second opinions. Utilize all these sources to help you.

Speaking of second opinions...
2) A doctor’s attitude and communication can make or break recovery, so learn how to communicate effectively with the health care team.

Doctors have tremendous influence and power over a patient. Oftentimes, that is a beneficial relationship for a patient to have. Patients dealing with a potentially life-threatening disease need the respected and commanding direction from an authority figure. Furthermore, a theory has emerged demonstrating just how powerfully a doctor’s standard of care can influence a patient's health and prognosis. Jonathan Fields, interviewing Lissa Rankin, M.D. on her book Mind over Medicine, says, “[w]hat [healing professionals] say and do, how they treat patients, how much time, presence, genuine nurturing and listening they offer, these things matter. They have a very real, measurable effect on clinical outcomes.” Put simply, if your doctor is positive about your prognosis, your chances of actually having better outcomes statistically increase. The inverse is true as well, and unfortunately my mom received the latter: The night before the first time my mom went into surgery, her oncologist called her on the phone to tell her that she had a 50/50 chance of living or dying. That should have been our first clue that we needed some effective communication skills, and possibly a second opinion from a new doctor.

We are also responsible for how we go into a doctor/patient relationship. According to a study by the Journal of Broadcasting and Electronic Media, we tend to think of doctors how television and media portray them. What this means is, if you are a fan of Medic, Ben Casey, or even House, you would view your doctor as fool-proof and have complete faith in him or her. However, if you are an ER or Grey’s Anatomy fan, you’re likely to see through the façade and know that doctors are human, and make mistakes all the time.

I am not saying that doctors are either great or terrible, but there are varying degrees of expertise. It’s more important to gain a rapport with your doctor, and make sure he or she understands and answers your questions and concerns. There is a plethora of guidebooks and references available to doctors to teach them how to effectively communicate with patients, and if your doctor does not have those skills, it’s a good idea to look elsewhere, degrees and accolades aside. Encouragement from the health care team can greatly influence health outcomes.

3) Be organized and keep information and legal documents up to date.

My mom was not an organized person before cancer, and traditional cancer treatment unfortunately doesn’t give patients new powers. In fact, cancer treatment can often contribute to patient confusion. Therefore, it fell on my dad and me to keep a comprehensive dossier of her full medical history. We unfortunately didn’t think to do this, and it was always a confusing experience to remember and keep track of what the new medication list included, what insurance changes were made, and her general health history. Trust my advice: get a patient file together, and update it frequently. Don’t just assume medical professionals will have everything on file, especially if you change doctors or years have gone by between treatments. Along those same lines, don’t just assume the patients will know all their relevant medical history. They may know it now, but may be incapacitated when you need it. Finally, get all relevant legal documents in order. Talking about living wills and durable power of attorney for health care (health care proxy) can be uncomfortable conversations to have, but the alternative can be chaos.

4) The patient needs to have an advocate at ALL TIMES. Do not be afraid to face the oncologist, the radiologist, or the insurance company.

Ask questions. Challenge recommendations. As the first treatment session begot the next and the next, several years passed and my mom never quite went into remission. As scientists are starting to discover, chemotherapy may cause new cancer growth, and can eventually cause a tumor to become resistant to traditional treatment. My mother’s oncologist was unwilling, however, to consider anything outside of his specific field, such as Gerson Therapy or antiangiogenesis trials. Because medical doctors have increasingly become specialized, I can hardly blame him for being unaware of additional or alternative options. Then again, since no pharmaceutical company was paying him to try these treatments, I have to wonder if he truly gave them a 50/50 chance of living or dying. That should have been our first clue that we needed some effective communication skills, and possibly a second opinion from a new doctor.

Nutrition is not even taught in most medical schools. My mom’s cancer team told her not to lose any weight during chemotherapy, and suggested ice cream. Suddenly, mom was eating a pint of Ben and Jerry’s for lunch every day, and according to the oncologist, that was just fine. As a nutritionist, the concept that mounds of ice cream could even be considered a part of a balanced diet, let alone appropriate for someone in the midst of cancer treatment, makes my head hurt. CANCER LOVES SUGAR! I cannot stress this enough. Cancer’s affinity for sugar is how PET/CT scans work. I will never forget being in a hospital room with my mom, nutritionally starved, and the dietitian came in to give her a popular liquid nutritional supplement. The second ingredient in that drink is corn maltodextrin, which is a fancy way of saying corn syrup solids, and the third is sugar! She so desperately needed a vitamin and mineral packed meal, and what she got was an expensive Coca-Cola. Nutrition has increasingly become important in the medical field, and to doctors’ treatment plans, which is fantastic. However, make sure your loved one meets with a nutritionist or dietitian who is familiar with the illness at hand at least once to get a comprehensive diet in place.
For these reasons and more, everyone needs an advocate. I could dedicate a book to the nonsense my mom experienced. The first round of chemotherapy my mom received, she was sicker than expected. Why? The medical staff forgot to put the antinausea medication (antiemetic) in her drip. The second round of chemotherapy my mom received, the nurse practically stabbed her to get the needle in her port. Why? The nurse used the wrong sized needle for her particular port. Those last few years were especially difficult—my mom received the wrong medicines, incorrect doses of radiation, and endured critical mistakes that went unreported. This is not an unusual occurrence: The Department of Health and Human Services (HHS) has acknowledged that only 14% of hospital medical errors are reported, and more often than not, these mistakes get repeated.14 If you are armed with information and unafraid to speak up, you can combat a lot of these medical snafus.

My dad and I gradually got better at being proactive caretakers, but I feel it was too little too late. The oncologist had made a directive that my mom was to have no food or liquid. There was a tumor pushing against her esophagus and without medical intervention, not even water could make its way to her stomach. My mom was literally dying of thirst and yet no alternative solutions were considered. At that moment, my dad and I found courage and we demanded to see a gastroenterologist. This being a hospital, there was one right downstairs. The gastroenterologist said, and I quote, “I can fix that, no problem,” and inserted a tube to push the tumor away, allowing her the ability to eat and drink again. Because we spoke up for her comfort, my mom was then able to come home, and be surrounded by her family, friends, and pets until she passed away in her sleep nearly a month later.

5) Do the best you can, but don’t blame yourself for not doing a perfect job — you are only human.

I wonder often what would have happened if I had spoken up sooner. I spent a lot of time blaming myself for my mother’s untimely demise. I told myself that I should have been there for her more, and not been so wrapped up in teen drama. I should have put my undergraduate skills to use and done research to help her, and asked more questions about her and gotten to know her better. I should have not argued with her over nonsense. I should have done a lot of things, but a person can punish herself or himself an entire lifetime with the “coulda, woulda, shoulda’s.” That won’t help your loved one and it will make YOU sick!

Yes, I saw a bright, beautiful woman shrivel into a husk of a person, bedridden and constantly in pain because of lack of care and no support system. And you know what? That’s on me. I was afraid to ask questions, and speak up when I knew something wasn’t quite right. I was downright petrified to go against the grain and find alternative help. I couldn’t stand up for myself, and therefore I couldn’t stand up for my mother, either. I failed her as her caregiver and advocate, and now it is my duty to make sure no one else ever goes through what my mom did.

I’ve endured, revived, and prospered since that fateful cancer diagnosis nearly 15 years ago, and it is my firm belief that you will, too. Do not just believe what someone tells you at first glance. Go look it up! Do research for yourself and your family member so that you can be engaged and informed. Keep up-to-date, organized, and vigilant. Don’t be afraid to accept help. Paying attention to the above five key principles for caregiver support will help a lot.

Important links

Center for Advancement in Cancer Education: http://www.BeatCancer.org The Center offers telephone cancer counseling to provide patients the tools to make informed decisions and understand various therapeutic options, nutrition choices, and lifestyle changes. Call 888-551-2223 to schedule an appointment with skilled counselors.

Caregiver Action Network: http://www.Caregiveraction.org A great first stop for the new caregiver, the experienced, long-term caregiver, the long-distance caregiver, and working caregiver. They have resources for a spectrum of different caregiver situations, from special needs children to ageing adults.

Family Caregiver Alliance: https://caregiver.org This group began as a community to care for people with long-term debilitating diseases, and now has lots of information and links to local advocacy groups.

Medicare Resources: http://www.medicare.gov/campaigns/caregiver/caregiver.html For the patient who is under Medicare, this organization also offers links to local senior services and financial benefits.

Cancer.net: http://www.cancer.net/coping-and-emotions/caregiver-support This group offers support for caregivers of patients with cancer.

Join the conversation. Create a topic in our forum.

References:
For many jobs a person will also need continued education even after a degree. Education to keep up on the changes in your chosen industry. As people receive experience from university and become more knowledgeable, friendly. Academic study makes people social and it helps a society to be strong and powerful. University degree also increases the chances of getting a dream job and leads to economic growth of the society. College is not needed to be successful. There are plenty of jobs that have high pay and has a great work-life balance that do not require a degree. Jobs such as mechanics, technicians, and even small business owners (all jobs that get good pay) do not require a degree, therefore it proves that you don’t need a degree to be successful. Report Post. Like Reply. But recently, more and more men are taking paternity leave from work to stay at home with their new borns. Mothers find it a welcome trend, as caring for an infant can be exhausting work. C. While it's true that kids must carry out their responsibilities just as adults do, sometimes Mum and Dad have to be a bit crafty to make it happen. They have to offer a little reward for a job well done. It may not be good practice to do it all the time, but if they promise a trip to the cinema, for example, the kids will be more likely to clean their rooms. D. Mam families live far away from one another t... Parents arc the carers of their children, but they are their friends, too, and in both senses they would never do anything to hurt them. But parents must never forget their role as figures of authority. then the informal sector has become an increasingly popular subject of investigation, not just in economics, but also in sociology, anthropology and urban planning. With the turn towards so called post-fordist modes of production in the advanced developing countries, many workers were forced out of their formal sector work and into informal employment. The relationship between the informal sectors and poverty certainly is not simple nor does a clear, causal relationship exist. Thus, they end up working without asking for an allowance or wage, because kids recognize that their parents cannot bring home enough income alone, thus their contribution is necessary and their involvement becomes instrumental for their family's economic survival.[54].