

Getting the Care You Deserve

BY STACY B. STRYER

I am a doctor, so when my husband, Dan, also a physician, was diagnosed with a brain mass we immediately knew he would need to see a long list of specialists. But I was not prepared for the gaps in care that we encountered. The emergency room admitted Dan into the hospital and set up a consult with a neurosurgeon, who recommended a biopsy rather than surgery. After a brain tumor was confirmed, the doctor made appointments for us with an oncologist and a radiation physician to discuss chemotherapy and radiation. For the next five days my father-in-law, also a doctor, and I were glued to our computers trying to decide the best action plan. Through our own detective work, we concluded that he needed to have surgery to remove as much of the mass as possible before receiving any other therapies.

This was the beginning of a year during which I learned how difficult—indeed, harrowing—it can be to obtain the comprehensive care you or a loved one need and deserve in a fight for life.

Multiple times throughout the course of Dan's illness I was so thankful that I had a medical background. I could identify and articulate his symptoms, and I knew the various types of specialists who could help him with some of the problems that developed. So many times I wondered how a person without a medical background could do this. From a physician's perspective, I know doctors are very busy and it takes much more time than we have to deal with what may seem to be less important issues of an illness. From the caretaker's perspective, however, it is these scores of subtle issues that can make a big difference in the quality of life.

In my husband's case, we traveled from Maryland to North Carolina so that Dan could have surgery with an eminent neurosurgeon at Duke University; then we returned to the care of our local oncologists. This is where the comprehensive care ended. While obvious issues such as tumor growth and blood tests were monitored, the more subtle aspects of quality care and improvement of quality of life were not even addressed.

Despite the fact that he had a 4-centimeter mass removed from his right frontal lobe and a smaller one removed from his left (the frontal lobe controls motivation, planning, reasoning, impulse control and multiple step processing), nobody mentioned the need for an occupational therapist to help with his profound deficits. In fact, no one discussed the majority of Dan's deficits in detail nor did they mention available care to improve both Dan's and the rest of our family's quality of life. Through my own research, I discovered a rehabilitation center near our house that specializes in helping people with brain injuries such as Dan's and, therefore, could help answer some of these questions.

Another important yet unaddressed topic was Dan's desire to drive. Although I was very concerned about his driving after surgery, he was unwilling to give this up because of his desire to keep some aspect of his independence. I asked multiple physicians and occupational therapists about receiving an evaluation before I found out that there actually is a therapist who assesses people like Dan and gives specific recommendations that physicians and the motor vehicle administration receive. These therapists also build in routine reassessments. Nobody had mentioned this to me or even knew about it.

He had other issues, too. He was on chronic high-dose steroids to control brain swelling. This led to significant lower leg weakness that kept him from getting out of bed or standing up from a sitting position. I couldn't leave him unattended in the shower for fear that he would fall. Again, nothing was mentioned about a referral to help with his lack of strength or devices to help him in the shower. As we were both physicians, we were aware that there were specialists who dealt with these issues.

Months later, when my husband refused to get out of bed in the morning or eat breakfast, the physicians blamed the tumor, not even considering other potential causes. Once again we questioned them, asking whether depression could be causing some of his refusal to get up or eat. We received a referral to a psychiatrist and my husband began antidepressants, which helped his mood and motivation.

What I've mentioned above are just a few of the less well-known services that became vitally important for my husband's quality of life and well-being. When you or a loved one is diagnosed with a chronic condition, you will face a long line of physicians. But to make sure you get the care you need, take charge by routinely reassessing your condition, looking for new issues that arise. Don't assume they are insurmountable—ask your doctor about them. If you're not happy with his or her answer, get a second opinion, research it yourself or seek advice from someone who has a similar problem. There may be something, however small, that can be done that will improve your quality of life.

While most of us are aware of the typical healthcare providers, such as oncologists, urologists and neurologists, I have listed below and briefly discussed less well-known healthcare providers who may be helpful to you or a loved one.

Psychologist/psychiatrist: Having a chronic illness is stressful. You may have to take many medications, some with undesirable side effects, have frequent blood draws or intravenous lines. You may have debilitating effects from your disease or even have to face the possibility of mortality. Whatever the reason, it helps to talk with someone who specializes in anxiety and depression, even if it is due to a medical illness. Sometimes talking is all that you need, but occasionally a therapist will recommend a medication to help you. Only psychiatrists can prescribe medication. Psychologists often work with psychiatrists who can prescribe medications when needed.

Physical therapist: This is a professional who can help improve your motor and sensory functioning and decrease pain. Decreased functioning can be from many causes, including prolonged inactivity secondary to an illness, major surgery, pain with movement or decreased mobility from other reasons, such as a stroke or

arthritis.

Occupational therapist: This is a professional who identifies problems you may have with daily activities, school, work or leisure time. An occupational therapist can find ways for you to perform these tasks independently or with as little help as possible. If needed, an occupational therapist will recommend appropriate devices to increase independence. They should also know about therapists who evaluate driving safety.

Neuropsychologist: This is a person with a PhD who identifies problems related to your brain and tries to find ways to alleviate them through medication and management strategies.

Pain management specialist: Pain management specialists are medical doctors and nurses, often connected with anesthesia departments at local hospitals, who specialize in the treatment of people who have chronic pain. They evaluate the type of pain you have and come up with a plan to decrease it, including anything from medication to massage.

Nutritionist: This is a professional who helps you design a meal plan based on your weight, height, food restrictions, medical issues and recent weight gain or loss due to your illness. Many medications cause diabetes. If that has happened to you, it is a good idea to see a nutritionist at least once.

Endocrinologist: This is a medical doctor who specializes in diabetes and other hormone abnormalities. If you have been taking steroids for a while, which is the case for many people with chronic illnesses, your risk of developing diabetes is significantly increased. Several other medications can also increase your risk of developing diabetes or other hormone imbalances. If this occurs you should see an endocrinologist.

Geneticist: This is a medical doctor who discusses inherited diseases and risks of passing them on to offspring. If you know or think you have a genetic mutation and are considering having children in the future, it is a good idea to have a consult with a geneticist.

All these options may seem overwhelming at first, but all you need to do is routinely reassess your condition or that of your loved one and discuss any changes with your primary healthcare provider. Ask him or her if there is somebody who can help minimize or resolve the new problem. Mention some of the providers, when appropriate, that I have discussed above. The time you put into the issues now can be very worthwhile for your future quality of life.

--Stacy Beller Stryer, MD, is a pediatrician working in private practice in Rockville, MD. She serves as a consultant and regular contributor on parenting and teen health issues for Revolution Health, a healthcare website that launches in January 2007.