

IN EVERY ISSUE

Lessons Learned

BY COLE A. GILLER, MD PHD

As the patient, as the doctor.

We live in an age of patient empowerment. We have the freedom to make our own medical decisions, and we have superb sources of medical information to help us. But as anyone who has had a medical problem can tell you, it's not that easy. Medical science has given us so many options that it's difficult to pick the best one. How can we decide between chemotherapy, surgery, radiosurgery and immune therapy when each choice has its own pros and cons, and when even our doctors don't agree? And how can our doctors possibly know which choice will fit our personality, hopes and expectations? We all want a say in what happens to us, but deciding between complex medical options can be overwhelming.

As a cancer survivor and doctor, here are six steps I think may help.

Step 1. Know your options. The first step is to discover your options. Don't try to decide which choice is best at this point—just find out as many options as you can, even if some seem far-fetched. Talk with your doctors, but don't hesitate to use friends, family, newspaper, television and, of course, the Internet.

Step 2. Find the trade-offs. Now that you have a list of options, find out the good and bad about each one. The goal is to find the compromise that hides in each decision. For example, a particular surgery might be great for tumor control, but might also have a risk of paralysis. Or the use of blood thinners might offer protection from blood clots, but would increase the risk of bleeding if you fall. You must know the bad along with the good in order to make a good decision.

Step 3. Discover the data. Find as much as you can about each option. Talk with your doctors, and don't be afraid to do research. A librarian can guide you to medical textbooks and articles. Use the table of contents and index to find information about your medical problem. You may not understand every word but the books contain valuable information. Finally, check out MEDLINEplus (www.medlineplus.gov), Gateway (gateway.nlm.nih.gov/gw/Cmd), www.clinicaltrials.gov, www.pubmed.gov, www.healthfinder.gov and www.healthweb.org. These are helpful user-friendly medical websites.

Step 4. Be skeptical. Make sure your sources are credible. For example, find out which companies sponsor the websites you are using. If you are reading about a particular treatment, make sure that the patients treated have the same medical problem that you do. Is the recommendation of a certain medication based on its success in just one patient or a randomized trial of 1,000 patients? A useful technique is to say things backward. A surgery that cures 75 percent of the time is the same surgery with a failure rate of 25 percent.

Step 5. Gather your beliefs. Because medical decisions are made in the face of uncertainty, our beliefs must guide us. Do you believe that medical care is best in large general hospitals or in small specialty centers? Do you believe that medication is bad in the long term? It's not that you should let old beliefs keep you from making rational decisions, but you will be happier following your beliefs if no other information is available.

Step 6. Contemplate the meaning. Each medical decision means different things to different people. The decision to undergo surgery to relieve back pain might be obvious to a 56-year-old man with a large family. But an 82-year-old man who is the sole caretaker of his ill wife might choose to endure the pain rather than take the risk that the surgery would prevent him from caring for his loved one. Find the meaning that your medical decision has for you and your life—it will be worth it.

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