

POSTS MADE IN MAY 2013

[HOW TO BE PARTICIPATORY IN THE FACE OF ADVERSITY](#)

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From the lens of a patient who recently experienced major surgery, I now realize how difficult it is to be participatory when you are in pain and taking large doses of pain medication which dull the senses and put you in a place where you are not really thinking about anything but how to get through the next couple of days.

I consider myself to be an empowered patient who fully participates in my healthcare, questions my clinicians, and evaluates the risk/benefit of treatment plans presented by my clinicians.

I use the health data my clinician offers, including the reports and notes that are in my electronic health record, and confer with people who have had some experience with the same or similar conditions. I always go one step further and search the web for relevant information that applies to my particular health concerns. I provide feedback to my doctors and never hesitate to speak up and ask questions. I tap the wisdom and advice of my peers and encourage my providers to be participatory.

By the time of my surgery I was fully prepared so that I completely understood what I was getting into. However, I could not anticipate that a cough that I had before the surgery would precipitate into a full-blown asthma attack for which I had not prepared. Nor could I have realized that the blood thinners that are automatically administered for two weeks following hip replacement surgery would be prescribed to me for three months because blood tests indicated that I had a much greater than normal potential for a blood clot. Additionally medication that I take to prevent a recurrence of breast cancer also elevated my risk for clots.

Ever the e-patient, I challenged the doctor to convince me that the risk of life threatening bleeding from blood thinners, if I were to fall or have

an accident, was less than the risk of a potentially fatal blood clot. He did.

Following the hip replacement surgery I went to rehab where my medication regiment was so complicated by so many different pills that had to be taken at various intervals that I had to monitor every pill I was given, to be sure it was at the right time and in the right dose. I also had to work closely with the medical staff at the rehab to determine which medication, at what dose would keep the cough and the asthma under control. We worked as a team that included the rehab physician and nurse practitioner, the therapists, and my regular PCP. This was true participatory medicine at work.

There are some actions that a participatory patient should always take to insure best outcomes. They include:

1. Prior to going into the hospital for surgery, research all of your options and be sure to ask the surgeon, as well as your PCP and specialists who may be involved, all of the questions that you have. Be sure you are satisfied that you have full information.
2. Appoint a person to be your advocate during those days when you are not well enough to monitor the medications you are being given and the procedures that may be ordered. Be sure that your advocate understands your release instructions so that with the assistance of your advocate, nothing falls through the cracks.
3. As your treatment evolves be sure you understand, and are in agreement with everything that is suggested. Do not accept vague explanations.
4. When you are released from the hospital, be sure that you have full information on the medications prescribed, the treatment process, follow-up appointments and any home services to expect. Double check to see that you have prescriptions for all of your medications and a viable way to get those prescriptions filled quickly.
5. As an e-patient you quickly realize that there are always follow-up questions. It is up to you to work collaboratively with your providers to insure that there are open channels of communication for this purpose.

Being a participatory patient is complex because where health is concerned nothing is static. Things change and as the patient member of the healthcare team, you have to be on top of it all and ready to adapt.