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Learning to Take Responsibility for my Health Care

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Abstract: The writer, as a surgical patient, discovers that he has developed a massive DVT. His concerns lead him to self education about his condition and to seeking out multiple sources of information and care. He adopts three guidelines: 1. learn the risks, 2. get a second opinion, and 3. take responsibility for your own health care.

The pain in my left knee had been increasing over the 25 years since I damaged it in my early 30's. The orthopedic surgeon referred to me by my primary care physician, ordered an MRI and informed me that arthroscopic surgery was the correct treatment. He offered me an outpatient surgery appointment for two days later. It seemed like a routine procedure, and I accepted it without further consideration.

When my leg became red, hot and swollen a few days after the operation, the surgeon responded to my phone call by confirming that I didn't have a fever and that I had a follow up appointment in a few days and I should come and see him then. I followed his advice. When he saw me one week after the surgery, the pain in my leg was extreme. He requested an ultrasound and I learned that all the deep veins in my left leg were completely clotted well up into my abdomen. He told me to get myself to my local hospital. I asked who would be overseeing my care and he said that since this didn't relate to my surgery, that my primary care physician would be in charge. Since my PCP was away, the doctor covering for him prescribed low molecular weight heparin injections and warfarin.

24 hours after I was admitted, I had my first visit from a physician, who was covering for the person who was covering for my doctor. I asked him what my treatment plan was, and he said that I could go home, that I would be taking warfarin for 6 months, and that I would have my INR checked regularly. When I asked what INR stood for he said he didn't know but that it measured the coagulability of my blood.

When I returned home, the swelling in my leg continued to increase. Standing up caused dizzying pains in my leg, chest and head, and I spent most of my time in bed. My primary care physician said that I would be uncomfortable for several weeks but that in 6 months I would be back to normal.

Two weeks after the surgery, I began to question whether I was getting the best information and treatment and began to research deep vein thrombosis on the internet. I discovered that there was a wealth of information available.



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I learned that many doctors prescribe compression stockings for DVT although no one had suggested these to me. After calling a medical supply store to see if I could purchase them, I was told that I needed a prescription. I called my PCP who said he didn't know if stockings would help. He referred me to a vascular surgeon who said that I wouldn't like compression stockings since they would be uncomfortable, but that I should elevate my heel higher than my heart to decrease the swelling. His recommendation was to lie on the floor with my foot on the edge of a sofa. Within two days of elevating my foot, the swelling and pain decreased dramatically.

I also learned from the internet that a proclivity for developing blood clots can be inherited. I remembered that 45 years earlier, my father had developed blood clots following an appendectomy. I then recalled that my father's brother had developed clots in his legs and lungs following a hip replacement.

At this point, I had a revelation. If I wanted the best outcomes from my health care, I needed to get involved. I created three basic guidelines for myself.

1. **Always ask what the risks are.** If I had done this before the surgery I might have learned about the relatively high incidence of clots following knee and hip surgery.
2. **Always get a second opinion.** Every doctor has different experiences from which to draw and there are many possible treatments and an even larger quantity of unknowns.
3. **Always remember that you are primarily responsible for your own health care.** You make the ultimate choices as to whether or not to undergo a procedure or follow a certain treatment. You need to be well informed about the alternatives and the possibilities.

I asked a friend who works as a nurse at one of the major teaching hospitals in Boston to recommend a vascular surgeon who could make the time to listen to my questions and answer them, and who would be knowledgeable about the best treatment options.

This surgeon made sure I got the best answers he had to offer and that I understood them. He immediately prescribed compression stockings which substantially decreased the pain in my leg. When he suggested clot dissolving thrombolytic drugs, I knew enough to ask, "What are the risks?" When he said there could be 1% chance of death from intra-cranial bleeding, I knew I wanted a second opinion. My uncle recommended Dr. Goldhaber at the Brigham who had treated his DVT and PE.

Dr. Goldhaber said I could make my own choice, but that he felt that eight weeks after the initial clotting episode, thrombolysis had a low probability of success, and that there was a small but real risk of fatal bleeding. He recommended that I use the Brigham's anti-coagulation service to monitor my INR and to answer any questions I had about drug and food interactions with warfarin. He also advised me to join the Brigham Support Group to



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draw on other patients learning to answer my questions about self-care and dealing with the uncertainties of my new situation.

I finally felt that I could say with confidence that I had the best medical advice available, and that I could make informed choices and follow the recommended treatment plans knowledgeably and effectively. While DVT and PE patients face many unknowns, well-informed patients give themselves the best chance of avoiding mistakes and living long and healthy lives. Today I am working to pass that information on to other patients and their caregivers in hopes that it may be of some use in improving their futures as well.