

Story Title: Surgery results in poor quality of life – could have used ERAS

Date Submitted

November 2019

Story Summary

Who: M a female over 50 years of age

What: Surgery

When: June 2019

Where: VGH

Why: M had surgery to remove an ovarian cyst

Tags

#elective surgery #cancer care #VGH #Vancouver Acute

Background Information

Age:

Language(s) Spoken at Home: English

Gender: Female

This story was written by a: Patient Family Member/Caregiver

VCH Staff (with permission from patient/caregiver) Other

This story is about a: Patient Family Member/Caregiver Other

Story

I feel frustrated and angry about the situation I find myself in now after my surgery. My life is a shadow of what it was. I have never felt worse in my life. Some days I wish I won't wake up. Prior to surgery I was asked to be part of a research project which I agreed to do as I felt it was important to help advance knowledge of my condition. Prior to surgery the surgeon indicated that the chances of my situation being cancer were 50% it would not be cancer, 40% it would be borderline and 10% that it would be cancer. Ten days after surgery the surgeon called to let me know the results of the pathology and that it was cancer. It was stage one and the surgeon felt he got everything. No need for anything else other than follow ups at the clinic every 3 or 4 months. Everything was great for the first couple of months. My energy had returned and I felt fantastic. Then about 4 months after the surgery things started to change. I started to find it difficult to walk. My family doctor is currently the only doctor I have other than going to the clinic every 3 months. So far my family doctor has sent me for six x-rays, a CT scan and I am awaiting an MRI. I go to 3 different physiotherapists and they feel that scar tissue might be an issue as well as nerve and muscle damage. No one really knows for sure what has caused my current condition. I started walking shortly after surgery up to 8 km but then had to slow down and shorten the walk due to

increasing pain. I feel there is direct connection between the surgery and my leg/hip breakdown. I want to have a better quality of life. I was expecting that my quality of life would improve after the surgery but it has, in fact, reduced quite dramatically. I was in the hospital for four days after surgery; I had 60 staples - major surgery, and something should have been done to activate me and support my recovery. I should have been referred to physio and was not. I had to seek out physio on my own. My muscles were quite weakened and I believe following an ERAS protocol would have benefitted me greatly.

Best and Worst Aspects of the Experience

There are no best experiences for me from this situation. What has really frustrated and angered me was my last follow up at the clinic where I spoke with the surgeon who dismissed everything I said. I was told that surgery had nothing to do with where I was at and if there was something wrong then I should speak with my family doctor. By the time I left that appointment I was pretty much in tears not having any idea of what to do from there. I was not even sure if I would ever go back. I felt so humiliated and stupid.

Experience after Receiving Care

After experiencing some pain and limited range of motion on one of my walks I saw a poster board on the sidewalk to advertise rehab support post-surgery. There was info about post hysterectomy recovery. I realize that the health care system has limited resources but we need to spend more time on prevention instead of cleaning up the mess. I do not want to blame anyone; I do not want to litigate what happened, I want to move forward. However I am fumbling and I need help to navigate. I don't even know what questions to ask or who to turn to for help. I want to have my quality life back. I don't do ill well and this is the one of the worst things that has ever happened to me. I do believe that if I had some tips and tools on what to do I would be in a better place. I understand that the recovery process will take a long time. I am learning to breathe more deeply from the diaphragm. My gait is not the same as pre-surgery and I have so many challenges. I don't want anyone to go through what I have been through

The stronger you are pre-surgery the easier your recovery would be - this makes sense. This is a learning opportunity and this is one of those instances where we can all learn together.

Take Home Message(s)

M has a few recommendations:

What do I recommend?

- I recommend that the surgical team set up a triage for all the surgeries to determine the complexity level and the level of support needed for pre and post-surgical support. I do feel that if I had some tips and tools on what to do I believe I would be in a better place.
- It is very good to talk to people who have been through the system to understand what they have experienced. It just makes sense that CEO's should be talking directly to the front line people to understand what the patient experience is. I believe that in the long run the health care system would save money if prevention was more of a priority.