



Making better
decisions together
with patients
and families



Enhanced Recovery After Surgery - Gastrectomy

Community Engagement Summary Report

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Background

Enhanced Recovery After Surgery (ERAS) protocols improve care and decrease complications. Intrinsic to these care protocols are pre-operative optimization behaviours that are practiced prior to hospitalization (prehabilitation). The ERAS protocols have been in place at VGH for 1 year and to support patients booklets detailing what to expect and how they can maximize their outcomes are provided to each patient. As the ERAS protocols are expanded to different surgical procedures the patient booklets are being developed to support patients and their families. The latest area of surgical focus for ERAS is gastrectomy. This engagement process focused on getting feedback from past gastrectomy patients on their experience of care and the value of the booklet in preparing them for the surgery, for their hospital stay and for post surgery.

How we engaged



Letters of invitation were sent to past surgical patients that were part of the Enhanced Recovery After Surgery protocol patients asking them to participate by sharing their experience of care and the impact of the booklet.

What we asked

- 1) How was this booklet helpful to you as you prepared for surgery?
- 2) What could be changed or added to the booklet to make it more useful to patients and improve their preparation and experience ?
- 3) Was there any information that could be clearer or made easier to understand?

What we heard

Format

- Cross reference table of contents to ensure it aligns with content
- The diagrams throughout the book are very helpful and should be used more to demonstrate an action
- Pg. 11 the diagram is very helpful; include diagrams as often as possible i.e. on page 26 there should be some illustrations or graphics included to demonstrate the movements
- On page 46 include more space between the bullet points and group them to delineate the areas of focus
- Really liked the faces for pain management and the nursing staff clearly wanted to support me to have no pain
- It was good to do the breathing and roll over practice and the pictures were very helpful
- Lots of notes pages which is great

Spelling

- Pg 22 check the word breath throughout for consistency. Should be breathe.

Clarity

- On the front cover stipulate that this booklet is intended to be read pre- surgical to support preparation and enhanced recovery
- Consider a time or location in the patient journey where the booklet could be reviewed together with the patients and the most relevant info highlighted.
- Page 15 you may be asked to visits the Pre admission this was not clear and needs to be clearer and that this may be optional. Be clearer and explain that not everyone will be called. i.e. You may be asked to meet with an anesthesiologist. If this is required you will be contacted to arrange an appointment to meet with anesthesiologist
- the nurse at the BC Cancer agency said I should ask for the cost of self-injection heparin to be waived but I did not know who the surgeon would be and the surgeon needs two weeks to apply so I could not find the information before I would need the drug. At the hospital, before I was to be discharged, the nurse on the ward told me that I would receive the medication and the cost would be waived. Consider adding *If applicable the surgeon will apply for a waiver of the drug cost for self-injection heparin. Please ask your nurse about whether you are eligible for this cost waiving.*
- Pg. 18 Be clear about the need for the Precovery drink as the way it is presented it sound like it is mandatory. I was even told to go to the gift shop to purchase it. This sounds like there is no choice.
- Precovery drink; the way that I was told about made it sound like it was mandatory and this was not appropriate and should not be presented in that way.
- Page 25 be explicit about anticoagulant does this include the self-injection
- Page 31 under When can I go home? Change the reference of reviewing the ERAS Stomach Surgery booklet to this booklet and the page # as it confusing when you refer to the booklet as if it something different

- Not sure why *When can I go home* is repeated in each Day. On Day 1 put the full details and then if repeated put less content
- Related to injectable blood thinner the nurse helped me practice the injection and this was very helpful I had to ask for this help and asked for it two times. I had extended medical so did not have to pay for injectable warfarin but this cost should be mentioned in the booklet.
- Not putting any creams or ointment on should be further up in the booklet
- The medication section should be clearer as it related to vitamins and when to stop to taking them before the surgery

Additional Information Required

- add that the hospital will call you to ask what bed you prefer so list the different options that are available i.e. two sharing, four sharing, private and be explicit about the potential for mixed gender in a shared room
- Page 12 Breathing exercise add in info about the breathing ball exercise as it is not in there.
- page 17 under Diet and wherever cranberry juice is mentioned - be explicit and state white and red cranberry juice
- Add info on blood thinners and injectables in the Medication section on page 39. Include that there is a cost and approximate amount. I had to pay for the warfarin injections myself. I was not told that or what to expect so I was surprised I had to pay for this and was told I had to inject for 23 days; this was costly \$250. Nobody discussed this with me
- There is just one line about blood thinners and should be more info. Include something like - Your doctor may prescribe blood thinner and that training will provided and should provide instructions. I did not receive the instruction about applying pressure post injection for 15 minutes More information is better than not enough
- Pg. 37 or 38 add info about arranging for any medications or filling prescriptions as needed

before you go home to pick up on the way home or arrange to have delivered.

- page 50 Constipation add prune juice on the same line as mild laxative, stool softener
- as somebody who has struggled with constipation and there could have been more info provided to begin a constipation program. I know my body and my needs and staff did not listen to me. They should have acknowledged my concerns and let me start at day one. When I did start using a laxative it was too late. Ask patients about their bowels and if they have any constipation concerns.
- I had a reaction to the anaesthetic and other meds in the days following the surgery. Delirium and hallucinations should be discussed in the booklet and shared in a way that provides info on what patients and families could expect. Put it in the Surgery section or create a separate section to address reaction to drugs and anaesthetic.
- have info about seeing the unit or nursing staff to ask about where your loved one will be post-surgery
- leave a few lines after each section for any questions that patients or families want to ask. Add Notes or questions after each section
- Page 50 - my constipation was so bad; I did not expect it to be this bad. Add language that this can be very difficult and to talk to your doctor. Consider adding information related to pre-empting or being proactive to avoid constipation.
- emphasize the drinking of water and to drink it often; add to pre optimization section and other areas of before and post care
- Should put in info about the importance of relaxing just before surgery and the more relaxed you are the better; information on breathing deeply is important
- There is just one line about the anticoagulant and should be more info. Your doctor may prescribe blood thinner and that training will provided and should provide instructions. Did not receive the instruction about applying pressure post injection for 15 minutes More information is better than not enough
- Add vaping to the info about smoking

Extraneous

- Page 8 What to bring – consider removing housecoat and pyjamas as patients have gowns

Resources

- Add UVic programs
- Check all links to ensure they are active and correct
- Page 55 Health Link 811 - add in what services you can access at this number
- I would have liked to know about who I could call to talk to a person or support group about my cancer
- I did use 811 to talk to a pharmacist and nurse which was very helpful
- For the BC Cancer URL just put the basic site bccancer.bc.ca and then info that you can search for specific types of cancer

When I received the booklet

- I never did receive the booklet. I had blood work and a pre- assessment appointment with my surgeon the day before my surgery “ I feel that if I had had the booklet it would have resulted in a better outcome for me”
- I received the booklet a couple of weeks in advance of my surgery and it gave me a feeling of being supported and in control.
- We had to request an additional booklet for my caregiver. Patients should be asked if they want copies for family or caregivers.
- One week before my surgery at the preadmission clinic. I would have preferred receiving it when I went to see my surgeon and definitely before the preadmission clinic as it would have helped me to formulate questions I had.
- I received the booklet about 4 weeks before my surgery from my surgeon

- I received the booklet 3 months in advance of my surgery
- I received it one month before my surgery at the BC Cancer Clinic appointment with the surgeon
- I received it a couple of days within booking the surgery at the surgeon admission and 2.5 weeks before the surgery; this was good timing
- I received the book after my surgery and not before and wished I had received it before as I was not told very much about the surgery; why or what to expect
- I received the book at preadmission clinic
- English is not my primary language and I did not receive the booklet nor did my family members

A patient story

I feel really angry and concerned about the procedure and after the surgery I felt very discouraged. 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. Following the surgery because of my complications I was asked to be part of a research project and was not interested. Initially I was told that 90% it would not be cancer. Following the surgery the doctor came in the room to update me and shared that there was a 50% chance it was not cancer, 40% chance that it is cancer and 10% uncertain. It was confirmed it was cancer. There was no follow up after surgery. I suffered nerve damage and my leg was impacted. Currently I receive no support. My family doctor is currently the only doctor I have. He has sent me for six xrays and CT scan and I am awaiting an MRI. I go to physio and the therapist feels that scar tissue might be an issue. I started walking shortly after surgery up to 8 km walks and then had to slow down and shorten walk due to the 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 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.

When discharged I saw a poster board on the sidewalk to advertise rehab support post-surgery there was info about post hysterectomy recovery. It makes me so angry that the surgeon is discounting what I say has occurred. The health care system is limited and we need to spend more time on prevention instead of cleaning up the mess. I do not want to blame; I do not want to litigate what happened, I want to move forward. However I am fumbling I need help to navigate, I don't know what questions to ask. I want to have my quality life back. I don't do ill well and this is the worst thing that has ever happened to me. I do feel that if I had some tips and tools on what to do I believe 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 I have so many challenges. I don't want anyone to go through what I have been through

The stronger you are 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.

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 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 CEO's should be talking directly to people to understand what the patient experience is.

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Other Stories...

- I was in hospital a little bit longer with a site infection. There was a gap in arranging home support and trying to determine if someone could change the drainage bag. There was an attempt to discharge me without the supports in place but that could have been more the doctor than the hospital pushing for discharge.
- You need to advocate for yourself if you are not receiving the information you need or know the supports are in place. It seemed the surgeon was getting pressure to release. Someone from the surgical team actually stated, to me and my family members, the additional cost incurred by me staying in the hospital. It was coming up to a weekend and because of this we could not confirm the home support to drain the bag.
- Advocacy of family members is important all through the process Encourage patients and families that anytime they need more info and keep asking the questions until you have all the answers and info
- The follow up care was disjointed as the surgeon was away and this creating a lack of consistency in the discharge process. When I went home I was seen by wound care and they were good points of contact. However it was not until I was discharged that I was told it was best for the wound dressing not to be changed every day. The protocol seems different in hospital and at home; why is this?
- Hearing info multiple times is helpful.
- I was there 5 days at VGH I felt supported but I did not feel ready for discharge. I would have liked more support to ambulate I did not feel ready to walk I was not comfortable being able to move and go up and down stairs. It would have been better to stay a couple of extra days to feel confident being discharged.
- It was very calm in the surgical suite. I really liked how they spoke to me and answered questions

- I wanted a private room and did not get one but was put in with a man who was very challenging; delusional
- I asked to be moved to a private room and was but for a very short time and then was moved into a shared room and was it was very disruptive and even scary
- The food was just awful
- The nurses and staff were wonderful and very caring
- I did not receive any follow up phone number to call after discharge
- I had hoped to stay a little longer than 3 days but it felt like I was being pushed to go home.
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"I wish I had known sooner how important exercise would be"

"the booklet was very helpful and medical care was excellent"

Who we heard from

We conducted one on one interviews with past surgical patients. Sixteen past patients, who experienced surgery in the last 8 months, and two family members, participated.

"I like details and the understanding it gave me about the surgery and what to expect"

"The quantity of material received can be overwhelming but I thought this booklet was very helpful and liked having all the info in one place"

"I had surgery in the past but this booklet was very helpful especially because ERAS was explained to me and this added significance to the content. I have kept this booklet since my surgery – 8 months ago"

"These are simple things that are very basic and common sense but if I had not read this booklet I am not sure if I would have thought of the 6 importance of this information in my recovery"