

Understanding what recovery may look like

Recovery from surgery can look very different from person to person. Some people may have a very smooth healing journey with little to no pain, complications and difficulty returning to daily activities and life after surgery. Other people may have a very difficult journey with frequent pain, numerous or acute complications and a much longer time than expected away from work, school or other activities. Journeys may also fall in-between.

There are many things you can do to reduce your chances of complications, pain and speed up your return to activities after surgery. The <u>Vaginoplasty Guidebook</u> contains more information.

However, it is not possible to predict or promise what one's healing journey will look like, even if you do everything you can to set yourself up for the easiest road possible. It is important to understand the range of ways your healing journey may unfold and consider in your pre-surgical planning what it may look like for you and what supports can draw on should your healing journey be more difficult than expected.

The **vignettes below** are examples of different healing journeys.

K's Story

K considers her vaginoplasty journey a smooth one. After being discharged from the hospital, K felt relatively independent and was able to walk short distances and make her own food. K did experience some pain and bleeding after surgery, but it was not above what she had expected or had prepared for.

Dilation was a hassle and it was difficult to organize her life around her dilation schedule. After a few months K was able to incorporate dilation into her daily routine and it became just another part of everyday care and hygiene. K was alarmed when she experienced some wound separation (a few millimeters), however after speaking with her surgical team she was reassured that this would resolve and sure enough it did.

"I had wound separation, which was really scary at first until my surgeon reassured me. Despite this I am really happy I had surgery and really like how things look so far!"

K returned to her office job 6 weeks after surgery. She initially returned to work on a graduated return which allowed her to work reduced hours for the first 2 weeks, however K felt able to work her full hours after 1 week back and life felt like it had returned to normal shortly after. Even after returning to work, K still felt that her activity was limited for another 6 weeks which was frustrating and caused some stress.

L's Story

L felt her vaginoplasty journey was what she had expected-- bumpy but manageable.

Dilations were hard for L, both because they were painful but also because they took up so much of her time. She once commented to a friend that she felt like dilations were a "full time job" especially for the first few months after surgery.

At one point L felt her mental health was especially low, so she sought out counselling to navigate feelings she had around her recovery. She didn't realize how challenging and time-consuming recovery, especially dilations would be. At times, L wondered if she should have opted for vulvoplasty and whether dilation was "worth it" to maintain her vaginal depth.

"I didn't really understand that vulvoplasty was an option. Given what I know now about post-op dilation I may have weighed my options differently were I to do it all again"

L experienced significant wound separation (multiple cm) which looked very scary. When she spoke with her surgical team, however, they were reassuring, and the separation resolved over time. She also experienced hypergranulation tissue which required frequent silver nitrate treatment which meant that L was going back and forth to appointments with her surgical team more often than she had anticipated.

L had to take more time off work and activities than she had initially thought, and L felt like she missed out on some activities she was hoping to attend, such as a camping trip with her friends. At the time this was really disappointing and made L feel "out of the loop" and isolated. However, after she was feeling better and her healing was more stable she was able to reengage with her friends, activities and work. By 4 months post-op L felt like life had returned to normal, albeit with the additional daily routine of dilation.

D's Story

D had a challenging surgery and surgery recovery. D developed a fistula which resulted in fecal matter moving into her vagina. This was very alarming and upsetting to D, and she

required a stoma which was an opening in her abdomen which diverted fecal matter into a pouch (colostomy bag) worn outside of her body. D was told that she would need a repair surgery in the near future, which she was not expecting to need.

With everything going on D's mental health greatly suffered. D accessed counselling, which was helpful, but D sometimes felt isolated because she saw other people in her friend group and community having a smoother vaginoplasty recovery than she had been experiencing. D eventually found an online peer group of people who were navigating more difficulty post-op vaginoplasty recovery and felt relieved to know that she was not alone in her experience.

D continued to see her surgical team, the pelvic floor physiotherapist and eventually a pain specialist for the next year following her surgery. She felt very frustrated and exhausted by her post-op experience and was unfortunately unable to work and attend activities she loved. D's life has changed since surgery and though she doesn't regret her decision to have surgery it has been hard. D is unsure what is ahead but is taking things day-by-day alongside her care team and supports.

"There are good days and bad days. My life has become really different and really challenging since surgery-- but despite everything I don't regret having surgery"