

FAQ Sheet for Caregivers and Support

People

Acknowledgement:

The primary source of information for this support document for caregivers and support people has been derived from the patient information from OHSU, Trans Care BC, and Kaiser Permanente.

Why do they need a caregiver?

People need to have a safe and reliable plan for recovery after surgery, especially with gender affirming genital surgeries. Gender affirming (genital) surgery requires a team both inside and outside the hospital so that people can heal well.

Gender affirming genital surgeries are extraordinarily complicated procedures, often involving multiple steps and surgeries. This also means being in the best possible physical and mental health before the surgery. A large part of these surgeries' success depends on the patient's preparedness which includes having appropriate post operative support and caregivers. This post operative support far exceeds that of any other gender affirming surgeries your loved one may have had.

Support during this post operative healing process is critical to the success for the individual patients. Caregivers are an important part of the total recovery plan. It is essential that the main caregiver and any other support people are caring, dependable, and safe to be around. The National Travel Assistance (NTA) programme offers partial funding to assist the main caregiver's travel to Wellington in the first week after the patient is discharged from the hospital.

Some patients may choose to have multiple caregivers to lessen the work for any single caregiver. (NTA only provides funding for one support person's flights to Wellington for post operative support when they are discharged from Hospital).

Caregiving is challenging, and it is best to have multiple people ready to help your friend or loved one. We encourage you and your friend or loved one to have a backup plan if you are the primary caregiver, in case you become sick or otherwise unavailable. It can also help to discuss your own needs beforehand. This period can add strain to your relationship and discussing this openly is important.

Below is a list of concrete ways that you can offer to support your friend or loved one through their gender affirming surgery and recovery.

Caregiving when your loved one is initially discharged from hospital:

Look at our “Choosing your Caregiver and Support People” resource so you will have a better idea of the support, tasks and care required post operatively, and have frank, open and honest discussions regarding what you feel able to do, with your friend or loved one. Encourage them to look at and develop emotional well-being coping strategies as you too will need emotional support during this time.

You will see on that sheet that there are three main types of support roles and that each have specific needs to cater for:

Hospital support:

The caregiver should be always with them as much as possible once they have been discharged from hospital. The caregiver will need to feel comfortable assisting them with genital hygiene care and surgical wound dressing changes.

Home support:

The caregiver will need to help with getting them to and from the bathroom and shower (and for phalloplasty patients, to complete dressing changes for the phallus and donor site,) and help with food, transportation, laundry and other household chores, and errands. The caregiver may also need to help with caring for any children or pets.

Emotional support:

They will need a lot of emotional support, especially those who are phalloplasty patients and will be lying flat for most of the time for four weeks after the first stage. Ask what it looks like when they feel low so you can recognize the signs.

We strongly recommend that you read the resources relevant to your friend or loved one's surgery we have compiled, to be better prepared for your role.

How long do I need to help?

The primary caregiver should be present at all times for three weeks after hospital discharge. After that, a caregiver should be available (not necessarily present) 24 hours a day for two more weeks. "Being available" means coming to help within 30 minutes when needed.

Start with the basics:

Before surgery, help your friend or loved one prepare for their return home. This may include helping them clean or declutter their space so they can return to a calm and safe living environment. You might want to help with grocery shopping or help preparing nutritious meals that can be frozen and heated later. When a person knows they are cared for, it reduces stress and helps with healing, and it also just feels good.

Take on household chores:

For the first few weeks post-discharge, they will need help with basic household chores. You might want to ask if you can assist with them. This might include grocery shopping, cooking, changing sheets, rearranging pillows, laundry, vacuuming, taking out rubbish, watering house plants, and pet care such as changing litter boxes, pet walking or picking up pet supplies. They might appreciate the offer of a ride to and from their spiritual gathering place (church or temple).

Assist with medical appointments:

Until they can resume normal daily activities, they may need help in driving to and from any medical appointments and picking up medication from pharmacies. Make yourself available for help with transportation.

Keep a running list for medical professionals:

There is a significant amount of information that is provided to any patient upon discharge from surgery. It is difficult to remember all the questions patients want to ask their doctors. Help them by keeping a running list of questions or concerns that they want to discuss with their doctors, nurses, therapist or other medical or health professionals.

Watch for changes:

You provide an important role in helping them heal during their recovery. Keep an eye out for changes that others—including the patient—might miss. Although not expected any complications from surgery and side effects from medication must be addressed promptly.

Provide emotional support:

Many patients have been looking forward to this surgery for years. But that does not mean that their recovery from surgery will be free from feelings of frustration, fear, or doubt. Ongoing support and encouragement will be very helpful during this process (Remember you may need emotional support too).

Being a caregiver can be an emotionally and physically draining task. Clear and direct communication will be helpful. Take time for yourself during this process, too. Caring for yourself is one of the most important things you can do as a caregiver. When your needs are taken care, the friend or loved one you are helping will benefit too. Make sure that you have scheduled breaks, free from these temporary responsibilities. If you are the primary support person, it is important to take regular time to be alone or to go out and do something you enjoy. There may be other people who would be more than happy to help if they knew what was needed, so just ask.

Preparing yourself:

- Seeing someone you care about feeling pain or discomfort can be hard, and taking on extra responsibilities can, at times, be stressful.
- This is a temporary and normal part of the process of care giving, and it can be made easier by reflecting in advance about what's ahead and thinking of ways to also care for yourself during this time.
- Be a positive distraction. Distractions help people manage pain, avoid boredom, and recover more quickly. This can include listening

to an audio book together, going on walks, sending texts and pictures, and dropping in for short visits.

Questions for Caregivers to think about:

- How do I feel about assisting my friend or loved one to the toilet, to bathe, or to dress?
- Am I comfortable providing wound care?
- What will I do to support myself if I feel overwhelmed?
- What are my strengths as a caregiver?
- Do I understand what is being asked of me?
- What are my needs and limits?
- Have I communicated my limits and boundaries?
- What conversations do I still need to have with my loved one before their surgery?
- What will I need to do to take care of myself while I am providing care for someone else?

It's also helpful to remember that your role isn't to be a magician and fix everything or make all pain or discomfort disappear – it is just to be with your friend or family member on their healing journey.

Just knowing someone understands can be a really big help. Even though it doesn't "fix" anything, empathy creates connection and makes it just a little easier to live through the harder parts of healing.

Caregiver and support people considerations:

- I have scheduled time to take care of myself (eat, shower, have some quiet alone time, participate in meaningful activities or go to work). Yes/No
- I have a good sense of what to expect leading up to, during, and after my friend or loved one's surgery. Yes/No
- I have spoken with my family or loved one and we have the same understanding about what kind of support I will be providing. Yes/No
- I feel as prepared as I can be to handle supporting someone after they have surgery. Yes/No
- I feel as prepared as I can be to care for myself during this time. Yes/No

- I have a plan for what to do if I feel stressed while my friend or loved one is healing from surgery. Yes/No

Look at the self-care section that follows; self-care is important and applies equally to all support people.

Gender-affirming surgery: the importance of self-care for patients and caregivers

About self-care:

Making sure that we take time for ourselves is one of the most important aspects of living a full and emotionally healthy life. Unfortunately, these activities of self-care are often the first things that drop off our daily “to-do” list when life gets stressful. Committing to self-care activities may assist both your loved one in their physical and emotional recovery, and you can also use them too, to help you to look after yourself as a support person.

What is self-care?

Self-care is any activity that you consciously do to tend to your mental, emotional, and physical needs. They are fun, enjoyable, or relaxing activities that replenish you.

What are some barriers to self-care?

You might not engage in activities of self-care for a variety of reasons. You might think that it feels selfish. You might think that self-care is indulgent. Sometimes, financial limitations restrict our ability to even brainstorm a list of self-care activities.

Remember this:

Self-care is necessary and not selfish. It may feel indulgent and that can be good. Most importantly, the vast majority of self-care activities are free!

Some self-care activities:

- Read a library book
- Meditate
- Prioritize sleep

- Eat a healthy, nutritious diet
- Cook something new
- Laugh with friends
- Write an uplifting letter to a friend
- Keep a gratitude journal
- Take a hot shower/bath
- Go for a walk
- Explore a new area of town
- Listen to your favourite songs
- Watch your favourite movie
- Talk with a friend—in person!
- De-clutter your closet or home
- Have a picnic with a friend
- Go to counselling
- Light candles or an oil diffuser
- Lie outside and watch the clouds
- Pamper yourself – dress in your favourite clothes or wear comfy clothes to help you relax/feel better, wear your favourite makeup, eat your favourite comfort food, get a haircut, moisturize your body.
- Eat the rainbow! Getting a balanced, nutritious diet with lots of fruit and vegetables will help your mind and body feel its best.
- Stimulate your senses – smell something (perfume, a flower), taste something (something strong flavoured or something you really like), listen to something (nature sounds or music), touch something (fabric, a furry pet, a teddy bear), stimulate your vision (by looking at a colour you like or pics of baby animals).

Add your own ideas to this list! Try to complete at least one activity of self-care each day. Make sure it is intentional, replenishing, and enjoyable!

Tips to help with an anxiety attack:

Look around you and find:

- Five things can see
- Four things you can touch
- Three things you can hear
- Two things you can smell

- One thing you can taste.

This is called grounding. It can help when you feel you have lost all control of your surroundings or are feeling overwhelmed.

Sight:

To engage your sense of sight, here are some ideas:

- Look at every little detail on a family photo on the wall.
- Focus on a small object, such as a pencil or coffee mug, and identify every colour and shape.
- Look at the sky for clouds, birds, sunrises, or anything else you can spot around.
- Focus your attention on a plant or flower and how it moves with the wind.
- Observe a pet while they play or rest.

You can pick large or small items to focus on. Once you choose an object, try to notice the colour, texture, and patterns.

Touch:

Activating your sense of touch can help distract you from anxious thoughts and may help you to decrease the physical signs of anxiety.

You might want to try these exercises:

- Put your hands under running water, alternating between warm and cold temperatures every 30 seconds, or try holding an ice cube.
- Focus on how your clothing feels on your body or how your hair feels on your head.
- Touch different body parts by pressing down and holding for 30 seconds before moving to a different area.
- Touch the furniture in your living area and focus on its texture. For example, take notice of a smooth table.

Hearing:

Focusing on external sounds can help ground you in the moment.

Here are some noises to notice:

- a barking dog
- a stomach rumbling
- a clock ticking

- traffic outside
- a car, bus, or motorcycle engine
- music
- conversation
- birds singing
- the wind blowing

Smell:

To incorporate smell into your grounding techniques, you may want to try these tips:

- Walk into your bathroom and sniff a bar of soap or shampoo.
- Light a scented candle.
- Diffuse a scented oil.
- Take in simple smells around you, such as the scent of a pillow on the couch or a pencil
- Walk outside and breathe deeply through your nose. Maybe you will smell fresh cut grass or flowers blooming.

Taste:

Try to pick something that you can easily taste, such as:

- a piece of gum
- a mint
- coffee
- sugar and salt
- a piece of food

You don't actually have to taste these items if you don't have them on hand. Instead, try thinking about the distinct flavours as you remember them.

A few more grounding tips:

- **Breathe:**

Try what's called "Boxed Breathing," in which you'll breathe in for four seconds, hold for four seconds, breathe out for four seconds, hold for four seconds, and so on until you feel grounded. You can also tighten

your muscles and release them while breathing, focusing on your breath, and practicing mindfulness all the way through.

- **Stretch:**

You can perform light stretches while you focus on your breath as well, paying close attention to the physical sensations that arise from the activity.

- **Exercise:**

Exercise, again with an emphasis on the physicality of your exertions, is an effective way to get back into your body. Whether simple jumping jacks, a long run on a favourite trail, or even a gentle walk around the block- feeling the sensations of exercise on your body can bring you back from a place of panic.

- **Mindfulness:**

Whether you engage your senses through a “five, four, three, two, one exercise,” – where you identify five objects, four different sounds, three textures, two smells, and one taste – or by simply focusing your awareness on the present moment and bodily sensation, it’s important to draw your attention to the present.

- **Senses:**

Focus on a particular sensation like holding an ice cube and noticing what it feels like or smelling an essential oil.

Or you could try following the three-three-three rule:

Look around you and name three things you see. Then, name three sounds you hear. Finally, move three parts of your body – your ankle, fingers, or arm.

Lastly, if you are feeling really down it’s important to get as much support as possible, including professional support.

You can:

- Free call or text 1737 anytime for support from a trained counsellor
- Outline: call 0800 688 5463 between 6pm – 9pm to talk to a trained volunteer from the LGBTIQ+ community. Call (09) 972 0054 to talk to the counselling team.
- Lifeline: Free text HELP (4357) Call 0800 LIFELINE (543344)
- Suicide Crisis Helpline: 0508 828 865 (0508 TAUTOKO)

- Healthline: 0800 611 116
- Depression Helpline: 0800 111 757 or free text 4202 (to talk to a trained counsellor about how you are feeling or to ask questions)
- Youthline: Free text 234. Call 0800 376 633; email talk@youthline.co.nz
- Talk to your GP