

Choosing your Caregiver and Main Support People

Acknowledgement:

The primary source of information for this support document has been derived from the patient information from OHSU and Kaiser Permanente

Choosing your support person: planning for recovery

Your support persons are an important part of your total recovery plan. Pick people who are caring, dependable, and safe to be around. The National Travel Assistance (NTA) programme offers partial funding to assist your support person's travel to Wellington in the first week after you are discharged from the hospital. We are going to refer to your main support person as your caregiver in this resource.

Why do I need a caregiver?

You need to have a safe and reliable plan for recovery after surgery. Gender affirming genital surgery requires a team both inside and outside the hospital so that you 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 your preparedness which includes having appropriate post operative support and caregivers. This post operative care and support far exceeds that of any other gender affirming surgeries you may have had.

Support during this process is critical to your success. 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 you are discharged from Hospital)

How long do they need to help?

You will need to have someone who is physically available at all times to help you with day-to-day activities for three weeks after you leave the hospital, and can be present at all times during this three week period. After that, your caregiver or a backup caregiver needs to be available (not necessarily present) 24 hours a day for two more weeks (in case of complications and prolonged healing). "Being available" means coming to help you within 30 minutes when needed.

Who would be the best caregiver?

This type of caregiving often relies on a close relationship, as you will need to discuss care of your genitals. We recommend asking a family member, partner, spouse or long-term close friend. In our experience, well-meaning colleagues and acquaintances are not consistently reliable or prepared for the involvement in this type of caregiving. Caregiving is challenging, and it is best to have multiple people ready to help you. You need a backup plan in case your primary caregiver becomes sick or otherwise unavailable. It can also help to discuss the caregiver's needs beforehand. This period can add strain to your relationship and discussing this openly is important.

What is my caregiver's role?

Hospital support:

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

Home support:

You will need your caregiver to help you get 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. You may also need help with caring for any children or pets.

Emotional support:

You will need a lot of emotional support, especially for phalloplasty patients who will be lying flat for most of the time for several weeks after the first and second stages.

We recommend that your caregiver read the resources relevant to your surgery we have compiled, to be better prepared for their role.

Your primary caregiver will need emotional support as well:

Think about what coping strategies you can use during this time when your caregiver needs some down time.

Questions to ask yourself:

- How would you feel about your caregiver assisting you to the toilet, to bathe, or to dress?
- Is your caregiver comfortable providing wound care?
- Can your caregiver drive, help with your grocery and household chores?
- What will your caregiver do to support themselves if they are overwhelmed?

Think about your needs:

- What makes me feel calm and relaxed?
- Who do I feel comfortable and safe to be around?
- Who provides me with the emotional support I need?
- Who makes me laugh?
- Who is most dependable?

Communicate your needs:

- Be proactive in your communication
- Identify which activities and roles you need help with
- Assign specific tasks to individual support people

- Brainstorm all aspects of your life, including day-to-day responsibilities around the house and activities of self-care that you enjoy.
- Meal preparation
- Social visits
- Light housework (dog walking, laundry and tidying up).
- Pharmacy runs
- Grocery shopping
- Transportation to post-op appointments and to your GP
- Emotional support

Additional considerations:

Housing:

You will need to have stable housing for the first six weeks after surgery. This should be a place that is physically and emotionally safe. Ideally it has either a walk-in shower or a removable showerhead (as this makes bathing and cleaning your surgical sites much easier) and not too many stairs.

Think about:

- Do you currently have stable, safe housing?
- What is your plan for stable, safe housing during recovery from surgery?
- Your own home.
- A friend or family member's home.
- Hotel, Airbnb and apartment rental.
- Do you have a "support person or team" — someone(s) to assist you in aftercare?
- Is your support person(s) available to be with you all the time for the first three weeks?

Thinking about all the ways your support person(s) is prepared for your recovery:

Transportation:

Are they available to:

- Accompany you from the Hospital including carrying your bags when you are discharged, and help you get to your follow-up appointments.
- Support you with grocery shopping, meal preparation and cleaning up after each meal.
- Help you to the bathroom, with showering and simple wound care.
- Pick up supplies such as medications from the pharmacy or other household items.
- Help with laundry, house cleaning, taking out the garbage, checking the mail.
- Help with any responsibilities you have to provide such as childcare, pet care or other caregiver duties.
- To keep you company so that you are not isolated or lonely during recovery.

You should have a backup support in case the person you have chosen is unavailable to assist you as planned.

Financial planning:

You should prepare to be out of work for up to six to eight weeks while you heal from your surgery. The length of time depends on the pace of your recovery and the nature of your job. You may be able to return sooner if you can work from home.

Think about:

- If you are working, are you able to take up to four weeks, or possibly more, time off from work to recover from surgery?

Think about (and you can use this handy checklist) all the ways you are financially prepared during recovery. Have you got money set aside or can you realistically expect your usual income to cover:

- Rent and mortgage
- Food
- Phone and other utilities
- Medication or medical supplies

- Transportation (This includes transportation to and from your local airport if you do not live in Wellington, or to and from the hospital if you are Wellington based, and transport to take you to your follow up appointments when you are initially discharged from hospital; note that you will have to stay close by until you are cleared to travel about 10 days or so later)
- Automatic payments and direct debits
- Other bills (credit cards, insurance, school loans, etc.)
- Additional accommodation costs that you will need to cover when you are initially discharged from hospital; you are required to stay close to the hospital for another 10 days until cleared to return home if you do not live locally. (The National Travel Assistance program provides only partial funding for this expense)

We also recommend that you:

- Make a backup plan, in case you need more time to heal because of complications.
- Find out if you are eligible for any medical or annual leave through your employer.
- Find out if you are eligible for any MSD/WINZ temporary sickness benefit or medical costs assistance.

For those undergoing phalloplasty, there are additional physical restrictions after surgery. After your first and second stage of surgery, you are not allowed to sit for up to four weeks, except to use the toilet. You can stand or lie flat. We recommend finding ways to function within those limits before surgery, while you are feeling well.

For instance, you will need to:

- Move from lying down to standing up while bending in your hips as little as possible.
- Pull yourself up with only one arm, if your other arm is healing from a tissue donation.

Getting dressed will be tough, especially when there is a bulky dressing around the phallus. It will be helpful to have pants that are loose and easy to put on, and slip on shoes.

Supplies to get before surgery:

We suggest, to reduce the financial burden, to consider buying some of the medical supplies you will need when you return home several months ahead of time and purchasing just a few items at a time. We can let you know as you begin to proceed to surgery what supplies you may need for your return home.

Adapting to change:

It is critical that you have a solid and safe plan for recovery, even if it means delaying your planned or anticipated surgery. We understand circumstances may change in the time leading up to your surgery. Please let us know right away of any such changes, so we can help you determine if and how they would impact your surgery or recovery plan.

Some unexpected changes may include:

- Moving or loss of housing.
- Loss of income and financial concerns.
- A change of caregiver(s).
- A new health condition.

Our patients who delayed their surgery due to unforeseen circumstances were grateful they did so. This is especially true given the challenges associated with this surgery and its recovery.

We understand the importance and urgency of this surgery.

We also know your success hinges on being well prepared. Remember, this is a lifelong investment in your health. Optimal preparation can improve your chances of positive physical and mental health outcomes.

Following surgery, people may sometimes experience feelings such as:

- Ups and downs in your mood and temporary feelings of tiredness, sadness, or irritability.
- Postoperative depression does not affect everyone, but when it happens it can be confusing; people expect emotions after surgery should be very positive, but that is not always the case at first.

- Disappointment that the results are quite different from what was expected and require surgical revision.
- Discouragement with postoperative care.
- Boredom or isolation during the recovery period.
- Sadness over the negative reaction of certain people close to you.
- Re-triggering of past trauma and/or sexual abuse; the pain experienced in your surgical area, limited mobility, and intimate post op cares needed, can be triggering.
- Feeling of loss of independence and control; recovering from surgery places people in a position that may feel very vulnerable.
- Feeling tired, exhaustion due to pain, and lack of motivation to look after yourself and adhere to the aftercare regimes, that are important for your recovery.

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 you in your physical and emotional recovery, or help you to look after yourself if you are 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 and 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.

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