TRANSGENDER HEALTH PROGRAM

Vulvoplasty

Guide to gender-affirming surgery



**ALM** 

# Usage statement

These patient education materials were developed by the OHSU Transgender Health Program and the Department of Urology. They are intended to be used only for the OHSU surgical program. These materials are being updated regularly as we continually evaluate and improve the program. Please credit the OHSU Transgender Health Program if you reproduce any of the text. Permission to reproduce any of the images is not included; any licenses, releases or permission must be obtained independently.

Sincerely,

OHSU Transgender Health Program and Department of Urology

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# Materials in your booklet:

- Checklists
  - Surgery scheduling checklist
  - Preparing for surgery checklist
  - Support and recovery plan worksheet
  - Packing bag for hospital checklist
- Letter of support template
  - Give this to your mental health provider to guide letter writing.
- Pain management tracking table



Dr. Daniel Dugi, a urologist and surgeon, is the surgical director of the OHSU Transgender Health Program. He has extensive experience in gender-affirming surgeries, including vulvoplasty.

# Section 1: Introductions

#### Welcome!

#### From the Urology Department

Welcome to the Urology Department's gender-affirming surgery division. We know you've probably waited a long time for this appointment, and we're very happy to meet you today.

Here in the Urology Department, our gender-affirming surgeries include vaginoplasty, vulvoplasty, orchiectomy and metoidioplasty. We also offer revision surgeries, and we help the Plastic and Reconstructive Surgery team with certain stages of phalloplasty.

Our team consists of:

- Surgeons
- A physician assistant
- Medical assistants
- Our surgery scheduler
- Resident physicians
- Physical therapists
- Behavioral therapists
- Social workers
- And you

That's right, you! We value your input, your perspective and all the work you are and will be doing to prepare for and recover from surgery. We are excited to get to know you better and to learn how we can help you.

We want to make your surgery and recovery as smooth as possible. We'll answer any questions you have and make sure you have the best possible outcome.

Preparing for and recovering from surgery is a long process with a lot of steps. We created this guide to help you navigate the process. It has three sections:

- Before surgery
- During surgery and your stay at the hospital
- After surgery

#### From the Transgender Health Program

Our surgery team is one part of a bigger team called the OHSU Transgender Health Program. At the Transgender Health Program, we are committed to your health and well-being.

We know that high-quality health care in an affirming, welcoming environment can be lifesaving. We work as an interdisciplinary team. This means our program's patient navigator, social workers and/or psychologist are all part of the care team and may be involved in your care. Your clinic visits with your surgeon may also include these team members. Or, supporting you in your surgery preparation may include meeting with members of the team between your clinic visits.

The Transgender Health Program — THP for short — provides support, information and advocacy, including:

**Support:** We can assist with care coordination, surgery planning, supportive counseling and/or connecting you to community resources.

**Top providers:** We can connect you with OHSU providers who are international leaders in caring for gender-diverse patients of all ages.

Access: We strive to increase access to health care for the transgender and gender-nonconforming communities at OHSU and beyond.

**Leadership:** We work with community partners to provide advocacy, to shape policies and to train health care professionals.

**Education:** We offer written patient education materials and classes on gender-affirming surgery.



Dr. Geolani Dy is a board-certified urologist specializing in genderaffirming surgery for individuals across the gender spectrum.



Dorian Scull, PA-C, is passionate about improving the health outcomes of their community through providing quality, culturally competent care.

#### **Overview of vulvoplasty**

We know this surgery is extremely important. It takes incredible trust to allow a surgeon to perform this operation. We want you to know we are humbled by that trust and take it very seriously.

#### What is vulvoplasty?

Vulvoplasty is a surgery to create a vulva — the outer genitals — without the internal vaginal canal. You may choose this option instead of vaginoplasty if you want the outward appearance of a vulva but don't want a vagina for sexual activity.

After vulvoplasty, your labia, clitoris and urethra look almost the same as they would after vaginoplasty. We also offer this option if you have had previous prostate or rectal cancer surgery or radiation therapy.

#### Expectations

• "I want my results to look like this ..."

You may have been waiting your entire life for this, and you may have an image in mind of what you want your results to look like. Some people have brought in pictures from the internet of what they think their results should look like. Others have told us they felt their results didn't look like a "normal woman" or "natural." We want you to be happy with your results, but we may not be able to meet 100 percent of your expectations.

#### • Our surgical technique

Our goal is to create a natural-appearing and functional vulva. We use techniques we believe are as safe as possible to protect your sexual, urinary and bowel function.

• How will I know what my results will look like? This is a complex surgery, and every person has different anatomy. Your results will be different from every other person's results. No two vulvas are alike, and no one is perfectly symmetrical. In our experience, the aesthetic results are highly related to a person's individual anatomy before surgery. We would like to match results to what you might expect in your mind's eye. But what we can realistically deliver is limited by a person's anatomy and safe surgical techniques.

#### What if I need a second surgery?

- We aim to create all the important structures during the main operation ("one stage"): outer and inner labia, clitoris and hood, and new urethral position.
- Whether you will need a second surgery cannot be known ahead of time. This is because of tissue swelling during surgery and the unpredictable nature of healing.
- Some well-known vulvoplasty and vaginoplasty surgeons report nearly half of patients need a second surgery to fix complications or for aesthetics. Some surgeons tell everyone that two surgeries are always necessary.
- We will submit to your insurance that we plan a two-stage operation. If you choose a second operation, hopefully it won't be hard to get insurance to cover it.

#### What if I decide that I want a vaginal canal later?

- It is more complex, and there are more risks, when a vaginal canal is created after vulvoplasty.
- This is because we use the skin of the penis and scrotum to make the vaginal canal during vaginoplasty. That skin is all removed during vulvoplasty, so we must get the skin from somewhere else if you want a vaginal canal later.
- One option for creating a vaginal canal after vulvoplasty is using the surgical robot to harvest peritoneal flaps to construct most of the vaginal canal for surgical candidates. This is a good option for later reconstruction but may require extra skin grafts.
- We usually take skin from both sides of the waistline and hips to create the vaginal canal. This is not ideal and leaves a linear scar on both sides of your waistline and hips.
- For these reasons, we urge you to consider if you would like a vaginal canal before you commit to vulvoplasty.

#### Surgery details

Initially, as a baby develops before birth, all the genital parts are the same. Through the influence of hormones, the genitalia then develop differently. Wherever possible, we will use the tissue that would have been the female part to make the new female part.

- For instance, the basic structures of the penis and clitoris are the same. The glans, or head, of the penis, with its nerves and blood supply, is used to make the clitoris.
- Skin from the penis and the urethra is used to make the area around the clitoris and the smaller or inner labia.
- Scrotal skin is used to make the larger, outer labia. Remaining parts of the penis and scrotum are removed.

We create these new parts and reposition the urethra in one surgery. Some people choose to have a second surgery at least 6–12 months later for aesthetic or other reasons.

#### **Risks and complications**

#### Wound healing complications

**Wound separation:** A common complication, wound separation happens where we have stitched two areas of skin together, but the skin edges pull apart after surgery. This typically heals on its own if you keep the site clean and dry. If you have wound separation, we will ask you to change your dressing with roll fluff gauze every time you use the bathroom or take a shower.

**Granulation tissue:** This is an area of bright red or pink tissue around an incision where healing wasn't complete. It can sometimes show up as painless bleeding and is common. We can treat this easily in the office at your follow-up appointment.

**Tissue necrosis:** This sounds scary but is usually minor. It is another more common complication. Tissue necrosis happens when there is not enough blood to supply healing tissue. If you have tissue necrosis, we will ask you to change your dressing with roll fluff gauze every time you use the bathroom or take a shower. If this results in unsatisfactory functional or cosmetic outcomes, we can usually fix it with a second surgery.

#### **Urinary complications**

**Urine spraying:** One-third of people in published studies report this complication. Patients often find that it can take more than 6 months before the urine stream is more directed. If you still have bothersome urine spraying after 6 months, we can often correct it with a second surgery.

**Urine retention:** About 1 in 5 people have difficulty emptying their bladder after the Foley catheter is removed in the hospital. If this happens, a nurse will replace the catheter. We will remove it at your first follow-up visit.

**Urinary urgency/frequency:** This is a feeling of having to pee suddenly and often. This is common soon after surgery because of bladder irritation. This typically resolves on its own.

**Urine leakage:** This can happen without warning. This usually happens when pressure increases in the abdomen, such as with coughing, laughing or sneezing. This usually gets better on its own as you heal. Pelvic floor physical therapy can help.

#### Surgery risks

**Infection:** Infections after surgery are uncommon but can be dangerous. The area we operate on tends to have a lot of bacteria, which increases the chance of infection. The risk of infection is higher for people who have diabetes or are overweight. You will be given antibiotics at the time of surgery to prevent infection. But we ask that you shower twice daily and keep the area clean and dry. If you have diabetes, be diligent about checking and correcting your blood sugar. The stress of surgery can make it more difficult to control blood sugar.

Hematoma: This is localized bleeding outside of blood vessels. If you develop a sudden, asymmetric swelling and/ or bruising at the surgical site, you may have a hematoma. Small hematomas typically heal on their own. Large hematomas may need to be drained, but this is rare. Remember, you will have a lot of swelling at the surgical site. This is normal, but sudden asymmetric changes are not.

#### Blood clots (sudden swelling of one leg or difficulty

**breathing):** Blood clots can form during and after surgery because of prolonged inactivity. If you take oral estrogen, we ask that you either stop taking your estrogen two weeks prior to surgery or switch to topical or injectable estrogen about four weeks before surgery. This is to help prevent blood clots. We also put squeezing devices on your legs while you are in the hospital to prevent this. When you go home, getting up and moving around periodically will help prevent blood clots. If one of your legs swells suddenly, or if you suddenly have a hard time breathing, you may have a blood clot. You should go to the emergency department immediately.

# Section 2: Before surgery

#### Surgery scheduling checklist

After your first appointment, we have no way of knowing if you are ready for surgery until you tell us you've finished all the preparation steps. We have created a checklist to help you. All items need to be complete before surgery can be scheduled.

Things to do (and send us) to be eligible for surgery scheduling
$\bigcirc$ Complete and return support and recovery plan worksheet (included).
<ul> <li>Two letters of support</li> <li>Written by certified mental health providers.</li> <li>Following WPATH criteria.</li> <li>Please visit the Transgender Health Program website (ohsu.edu/transgender-health) for more information about mental health referrals and/or to give your provider our WPATH letter template.</li> <li>Contact the Transgender Health Program if you need help connecting with a mental health professional.</li> </ul>
$\bigcirc$ Your health plan (insurance) requires one of your two letters of support to be dated within 1 year of your surgery.
O Documentation of recent A1C < 6.5% (diabetic patients only)
<ul> <li>Successful nicotine cessation</li> <li>Must be nicotine-free for a minimum of 10 weeks before surgery.</li> <li>Nicotine levels will be tested twice before surgery.</li> </ul>

- We kindly ask that as you complete items on the checklist, you contact us to let us know and/or send in the required documentation.
- Once we have documentation that the checklist is complete, we can schedule your surgery. You can call the clinic to find out what we have on file and what we still need.

#### Support and recovery plan worksheet

Your name:	Date of birth:
<b>HOUSING:</b> You will need to have stable housing fo that is physically and emotionally safe.	r the first 6 weeks after surgery. This should be a place
Do you currently have stable, safe housing?	🗌 Yes 🗌 No
What is your plan for stable, safe housing during r	ecovery from surgery?
Your own home	
A friend or family member's home	
☐ Hotel	
Rood Family Pavilion (your reservation	
has been accepted and confirmed)	
Other (please specify):	

**SUPPORT:** You will need to have someone who is physically present to help you with day-to-day activities for at least several hours a day for a week after surgery.

Do you have a "support person or team"	- someone(s) to assist you in aftercare?	🗌 Yes	🗌 No
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Is your support person(s) available to be with you for several hours or more for the first week after surgery?

Yes No.

Please check all the ways your support person(s) is prepared for your recovery:

- **Transportation:** Take you to and pick you up from the hospital, help you get to follow-up appointments
- **Food:** Grocery shopping, meal preparation, food cleanup
- **Hygiene/wound care:** Someone to help you to the bathroom, with showering and simple wound care
- **Supplies/errands:** Picking up supplies such as medications or other household items
- **Household chores:** Laundry, housecleaning, taking out the garbage, checking the mail
- **Dependent care:** Someone to help with any responsibilities you have to provide childcare, pet care or other caregiver duties
- **Companionship:** Someone to keep you company so you are not isolated or lonely during recovery

Please provide the contact information for your support(s): Name: \_\_\_\_\_ Phone number: \_\_\_\_\_ Name: \_\_\_\_\_ Phone number: \_\_\_\_\_ You should have a backup support in case the person named above is unavailable to assist you as planned. Please provide the contact information for your backup support person(s): Name: \_\_\_\_\_ Phone number: \_\_\_\_\_ FINANCIAL PLANNING: If you are working, are you able to take up to 4 weeks, or possibly more, time off from 🗌 Yes 🗌 No work to recover from surgery? Unsure Please check all the ways you are financially prepared during recovery by indicating you have money set aside or expect your usual income for: Rent/mortgage Food □ Phone and other utilities ☐ Medication/medical supplies ☐ Transportation Other bills (credit cards, insurance premiums, school loans, etc.) SOCIAL WORK SUPPORT: Are you interested in speaking with a Transgender Health Program social worker to assist with any of the following? ☐ Housing Social support ☐ Finances □ Mental health Other (please specify): \_\_\_\_\_\_

Please return this worksheet to us via email at urologyTHP@ohsu.edu as a PDF or JPEG or fax to 503-346-1501. The Transgender Health Program does not consider being transgender or gender-nonconforming a disorder or diagnosis. Instead, we recognize that mental health professionals can offer support and guidance. They can also provide the **letters of support** needed for some surgeries.



Amy Penkin, the Transgender Health Clinic program manager, has led the program since it began in 2015. She has a long history of serving the LGBTQ community.

# Finding a mental health therapist

**Transgender Health Program services:** The THP offers psychological services for shorter-term assessment and support, including providing letters of support. We can also help you find a therapist in the community if you're interested in ongoing care.

**Searchable database:** Psychology Today maintains a Find a Therapist tool at psychologytoday.com/us/therapists. You can click on your state and filter by ZIP code, specialty area (such as transgender care) and type of insurance, such as the Oregon Health Plan.

## Letters of support

### Why do we require letters of support?

We follow the World Professional Association for Transgender Health (WPATH) Standards of Care (wpath.org/publications/ soc) guidelines and adhere to the requirements of your health plan. This often requires that you have letters in support of your transition surgery written by mental health providers before scheduling surgery. Insurance also requires these letters. Many insurance companies will not cover the cost of surgery without them. Your letter(s) should be written by a mental health professional who knows you well.

The requirement for letters of support is not meant to be a barrier or burden, or to be stigmatizing. We understand it's an insurance requirement. There may be some variability in the number of letters required based on your specific health plan. We also see the value of making sure people have considered all the implications of a major, irreversible surgery that affects their identity, physical health, sexual function and fertility. Also, surgery and recovery from surgery are parts of an extremely stressful time. It's important to have a relationship with someone who can help with that stress if needed.

### Do the letters ever expire?

Insurance often requires that at least one letter be dated within 1 year of surgery. Current waiting times for surgery mean you may need one or both letters updated about 3 months before surgery. We apologize for any inconvenience. We are always working to improve this process and to reduce waiting times.

#### Who can write the letters?

Only a licensed and qualified mental health provider can write the letters of support. Your primary care provider cannot write the letters. Here are some examples of mental health professionals who can write your letter:

- Licensed clinical social worker (LCSW or LICSW)
- Licensed marriage and family therapist (MFT)
- Licensed social work associate & independent clinical (LSWAIC)
- Licensed professional counselor (LPC)
- Clinical psychologist (Ph.D. or Psy.D.)

#### What must be included in the letters?

WPATH recommends the letters contain:

- 1. The client's general identifying characteristics.
- 2. Results of the client's psychosocial assessment, including any diagnoses.
- 3. What surgery or surgeries the patient is seeking.
- 4. How long the patient has been on hormone therapy and living in a gender role.
- 5. The duration of the referring health professional's relationship with the client, including the type of evaluation and therapy or counseling to date.
- 6. An explanation that the criteria for surgery have been met, and a brief description of the clinical rationale for supporting the patient's request for surgery.
- 7. A statement that the patient has given informed consent.
- 8. A statement that the referring health professional is available for coordination of care and welcomes a phone call to establish this.

Make sure your certified mental health professional is familiar with the WPATH Standards of Care and includes all the above information. Consider giving the person these guidelines to help in writing the letters.

#### Is there a template that my mental health provider can use to write the letters?

Yes! We made a template that your mental health professional can fill out and mail or fax to us. Find it on the THP website at ohsu.edu/transgender-health/patient-guide-gender-affirming-care, under "Letters of support."

#### Where do I or my mental health professional send the letters?

Please fax, mail or email a PDF of the signed letters to us at:

OHSU Department of Urology 3303 S.W. Bond Ave., 10th floor Portland, OR 97239 Fax: 503-346-1501 Email: urologyTHP@ohsu.edu

### Nicotine cessation and diabetes control

#### Stopping smoking/nicotine

#### Why is it important?

Nicotine is a powerful drug that constricts your blood vessels and decreases blood flow to the tissues we are operating on. This can cause complications, including poor wound healing, delayed wound healing and graft failure. Research shows that the risk of surgery failure increases 10 times for people who smoke even 1 cigarette a day.

#### How long do I need to be nicotine free?

We require that people not smoke or use any nicotine or tobacco products for at least 10 weeks before surgery.

# What about nicotine patches, gum, e-cigarettes, etc.?

All these products are a healthier alternative to smoking tobacco, but they all contain nicotine. They have the same negative effect on wound healing. Therefore, we require that you not consume any of these products for 10 weeks before surgery

#### How do you test for nicotine?

You will take a blood test as part of your appointment about 4 weeks before surgery. This test can detect nicotine use within several weeks before. Secondhand smoke can also cause you to test positive, so it's important to avoid it for 10 weeks before surgery. We also test for nicotine on the day of surgery to make sure you remain successful in stopping nicotine in the month before surgery.

# What resources are available to help me quit using nicotine?

- Your primary care provider can prescribe nicotine replacement such as patches and gums, or connect you with behavioral health services.
- If you are interested in tobacco cessation groups, please contact the Transgender Health Program or look online for groups in your area.
- Consider the Oregon Tobacco Quit Line, open 24/7, at 1-800-QUIT-NOW (800-784-8669) or quitnow.net/ oregon. These resources may refer to tobacco, but they may help with quitting nicotine in any form.

#### What about marijuana?

If you use cannabis, please do not smoke for at least 4 weeks before surgery. That will help you avoid the carbon monoxide poisoning from inhaling any type of smoke. It is better to use edibles and other forms of cannabis. Though no studies show cannabis use is safe in surgical recovery, especially when combined with narcotic pain medication, we do not prohibit it or test for it. Please be cautious.

#### **Controlling diabetes**

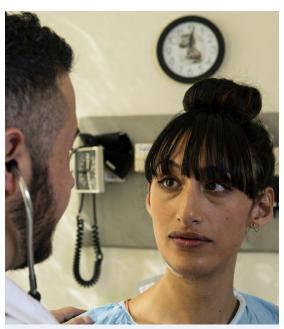
#### Why is it important?

People with diabetes may have greater risk of poor healing and infections, especially if their diabetes is not well controlled. Your primary care provider or endocrinologist can help you make sure your diabetes is under control before surgery.

#### What are the requirements for surgery?

A test called Hemoglobin A1C (HbA1c) can help show what your blood sugar control has been like over the past 3 months. At the time of surgery, your HbA1c should be 6.5 or less.





These appointments will be held when you are scheduled for surgery. We do our best to schedule them on the same day and around the same time so you only have to make one trip.

#### **Presurgery appointments**

#### **Urology Department**

About 1 month before surgery, you will return to the Urology Clinic on the 10th floor of the Center for Health & Healing Building 1. You'll meet with our physician assistant, Dorian Scull. This appointment will give you the chance to ask any last-minute questions before surgery. It can be easy to forget what questions you wanted to ask, so make a list. Be sure to bring:

- A list of last-minute questions.
- A list of any recent surgeries.
- A list of any recent changes to your medical history.
- Family Medical Leave Act paperwork, if you have any.

#### **Preoperative medicine**

This appointment is for tests (including a nicotine test) to check on your general health. We will also tell you what medicines to take or not take before surgery. Be prepared:

- Bring an updated list of medications you're taking.
- Bring a list of any recent surgeries.
- Be nicotine free.
- Come hydrated for a blood draw.

You will be asked to either stop taking estrogen for 4 weeks before surgery or to switch to non-oral estrogen (patch or injection). We know this can be stressful and unpleasant, but it's important to reduce your risk of dangerous blood clots after surgery. You can restart about 1 week after surgery, when you leave the hospital. You do NOT need to stop taking spironolactone or progesterone before surgery.

# Preparing for surgery checklist

We created this checklist to guide you in preparing for surgery. Check off the boxes as you complete the items to make sure you don't miss any important preparations.

Continue nicotine cessation.	Attend your presurgery appointments
You will be tested about 1 month before surgery and on the day of surgery.	(we try to schedule these on the same day 1 month before surgery:
Keep diabetes under control (if applicable).	<ul> <li>Urology Department appointment</li> <li>Bring FMLA paperwork (if applicable)</li> </ul>
You will have an A1C test about one month before surgery.	Medical appointment for tests, including nicotine test
Finalize time off from work/school/volunteer work (if applicable).	<ul> <li>Buy recommended supplies</li> <li>(see list in your booklet).</li> </ul>
$\Box$ You will need to request 6–8 weeks off.	
Finalize details of postsurgery care plan:	<ul> <li>Read through what to expect during your hospital stay and reread</li> </ul>
Confirm care team and assign roles to caregivers.	discharge instructions.
Aintain safe, stable housing.	Clean house, do laundry, create easy
$\Box$ Have a ride to and from the hospital.	pathway to bathroom.
$\Box$ Have some money saved to help with	$\bigcirc$ Meal prep (cook and freeze meals).
expenses (supplies, food, copays, transportation, unforeseen expenses).	<ul> <li>Pack hospital bag (see suggested items in your booklet).</li> </ul>
Start State Disability Insurance paperwork and bring completed Family Medical Leave	<ul> <li>Finalize ride to the hospital the day before (this will be a very early morning).</li> </ul>
Act paperwork to appointment 1 month before surgery (if applicable).	$\bigcirc$ Practice stress reduction exercises.

#### Supplies to get before surgery

**Roll fluff gauze:** This is helpful to put on the surgical site as it heals. After surgery, you will have a fair amount of drainage and discharge. The gauze helps absorb that drainage. It keeps the wound clean and dry, prevents infection and protects your underwear. It is especially useful if you have any areas of wound separation that need a little extra attention. We recommend buying about 10 rolls. You can buy them on Amazon.com for about \$1 a roll. Search for "fluff gauze roll."

**Donut pillow:** Sitting, even for short periods, can be very uncomfortable after surgery because it puts pressure on the surgical site. Some patients have found that sitting on a donut pillow, hemorrhoid pillow, U-shaped neck pillow or "portalee gel seat" makes this more comfortable.

**Maxi pads:** Pads can help with drainage or a small amount of old blood that leaks from the surgical site for a while after surgery. You may have to use large maxi pads as needed at first. Putting a maxi pad in a snug pair of underwear can put a little pressure on the site. That can help with swelling, but it should not be too tight. You can switch to smaller pads as the drainage slows.

**Lots of toilet paper:** You are likely to spray urine after surgery. This can be messy, so you will want a large supply of toilet paper for wiping.

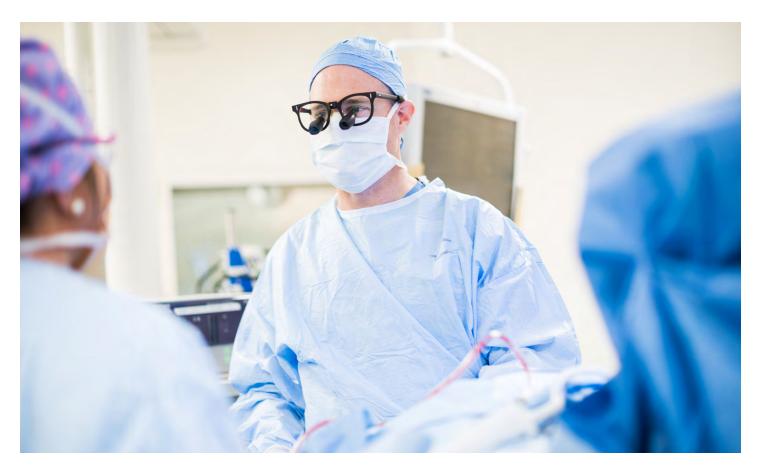
**Extra pairs of loose or mesh underwear:** With dressing and maxi pads, your regular underwear may be too tight. You also may have some drainage that might ruin your underwear. For this reason, we recommend having loose-fitting, inexpensive underwear on hand.

**Stool softeners:** Your opioid pain medication and inactivity will likely cause some constipation. You may want to have some extra stool softeners to prevent constipation. We recommend a gentle, nonstimulant stool softener such as polyethylene glycol (brand name Miralax).

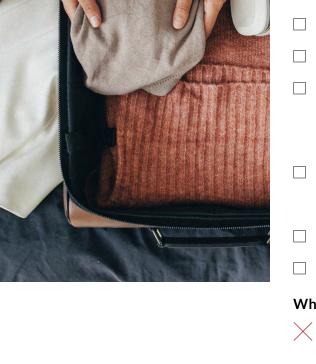
**Mild, unscented soap:** The only wound care that you will likely be doing when you leave the hospital is showering twice daily. This will keep the surgical site clean and dry and reduce the risk of infection. We recommend washing with a mild, unscented soap. Something designed for sensitive skin that will be gentle on healing tissue.

**Ice pack:** Keeping the surgical site cool can reduce swelling, inflammation and pain. Using an ice pack on top of a towel can help.

**Peri bottle:** For the first few weeks after surgery, you should shower twice daily with gentle soap and water. Use your hand rather than a washcloth to clean the surgical site. Some patients find a peri bottle, designed for postpartem mothers, to be a gentle way to clean the area after surgery, in addition to showering twice daily.



Dr. Daniel Dugi and other team members strive to create functional female genitals. We use techniques we believe are as safe as possible to protect your sexual, urinary and bowel functions.



# Packing your bag for the hospital

Here's a list of things you'll need during your hospital stay. You will be in the hospital for a few days and while that may sound nice, it can be uncomfortable and boring. You will get regular meals you can order from our cafeteria, but bring snacks for between meals.

# What to bring:

🗌 ID

- □ Paperwork
- Payment method
- $\Box$  Comfortable, loose-fitting, low-hassle clothes
- $\Box$  Items that make you comfortable
  - □ Favorite blanket, pillow, aromatherapy, eye pillow, massager
- $\hfill\square$  Items that keep you entertained
  - $\Box$  Games, music, books, puzzles
- □ Chargers for electronics
- □ Snacks

# What not to bring:

imes Valuables, including jewelry

# Food and drink restrictions

- No food or drink starting at midnight the night before surgery.
- It's OK to take small sips of water with medications.

# Section 3: During surgery and your hospital stay

## Hospital welcome and tip sheet

#### Surgical unit welcome and tips

Welcome to the inpatient unit at OHSU. Our patient population consists of kidney and liver transplant, urology and reconstructive surgery patients. We also care for all genderaffirming surgery patients who need to stay in the hospital after surgery.

#### Who's who?

**Providers:** These are your surgeons, surgical residents, physician assistants and nurse practitioners. They perform your surgery and/or create the pathway for your recovery. They visit you daily to answer your questions, see how you are doing and make changes to your plan, if needed.

**Registered nurses:** These are the people you see the most during your stay. They bring your medications, monitor your recovery and help you stay comfortable. They check in on you throughout the day and night. The more we know about how you feel, the better we can help you. The nurses can answer questions about your plan and recovery.

**Certified nursing assistants:** Nursing assistants check your vital signs (temperature, blood pressure, heart rate, etc.) periodically. They check on you throughout the day and night. You can ask them about how to get comfortable, for water or snacks, or for help if you need to go to the bathroom.

**Room service attendants:** These people bring your food and take away your tray.

#### Medications

You will have 2 sets of medications:

**Scheduled:** Your providers order these medications to be given on a schedule. Your nurse will bring them to you at a set time each day (typically 9 a.m. and 9 p.m.).

As needed: These medications, also called PRNs, are given to you when needed to make you more comfortable — for example, if you have breakthrough pain, sore throat, gas pain, bladder spasms, constipation or heartburn. If you have any of these symptoms, tell your nurses and they can give you a medication that should help.



**Preventing lung infections** 

Your nurse will give you an incentive spirometer and teach you how to use it. This helps you open up your lungs and prevent infection. **Try to use this 10 times** *an hour when awake*.

### Eating

It's important to eat what you have an appetite for. We also have a few recommendations:

- Protein is important for healing. Protein can be found in meat such as chicken, fish, pork and beef. Nuts, whole grains, beans and legumes are also good sources.
- Since you are in bed and not up moving around like normal, your bowels will slow down. Stay away from heavier foods (fried, greasy, etc.) because they are harder to digest and may lead to gas pain.

To order food, call 4-1111 from your room phone. Delivery usually takes about an hour, so call before you get too hungry.

#### Toileting

You will have a catheter (tube) draining your bladder, so you shouldn't feel the need to pee. If you feel like you have to pee, the nurse may have to adjust your catheter so the urine flows more easily.

#### If you need help

You will have a button you can press to call us. Don't be afraid to call if you need anything.

### Your hospital schedule

This is a general guide of what to expect during your hospital stay. Everyone's healing is different. This schedule, including what medications you get, may change based on your unique medical needs.

#### Day of surgery – before surgery

- No food or drink.
- Arrive and check in.

- Sign paperwork for surgery.
- IV put in arm.
- · Meet your surgery team, including the anesthesiologist.

## Day of surgery – after surgery

- Your doctor will talk to friends What's on my body? and family after surgery.
- Spend 2–3 hours in the postanesthesia care unit:
  - Staff will keep a close eye to make sure you are safely recovering from anesthesia.
  - You might feel nauseated, elated, groggy, tearful, hungry or thirsty.
- Move from post-anesthesia care to a hospital room:
  - The inpatient unit where most of our patients recovering from genderaffirming surgeries stay.
  - The staff is trained to provide culturally competent and genderaffirming care. They are very familiar with the recovery process from these procedures.

- Urinary (Foley) catheter a
- tube to drain urine.
- Dressing on the surgical area — keeps the site clean and protected. Provides compression to keep swelling down and prevent bleeding and hematoma.
- Drains tubes that take extra blood and fluid out of your body and collect it in a bag.
- Sequential compression devices on your legs; cuffs fill with air and squeeze your legs to increase blood flow and prevent blood clots.
- IV in arm.
- Medications:
  - You will be given antibiotics before surgery and IV pain medication during surgery.
  - If you feel nauseated after surgery, we can give you a medication to help.

- You may be able to press a button to control how much narcotic pain medication you get through your IV. This is called patientcontrolled analgesia (PCA).
- If you have trouble with bowel movements after surgery, we can give you stool softeners.
- Food and drink:
  - Start with ice chips because your throat might be sore.
  - Drink water slowly. If you drink too much, you might feel sick to your stomach.
  - Move to small bites of food, then regular meals when you feel ready (maybe the next day).
  - Eating yogurt can help build up good bacteria after taking antibiotics.

#### Day 1 after surgery

- You are not on strict bed rest. You can get out of bed and move around as much as you can tolerate.
- Stand up and walk, with the nurse's help:
  - You might feel a little dizzy and weak getting up for the first time.
  - Call the nurse when you feel ready to try to walk. The nurse will take the compression cuffs off your legs and help you move.
  - First you will sit on the edge of the bed and dangle your feet. Next you will stand up for a little bit. Then you will try to walk.
- Rolling over in bed is most comfortable if you do a "log roll." The nurse can show you how to do this.
- The head of your bed should be raised to 45 degrees or less.
- If you feel gas and bloating, start abdominal massage exercise from physical therapy for 5–15 minutes, 1–3 times a day.

- Pain medication:
  - You will be given 650 mg of acetaminophen (Tylenol) by mouth every 6 hours.
  - You will be given 15 mg of Toradol
     (a nonsteroid anti-inflammatory drug similar to ibuprofen) by IV every 8 hours.
  - You can be given 5–15 mg of oxycodone
    (a narcotic pain medication) by mouth every
    4 hours, as needed, for moderate pain.
  - If you are still in pain after taking the oxycodone, or if your pain is sudden and severe, tell your nurse.
- You will be given Miralax (stool softener) to prevent constipation.
- You can have a bed bath if you want.
- If you need to have a bowel movement, tell your nurse.

#### Day 2 after surgery

- Continue to get up and move around with help as much as possible.
- Do bed exercises from physical therapy every hour you are awake. Do abdominal massage if you want.
- Many patients will leave the hospital and go home on day 2 after surgery with a catheter and external dressing in place. You will have these removed in clinic on day 3 or 4 after surgery. To prepare for dressing removal, you may use adhesive remover to peel down the dressing on your belly (down to the portion between your legs) the night before your clinic visit.

#### Day 3 after surgery

- Pain medication:
  - You will be given 650 mg of acetaminophen (Tylenol) by mouth every 6 hours.
  - You can be given 600 mg of ibuprofen by mouth every 8 hours, as needed, for mild pain.
  - You can be given 300 mg of gabapentin by mouth every 8 hours, as needed, for moderate pain.
  - You can be given 5–15 mg of oxycodone by mouth every 4 hours, as needed, for moderate pain.
  - If you are still in pain after taking the oxycodone, or if your pain is sudden and severe, tell your nurse.
- You will be given Miralax to prevent constipation.
- Pressure dressing on vulva is taken off.
- Drains may be taken out, depending on how much fluid is still draining.
- Bladder catheter taken out:
  - Removing the catheter is quick. You might not feel anything, or you might feel briefly uncomfortable.
  - Try to pee. Your bladder will be empty and will take a couple of hours to fill. So drink lots of water! Expect the pee to go all over the place — not a steady stream!
  - One in 5 people can't pee at all or can't pee well enough. If this happens, we put the catheter back in so you are safe when you go home. We will take it out at your first followup visit in the office.

- The nurses will give you plenty of time to try to pee. After you go, they will scan your bladder to see how much urine is left.
  Some people can pee a bit, but too much urine is left. The surgery and anesthesia can affect your nerves and make it hard to empty your bladder. You're not doing anything wrong if you have trouble peeing.
- Tips to pee:
  - Run the sink or shower water. The sound can help.
  - Put your hands in warm water. This can help you relax.
  - If allowed, use a small container to pour warm water over the skin between your legs.
- Take a shower, with the nurse's help:
  - Use warm water, not hot, for this first shower. Hot water can cause your blood pressure to drop and make you dizzy.
  - Get your hands soapy and use them to clean all the folds and creases between your legs.
    Be gentle, but clean yourself as well as you can. It will feel very sensitive. Don't scrub hard and don't use a washcloth.
  - Let the water flow over your vulva to wash away the soap. If you use a handheld shower, spray the water on your belly and let it flow down between your legs.
  - Gently pat the skin dry with a towel. Don't rub. If you can, let the skin air dry.
  - Sit on a shower chair if you feel dizzy or tired. The nurse can bring one.

## **Before discharge**

- You and your caregiver should read your discharge instructions. Ask questions about anything you don't understand.
- Your caregiver will pick up your prescription medications before you leave the hospital.
- Make an appointment for your first follow-up visit.



Jess Guerriero, a social worker with the Transgender Health Program, is an excellent resource for patients seeking gender-affirming surgery.

## **Exercises for your hospital stay** From our physical therapy colleagues

You will be allowed and encouraged to move around as much as you can in the hospital. But there are still times that you may be lying in bed for hours and not up and walking. Sometimes this can cause your legs to swell with fluid. These exercises will help reduce the swelling and the risk of blood clots and increase circulation to help you heal. Do them for 5–10 minutes every hour that you are awake and in bed.

#### Deep belly breathing: 5–10 reps

- Movement: Breathe in deeply, allowing your belly to expand. Exhale slowly, allowing your belly to drop back down.
- **Tip:** Keep your breaths even and gentle. Try breathing in through your nose and out slowly through your lips.

#### Ankle pumps: 20-30 reps

- **Movement:** Slowly pump your ankles by bending and straightening them.
- **Tip:** If possible, elevate your legs. Try to keep the rest of your legs relaxed while you move your ankles.

#### Quad sets: 20-30 reps

• **Movement:** Tighten the muscles in your thigh to push your knee into the bed and straighten your leg. Hold, then relax and repeat.

#### Glute sets: 20-30 reps

- **Movement:** Tighten your buttock muscles, then release and repeat.
- **Tip:** Don't arch your low back during the exercise or hold your breath as you tighten your muscles.

#### **Abdominal massage** From our physical therapy colleagues

**Purpose:** After surgery, you may have constipation or bloating. Abdominal massage can help relieve constipation by stimulating the large intestine. It can also relieve bloating and gas. Your physical therapist will review this with you at your appointment before surgery. If you had robotic approach vaginoplasty, you won't be able to do this because of the belly incisions where the robotic instruments were inserted.

**Directions:** Do this for 5–15 minutes, 1 to 3 times a day, while on your back. All steps should be pain free.

- **Step 1:** To relax, gently move your hands across your belly from one hip to the other. Breathe slowly and gently.
- **Step 2:** Provide firm downward pressure on the lower left side of your belly. Hold for a few seconds and repeat.
- Step 3: Make small clockwise circles with firm pressure over the large intestine from your lower left side to your lower right side. Continue the circles up, over and down to make a "U" shape.
- **Step 4:** Starting on the lower right side, provide firm, long strokes in I, L and U motions over your belly ("I Love You" strokes).

#### **Discharge instructions**

#### Diet

- No restrictions to your diet.
- You will go home with stool softeners to help with constipation that may come from taking narcotics. Drink plenty of fluids and eat a wellbalanced diet.
- Take 1 capful of Miralax dissolved in 8–12 ounces of water daily for 1 month to prevent constipation.
- Avoid bearing down or straining with bowel movements.

#### Activity

- Limit walking to 2,000 steps a day for the first 4 weeks.
- You can use stairs. Take one step at a time slowly (both feet on the step).
- Do not lift anything greater than 10 pounds for the first 4 weeks.
- Do not drive while on narcotics or with a urinary catheter in place.
- You will get tired easily as your body recovers. Take time to rest and limit activities.
- Please refer to "Getting back to my normal routine" in this guide for more activity restrictions.

#### Pain control

- Take 650 mg of Tylenol (whether in pain or not) every 6 hours until your first follow-up appointment.
- Take 600 mg of ibuprofen every 8 hours for moderate pain that persists after taking Tylenol. Do this until your first follow-up appointment.

- We may also give you a prescription for a medication called gabapentin. This can help with nerve-related pain and can reduce the need for narcotic pain medication. You can take between 100 and 300 mg every 8 hours, as needed, for pain that is not controlled by ibuprofen and acetaminophen. It does not have the risk for dependency, overdose, or constipation that is associated with narcotic pain medicine. But it can cause drowsiness and increase other side effects associated with narcotic pain medication.
- We will give you a limited supply of 5 mg oxycodone tablets. This is a narcotic pain medication. Take 1–2 tablets as often as every 6 hours. This is for severe pain that "breaks through" after you have taken Tylenol and ibuprofen. Take this only as directed.
- Do not drive while taking narcotics.
- Apply ice packs to the mons (the fatty tissue over the pubic bone) for 20 mins every 1–2 hours. Put a cloth between the ice and your skin.

# Please see the "Pain management" section of this guide for more information.

#### Wound care

- You will have some drainage when you go home.
- Some small bloody or white drainage is expected. Have sanitary pads on hand.
   You may need to wear them until your wounds have healed.
- Shower twice a day for the first 6 weeks.
- DO NOT immerse in a tub or pool for 3 months or until your surgeon says it's OK.

- When showering, lather hands with soap and clean your surgery site gently but thoroughly. Do not scrub incisions. After cleaning, pat dry or air dry.
- Hypoallergenic soap or mild soap without fragrances may be less likely to irritate your already sensitive skin.

#### Estrogen

- Restart oral estrogen when you get home, if you switched before surgery.
- You may need to make an appointment with your hormone provider. Your dosage may need to be adjusted.

#### **Catheters or drains**

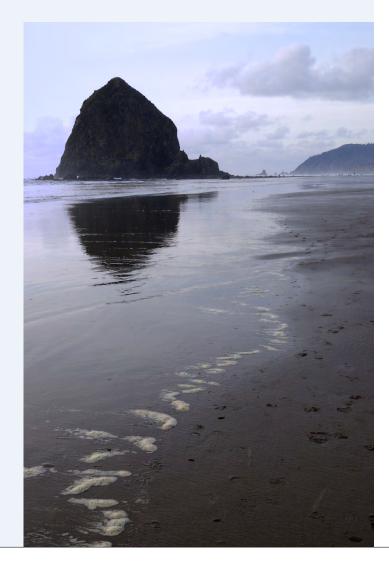
• If you go home with a catheter or additional drains, they will be removed at your first follow-up appointment. We'll tell you how to manage your catheter or drains when you're discharged.

#### Sexual activity

- No anal or oral sex for 3 months.
- You can gently massage the area to help desensitize overstimulated nerves. Do only what massaging you can tolerate.
- You can use a vibrator at any point after surgery if you find it pleasurable. As you heal, use a vibrator rather than your hand for stimulation to prevent injury.

#### How will the surgery site look?

- You will have a lot of swelling and bruising. It will look puffy. It can take many months for the swelling to go down.
- You will know how the area will look 6–12 months after surgery.
- You will have stitches. They will dissolve and fall out on their own.
- Use ice to help with swelling. Cover the ice pack with a thin towel or shirt. Leave it on the surgical site for 15–20 minutes. Take it off for 15–20 minutes. Repeat.



# Section 4: After surgery



The Gender Spectrum Collection

### Caregiver(s) role and FAQ

# What tasks will my caregiver(s) need to help me with and for how long?

Everyone responds to the trauma of surgery differently. Some people bounce back quickly and need little help. Others are slower to heal and need more help. It's impossible to know how you will respond, so your caregiver(s) should be ready to help with these tasks:

#### Drive you home from the hospital:

- Carry your bags.
- Get you situated at home: Help you into a comfortable position. Make sure water, food, phone and supplies are within reach.

#### Be available for 24-hour support (for about 2 weeks):

- Most patients do not need around-the-clock care after leaving the hospital. But some do, so a caregiver should be prepared for that for about 2 weeks.
- Most patients need someone present for several hours a day for the first 2 weeks.
- Your caregiver(s) should be available in person or by phone and close by.

#### Be available for emergencies (for about 2 weeks):

- Be available 24/7 for about 2 weeks to take you to the hospital or urgent care.
- Be mentally prepared and available to call doctors or emergency medical personnel.
- Be available to provide extra support or wound care.

# Help with cleaning, dressing, looking at the surgical site (for about 4 days):

- Many patients can care for their wounds. But sometimes it's hard to see or reach the site. It may be too painful or mentally difficult at first. A caregiver should be available to help for the first 4 days or so.
- Someone on your support team needs to be comfortable with blood, genitals, pee and poop. It should be someone you are comfortable with helping you with genital care and going to the bathroom.

#### Run errands (for about 3 weeks):

- Pick up medications
- Go grocery shopping
- Walk your dog
- Other errands that require driving or a lot of walking

#### Help around the house (for about 3 weeks):

- Tidying up
- Childcare
- Laundry
- Lifting anything over 10 pounds

#### Drive you to appointments (for about 3 weeks):

- Remember not to drive while taking narcotic pain medication.
- Your driving skills and reaction time are likely to be compromised by the physical trauma and discomfort of your surgery.

#### Keep you company:

- Recovering from surgery can be lonely.
- It's nice to have someone to talk to, listen to or watch movies with.

# What if I don't have a caregiver(s) or anyone I can ask?

- Try reaching out to online support groups and communities for help.
- If you don't have any luck, contact the Transgender Health Program.

#### Where can my caregiver(s) get support?

- For questions related to wound care or complications from surgery, call the Urology Department at 503-346-1500.
- For mental and emotional support (caregiving can be draining): Brave Space LLC has parent and caregiver community group meetings. Contact Brave Space at 503-486-8936 or Info@BraveSpaceLLC.

# What events and appointments can my caregiver(s) attend?

Only you can decide how comfortable you are with your caregiver coming to appointments. You'll get the most out of these appointments if you feel comfortable, relaxed and safe. That should guide whether you would like your caregiver(s) present.

Here are appointments caregivers can attend, and what to expect, to help you decide how involved you want your caregiver(s) to be.

- Surgery information class:
  - We go over surgery details, including preparation and recovery.
  - We recommend you bring your main support person. If you need to bring more than one person, tell us when you sign up.
- Pre- and postop appointments:
  - We'll do a genital and wound exam at every appointment except for the one right before surgery.
- Can my caregiver(s) stay overnight in the hospital with me?
  - Yes. An extra bed can be set up.
  - Space may be limited, so you may not be able to have more than 1–2 people stay.

#### **Urination and bowel movement strategies** From our physical therapy colleagues

#### Urination after surgery

You will have a catheter to drain your bladder while you're in the hospital. The catheter is typically removed about Day 3. Some patients find it difficult to urinate at first. Here are a few tips to help. If you can't urinate, you may need to go home with a catheter.

- Go on a short walk. Being upright can stimulate the bladder.
- Sit on the toilet with your feet flat on the floor. Take deep breaths. Do not strain, hold your breath or push.
- Try running the sink or shower. Hearing water may help the bladder start.
- Put your hands in a basin of warm water. This can help relax the pelvic floor to allow the bladder to begin.
- Ask the nurse for a peri bottle and fill it with warm water. Gently pour the water over your vulva and let the water drip into the toilet.
- Take a shower and try to void there.

#### Bowel movements after surgery

Having regular bowel movements after surgery is very important. Becoming constipated can lead to increased pain and bleeding, can cause difficulty urinating.

If you need to have a bowel movement, while on bed-rest in the hospital, the nurse will help you use a bedpan.

Surgery, stress, medications and inactivity can all contribute to constipation. You will be given stool softeners to help you have regular, non-strained bowel movements after surgery. Eating a diet rich in plant-based fibers, such as fresh fruits and vegetables and staying well-hydrated will help to keep you regular. Medication management suggestions for bowel regularity after surgery:

- Take 1 capful of MiraLAX (polyethylene glycol), dissolved in 8–12 oz of water 1–2 times per day.
- Add on 8.6 mg tablet of Senna (sennosides) daily if not able to produce daily to every other day bowel movements with twice daily MiraLAX.

If no bowel movement after 4 days, please notify your surgical team for further recommendations.

MiraLAX and Senna are sold over the counter, but we will also write you a prescription before you leave the hospital.

If bowel movements are difficult, try these additional tips:

- If you feel constipated or bloated, refer to the abdominal massage information in this guide.
- Put your feet on a stool or box to raise your knees above your hips. Lean forward and rest your elbows on your knees. This improves the angle of the rectum to allow stool to pass more easily.
- Take a few slow, deep breaths to relax.
- If you need to push, avoid straining and holding your breath. Instead, exhale gently as you tighten your stomach muscles.
- -Sometimes it can help to support your vulva and vagina with your hand if you need to bear down to have a bowel movement.

It is important manage any constipation before surgery and make sure that you are having regular bowel movements in the weeks leading up to surgery. If you are struggling with constipation, please let us know at your pre-op visit. If constipation has been a lifelong struggle, please let us know at your consult. We can likely offer suggestion to help improve your bowel regularity.

#### Pain management

Everyone handles pain from surgery differently. Previous surgeries can offer insight to your pain threshold, but it can vary by surgery type. You should expect some pain and discomfort for several weeks after surgery. It will be worse right after surgery and for several days afterward as you become more active.

Your pain should be manageable so you can still sleep and do basic household activities. We know relying heavily on narcotic pain medication can be dangerous:

- You can become physically and/or mentally dependent on the medication.
- It can cause constipation and/or intestinal blockage.
- It can make your pain more difficult to manage long term.
- It puts you at risk for accidental overdose, which can lead to death.
- It is not safe to drive or operate heavy machinery while taking narcotic pain medication.

We've put a lot of thought into your pain management, offering ways to help you minimize how much narcotic pain medication you need.

- We recommend you take acetaminophen (Tylenol) on a regular schedule and supplement it with ibuprofen (Motrin, Advil), ice packs and lidocaine patches.
- If you still have pain, we recommend taking the narcotic pain medication oxycodone to help with "breakthrough pain" — pain so severe that it breaks through after other treatments have been tried.

#### Acetaminophen (Tylenol):

- Take 650 mg (2 regular-strength 325 mg pills) every 6 hours if you're not in pain.
  - Do this until your first follow-up appointment.
  - Don't take acetaminophen if you have liver disease, reduced liver function or an allergy to the active ingredients.
- Do not take more than 4,000 mg in a 24-hour period. Know that acetaminophen is a common ingredient in narcotic pain medications such as Vicodin and Percocet. It's also in over-the-counter medications, so be sure to read the labels.

#### Ibuprofen (Motrin, Advil):

- Take 600 mg (3 regular-strength 200 mg pills) every 8 hours as needed for mild pain.
  - If you still feel pain after taking acetaminophen, supplement with ibuprofen. Take 600 mg (3 regular-strength 200 mg pills) every 8 hours as needed for mild pain. Do this until your first follow-up appointment.
- Don't take ibuprofen if you have kidney disease, reduced kidney function, only one kidney, a history of stomach ulcers or bleeding in your stomach or intestines, or an allergy to the active ingredient.

#### Oxycodone (narcotic pain medication):

- We will give you a limited prescription of 5 mg oxycodone pills. Take these only as directed and only as needed for severe pain.
- You can take 1 pill every 6 hours, but we urge you to limit this to when you need it most. Many patients find they can tolerate some pain while awake and need oxycodone only to rest or sleep.
- There is a risk of accidental overdose, dependency, nausea, drowsiness, sleepiness and constipation.
   Do not drive or operate heavy machinery while taking this medication.

#### Gabapentin (nerve pain)

Patients going through surgery may also benefit from gabapentin, which targets nerve-related pain.

Doses of gabapentin can vary, but you should plan on slowly increasing and slowly decreasing doses. You can take 1 tablet (300 mg) 3 times a day to start, and we may increase your dosing depending on your needs.

The main side effect is drowsiness.

• If it looks like you will run out before your next clinic visit, call the Urology Clinic at 503-346-1500 during business hours. Give us 24–48 hours to prepare the prescription. You will probably need someone to pick up the prescription, so plan ahead.

#### Gabapentin (for nerve related pain)

We may give you a prescription for gabapentin, which is a medication used to treat nerve-related pain. This does not have the overdose or addiction risk of narcotic pain medications and does not tend to cause constipation. It can reduce the amount of narcotic pain medication needed after surgery.

You can take between 100 and 300 mg every 8-hours, as-needed, for pain not controlled by Ibuprofen and Acetaminophen.

Drowsiness and dizziness are the most common side effects.

Do not exceed 3,600 mg in a 24-hour period.

#### Ice packs:

• Apply ice packs to the surgery site for 20 minutes every 1–2 hours, as needed. This can reduce pain and swelling. Put a cloth or towel between the ice pack and your skin.

#### Lidocaine patches:

- Lidocaine patches can help with pain on the surface of the skin. You can buy them over the counter, but we can write you a prescription, if you like. Many insurance companies don't cover the cost, so you may want to look into this.
- Each lidocaine patch can be cut in half and applied 1–2 inches from each labia majora.
- If you find the lidocaine patches helpful, you can use up to 1 patch a day until your first follow-up visit. Apply it for 12 hours, then remove it for 12 hours before applying a new one.
- If you have discomfort or burning, remove the patch and stop using them.

# Tracking your pain

Keep track of how you're managing your pain with this tracking table. Please fill in the times you take each medication so you don't accidentally double or miss a dose. Find more copies in your booklet pocket.

Name of Medication	Dose	Frequency	Notes	<b>Schedule</b> Write down the time you took the medication			
				A.M.	Midday	P.M.	Bedtime
Acetaminophen (Tylenol)	650 mg	Every 6 hours	Take on a schedule whether in pain or not. Do not exceed 4,000 mg in a 24-hour period.				
lbuprofen (Motrin)	600 mg	Every 8 hours	Take only as needed for moderate pain.				
Oxycodone	1 tablet (5 mg)	Every 6 hours	Take only as needed for severe pain.				
lce	N/A	20 mins every 1-2 hours	Put ice pack on cloth over the mons (not touching skin).				
Gabapentin	100- 300 mg	Every 8 hours	Take only as needed for moderate to severe pain				
Polyethylene glycol (Miralax)	1 capful in 8–12 oz liquid	Every day	Take daily for 1 month to prevent constipation.				

#### Pain management tracking table

# Signs of a possible surgical site infection

If you have any of the following:

- An increase in swelling, redness and pain
- A fever of over 101 degrees F
- Chills

Call the Urology Clinic:

- 503-346-1500 business hours
- 503-494-9000 evenings and weekends

If you also feel dizzy or lightheaded, go to the emergency room. Don't drive yourself.

# Is this normal or should I be worried? Frequently asked questions after surgery

#### Bleeding/discharge

# I have a constant, gushing stream of bright red blood. I am soaking through 2 large pads every hour. What should I do?

- Apply firm, direct pressure with a clean rag or gauze for 10 minutes.
- If the bleeding has stopped and you don't feel dizzy or lightheaded, you should be fine. Rest and limit activity to keep the site from bleeding again.
- If the bleeding slows but doesn't stop, apply firm, direct pressure for another 10 minutes to see if it stops.
- Douche in the shower (or rinse with water) to release blood clots, then repeat firm, direct pressure where there is bleeding.
- If you still can't get the bleeding to stop, call the Urology Clinic at 503-346-1500 during business hours or call our evening/weekend number, 503-494-9000.
- If you also feel dizzy or lightheaded, go to the emergency room. Don't drive yourself.

### I am still bleeding regularly and having to wear pads, but the bleeding isn't super heavy. Is this normal?

- It's normal to have bleeding, oozing and discharge from the surgical site for up to 1 month, possibly longer.
- Increasing pain or redness with or without fever or chills is not normal. It could be a sign of an infection. Call the Urology Clinic or our evening/weekend number.
- If you also feel dizzy or lightheaded, go to the emergency room. Don't drive yourself.

# I see an open red wound in the surgical site. It's not bleeding much, and it's not very painful. Should I be concerned?

This is most likely an area of wound separation or granulation tissue, which is not an immediate concern. Apply gauze after each shower and change the gauze after each trip to the bathroom. Use a small amount of gauze, but have it touching the area of concern. Bring this up at your follow-up visit.

#### Swelling

### I am more swollen than I think I should be. How much swelling is normal and for how long?

It's normal to have significant swelling. The appearance of the vulva can be quite shocking at first.

- By 3 months, the swelling should calm down. It may come and go with activity.
- By 6 months, you should have no routine swelling and less swelling with activity. You'll begin to see what your vulva's final appearance will be. It also may continue to change with time.
- By 1 year, swelling should be resolved. You will know what your vulva will look like long term.

### I developed sudden swelling and pain. What should I do?

That could be a hematoma or an infection. Call the Urology Clinic or our evening/weekend number. If you also feel dizzy or lightheaded, go directly to the emergency room. Don't drive yourself.

#### **Urology Clinic:**

- 503-346-1500 business hours
- 503-494-9000 evenings and weekends

#### Pain

# How long should I have pain and how can I manage it?

Everyone responds to surgery and pain differently. Some patients recover quickly and report minimal pain. Others take more time and have much more bothersome pain levels.

- The worst of the pain should be over within 2 weeks. You will still have significant discomfort, but things should be calming down.
- You may notice that the more active you are, the worse your pain and swelling. This is your body telling you to slow down.

### My pain is getting worse, and I'm almost out of the narcotic pain medication. What should I do?

Try these things first:

- Supplement narcotics with Tylenol, ibuprofen and lidocaine patches as suggested in the "Pain management" section of this guide.
- Apply ice for 20 minutes each hour.
- Limit activities that increase pain and swelling.

If these don't control your pain, call the Urology Clinic:

- 503-346-1500 business hours
- 503-494-9000 evenings and weekends

#### Odor

# I have noticed my vulva is starting to smell bad. It doesn't hurt, and I feel fine otherwise. Is this normal?

A foul odor from the vulva could indicate an area of tissue necrosis. Small areas of tissue necrosis — dead cells — are not uncommon. Bring this up at your follow-up visit. We'll have you treat it with regular dressing changes.

It could also be the sign of poor wound hygiene. Gently wash the surgical site, labia folds and between your legs with mild soap and water twice daily. Don't use a washcloth or scrub for the first 6 weeks.

# Signs of a possible urinary tract infection

If you have any of the following:

- An increase in swelling, redness and pain
- A fever of over 101 degrees F
- Chills

Call the Urology Clinic:

- 503-346-1500 business hours
- 503-494-9000 evenings and weekends

If you also feel dizzy or lightheaded, go to the emergency room. Don't drive yourself.

#### **Urinating/catheter**

# There is a little blood and/or sediment coming out of my catheter. Is this normal?

Yes. Your bladder is irritated because there is a catheter in it. Call us if you have any concerns.

Other possible problems with a catheter:

- The catheter is not draining (no urine is coming out of your body).
- The catheter starts leaking.
- Urine is thick and cloudy, or it has blood or sediment in it.
- There is no urine in 6–8 hours.
- You have pain or burning in your urethra, bladder or belly.
- A steady stream of blood comes out of the catheter.

If you notice any of these problems, call the Urology Clinic:

- 503-346-1500 business hours
- 503-494-9000 evenings and weekends

### I am spraying all over when I pee. Is this normal? Will it get better?

This is common after bottom surgery. It will often resolve on its own after the swelling goes down. Sometimes it persists because of asymmetry or excess tissue. If it lasts 6 months, bring it up in your follow-up visit. We may be able to improve this with a small revision surgery.

# I haven't been able to pee for more than 8 hours. I feel like I have to pee but can't, and it's starting to hurt. What should I do?

Go to the emergency room. If you can't empty your bladder on your own, it will have to be drained with a catheter. That will keep urine from backing up and causing damage to your bladder or kidneys.

We will do some tests to figure out why you're having trouble peeing so we can treat it.

It's important that you show up to all your followup visits. These let us assess your healing and teach you about dilation and wound care. We know it can be time consuming, especially if you're coming from far away. But it's an expectation for our patients to ensure the best possible outcome.



# What to expect at follow-up visits

Below is a typical postoperative visit schedule. Your schedule may be slightly different depending on where you are traveling from and/or our providers clinic schedules.

#### 3-4 days after surgery

- If you leave the hospital with your dressing and a catheter still in place, we will remove these at this visit. If your dressing and catheter were removed in the hospital, then this visit may not be needed.
- We will check the surgical site and see how you are doing with pain, urination and bowel movements.
- If there are any wound concerns, they will probably come up between your first and second visits. We will go over any issues.

### 2 weeks after surgery

- This is a 15-minute visit.
- We'll make sure you're healing well and answer any questions.

#### 4 weeks after surgery

- This is a 15-minute visit.
- We'll make sure you're healing well and answer any questions.

#### 3-6 months after your last visit

- This is a 15-minute visit.
- We'll assess your progress, see how you are healing and answer any questions.

### 1 year follow-up visit

• This is a 15-minute visit to see how you're doing.

#### Getting back to your normal routine

#### When will feeling come back?

It can take 6–9 months for the nerves to heal after surgery. Nerves don't regrow for the first 3–4 weeks. Then they grow at 1 millimeter a day (about 1 inch a month). The speed and amount of nerve regrowth is different for everyone. Younger people usually get more nerve regrowth.

You might feel numb in some areas of the surgical site. Nerves regrowing or "waking up" can feel like pins and needles, tingling or a quick electric shock. It might take a while to get feeling in your clitoris — or it might be annoyingly oversensitive.

#### What if touching my vulva is too sensitive or painful?

This could be a sign that your nerves are healing, inflamed or oversensitive. Sometimes gently touching or massaging the vulva can send a signal to your brain that touch is "safe" and "not harmful." This can help if it is too sensitive.

#### When do I resume my normal activity?

- Walking: We ask that you limit your walking to 2,000 steps a day for the first 4 weeks. This is about 1 mile or 20 minutes of walking for the whole day. After 4 weeks, you can begin to gradually increase the number of steps. You may notice that the more active you are, the more swelling, pain and fatigue you have. This is your body telling you to slow down. Listen to your body and don't overdo things.
- Showering and bathing: We ask that you shower twice a day for the first 6 weeks. Then you can resume your normal shower schedule. No baths, hot tubs or swimming for the first 3 months.
- Lifting: Don't lift anything over 10 pounds for the first 4 weeks. Then you can slowly increase the amount of weight you lift.
- Workouts: No working out, running or strenuous yardwork for 6 weeks after surgery. Then you can slowly reintroduce these activities to your routine. No bicycling for 3 months.

#### What about sexual activity?

- If you can orgasm before surgery, you can probably orgasm after surgery. Most people say it takes longer to orgasm after surgery and "feels different."
- Consider using a vibrator instead of your fingers to explore early after surgery. A vibrator is gentler on the healing skin. You can start using a vibrator as soon as you can tolerate it or find it pleasurable. Many patients find that stimulating the mons (the area of fat on the pubic bone) to be pleasurable soon after surgery.

#### When can I start having sex again?

• Wait 3 months before having oral or anal sex. This will protect you from infection and let your body heal.



The Gender Spectrum Collection

### **Scar massage** From our physical therapy colleagues

Massage can help loosen scar tissue, soften your scars and make them more comfortable and less visible over time. Your physical therapist will teach you how to massage your surgical scar. Begin at 5–8 weeks after surgery, once the wound is closed. Do this daily for 5–10 minutes.

**Scar massage should not be painful.** If the scar is painful to touch, begin with desensitizing strategies:

• **Desensitization:** Use a tissue, light cloth, dry or wet towel, or your fingertips to gently rub or tap on the scar in all directions. Use light pressure so it's not painful. Gradually use firmer pressure. This will decrease the sensitivity of the scar, and you will become more comfortable touching it.

When the scar is no longer sensitive, use these techniques:

- **Push and pull:** Put two fingers on the scar and move them slowly straight up until the skin stops moving. Hold firm pressure for 20–30 seconds. You might feel a strong pulling sensation, but don't make it hurt. Repeat in the downward direction and to the left and right. Continue with these four motions along the scar's length. You may notice a direction or spot that feels especially "stuck." Spend more time holding in these directions.
- Skin rolling: Gently pinch the skin on either side of the scar and lift. Start at either end and move forward and backward, rolling and raising the skin as you move. A stuck scar dimples inward; a free scar will lift easily.
- **Plucking:** Put your index finger on one side of the scar and your thumb on the other. Try to pick up the scar, separating it from the underlying tissue. If you can pick up the scar, move your fingers up and down and side to side. Continue along the length of the scar.

Section 5: Resources

#### **Crisis and support lines**

Transition can be liberating. It can also be scary, feel unsafe, create more dysphoria, disrupt personal relationships and be an emotional roller coaster. Several organizations offer immediate help if you are in a crisis, just need to talk to someone or have questions. Their confidential services are available 24/7.

**Trans Lifeline:** Offers emotional and financial support to transgender people. Has a peer support hotline for trans and questioning callers. The hotline is staffed by transgender volunteers.

- 877-565-8860
- translifeline.org/hotline

**The Trevor Project:** Offers crisis intervention and suicide prevention for LGBTQ people younger than 25.

- 866-488-7386
- thetrevorproject.org
- Online instant messaging: TrevorChat
- Text-based support: TrevorText

**National Suicide Prevention Lifeline:** This national network of local crisis centers has a hotline to provide emotional support to anyone in suicidal crisis or emotional distress.

- 800-273-8255
- suicidepreventionlifeline.org



#### Support and information groups

In Oregon

- **Basic Rights Oregon:** Statewide LGBTQ advocacy and social justice organization, basicrights.org
- Brave Space LLC: Creates community and connects transgender and genderqueer children, teens, adults and allies with expert providers, bravespacellc.com
- Central Oregon Coast Trans Community: Newport-area support group for transgender people and their families, on Facebook
- Human Dignity Coalition: Bend-based group seeks equality for the LGBTQ community and allies, humandignityco.wordpress.com
- Northwest Gender Alliance: Nonprofit social, support and educational group, nwgenderalliance. org
- **Outside In:** Offers resources for name and gender change on identity documents, outsidein.org
- **Portland Q Center:** Provides a safe space to support and celebrate LGBTQ diversity, visibility and community building, pdxqcenter.org
- **Rainbow Youth:** Salem-area organization offers welcoming spaces where LGBTQ and genderdiverse young people and their friends can connect, rainbowyouth.org
- Sexual and Gender Minority Youth Resource Center: New Avenues for Youth's safe, supervised space with activities for sexual and gender minorities ages 13–23, newavenues.org/smyrc
- SO Health-E: Southern Oregon group dedicated to improving access to health care across lines of race, gender, sexual orientation, disability and income, sohealthe.org. Includes the LGBTQ+ Equity workgroup, which seeks to remove barriers to health care in Jackson and Josephine counties for people in the lesbian/gay/bisexual and gender-diverse communities.

- **TransActive Gender Project:** Provides support groups, information, advocacy and other services to families of Portland-area transgender and gender-diverse youths ages 4–18.
- **Trans\*Ponder:** Eugene nonprofit offers support, education, advocacy and other services for transgender and gender-diverse people, transponder.community

#### National and international

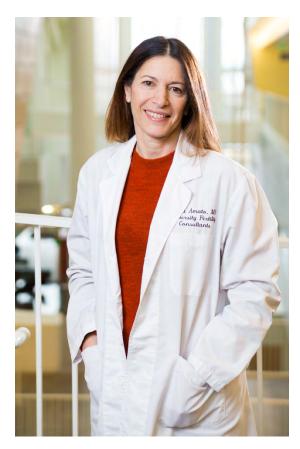
National Center for Transgender Equality: Social justice advocacy organization for transgender people, transequality.org

National LGBT Health Education Center: Provides education, resources and information to health care organizations to improve LGBT health care, lgbthealtheducation.org

**Transgender Law Center:** Civil rights group working to advance transgender self-determination, transgenderlawcenter.org

**Transgender Youth Equality Foundation:** Works to advance the rights of transgender, gendernonconforming and intersex youths ages 2–18, transyouthequality.org

**World Professional Association for Transgender Health:** Promotes evidence-based care, education, research, advocacy, public policy and respect in transgender health, wpath.org



Dr. Paula Amato, an expert in fertility, includes transgender care among her focus areas.

# Transgender Health Program class schedule

#### Gender-affirming surgery class

The THP offers **classes** on gender-affirming surgery. All classes are available as recorded videos. Your caregivers and loved ones are also welcome to register and attend our class.

Vaginoplasty/vulvoplasty classes feature slides and photos to review anatomy, genital reconstruction and surgical outcomes.

Classes are free, but registration is required. Please go to the website to register.

# Fertility and assisted reproduction

We offer patient education content regarding fertility and reproductive options for gender-diverse people and their partners or allies in the next section of this booklet. You may also visit the OHSU Fertility Preservation website and review an overview of fertility options written by our Transgender Health Program expert, Paula Amato, M.D. Free video-based classes are also available regarding fertility preservation and assisted reproduction.

# Transgender Health Program Gender-Affirming Surgery Patient Education Program

#### Orchiectomy/vulvoplasty/vaginoplasty

Free video-based classes are available on the Transgender Health Program website.

This class is designed for patients and welcomes the patient's support team of friends, family and/or health care providers.

#### **Covered in class:**

- Presurgery health and wellness
- Surgical options and how to choose
- How to prepare for surgery
- What to expect from surgery
- Recovery in the hospital
- Recovery at home

Registration is required. Visit ohsu.edu/transgender-health to register.

If you have questions or need help with registration, please contact us at transhealth@ohsu.edu or **503-494-7970**.

#### **Fertility preservation**

Vaginoplasty, vulvoplasty and orchiectomy all require removal of the testicles. Once the testicles are removed, you can no longer produce sperm. If you have not already frozen and stored a sample of sperm, you won't be able to have future biological children.

On average, transgender women want to become parents at the same rates as other LGBTQ+ people.

About half of transgender women wish they had preserved their fertility before transition. But only 3 percent of transgender people do so.

Please contact us if you're interested in learning more or want us to refer you to a sperm-banking clinic or fertility specialist.

#### Estrogen effects on sperm production

Long-term estrogen therapy harms sperm production. These effects can be permanent. Some studies suggest transgender women may have lower sperm quality and quantity even before starting hormone therapy.

- It's best to preserve fertility in someone who produces sperm — after puberty (sperm are not made until puberty) and before starting estrogen therapy. That is not always possible.
- Sometimes sperm production recovers after stopping estrogen for 3–6 months, but not always.
- Sometimes medications, such as **clomiphene citrate** or hCG injections, can stimulate sperm production.

Patients who are interested in fertility preservation and have been on estrogen for more than 6 months will typically be asked to stop estrogen for 3–6 months. You will then be asked to provide a semen sample through ejaculation. This sample will be looked at under a microscope to determine how many sperm are present, how active they are and if they have a normal shape. If these things are OK, you can bank sperm.

#### Collecting and storing semen

#### Sperm banking:

- Sperm are frozen and stored at a sperm bank. This is called cryopreservation.
- The semen (sperm) is obtained through ejaculation (by masturbation) or surgery (microscopic testicular sperm extraction; see below).
- The sample is looked at under the microscope to determine quality.
- Collecting and freezing sperm costs about \$500-\$1,000.
- Storing it costs \$275–\$500 a year. Sperm can be stored for many years.

#### Microscopic testicular sperm extraction:

- A sperm sample is taken directly from testicle tissue with surgery.
- It is often used if someone can't produce a quality sample through ejaculation. We may be able to do this when you have gender-affirming surgery.
- Collection costs \$1,500-\$1,800.
- The annual storage fee is \$275–\$500.

#### Using sperm for pregnancy

**Intrauterine insemination (IUI):** The sperm are washed and put into the uterus of the person who will carry the baby. A small catheter is guided through the cervical canal. The timing must align with ovulation. The hoped-for outcome is that the sperm swim into the fallopian tube and fertilize the egg, resulting in pregnancy. For this to be successful, the sample must have a lot of active sperm.

- This can be done in the fertility clinic.
- Cost is \$300-\$500 and requires a semen sample with a lot of active sperm.
- Many people who have been on estrogen therapy can't produce enough active sperm for intrauterine insemination to succeed. In this case, in-vitro fertilization (IVF) is necessary.
- The success rate of IUI and IVF depend on the age of the person providing the egg.

**In-vitro fertilization (IVF):** Fertilization is achieved by extracting eggs, retrieving a sperm sample and combining an egg and sperm in a lab dish. If successful, the fertilized egg becomes an embryo, and the embryo is transferred to the uterus.

- This is best for people who have low sperm production because it greatly increases the chance that a sperm makes it into the egg.
- Cost ranges widely depending on how many times you try to transfer an embryo (each time is called a cycle).
  - One cycle of transferring a fresh embryo typically costs \$12,000-\$17,000.
  - More cycles can be done if the embryos are frozen (see Frozen embryo transfer below).
  - Hormones and medications are often needed for the person with the eggs, costing an additional \$3,000–\$5,000.

**Frozen embryo transfer (FET):** Embryos not used in the first "fresh cycle" can be frozen for later use. This costs \$3,000–\$5,000 a cycle, plus an annual storage fee of \$200–\$500.

# Fertility preservation FAQ

# Will insurance cover the cost of fertility preservation?

Most insurance companies don't cover the cost for transgender people who want to preserve fertility before gender-affirming surgery or hormone therapy. Insurance sometimes covers the cost for people with certain cancers undergoing medically necessary cancer treatments that negatively affect fertility. We hope insurance soon covers the cost for transgender folks undergoing medically necessary gender-affirming treatments that negatively affect fertility.

# If my partner doesn't have a uterus or can't carry the baby, what are my options?

Surrogacy is the most widely used option to have a biological child in this situation. With surrogacy, a person with a uterus (the surrogate) agrees to bear a child for another person who will become the child's parent after birth. This often involves a legal agreement. Surrogacy costs \$90,000–\$130,000.

Adoption is another option. Adoption through an agency costs about \$30,000. Adoption from an expectant mother costs \$15,000–\$40,000. Adoption from foster care is essentially free but comes with its own challenges.

#### What about uterine transplant?

A donor's uterus can be transplanted into another person's body. This allows the recipient to carry a child. There have been a few successful uterine transplants in ciswomen worldwide. Most took place in countries that do not allow surrogacy. Uterine transplant may be available to transgender women in the future.

# How much does fertility preservation cost altogether?

Preserving sperm alone costs roughly \$1,500-\$2,000 to collect and store for the first year, then \$500 a year to store. The cost of storing the sperm and using it for pregnancy can vary greatly depending on many factors. These include:

- The semen sample's quality.
- The age of the person providing the egg.
- Whether intrauterine insemination or in-vitro fertilization is needed.
- How many attempts are needed to achieve pregnancy.

This may not seem like an option for many people because of the cost. But insurance coverage of treatments is always changing, and this may be covered in the future. If having a biological child is important to you, consider sperm banking now, with the hope of more affordable options soon.

More online resources:

- transcare.ucsf.edu/guidelines/fertility
- familyequality.org/family-building/ trans-family-building



OHSU accepts most health plans. OHSU is an equal opportunity, affirmative action institution.

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