

FAQs Phalloplasty (Frequently Asked Questions)

Acknowledgements:

The primary source of information for this decision support booklet has been derived from the patient information from OHSU. Please remember the information provided here does not replace the information you receive from your surgeon. We are constantly working to improve our resources to better suit your needs, this resource will continue to be updated.

What are the complications related to my surgery?

- It is important to remember that complications can occur with any surgery. Generally, minor wound healing problems and functional issues relating to wound site swellings are the most common. As part of your surgical informed consent, you will be presented with information regarding potential complication of your surgery. Please see the sections on wound healing in our "What is Phalloplasty?" and "What is Phalloplasty without Urethral Lengthening?" information resources.
- Serious complications are uncommon. But choosing to have surgery is choosing to accept that risk. We do everything we can minimise the risk of complications during and after surgery.
- Although all surgical procedures involve risks, our surgeon is continually working to prevent them by ensuring the ongoing maintenance and development of safe surgical practices. In your first consultation, physical and lifestyle factors that play a role in decreasing the surgical risk will be discussed with you.

Please note: In the unlikely event you need to return to theatre this will be arranged for you by our team.

What are the risks?

• Phalloplasty is complex, with urethral lengthening further increasing the risk of complications. Risks include a narrowed urethra or urine leaks, infection, scarring, lack of sensation and the death of transferred tissue. Please see the post operative expectations sections in our "What is Phalloplasty?" and "What is Phalloplasty without Urethral Lengthening?" information resources for more information.

What preparations are involved in having phalloplasty surgery?

- Hysterectomy including removal of the cervix (at least six months before the procedure) for those wanting vaginectomy as part of their phalloplasty procedures.
- Permanent hair removal on the donor arm/site by laser and/or electrolysis (must be completed at least three months before the procedure) for those wanting urethral lengthening.
- Smokers including nicotine based vapes are not candidates for phalloplasty.

Phalloplasty is an extraordinarily complicated procedure, involving multiple steps and surgeries. A large part of its success depends on your preparedness. This means being in the best possible physical and mental health before the surgery. Above all else, it is critical to have reasonable expectations about what is possible for your body and what your surgeon can realistically accomplish. These conditions are essential; without them, surgery will not be able to proceed or will be postponed.

Please note that due to the high risk of complications such as vaginal entrance stenosis and urinary fistula, urethral lengthening is not an option when preserving the vaginal cavity.

What preparation is required for construction of the urethra?

- It will be necessary to do permanent hair removal of a small portion of skin from the donor site that will become your new urethra as part of the preparation. This hair removal is mandatory to prevent hair from growing inside the newly constructed urethra.
- Permanent hair removal must be satisfactorily completed at least three months before our team can assign you a surgery date.

Is it possible to proceed to phalloplasty without construction of the urethra?

- Yes, it is possible to have phalloplasty without constructing a penile urethra. However, if you choose this option, it will never be possible to add a urethra later so you can urinate standing up.
- This is an important decision to make, which needs to be made before you can proceed to surgery.

Can I undergo a phalloplasty without including the procedure that will close my vagina?

• Yes, it is possible to have phalloplasty without vaginectomy, however urethral lengthening is not then possible, and we will not construct a urethra that will allow you to urinate standing up.

Can I have a complete phalloplasty including urethral lengthening so I can stand to pee without a vaginectomy?

• No, it is not possible to have a complete phalloplasty including urethral lengthening without a vaginectomy, due to the high risk of complications such as vaginal entrance stenosis and urinary fistula when retaining the vagina.

Why do I need hair removal for phalloplasty?

- You may need electrolysis or laser treatment to permanently remove hair on the donor site (forearm or thigh) used to make the urethra.
- Hair remaining within the urethra can lead to significant urologic complications, such as urethral stones and recurrent infections. Therefore, hair removal from the part of the donor site that will be used for the construction of the inside of the urethra is mandatory.
- Many people also want to remove hair from the outside of the phallus, but it's not required - That can be done before or at a later date after your surgery. Your surgeon will determine whether and where you need hair removal.

Why do I have to remove the hair on my forearm?

- The skin of the forearm will be used to construct the phallus. Removing the hair from the forearm is therefore necessary, otherwise:
 - hairs may grow **inside** the urethra and cause complications.
 - hairs may grow on the penis. In this case, it is possible to continue hair removal treatments once your wounds and surgery have completely healed.

During your preoperative appointment, your surgeon will confirm which arm's skin will be used for surgery and will provide you with more information about the area to remove hair from.

Can I start permanent hair removal before the consultation with the surgeon?

• The analysis of your file and the consultation with the surgeon are two essential steps before starting your permanent hair removal. Some medical conditions may require the surgeon to use another donor site such as the dominant arm. This can only be determined during the consultation.

When should I start hair removal?

- You can start hair removal as soon as your surgeon confirms the donor site and specific area that needs to be free from hair. When a skin flap site has been chosen, after your consultation you will get a template for hair removal that you can give to your hair removal professional.
- Hair removal can take nine to 18 months. Treatments need to be spaced apart due to hair growth cycles. This timeline also accounts for potential difficulty scheduling hair removal treatments with busy providers.
- Hair removal must be complete at least three months prior to the scheduled surgery.

Please note: there is no reimbursement available to patients who pay for hair removal prior to their first specialist assessment. After the patient has been seen by the service at the FSA, then the service will arrange funding for hair removal procedures if this is required.

How do I know when I am done with hair removal?

- It is impossible for us to determine at any one point if your hair removal will be permanent. This is because each strand of hair is in a different stage of growth. Some hairs may be inactive, or not growing now, then start to grow a month later.
- The best approach for a good result is to discuss this with your electrolysis or laser provider. This usually involves going through several cycles with the area completely cleared followed by waiting four to six weeks. Then waiting a further three (or more) months to see if you have significant regrowth.

Please note: despite permanent hair removal, it is possible that hair may grow back inside the urethra after a certain amount of time. This can cause urinary problems. **You will need lifelong, ongoing yearly urology follow up.**

What are the complications of Urethral Lengthening?

• The most common complications for urethral lengthening include urethral strictures (narrowed areas of the urethra), fistula (creation of a

passageway between the urethra and another location) and diverticula (formation of a pouch in the urethra). This may require an additional surgical procedure to fix.

Will I need a catheter?

- Yes. During your inpatient stay for stage one and two surgeries, you will have a catheter in your native urethra for at least five days. It is typically removed in the hospital before you go home.
- If you decide not to have urethral lengthening, you will have a Foley catheter placed in the operating room and removed before you leave the hospital.
- If you decide to have urethral lengthening, following stage two surgery you will go home with a Foley catheter in the new urethra and a suprapubic tube. A clamp ensures that the urethra does not leak urine.

What is a suprapubic tube?

• A suprapubic tube (SPT) allows urine to drain from your bladder. It is placed in the lower part of your abdomen, below the belly button. The SPT stays in for four to five weeks, depending on your healing and recovery.

When will my SPT be removed?

• Before the SPT is removed, around four weeks after surgery, a urologist will perform a retrograde urethrogram. This involves putting dye into the bladder through the new urethra. An X-ray tracks the dye to see if the new urethra is open and ready for urination. If so, the doctor will clamp the SPT and you will be allowed to urinate from your new urethra. If everything looks good after a few days, the SPT is removed.

What can I expect with a catheter?

- If you had urethral lengthening, you will have a catheter in place to allow urine to drain from your bladder while your new urethra heals.
- Many people say that having a catheter in place for a prolonged period of time is one of the most challenging aspects of the overall experience.
- To make having a catheter a bit more comfortable you will be encouraged to drink enough water to have clear, light, yellow-coloured urine. This will likely mean about two to three litres of water every day. This will help to reduce bladder spasms and dilute your urine.

What about having a bowel movement after surgery while I am on bedrest?

• You will use a bedpan to have a bowel movement until you recover enough to use the bathroom. This can be intimidating for some people, but it happens in hospitals all the time, so don't worry!

I currently have tattoos on one or both arms. Am I still eligible for phalloplasty?

 Yes, the surgery can still be performed despite the presence of tattoos. However, these tattoos or parts of them may be present on your penis after surgery. The first specialist assessment is the appropriate time to discuss with your surgeon what options are available to you. As long as there is good blood flow and nerve function, donor sites —including those with a tattoo — can be used.

How can I know which forearm (donor arm) will be used for the construction of my penis?

• The skin is usually taken from the non-dominant arm unless you present a medical reason not to, or if you have tattoos that you do not want on your penis. During your assessments, your surgeon will perform a painless test to determine which arm will be the best donor and go over the alternatives with you. It is possible to use your dominant arm if necessary.

Before surgery, should I work out to strengthen the muscles in my forearm?

- No, exercising the forearm before surgery will have no beneficial effect on the surgery, or on your postoperative recovery. It is, of course, important to maintain good overall fitness.
- After surgery, you will have to perform specific exercises on the operated forearm to promote rapid and maximum recovery. The care team will inform you about these exercises and their frequency of execution.

Will I have less feeling in my arm after surgery?

 Because the nerves will be affected, the donor arm will no longer have the same sensitivity after surgery at the site of the graft. It is therefore important after surgery to pay particular attention to that region as the sensation of pain after an injury and the perception of temperature variations will be altered.

Why do I have to wear a compression sleeve on my arm after surgery?

• The compression sleeve helps reduce the appearance of scars on the donor arm. Once the wounds on the arm are completely healed, you will have to wear the compression sleeve 24 hours a day except in the shower, for a period of about one year.

Can I tattoo the donor arm after surgery?

• Yes, it is possible to get a tattoo on the operated arm about one year (or more) after surgery.

Can I choose the length and size of my penis?

- The length and size of your penis are determined according to the thickness and length of the skin of the donor site. The size of your phallus will be proportional to your morphology.
- One factor affecting phallic length that is not within our control is the amount of skin elasticity.
- Your surgeon will give you more information about this subject during your preoperative consultation.

Expectations: It's also important to have realistic expectations. Appearance can vary depending on your anatomy and tissue.

Do I have to stop taking my testosterone before or after surgery?

• No, we do not routinely recommend stopping testosterone (T-GAHT) before your surgery. You can continue taking your testosterone according to your regular schedule.

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 (GP) or endocrinologist can help you make sure your diabetes is under control before surgery.

Weight loss: Why is my weight important?

• We understand that bodies come in all shapes and sizes. You don't have to be skinny to be healthy. However, for phalloplasty the surgery involves very small blood vessels and nerves that are being connected under the microscope. Further, we are manipulating tissue, and the thickness of the tissue matters in our ability to be able to manipulate it as the fat layer under the skin is being incorporated into the phallus. So even individuals that are not significantly overweight often need to lose weight to make the surgery possible or less risky.

- For some people phalloplasty may not be possible because of their body shape and weight.
- Being overweight also increases your risk of complications such as breathing problems, infections and blood clots in the legs and lungs.

What resources are available to help me lose weight?

 Contact your primary care provider (GP) to discuss healthy weight management programmes. Your GP might be able to refer you to a nutritionist, or dietitian, or you may be eligible for the Green Prescription.

How long before and after surgery will I need to stop drinking alcohol and quit smoking?

- Avoid consuming alcohol for two weeks before and after surgery. Mixing alcohol and drugs can cause unpredictable and undesirable reactions.
- Access to our establishment will be prohibited to anyone who presents themselves with drugs or alcohol or who are under the influence of these substances.

Tobacco and nicotine substitutes:

We are not accepting patients who smoke (including nicotine based vapes) Substances contained in tobacco and nicotine can:

- Constrict small blood vessels and therefore negatively influence the healing of your wounds and the results of your surgery. The complications nicotine can cause include poor wound healing, delayed wound healing and graft failure.
- Cause, upon rising, nausea, vomiting and excessive coughing which increase the risk of bleeding after surgery.
- Research shows that the risk of surgery failure increases 10 times for people who smoke even one cigarette a day. All products that contain nicotine including vapes and gum, although healthier alternatives to smoking tobacco all still have the same negative effect on wound healing (Source: OSHU Transgender Health Program and Department for Urology).
- You are encouraged to talk to your GP for nicotine cessation support.
- Smoking cannabis, just as for smoking tobacco, contributes to the deterioration of your respiratory system and may interfere with your postoperative recovery.

Can I have surgery if I use recreational drugs?

- Please note that access to our hospital is prohibited to anyone presenting themselves with drugs or alcohol or who are under the influence of these substances.
- Drug use can impact patient safety during surgery. Any drug use should be reported to us during the planning of your surgery. Your surgeon and the anaesthesiologist must have this information to ensure that the surgery is safe.

Sensation and sexual activity after surgery:

There has not been thorough research about what types and strength of sensation you can expect to have in your new phallus. How much sensation you experience depends on several factors, including how successful the surgery was at connecting nerves, how well your nerves regenerate (grow) and how well the brain integrates the phallus and interprets sensory stimuli. Our surgeon can do nerve hook up in phalloplasty. However, nerves regenerate at a rate of about one millimetre every day or roughly one inch per month. It often takes at least six months for the nerve fibres to reach the base of the phallus and much longer to reach the tip.

Your sensation will continue to evolve and improve over years. You might ultimately have partial sensation, where some parts of the phallus have more feeling, and some have less. Age and certain medications can affect nerve regeneration. With phalloplasty surgery, we are in effect performing "nerve transfers" in order to restore sensation. This means we are transferring the function of one nerve to another. For this to work, sensory re-education in the form of "nerve rehabilitation" is critical. A 'learning" period is also necessary for the brain to identify the nerve stimulus as coming from the penis. There are many things you can do before, during and after recovery from surgery to optimize your chances of successful and meaningful sensation in your phallus.

Please note: Nerve regeneration is significantly influenced by your age and lifestyle habits, such as smoking. The younger and healthier you are, the better the chances for nerve regeneration are. In the case where the nerves do not develop, the clitoris can still be stimulated in its new location at the base of the phallus. Your ability to achieve orgasm after phalloplasty remains essentially the same as before surgery.

Will I have sensitivity in my penis?

- The sensitivity of the penis is divided into two components: one the one hand we have sensitivity to touch, heat, and pain- that is the sensitivity we have in any body part. On the other hand, we have erogenous sensitivity, specific to certain parts of the body, such as the penis or clitoris.
- Despite a union of nerve from the phallus to one of your feeling nerves, there is no guarantee of nerve regeneration.
- It can take six to nine months for the nerves to heal after surgery and for full sensory recovery. Nerves don't regrow for the first three to four weeks. Then they grow at one millimetre a day (about one 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.
- A "learning" period is also necessary for the brain to identify the nerve stimulus as coming from the penis.

Will I be able to have an orgasm after phalloplasty?

- Orgasm after surgery is almost always possible, but it may take longer or feel different. A small percentage of patients may experience orgasm just from stimulating the phallus; however, this is not guaranteed. Most patients will have to stimulate the buried clitoris to achieve orgasm.
- If you can easily and quickly have an orgasm now, you are more likely to be able to orgasm after surgery. If you choose to have the clitoris buried at the base of the phallus as part of perineal masculinization, you will still be able to stimulate it indirectly. Therefore, you will be retaining your sensitivity allowing for sexual pleasure in this area, and possibly also on the phallus.

The forearm donor site is the most reliable option to experience postoperative sensation. The thigh donor site might only get partial sensation. If sensation is the most important goal for you, consider the forearm donor site.

Sexual activity:

 To decrease the risk of wound separation or infection, it is prudent to avoid sexual activity (including manual masturbation) for at least eight (or more) weeks after surgery and not until all wounds are completely healed.
Masturbation using low intensity vibrating devices with gentle pressure can be used as early as six weeks postoperatively.

Will I be able to penetrate my partner with my penis?

- After an internal erectile device placement, you will have to wait four months prior to engaging in penetrative sexual intercourse. Before proceeding with this surgery, you must have regained sensation in the penis.
- It may be possible to use an external erectile device if you do not want an internal erectile device and desire the ability to penetrate. Your surgeon will discuss these options with you during your assessments as part of the surgical planning.
- Without any form of erectile device, your penis will lack the rigidity required for penetrative sex it will be too flaccid.

These surgeries change the appearance and function of your genitals. It may take you a while to adjust, both mentally and sexually. Over time, you will learn how to best stimulate your erogenous tissue in a new, less accessible location. Please feel free to ask our team anything about this important and sensitive topic. We want you to know that no question is off limits. We are comfortable with discussing your sexual health and well-being.

Can I procreate (father a child) after having phalloplasty?

• No, this surgery will not allow you to father a child. To have children it would be necessary to implant external and internal reproductive structures like testes, where sperm is created, and a prostate, which makes secretions of male seminal fluid possible, which is not possible at this time.

Will I be able to ejaculate after my surgery?

 No, because internal male structures, such as the prostate, seminal vesicles, and glands are absent. However, a clear fluid from the Skene's glands (preserved during surgery) may flow from the urethra in an amount that varies from one person to another.

Can I choose the size of my testicular implants?

• The size of the testicular implants will be chosen with the surgeon and will depend on a number of factors including the elasticity of your tissues and the available space in your scrotum. Your surgeon will advise you so you can get the best possible results depending on your body.

What determines scrotum size?

• Scrotum size is specific to the patient and depends on the amount of skin that is present in the genital area before phalloplasty. The more genital tissue there is, the larger the scrotum and the testicular implants can be.

Can I choose the length of my penile implant before having surgery to insert it?

• The penile implant is available in different lengths but will be chosen by your surgeon in the operating room according to the length of your phallus.

Is having the erectile device implanted painful?

- The implantation is painful after surgery. From the feedbacks we have received so far, it is normal to feel the pain for the first three weeks after the surgery. This might take longer; it is important to be aware of this.
- Some people cannot stand during the first week. It is also normal to have difficulties walking properly for the first six weeks. This is because a sizeable foreign body is inserted in a very tight space, so it takes time for the body to get used to this foreign body.

After the insertion of my penile implant, will I be able to have sexual relations with penetration?

• Yes, you can have sexual relations with penetration about 16 weeks after surgery as you will have satisfactory rigidity of the phallus. It is important to note that the penis will not grow in length and will not rise as much during an erection as in cisgender men.

What is the lifespan of the testicular and penile implants?

• The implants can be left in place as long as no complications arise. If you do have a problem, it will be important to contact your GP and urologist.

Can I travel with implants?

• You can travel with implants. They cannot be detected by airport scanners. The implants are also safe in medical scanners.

What are the delays between the stages of phalloplasty?

• You must wait at least six months between each step. This is the minimal delay that is applicable for healing process without complications. In case of complications or delayed healing, the recommended wait time will be adjusted depending on the progress of your healing.

Do you offer phalloplasty with using other donor sites?

• Our surgeon can also offer abdominal and ALT phalloplasty. These options can be discussed at your first specialist assessment.

Can I get a revision surgery?

• Some complications may happen during your healing process. In case of complications, our team will provide you with treatment recommendations, including whether revision surgery is needed.

I have had phalloplasty without lengthening of the urethra and I am satisfied with my results, but I would like to be able to urinate standing up. Can I come back for another procedure to lengthen my urethra?

• Unfortunately, no, it is not possible to lengthen the urethra at a later time since the tissues required for the elongation of the urethra will have been modified or removed during the first procedure.

Can I get my penis medically tattooed?

• Medical tattooing can add to the aesthetic result. The skin colour on your forearm is often lighter than on a penis. You can tattoo your new phallus to make it darker and add details such as small blue veins. Tattooing can be done 12 (or more) months after the final stage of surgery.

I am afraid of having pain after my surgery, will I be given medication?

- The majority of patients experience pain after surgery, and everyone handles pain from surgery differently. Its intensity differs from one person to another, the experience of pain being unique to each person. You may have an idea of your pain threshold from previous surgeries, but it can vary by surgery type. You should expect some degree of pain and discomfort for several weeks after surgery. We want you to be prepared for this pain and discomfort and know that it is a normal part of healing.
- You will be taking regular paracetamol, non- steroid anti-inflammatory and gabapentin which treats hypersensitivity. Some patients require in the first week additional medication for break through pain, this will be discussed with you prior to your discharge from the hospital.

After surgery, will I have to share a room?

• After surgery, you will have a private room with an attached private bathroom where you can focus on your own recovery.

If my recovery is difficult, can I find psychological support at your hospital?

• We do not have a mental health professional on site at our facility. It is therefore important to maintain contact with the healthcare professionals involved in your follow-up and to bring their contact details with you.

Will I have access to entertainment during my stay?

• Yes, each room has its own television and wireless internet service is offered free of charge. In order to respect other recovering patients, we ask that you bring your personal headphones with you. You can if you wish, bring music, your laptop, or iPad, a book or other entertainment.

Please note: we recommend bringing comfortable, large, loose fitting, low hassle clothes to go home in when you are discharged.

When do I resume my normal activity?

- **Walking**: We ask that you limit your walking to 2,000 steps a day for the first four weeks. This is about one and a half kilometres or 20 minutes of walking for the whole day. After four 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. You will get tired easily as your body recovers. Take time to rest and limit activities.
- **Showering and bathing**: We ask that you shower twice a day for the first six weeks. Then you can resume your normal shower schedule. No baths, hot tubs, or swimming for the first three months.
- **Lifting**: Don't lift anything over five kilograms for the first four weeks. Then you can slowly increase the amount of weight you lift.
- **Workouts**: No working out, running, or strenuous gardening etc for 16 weeks after surgery. Then you can slowly reintroduce these activities to your routine. No bicycling for four months.

Please note that the recovery time depends on the progress of your recovery and the type of work you do. The estimated duration is given for informational purposes only.

Additional Informative Resources for Phalloplasty:

OHSU's <u>Phalloplasty Guide</u> is a comprehensive look at the three types of phalloplasty (radial forearm free flap, anterior lateral thigh flap, and abdominal

flap.) It provides extensive information about what to expect during surgery preparation and recovery.

<u>Phallo.net</u> is a detailed website dedicated to all things phallo and has a great guide to the different techniques. It can be pretty technical but does discuss each surgery option in-depth. Pictures and links to surgeons performing each type of surgery are available. Often surgeons will have photos on their individual web pages or their clinic's web pages. Phallo.net also provides a guide to <u>hair</u> <u>removal for phalloplasty</u> and a link page to <u>phalloplasty blogs</u> for first-person accounts of phalloplasty.

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