



Penile Cancer

Information for Allied Healthcare Professionals

Speak to one of our nurses

0808 802 0010



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Penile cancer is a rare cancer with 700 men being diagnosed each year in the UK, 6,000 in Europe and around 36,000 men globally.

Due to its rarity many healthcare professionals will never have encountered penile cancer and may be unable to offer support and advice to men following their treatment.

This guide provides an overview of the patient journey and gives an insight into some of the short and long-term problems which men may experience along with some practical advice on how to support them.

It has been created for Orchid's Four Nations Penile Cancer Programme which aims to raise the profile of penile cancer within the UK, by developing new initiatives to help support men and their partners.

The guide has been compiled with the help of men who have been affected by penile cancer and clinicians involved in their care.

The aim of the guide is to give allied healthcare professionals working within primary care or the community, a reference guide which may help them to support patients outside of the clinical setting.





Signs and Symptoms

I was misdiagnosed with balanitis and sent away with some creams that I couldn't use. A week or so went by, and nothing changed so I went back. My lump was bigger, my skin was thicker and the marble sized lump in my groin had started to show. I asked for a referral but was sent to the sexual health clinic instead. More negative tests and another two weeks went by, and my GP was out of ideas.

Over the next 8 months I also visited the local doctor and dermatologist at least six more times regarding the wart on my penis as the cream was not working and it was getting larger. Then eight months after my initial consultation with the dermatologist I was finally diagnosed with Bowens Disease, with invasive SCC. In short, it was Penile Cancer.





One of the biggest problems associated with penile cancer is a delay in diagnosis. This can occur because men do not seek medical advice at an early stage but can also be delayed by inappropriate treatment or referral.

Many GPs will never see a case of penile cancer in their careers. Early symptoms, especially rashes, can mimic many non-cancerous conditions such as balanitis (inflammation of the head or shaft of the penis), or sexually transmitted infections (STIs).

Men may be treated with several courses of topical ointments or steroidal creams while some may be referred non-urgently, to dermatologists or sexual health clinics further delaying diagnosis.

Most treatment for penile cancer will involve surgery to the penis, so the longer the disease is undiagnosed and untreated the more invasive subsequent surgery may become.

Possible symptoms of penile cancer may include:

Penis

- Rash
- Growth/lesion/lump
- Swelling
- Bleeding
- Ulcer
- Discharge
- Change in colour of foreskin.

Groin

- Lumps felt under the skin or in the groin area.

Any abnormal rash, lesion, ulcer, or discharge, on or from the penis should be checked by a doctor as soon as possible. If it is not possible to identify an obvious cause, men should be referred to a urologist for urgent assessment, especially if a condition has not resolved after an initial treatment with topical therapy.

Useful links

[Current NICE Guidelines](#)

[Penile lesions](#)

[Sexually Transmitted Infections II: genital lesions](#)





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Risk Factors

The causes and the way that penile cancer develops is not fully understood but there are some factors which increase the risk.





Human Papilloma Virus (HPV)

There are many different types of HPV virus. Common types can cause warts and verrucas which are spread by skin-to-skin contact. Some types such as 16 and 18 which are transmitted via sexual intercourse are considered high risk. These can infect the anus, penis, throat, and cervix, and are linked with the development of cancer. The body's immune system is usually able to neutralise the virus, but sometimes it can persist for many years without causing any obvious symptoms before developing into a cancerous or pre-cancerous condition. Around 50% of men diagnosed with the most common type of penile cancer will have evidence of infection with one of these types of HPV.

It has been estimated that over 80% of the world's population are exposed to some type of HPV during their lifetime, and developing penile cancer does not mean that an individual's lifestyle is to blame. Practising safe sex using a condom can help reduce the risk of HPV as well as Sexually Transmitted Infections (STIs).

HPV Vaccination

Recently, some countries have begun to offer this vaccination to boys, to reduce the risk of HPV related cancer. It may also be given to men following a diagnosis of penile cancer if the cancer is linked to HPV infection.

The Presence of the Foreskin

Penile cancer is rare in men who have been circumcised (surgical removal of the foreskin) as a baby. Circumcision in later life does not reduce the risk of penile cancer and the risk is greater in the presence of phimosis.



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Phimosis

This is the inability to pull back or retract the foreskin fully. It can be a result of skin irritation or inflammation or affect some men from birth. It will reduce the ability of a man to clean the penis thoroughly or notice any abnormal changes. It may also increase the risk of HPV infection. Research suggests that men with phimosis are around 10 times more at risk of developing penile cancer.

Smoking

Some research has suggested that smoking may increase the chance of developing penile cancer. This may be due to harmful chemicals excreted in urine damaging cells in the penis.

Psoralen-UV-A Photochemotherapy (PUVA)

Psoralen-UV-A Photochemotherapy (PUVA) is used to treat some forms of skin disease such as psoriasis, as well as some types of cancer. High doses of PUVA can increase the risk of penile cancer.

Useful links

Human papillomavirus (HPV)
– NHS (www.nhs.uk)



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Diagnosis and investigations

In the UK, men diagnosed with penile cancer will be referred to a regional specialist centre or supranetwork. These centres have surgeons who specialise in treating penile cancer, along with supportive services.





- ↘ **St. George's Hospital, London (Tooting)**
- ↘ **University College Hospital, London, Euston Square**
- ↘ **The Christie Hospital, Manchester**
- ↘ **The Leeds Teaching Hospitals NHS Trust**
- ↘ **The Norfolk and Norwich University Hospitals NHS Trust**
- ↘ **Southmead Hospital, North Bristol NHS Trust**
- ↘ **Sunderland Royal Hospital, South Tyneside and Sunderland NHS Trust**
- ↘ **University Hospitals Birmingham**
- ↘ **University Hospitals of Leicester NHS Trust (UHL)**
- ↘ **The Gartnavel General Hospital (Glasgow and Clyde)**
- ↘ **The Western General Hospital (Lothian)**

Penile cancer is most commonly diagnosed following a biopsy or circumcision of the penis and men will be referred to a regional treatment centre. Around 95% of penile cancer will be Squamous Cell Carcinoma (SCC).

Further investigations such as an MRI or CT scan may be requested and in some cases a Dynamic Sentinel Lymph Node Biopsy may be performed to help determine metastatic disease. This can sometimes cause lymphoedema.

Following a Multi Disciplinary Team (MDT) and discussion of all results, further treatment will be recommended and will typically involve surgery. The aim of all surgical treatment is to remove all of the cancer while preserving as much of the penis as possible.





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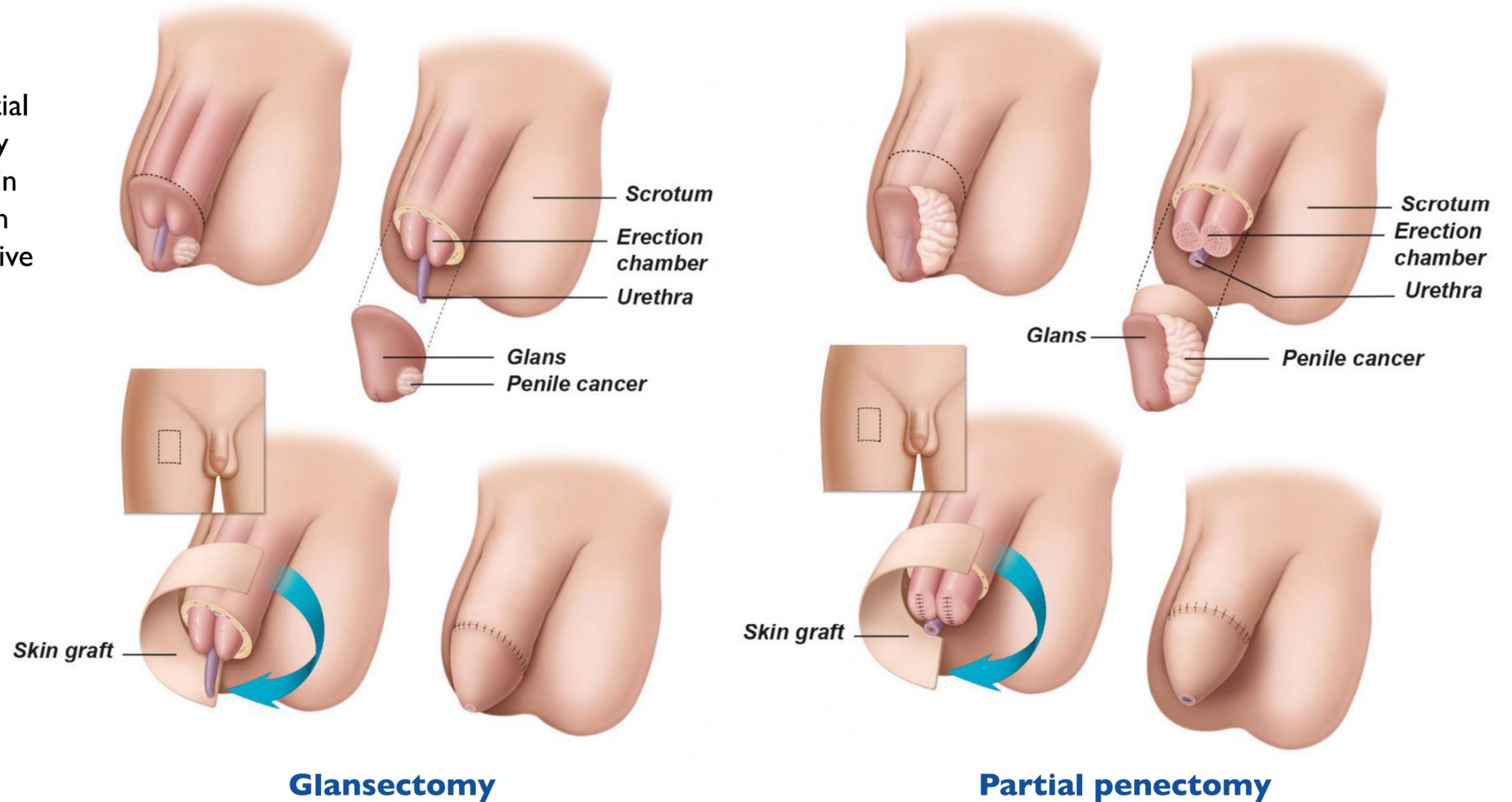
Treatment

For pre-cancerous conditions known as Penile Intraepithelial Neoplasia (PeIN), and some early penile cancer, cancer, treatment may involve topical immunotherapy or chemotherapy in the form of creams. Laser ablation or wide local excision may also be performed.



Surgery

For more extensive early-stage disease involving the glans, a partial glansectomy or total glansectomy may be performed (below). A skin graft from the thigh may be taken to refashion the glans. This can give a good cosmetic result, but the penis will be shorter.



Glansectomy

Partial penectomy

Images courtesy of European Association of Urology



For more invasive disease a partial penectomy may be performed resulting in the loss of part or most of the penis. In more severe disease a radical total penectomy (total amputation) may be needed. This will result in the formation of a perineal urethrostomy (an opening into the urethra through the perineum). This will mean that man will need to sit down on a toilet to urinate.

If cancer has metastasised to inguinal or pelvic lymph nodes (lymphadenectomy), surgical removal may be appropriate increasing the risk of lymphoedema. Systemic chemotherapy or immunotherapy may also be recommended, usually as part of a clinical trial.

An alternative to surgery for localised disease is radiotherapy, either external beam or brachytherapy (internal). This type of treatment is rare in the UK.

Useful post-operative advice

Topical chemotherapy and immunotherapy creams may cause blistering to the penis and a barrier cream or emollient may be needed. These symptoms may take some time to settle after treatment.

Although men will usually be able to return to normal physical activity within weeks, (depending on the type and extent of surgery), the complete healing process will take longer. The initial appearance of the penis following surgery may be traumatic. For minor surgery and glansctomy the appearance will improve over time as healing takes place. The colour of a skin graft may be slightly different to the normal colour of the penis.

Surgical dressings will be managed by the specialist team. Once no longer needed it is best to advise careful management e.g., preventing friction when drying healing areas to avoid skin irritation and infection by gently patting the wound site dry with a clean towel or gauze, and avoiding any material that may leave fibres on the site. Alternatively, a hairdryer on a cold setting can be used to gently dry the area.

If a graft has been taken from the thigh a waterproof dressing will be applied which will need to remain in place for 2-weeks. As the site of the skin graft heals it may cause an unusual odour. Infection should always be ruled out but it can occur as a result of the normal healing process.

Stitches will be dissolvable but may take 4 – 6 weeks to dissolve.

A urinary catheter may need to remain insitu for some types of surgery. Information on managing catheters can be [found here](#).



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When I returned home from my operation those first couple of days were tricky to get around. Trying to put pants on was out of the question. I wrapped myself up in a cotton bed sheet. I could wrap this around me like a toga if I needed to move.

My husband wore one of my t-shirt nighties which is quite oversized, and he loved it. He said it was so comfortable and didn't rub anywhere whilst maintaining his dignity. Also make sure the catheter is fastened at the top of the leg with a support.



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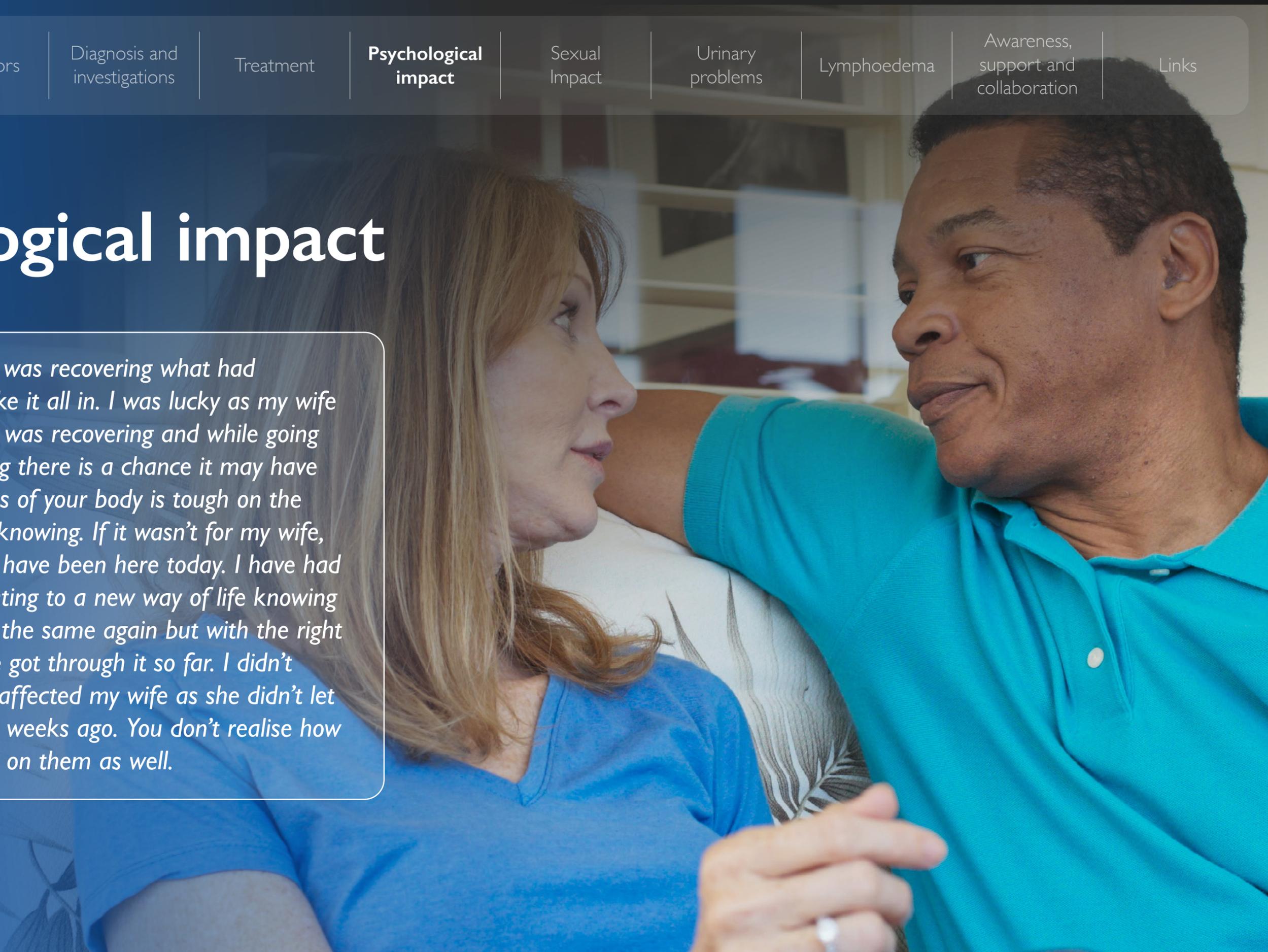
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Psychological impact

It only hit me once I was recovering what had happened and to take it all in. I was lucky as my wife cared for me while I was recovering and while going through that knowing there is a chance it may have spread to other parts of your body is tough on the both of you. It's not knowing. If it wasn't for my wife, I don't think I would have been here today. I have had dark moments adjusting to a new way of life knowing my life will never be the same again but with the right support network I've got through it so far. I didn't realise how much it affected my wife as she didn't let on to me until a few weeks ago. You don't realise how much it takes its toll on them as well.





The psychological impact of surgery cannot be underestimated. The trauma of treatment and the isolation of living with the consequences of such a rare cancer, can have a profound impact on psychosocial function. In addition any change to the appearance and function of the penis and loss of normal sexual function can be devastating.

Although many men may shy away from any form of counselling it can be of enormous benefit and should be recommended and encouraged. General cancer counselling may be sufficient, but more invasive treatment may require psychosexual support and counselling.

Orchid Male Cancer Telephone Counselling Service

In the UK Orchid Male Cancer has a free telephone counselling service for men affected by penile cancer. It offers six counselling sessions over the phone. It also offers a degree of anonymity which men may find beneficial, rather than talk face to face with a counsellor.

For more information email robert.cornes@orchid-cancer.org.uk or sinead.collins@orchid-cancer.org.uk or [click here](#)

Peer Support

Peer support is often invaluable, allowing men to discuss their shared experience and coping strategies. The biggest peer support group that Orchid are aware of is an online Facebook Group called [Penile Cancer Awareness and Support](#). The group has a global reach with over 500 group members.

Like all support groups there will be people in different stages of disease or recovery. Although there will be many positive stories and experiences which will help individuals come to terms with treatment, there will also be those that are negative.

Orchid also facilitate virtual and physical support groups. For further information please email robert.cornes@orchid-cancer.org.uk or sinead.collins@orchid-cancer.org.uk.



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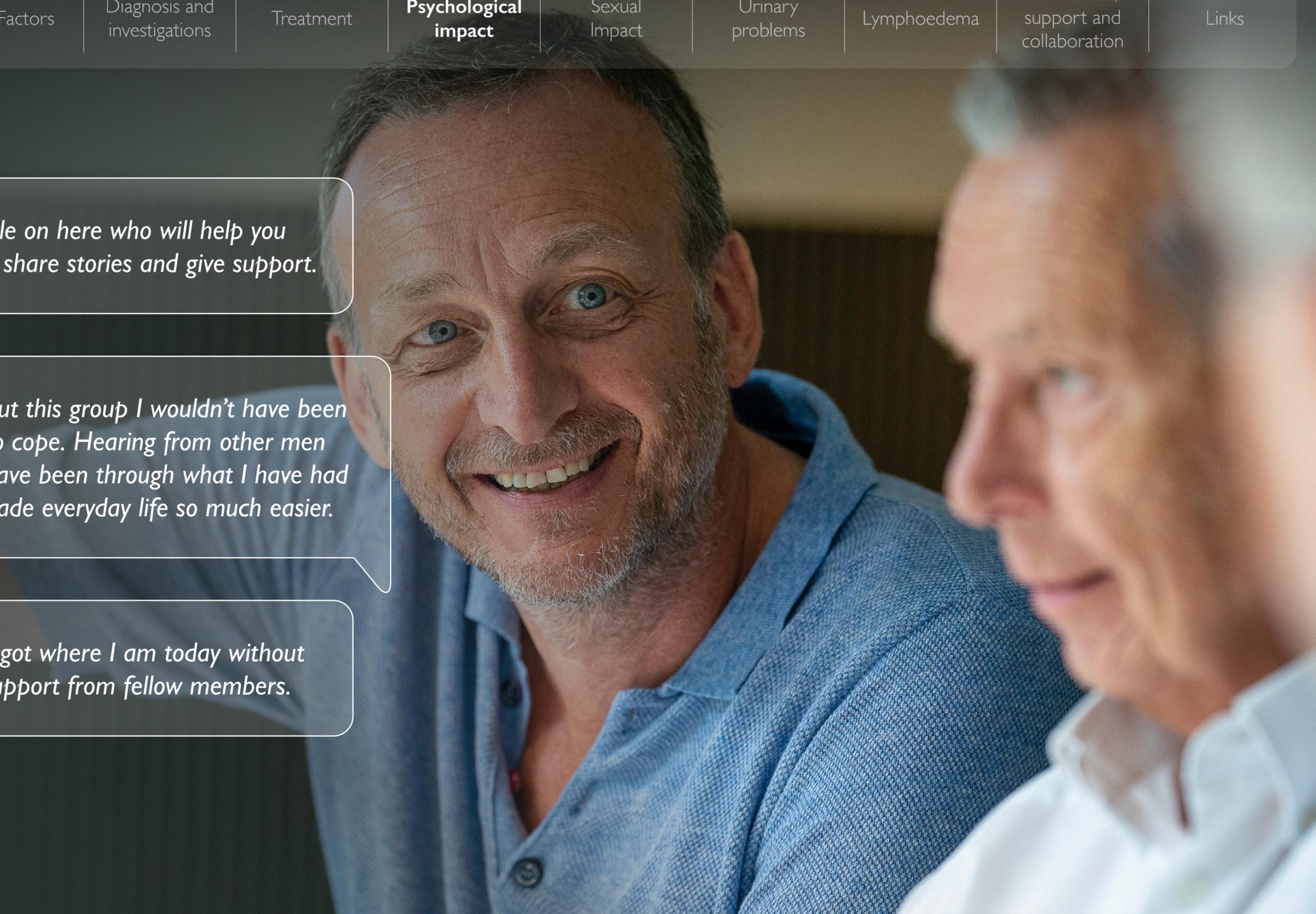
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Some great people on here who will help you through, there to share stories and give support.

Without this group I wouldn't have been able to cope. Hearing from other men who have been through what I have had has made everyday life so much easier.

I would not have got where I am today without the advice and support from fellow members.





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Other Support groups

London

University College Hospital, Euston Square (UCLH), holds a [Penile and Urethral Cancer Support Group](#). The group meets on the first Tuesday of every month (excluding January and August), 12 midday to 1.30pm. The meetings comprise an educational and supportive discussion that is open to all men regardless of the stage of their treatment journey. There is no need to confirm attendance and men can attend meetings as they wish.

For more information about the penile cancer support group contact Sadie Molloy, Clinical Nurse Specialist on 07852219921 or email uclh.andrologycancercns@nhs.net

Manchester

A support group for those affected by penile cancer meets every two months at the Maggie's Centre Manchester and is supported by Orchid. This group meets on the first Wednesday between 3-4.30 pm.

Scotland

There is an independent monthly virtual support group, available on the first Wednesday of every month from 3-4pm. It was created by a young penile cancer advocate and is supported by both a Scottish Specialist Nurse as well as Orchid.

Virtual Meetings

Orchid along with several health care professionals and penile cancer advocates, hold an online penile cancer support meeting every few months. The aim of this is to bring together those who have been affected by penile cancer with health care professionals who are working in the field of penile cancer in a show of solidarity. Sometimes the group will have individual speakers or sometimes a general discussion. People from all over the world can attend these meetings virtually. If you would like any further information about meetings or support groups please email robert.cornes@orchid-cancer.org.uk or sinead.collins@orchid-cancer.org.uk.



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Sexual Impact





Circumcision and Wide Local Excision

The penis will be swollen and sore after this type of surgery but will heal and function normally. There may be some scarring and a slight change of shape in the appearance of the penis, but normal sexual function will be preserved.

Glansectomy

The glans penis is the most sensitive part of the penis and following removal and refashioning with a skin graft there will be swelling and inflammation. Once this has settled the penis should function normally but the sensation may feel different and the graft area may be a slightly different colour. It may take some time for men to adjust to the appearance of their penis and the penis will be shorter.

Partial Penectomy

Penetrative sex is still possible with 4cm of penile length. Men can still ejaculate but it will take some time for men to adjust to the appearance of the penis. In this situation psychosexual counselling (below) will often be of benefit.

Total Penectomy

Normal sexual intercourse will not be possible following a total penectomy and although men should be able to orgasm (sometimes by touching sensitive areas where the penis used to be), they will not be able to ejaculate.

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Psychosexual aspects

It is vital that men talk to their partner and explore other ways of maintaining a satisfactory sex life. Sometimes hugging, kissing, or petting can be just as fulfilling as penetrative sex. The use of adult toys such as massagers and vibrators may bring equal pleasure to both men and their partners. Adult films/pictures or role playing may also achieve similar results and fulfilment. Although men may feel that there is stigma attached to these types of sexual gratification, many people all over the world use them to enhance their sex life. There are also other sensitive zones throughout the body that may allow men to have similar sensations of sexual arousal, for instance stimulation of the prostate gland or nerves behind the scrotum.

Psychosexual Counselling

Referring men for psychosexual counselling can have a huge impact on their quality of life. This will require a GP referral.

For further information about psychosexual therapy

<https://www.relate.org.uk/what-we-do/counselling/sex-therapy>

or information for patients

<https://www.cosrt.org.uk/factsheets/>



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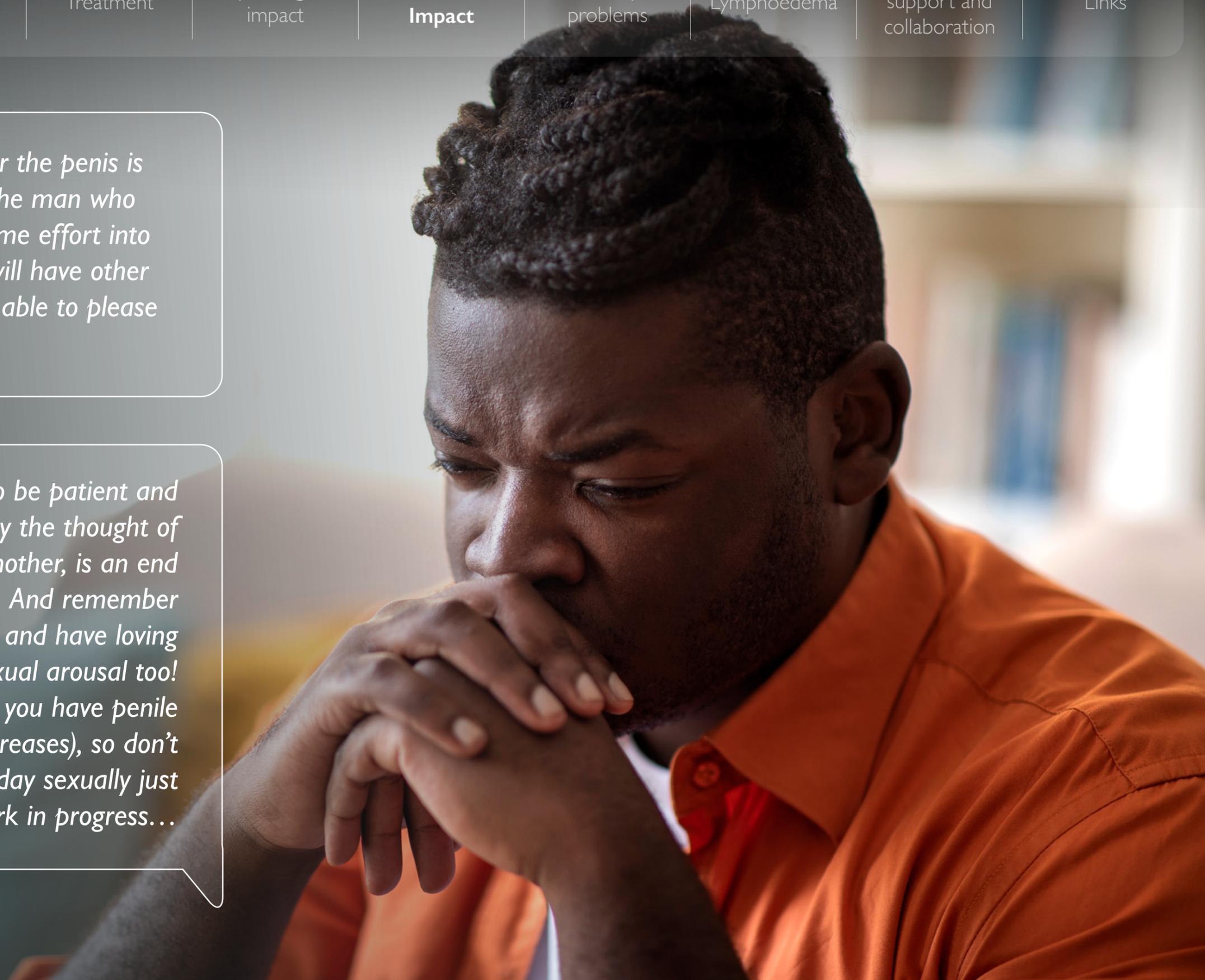
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A fulfilling sex life is very possible after the penis is amputated if both parties especially the man who has lost his penis are willing to put some effort into it. One of the biggest fears the man will have other than rejection is the fear of not being able to please a girl. This is complete nonsense.

For partners I would say try to be patient and understanding. It's just that for a guy the thought of losing your manhood, or acquiring another, is an end of the world as we know it scenario. And remember that your partner will still love you and have loving feelings for you – that includes sexual arousal too! (That doesn't go away because you have penile cancer – if anything I reckon it increases), so don't think that YOU need to call it a day sexually just because your man has some work in progress...





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Urinary problems

The blocking of the gap on the toilet between the cistern and lid with toilet roll helps with a sit down wee.

I have always found it very hard after having a partial penectomy to “aim”. I use the disposable cones when out in public otherwise a sit down wee is often the best bet.

The funnel folds flat in my pocket, wash it when I wash my hands. Changed going out or to work for me. Spraying everywhere and on clothes wasn't for me.

My radar key is a God send as well. Just gives me time and space when I am out and also, I don't have to worry about the sprayers at events and pubs that like to miss.

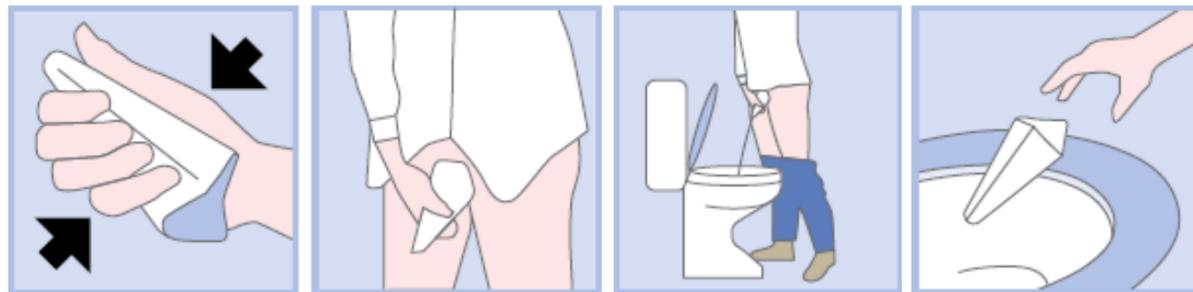
Practicalities of using the funnel: it's so much easier in a disabled toilet rather than a cubicle as you have somewhere to wash the funnel after use. When I don't have a bag I've taken to wearing combat / cargo style trousers with deep pockets. I store the funnel in a Ziploc bag with a sheet of kitchen roll inside.



Surgery or radiotherapy to the penis will cause swelling and inflammation which may reduce urinary flow or cause the urinary stream to spray. It may settle as the penis heals but can sometimes be permanent. Urinary spraying can be reduced by using a urinary funnel (see below). Some men have suggested that while the penis heals, passing urine in a bath or shower rather than a toilet, may help reduce anxiety and be more practical. Men who have had a total penectomy will need to sit down on the toilet to pass urine.

Urinary Funnels

There are several types of urinary funnel. Most are designed for camping or attending concerts where toilet facilities may not be available.



There are also many funnels which are designed for everyday uses, which men may find helpful for instance [urinary funnel](#), [camping urinal](#), [collapsible funnel](#), [shrinkable urinals](#).

In the UK [Beambridge Medical Ltd](#), produces a range of plastic funnels which are available on prescription. The male funnel, male funnel mini, flexi funnel, youth funnel and female funnel.

Other devices that are designed for women but may be helpful are the [Whiz and Whiz freedom](#) as well as the [Shewee](#). These are also available on prescription within the UK.

Toilet Keys

In Europe and the UK, it is possible to obtain special keys such as a RADAR Key. These are keys which will open toilets that are not usually available to the public. More information can be found here <https://disabledaccessibletravel.com/european-toilet-keys/>

Orchid may sometimes be able to supply a toilet key and card. Please email robert.cornes@orchid-cancer.org.uk or sinead.collins@orchid-cancer.org.uk.

Toilet Cards

Several charities and organisations also produce Toilet Cards which may allow men access to toilets found in shops etc. Further information can be [found here](#)

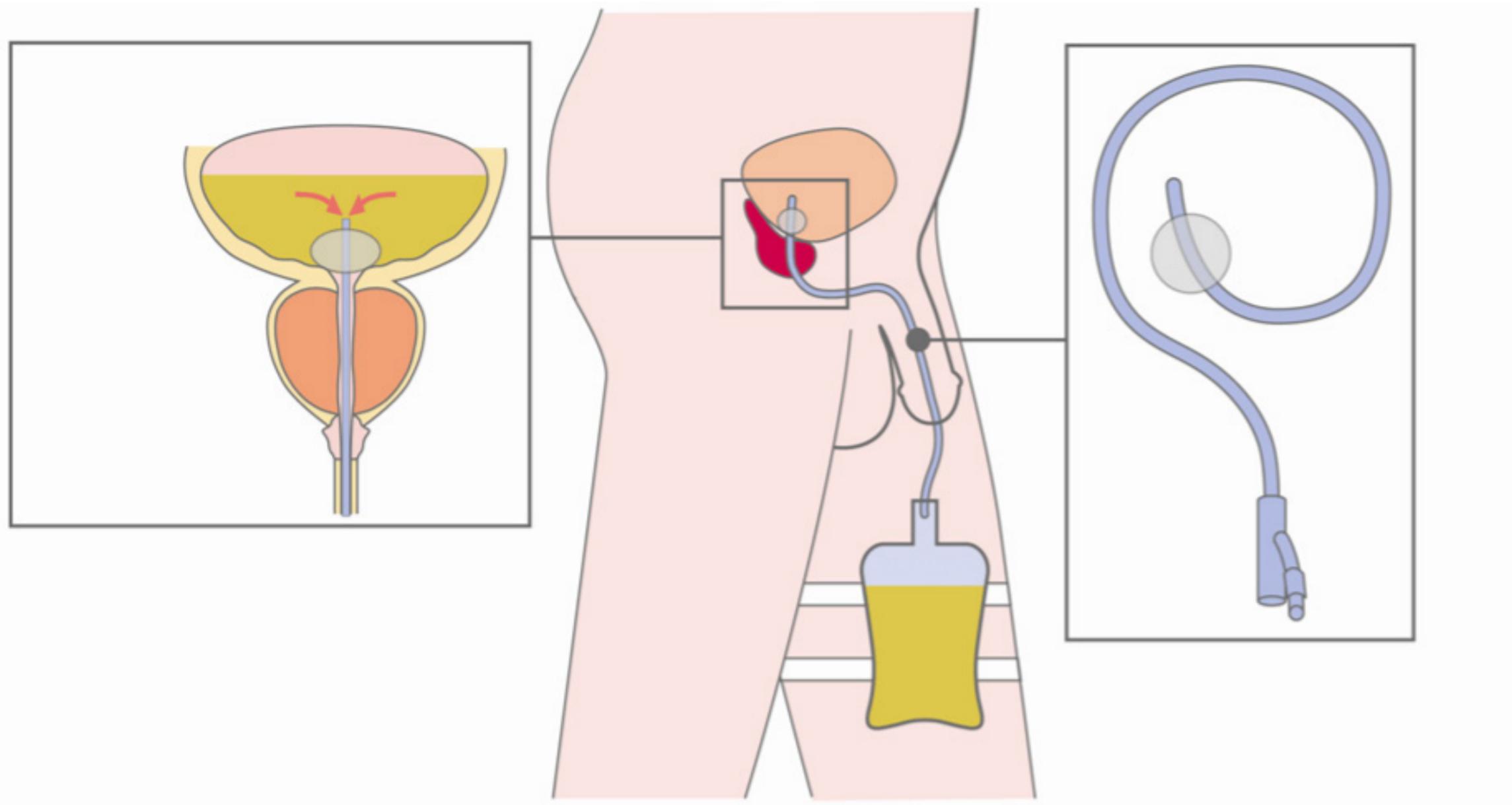
Male Incontinence Pads

There are also different types of protective [male incontinence pads](#) which may help with mild urinary incontinence.



Urinary Catheters

Some surgery for penile cancer will require a urinary catheter to be inserted.





Catheter Care Advice

- The catheter should not be pulled.
- It is very important to drink 2 – 3 litres of water-based fluid daily, to help flush the urine through the catheter and reduce the risk of urinary infection.
- The catheter bag should always be kept below the bladder to prevent urine flowing backwards into the bladder which could increase the risk of infection.
- A leg bag should be emptied every 3-4 hours or when half full to prevent pulling on the catheter.
- Leg and night drainage bags should be replaced approximately every 7 days.
- Constipation should be avoided.
- When emptying or connecting catheter bags, men should always wash their hands thoroughly before and after with soap and water.
- Painkillers such as paracetamol and ibuprofen may help ease discomfort caused by the catheter.

- The catheter balloon may irritate nerves in the bladder causing a small amount of urine to pass around the catheter. Using a strap or tape to fix the tube of the catheter to the thigh or top of the leg to prevent it from pulling or dragging may help (unless [lymphoedema](#) is present). If [lymphoedema](#) is present, men should avoid using tight straps or tape.

In some cases it may be possible to use a catheter *flip flo* valve. This is a valve similar to the one found on the bottom of a catheter bag which can be connected directly to the end of the catheter tube. This means that providing the valve is released on a regular basis (for instance every 2 hours) to allow urinary drainage, a leg bag is not needed, although a drainage bag can still be connected. This is not suitable for everyone and should be assessed by the nursing or medical team.

Catheter Removal

The catheter will be removed by deflating the balloon. Sometimes it can take some time for the bladder to work normally again, and men may find it difficult to control the flow of urine. This will usually improve quickly. It can be helpful to reduce intake of carbonated drinks and those which contain caffeine for a few days. These can stimulate the bladder and have a diuretic effect.



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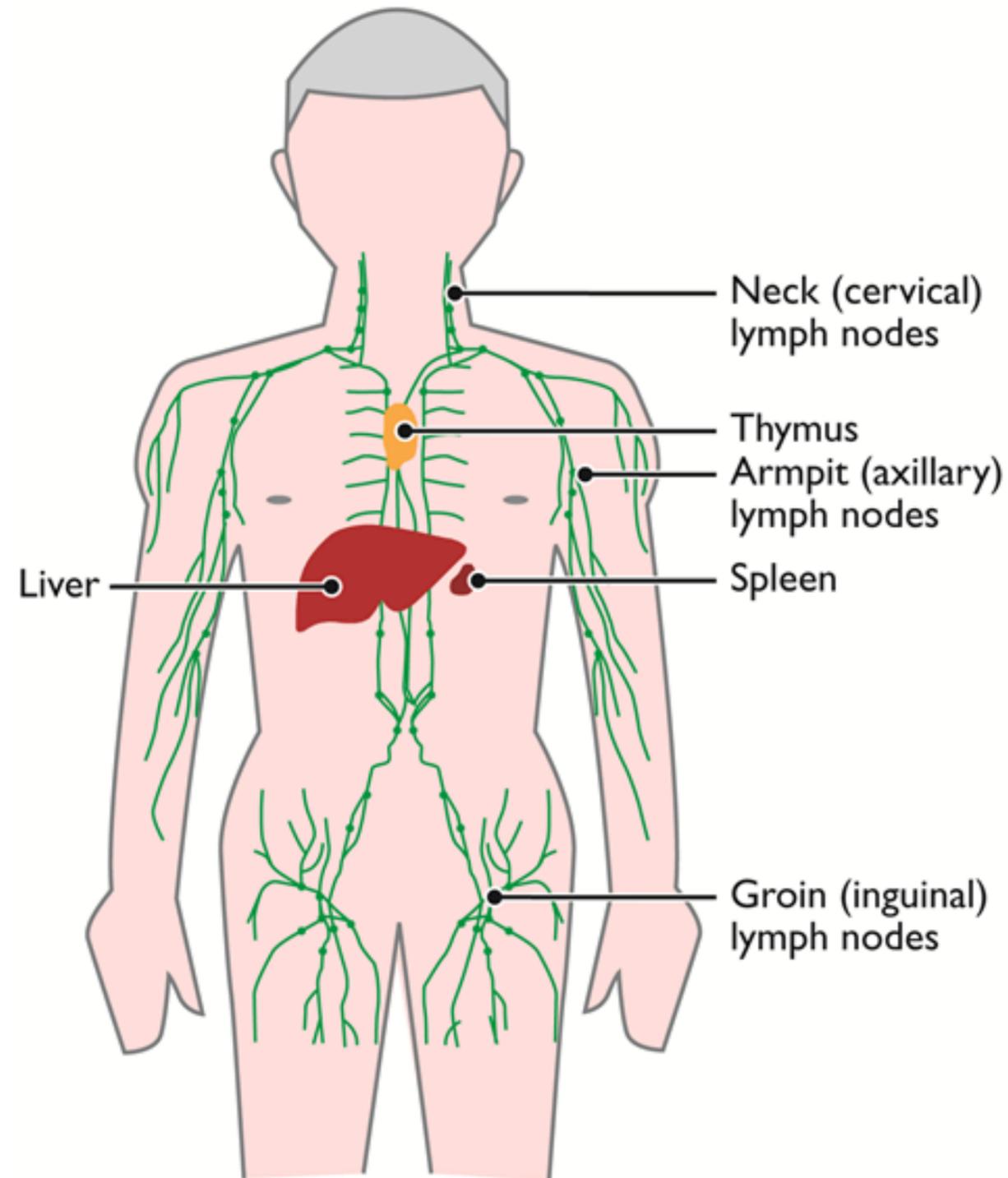
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Lymphoedema

The lymphatic system transports a fluid called lymph. Lymph fluid will contain various cells and substances that the body no longer needs. Lymph passes through small oval structures called lymph nodes.

These filter out unwanted substances. Cancer can travel in lymph fluid and can spread to other areas of the body.



Lymphoedema is swelling that develops due to a build-up of lymph in the body's tissues. It is a condition that may occur following surgery (lymphadenectomy), or radiotherapy to the groin area. It can cause the scrotum and legs to swell. This can be temporary and may improve as the body heals but can sometimes be permanent.

Lymphoedema will need to be assessed by a specialist medical team and men should be referred to local services for management of the condition. Treatment for lymphoedema may involve special types of skin massage, to promote the movement of lymph fluid, compression bandages and support garments. Treatment will need to be given regularly over a period of months and sometimes permanently.

To help prevent lymphoedema and reduce the risk of infection occurring it is extremely important to ensure meticulous skin hygiene and care. Washing the area with an emollient wash may help and supportive garments like cycle shorts or other lycra type briefs, jock straps, or speedo swimming briefs, may help reduce scrotal swelling.



In general men should:

- Try and avoid scratches or bites on the legs, for instance from insects (use insect repellent) or pets. Try and keep vulnerable areas covered if possible. Any cut or scratch should be cleaned immediately with soap and water to prevent infection. If the area becomes red, painful or swollen, men will need to be assessed urgently and antibiotics may need to be prescribed.
- Avoid sunburn to the area. Ensure a high factor sun is used if the area is going to be exposed to strong sunlight. Avoid extremes of temperature to the area.
- Use an electric razor rather than a wet shave to shave personal areas.
- Avoid vaccinations and injections in the affected leg or tatoos. This includes complementary treatments such as acupuncture.
- To maintain a healthy blood circulation which will help stimulate the movement of lymph fluid men should avoid wearing tight garments such as socks or trousers that may restrict blood flow. Men should also avoid becoming overweight and standing still or remaining on their feet for excessive periods of time.

- Try and remember to perform leg exercises (moving the legs) every so often and avoid keeping them crossed for long periods of time. This will help prevent lymph fluid build-up and reduce the risk of potential blood clots from occurring.

The following websites have useful information about lymphoedema.

<https://www.lympho.org/films>

<https://www.lymphoedema.org/information/what-is-lymphoedema/>



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Penile Cancer - The Way Forward

Penile cancer presents a difficult challenge, both in raising awareness of the disease and providing support for those who have been affected.

Improving this situation requires the engagement of patient advocates and HCPs, as well as international organisations involved in patient advocacy.

Orchid is committed to facilitating this and is involved in a number of initiatives to increase awareness and long term support for anyone who has been affected by this rare disease.

Advocacy and Support

Orchid currently facilitates regular virtual penile cancer support meetings. These are designed to bring those who have been affected by penile cancer together with HCPs who are working in the field of penile cancer in a show of solidarity and support. In this way both groups can learn from each other and continue to promote awareness, education and peer support. Further information about these meetings can be [found here](#)

Support

Orchid provide a freephone UK National Male Cancer Helpline for anyone who has been affected by penile, testicular and prostate cancer and a Telephone Counselling Service for anyone affected by penile or testicular cancer. More information on the counselling service can be [found here](#)





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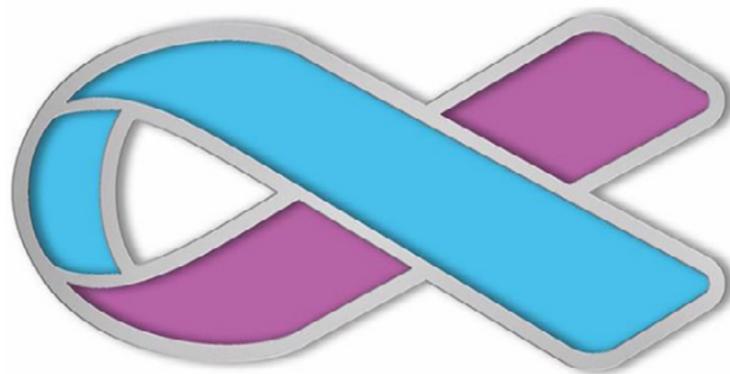
International Penile Cancer Awareness Day

September 20th

In 2020 Orchid suggested that an International Penile Cancer Awareness Day should be recognised as 20th September.

Each year Orchid will strive to promote International Penile Cancer Awareness Day by engaging with health care professionals, medical organisations, survivors of the disease and advocates through social and other media.

If you would like to learn more or want to help promote this day please contact robert.cornes@orchid-cancer.org.uk or sinead.collins@orchid-cancer.org.uk.



In 2017 John Francis Grasso was diagnosed with penile cancer and decided to design a ribbon to raise awareness of the disease. In his own words;

“One of the most powerful lessons I’ve learned is that the rarer a cancer is, the deadlier it can be. Another lesson I’ve learned, is that men need to shed the stigma and start talking about our urogenital and sexual health. Lack of information is as destructive as misinformation. Finally, I’ve learned that I, as a survivor, have to be proactive in caring for other men with this cancer. This cancer is uniquely psychologically traumatic. When I was diagnosed with Penile Cancer, one of the first things I did was scour the internet for an awareness ribbon. An awareness ribbon by its very definition is a symbol of the fact that people know what you’re going through. We had none. It made me feel like no one knew because no one cared. But I knew, and I cared, and I needed other men to know that I knew, and I cared. So I created a ribbon of my own. I drew on other designs to craft ours. Penile Cancer is often caused by the HPV virus, just like Cervical cancer. So I made my ribbon two toned, like theirs. I had a symbol now. We need it. Anyone suffering does.”

Inspired by John’s story Orchid commissioned the design of a physical badge to represent his vision. We are very proud of this initiative and are the only charity to stock this badge which can be ordered here. All proceeds go towards our ongoing fight to raise awareness of and support those affected by the disease.



Signs and
Symptoms

Risk Factors

Diagnosis and
investigations

Treatment

Psychological
impact

Sexual
Impact

Urinary
problems

Lymphoedema

Awareness,
support and
collaboration

Links

Links

European Association of Urology/ASCO
Guidelines Penile Cancer

<https://uroweb.org/guidelines/penile-cancer>

