

Orchid is a small charity dedicated to supporting the needs of those affected by male cancers. We fund pioneering research, raise awareness and offer a range of support services to men affected by **penile**, **testicular and penile cancer**.



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CONFIDENTIAL MALE CANCER HELPLINE



0808 802 0010



helpline@orchid-cancer.org.uk



www.orchid-cancer.org.uk



around 700 men

will be diagnosed with penile cancer in the UK each year.

Although it is a rare disease you are not alone.

Being diagnosed with any type of cancer may affect you in different ways. Frustration, apprehension, and fear of the future are all normal reactions. In addition, because of its intimate nature and rarity, a diagnosis of penile cancer may feel very isolating. Many people will not be familiar with the disease, its treatment, or implications.

This leaflet has been designed by Orchid and has been reviewed by urologists and other Healthcare Professionals (HCPs) who treat penile cancer and men who have been affected by it. We hope that it will provide you with information and support which may be helpful for the journey ahead.



The Journey

I was completely stunned when I was told. As far as I was concerned, everybody else got cancer – not me. I was fit and healthy. Why should I get cancer? People don't even know of penile cancer; it is so rare. I kept thinking of how this might end. But during treatment I felt that I got stronger and better able to cope as I came to terms with what was going on and got a better understanding of treatment and the way forward.

In the UK men who are diagnosed with penile cancer are referred to a specialist regional centre, where a team of urologists and other HCPs will be able to discuss all aspects of treatment. The specialist team will be dedicated to reducing surgical treatment to a minimum wherever possible and will be able to talk to you about the implications of surgery or other treatment options.

Remember

Although there is a lot of information on the internet about penile cancer and its treatment, it is best to wait until the specialist team have made a treatment decision based on your situation and have discussed it with you. This will help to avoid information which may not be relevant to your situation and cause unnecessary concern.



Feelings

It can be difficult to explain how you are feeling. The impact of treatment and readjusting to normal life afterwards can create many challenges.



You have been offering fantastic advice to my dad recently. I can't begin to describe the difference that it has made.

In this situation it can be beneficial to talk to a professional counsellor about the psychological impact penile cancer will have on your life. A counsellor may be able to help you adjust and come to terms with your diagnosis and treatment. Most specialist centres will have a counselling service and it is always worth asking the specialist team whether this is available. Talking about your fears, worries, and concerns for the future with someone who understands some of the issues that you face, can make a huge difference to your mental outlook. Orchid currently provides a free telephone counselling service for men affected by penile cancer who feel that they need to talk to a professional. This can be accessed by calling our National Male Cancer Helpline.



support

Male cancer helpline & virtual support

Men should be given the contact details of a specialist nurse who will act as a key worker during their treatment journey.

The nurse will be a member of the specialist team and can often access information or other members of the team if help or advice is needed. They are often the best point of contact for any queries, so it is always a good idea to keep their contact details close to hand.

Sometimes knowing that you are not alone and that others have been through a similar diagnosis and treatment can be very supportive. However due to the rarity of penile cancer it is often difficult to find anybody else who has been affected. Details of support groups in the UK can be obtained by calling our National Male Cancer Helpline.

Orchid also facilitates in-person and virtual support meetings around the UK and is working with HCPs and men who have had penile cancer to increase the support and information that is available. Orchid also facilitates a virtual support group for wives, husbands, and partners. Please contact Sinéad for more information.



To learn more about regional meetings, virtual support sessions and other support groups around the UK:



Connect:

sinead.collins@orchid-cancer.org.uk robert.cornes@orchid-cancer.org.uk



National Male Cancer Helpline:

0808 802 0010



Information on all aspects of penile cancer: orchidcancer.org.uk/penile-cancer-hub



Scan our QR code

Open your Camera app and point it steadily for 2-3 seconds towards the QR Code to scan. Whenever scanning is enabled, a notification will appear. Select and Orchid website will load.



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