ovacome..
ovarian cancer



Ovarian cancer information for transgender, non-binary and intersex people

Ovacome is a national charity providing support to those affected by ovarian cancer.

We give information about symptoms, diagnosis, treatments and research.

Ovacome runs a telephone and email support line and works to raise awareness and give a voice to all those affected by ovarian cancer.

This information is for transgender men, non-binary people, and intersex people who have, or had, ovaries.



Ovarian cancer information for transgender, non-binary and intersex people

Content warning for discussion of sexual/reproductive anatomy

If you were born with ovaries, then it is important to be aware of your risk of ovarian cancer. This information is for transgender men, non-binary people, and intersex people. It explains the signs and symptoms of ovarian cancer, has tips for planning for GP appointments, and explains possible risk factors.

This is general information for those who have not been diagnosed with ovarian cancer. If you have been diagnosed with ovarian cancer it is important to get specialist advice from your multi-disciplinary team. Find out more about our support for those affected by ovarian cancer here: ovacome.org.uk/support-line

We know it can be difficult to read about parts of the body that you may associate with being assigned the wrong sex at birth. So we have split this into different sections making it easy to read and come back to at a later time. If you need any support or want to talk anything through, please contact our support team on 0800 008 7054 or at support@ovacome.org.uk .

Ovarian cancer signs and symptoms

The four most common signs of ovarian cancer are:

- Bloating that doesn't come and go
- Eating difficulty and feeling full more quickly
- Abdominal and pelvic pain you feel most days
- Toilet changes, in urination or bowel habits

If you have had the ovaries removed then your risk of ovarian cancer is significantly reduced. However, it is not completely eliminated as disease can develop in the peritoneum (a layer of tissue that lines the abdomen and organs inside it). You still need to be aware and see your GP if you experience symptoms that are new for you and persistent.

Seeing a GP

The thought of talking to a GP about ovarian cancer symptoms can be stressful. There is evidence that trans and non-binary communities face healthcare discrimination, so it can be especially worrying if you are registered as male at the surgery and expect to discuss your gender as part of the consultation. There are some resources at the end of this booklet which may be useful, including a database of trans-friendly GPs.

The list below has some suggestions for how to make GP appointments feel more comfortable. The Ovacome support line is here to help too. Do get in touch with us if you'd find it helpful to discuss and plan what you want to say.

- Remember, you are in control of the appointment. You don't have to talk about anything you don't want to, and you can leave at any time.

- If there is a member of the staff at the surgery you trust, you can ask for an appointment with them.

- You can ask for a video or telephone call appointment if that would be easier for you. Some surgeries also provide email consultations.

- If you are attending a face-to-face appointment, you can ask to bring someone with you for support. Usually this will not be a problem.

- You can ask to book a double appointment, so you don't feel rushed during the consultation.

- You could write down what you want to say and read it out, or give it to the member of staff to read.

- If you have time in your day, plan something enjoyable to do after the appointment.

Your risk

Currently there is no conclusive evidence that trans men have a higher risk of ovarian cancer.

A systematic review of evidence in 2018 concluded "There is insufficient evidence to estimate breast or reproductive cancer prevalence in the transgender population."

There is more information on the risk of ovarian cancer on the Cancer Research UK website here: cancerresearchuk.org/health-professional/cancer-statistics/statistics-by-cancer-type/ovarian-cancer/risk-factors#heading-Zero
(Please note, this information refers to women throughout, as most research has involved cisgender women).

If you are worried about your family history of cancer, Ovacome has further information available here: ovacome.org.uk/about-ovarian-cancer/risk-factors/genetic-risk



A systematic review of evidence in 2018 concluded "There is insufficient evidence to estimate breast or reproductive cancer prevalence in the transgender population."

Testosterone Hormone Therapy

Currently there is no identified increased risk of ovarian cancer from taking testosterone hormone therapy (THT). A systematic review of evidence in 2018 concluded "Gender-affirming hormones have not been shown to affect cancer risk" but identified a need for more research.

THT may increase the risk of thickening of the womb lining, which can increase the risk of womb cancer. However, it more often causes thinning of the womb lining. A pelvic ultrasound is recommended every two years for those who are taking THT for more than two years and have not had a hysterectomy. You can always discuss with your medical team the possibility of having the ovaries scanned at the same time, if you are concerned.

Tests for ovarian cancer

There are more details on tests for ovarian cancer here: ovacome.org.uk/tests-for-ovarian-cancer

Your GP may offer you a CA125 blood test. This is a protein that acts as a cancer marker.

Sometimes a GP will examine you by placing gloved fingers inside the vagina and pressing on your abdomen. This is to check for any lumps or swelling. You can decline this examination and you do not have to give a reason.

You may be referred for an ultrasound. Often this is a transvaginal ultrasound, where a small transducer is placed inside the vagina. It uses ultrasound waves to create images of the ovaries. You can decline this examination, and do not have to give a reason. You can request an abdominal ultrasound instead, where a transducer is moved across your abdomen.

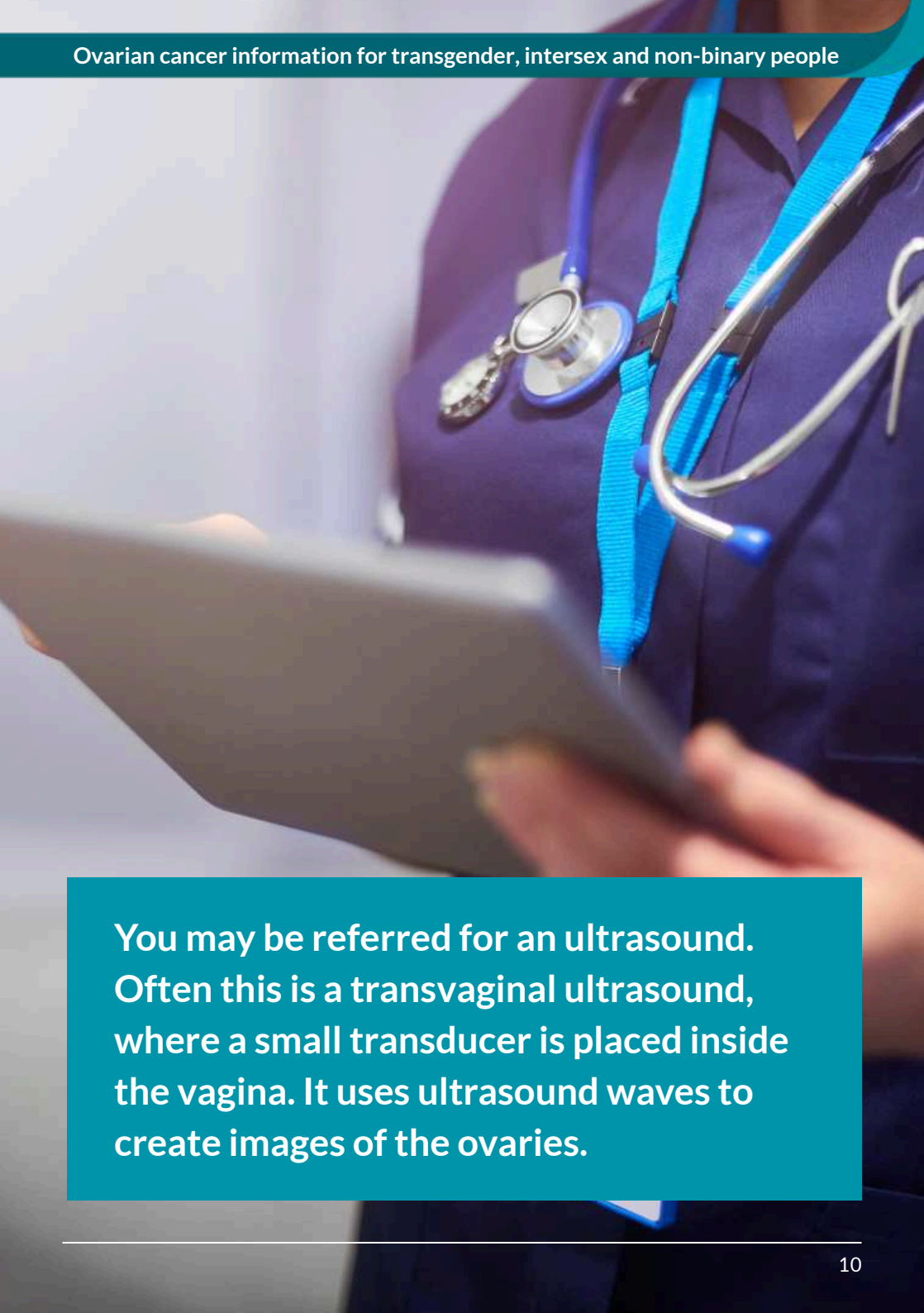
It is important to have diagnostic imaging if needed. If you feel able to talk to the medical team about your concerns this will help them plan appropriate imaging for you.

Experiences

A trans man describes his experience of being diagnosed with ovarian cancer here:
medium.com/matthews-place/yes-a-trans-man-can-have-ovarian-cancer-part-1-4e51987169d7

A non-binary person blogs about their experience of being treated for ovarian cancer here:
blog.dana-farber.org/insight/2017/09/ovarian-cancer-can-present-unique-challenges-around-gender/

An article about a trans man's experience of being diagnosed with an ovarian tumour during the covid-19 pandemic is available here. He also documents his experience on TikTok here:
tiktok.com/@hotboytiktok1000



You may be referred for an ultrasound. Often this is a transvaginal ultrasound, where a small transducer is placed inside the vagina. It uses ultrasound waves to create images of the ovaries.

Useful organisations

OUTpatients a cancer support and advocacy charity for LGBTQ+ people affected by cancer: outpatients.org.uk

TranzWiki a directory of groups campaigning for, supporting or assisting trans and gender non-conforming individuals, including those who are non-binary and non-gender, as well as their families across the UK: gires.org.uk/tranzwiki

LGBT Foundation providing advice, support and information: lgbt.foundation

TransgenderNI support and advocate for the rights of trans people in Northern Ireland: transgenderni.org.uk
Action for Trans Health database of trans-friendly GPs: transgenderni.org.uk

TransActual a national, trans led and run organisation focussed specifically on working for trans adults in the UK with a particular focus on healthcare and trans people's legal protections: transactual.org.uk

How to complain about the NHS: nhs.uk/using-the-nhs/about-the-nhs/how-to-complain-to-the-nhs

Healthwatch, the independent national champion for people who use health and social care services: healthwatch.co.uk/your-local-healthwatch/list

Ovacome would like to thank OUTpatients, TransActual and the focus group participants who generously gave their time to help us with our LGBTQIA+ work.

If you would like to discuss anything about ovarian cancer, please phone our support line on **0800 008 7054** (phone calls only) or **07503 682311** (phone calls, text messages, Whatsapp). You can also email **support@ovacome.org.uk**
The support line is staffed Monday to Friday between 10am and 5pm, and until 8pm on Tuesdays.

You can also visit our website at **www.ovacome.org.uk**