

ENDOMETRIOSIS^{UK}

ENDOMETRIOSIS CARE FOR TRANSGENDER COMMUNITIES

www.endometriosis-uk.org



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Accessing culturally competent, gender-affirming treatment pathways and care for endometriosis can be a challenge for transmasculine and non-binary people, but there are steps you can take to empower yourself and help to make things easier.

Statistics from TransActual research shows that 70% of trans people have been impacted by transphobia when accessing general healthcare and 57% avoid going to the doctor when unwell, so you are not alone if this is your experience too.

“57% OF TRANS PEOPLE AVOID GOING TO THE DOCTOR WHEN UNWELL”

Statistic from TransActual research



PREPARING FOR APPOINTMENTS

There are currently no NHS pathways specifically for endometriosis in transmasculine and non-binary patients and most will go through the same pathway as the cis population. However, there are ways in which you can prepare for appointments if you have or are suspected of having endometriosis. Taking in a list of the information that you would like to tell the doctor along with what should be asked if you are trans or non-binary can be helpful. This includes:

- Your pronouns (or this can be done beforehand by emailing or calling the clinic)
- What symptoms you have been having, such as pelvic pain, bowel symptoms, bladder symptoms etc
- Which hole you use for sex (if you are sexually active)
- Testosterone history ie what preparation is being taken and for how long, and whether it has improved symptoms
- Other details such as being on hormone blockers or contraception
- Smear history
- Medical and surgical history, such as chronic conditions

TERMS USED IN MEDICAL APPOINTMENTS

Some medical terms can be dysphoria-inducing for a trans or non-binary person. They may have provided you with triggering terms beforehand and asked for alternatives to be used. If not, here are some examples that you could use:

- Vulva** – outer parts/outer folds/outer lips
- Vagina** – front hole
- Urethra** – the hole where urine leaves the body
- Uterus/womb** – internal organs/pelvic organs
- Breast** – chest
- Cervical smear** – smear test
- Periods/menstruation** – cyclical bleeding

There are, however, limits on this and a doctor may need to use more precise language for medical consent forms and other written information.

EXAMINATIONS

If an internal examination is required, which is common in endometriosis appointments, you can decline it if you wish. If you choose to go ahead, it's important that you feel in control throughout and the examination should be stopped if anything is too painful or dysphoria-inducing. The examination can be done under sedation or general anaesthetic on another day if preferred.

ENDOMETRIOSIS TREATMENT

The aim of treatment is to stop ovulation, cyclical bleeding and suppress endometriosis. What is chosen depends on whether you take testosterone or not. For example, if you are on testosterone gel, you can switch to an injectable. Long-acting injectables are better for stopping ovulation or bleeding than short-acting daily gels. If that doesn't work, a blocker or progesterone may be added in. It should be remembered that testosterone is not a contraceptive, so you need to take precautions if you use the front hole during sex.

If you are not on testosterone, there can be a discussion about starting, depending on where you are in your journey. If you can't or don't want to then a progesterone is an option.

The combined oral contraceptive pill should not be taken if you want to avoid feminising effects, but vaginal oestrogens are safe, have no feminising effects and can help with atrophy (thinning, dryness and inflammation of the vaginal walls).

SURGICAL PATHWAYS

If you're considering surgery, it's important to remember that it's not a cure for endometriosis – the aim is to reduce the disease burden and manage symptoms. It is not without risk and it's important to find a gynaecologist with a specialist interest in endometriosis and, if possible, gender-affirming treatment. The type of surgery you may have depends on whether you have a diagnosis of gender dysphoria and whether you have plans for gender-affirming bottom/lower surgery and/or gender-affirming hysterectomy (removal of womb), either with or without removal of the ovaries.

For more information about surgical management for endometriosis visit:

endometriosis-uk.org/surgery-endometriosis

Other considerations include whether you want to use cryopreservation (the process used to freeze eggs and embryos) to store eggs to donate to a partner with a uterus in the future. A letter from an NHS gender identity clinic will be required for this. Funding criteria for fertility preservation for trans women and non-binary people are set by local commissioning authorities known as integrated care boards (ICB). This will be assessed when your doctor refers you for fertility preservation.

If you do not have a gender dysphoria diagnosis or want to keep your uterus the surgeon will remove or destroy endometriosis without removing the uterus and ovaries. If significant disease is expected because of symptoms or scan results, then pre-operative cryopreservation should be discussed because more extensive surgery may be necessary.



THE IMPORTANCE OF SMEAR TESTS

It's vital to emphasise the importance of smear tests to trans or non-binary patients as this may be something that they actively avoid because of pain due to atrophy or because it's too dysphoria-inducing. Let them know that a course of local oestrogen before a smear can help to reduce pain or that a sedative or general anaesthetic can also be an option.

If they are undergoing a vaginectomy with bottom surgery, it is important for them to have a normal smear result beforehand.

NAVIGATING MEDICAL APPOINTMENTS - ACTIONS A PATIENT CAN TAKE

It can be difficult to feel comfortable and ask for what you need during a medical appointment, but taking steps beforehand can help. The website outpatients.org.uk suggests the following actions:

- Call the clinic to discuss how to make your appointment a better experience
- Let the clinic know the name and pronoun you would like them to use
- Ask to be seen at the beginning or end of a clinic to avoid busy waiting rooms
- Can they call you into an appointment without putting your name on display?
- Can you take someone you trust with you?

Taking someone with you can be really helpful as they can do things like take notes or pronoun check for you. Another good resource can be found at transactual.org.uk, which provides information on trans healthcare. Look at 'Nobody teaches you how to be a patient' found in its Resources section. It collects the lived experiences of neurodivergent, disabled and chronically ill trans people and has tips on how to navigate medical appointments.

FURTHER SUPPORT AND INFORMATION

ENDOMETRIOSIS-UK.ORG

NURSE-LED SUPPORT LINE:

www.endometriosis-uk.org/nurse-support

VOLUNTEER PEER SUPPORT HELPLINE:

0808 808 2227

ENDOMETRIOSIS CARE FOR TRANSGENDER

COMMUNITIES: youtube.com/@endometriosis-uk

The charity Gendered Intelligence offers a support line for anyone over 18 who is affected by the current NHS trans healthcare waiting lists, as well as youth work for people aged 8-25 and support groups for parents and carers.

GENDEREDINTELLIGENCE.CO.UK

HELPLINE: 0800 640 8046

OR WHATSAPP ON: 07592 650496

EMAIL: supportline@genderedintelligence.co.uk

WEBINAR

Endometriosis UK has produced a detailed webinar called Endometriosis Care for Transgender Communities – it has more detail on all of the above as well as a Q&A.



Scan to view Webinar



 Visit **www.endometriosis-uk.org**

 Helpline: **0808 808 2227**