

# Ovarian cancer: identifying and managing familial and genetic risk

Information for the public  
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[www.nice.org.uk](http://www.nice.org.uk)

## The care you should expect – for people at risk of having a gene linked to ovarian cancer (familial ovarian cancer)

Ovarian cancer affects women, trans men and non-binary people born with female reproductive organs (ovaries, fallopian tubes and/or a uterus).

Sometimes ovarian cancer runs in families so there are more cases in a family than would be expected by chance. This is called 'familial ovarian cancer' (or 'hereditary ovarian cancer'). It happens because there is a faulty gene (the medical term for this is a 'pathogenic variant') that is passed down from mothers or fathers to their children. Having a faulty gene is a risk factor, but does not automatically mean that you will develop ovarian cancer.

Men, trans women and non-binary people with male reproductive organs can also carry a gene linked to ovarian cancer. This means that they may have a higher risk of developing other cancers, and they can pass the high-risk gene on to their children. It is thought that only around 3 in 100 people who have a high-risk gene know about it.

We want this guideline to make a difference to people by:

- raising awareness about genes linked to ovarian cancer and the risk of developing ovarian cancer
- making sure that people who are at risk of having a high-risk gene are referred to genetics services for counselling and testing
- making genetic testing available for more people who may be at risk
- making sure that people who carry a high-risk gene are offered information and support about how to reduce their risk of developing ovarian cancer.

## Making decisions together

Decisions about treatment and care are best when they are made together. Your health professionals should give you clear information, talk with you about your options and listen carefully to your views and concerns.

To help you make decisions, think about:

- What matters most to you – what do you want to get out of any tests or treatment?
- What are you most worried about – are there risks or downsides to the tests or treatments that worry you more than others?
- How will your day-to-day life be affected?
- What happens if you do not want to have treatment?

If you need more support to understand the information you are given, tell your health professional.

Read more about [making decisions about your care](#).

## Where can I find out more?

The [NHS website has more information about ovarian cancer](#).

The organisations below can give you more advice and support.

- [CancerHelp UK](#) (the patient information website of Cancer Research UK), Nurses' helpline 0808 800 4040
- [OUTpatients](#), [contact@outpatients.org.uk](mailto:contact@outpatients.org.uk)
- [Ovacome](#): 0800 008 7054 (support) or 0207 299 6654 (general enquiries)
- [Ovarian Cancer Action](#), 020 7380 1730
- [Target Ovarian Cancer](#), 020 7923 5475

To share an experience of care you have received, contact your local [Healthwatch](#).

NICE is not responsible for the content of these websites.

We wrote this guideline with people who have been affected by ovarian cancer and staff who treat and support them. All the decisions are based on the best research available.

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