

Primary peritoneal cancer



This information is for women who have been diagnosed with primary peritoneal cancer (sometimes referred to as PPC). Many women are told that primary peritoneal cancer is a type of ovarian cancer, and it is usually treated in the same way. However, it does not originate in the ovaries but in another part of the body called the peritoneum.

What is primary peritoneal cancer?

The peritoneum is a large, thin, flexible sheet of transparent tissue that covers the organs inside your abdomen (tummy) including your bowels, stomach, liver and reproductive organs. It may be helpful to think of the peritoneum like a type of 'cling film' which has a number of jobs including protecting your organs and keeping them securely in place. It also produces a fluid which covers your organs making them slick and smooth, this stops them from sticking to each other and allows them to move smoothly when you are active.

Primary peritoneal cancer is a type of cancer which starts growing in the peritoneum. It can start in any part of the peritoneum, and sometimes in more than one place, but most commonly it starts in the area that covers the organs low down in your pelvis (pubic area). Cancers that start in the peritoneum can sometimes spread to other organs in the abdomen, which may include the ovaries.

It is never easy being told you have cancer and the news can trigger a wide range of questions and emotions. It is normal to feel shocked or bewildered and you probably have many questions racing through your mind.

"I knew a little bit about ovarian cancer but not so much about PPC. So when I was told there were lots of small tumours in my omentum... What on earth was the omentum?" Dorothy

Why am I being treated by gynae-oncology?

Primary peritoneal cancer is very like epithelial ovarian cancer, as both cancers

- can cause similar symptoms, in particular a large build-up of fluid in the abdomen
- are treated in the same way
- appear identical when looked at under a microscope.

Since the treatments for ovarian cancer and primary peritoneal cancer are so alike, and because surgery for primary peritoneal cancer can require the removal of a woman's reproductive organs, women are looked after by health professionals experienced in treating women for gynaecological cancers.

Who will be looking after me?

After your diagnosis you should be told who the main person looking after your care is. This person is usually known as your 'key worker' and is often a Clinical Nurse Specialist (CNS). Your CNS will be happy to support you during and after your treatment, you can contact them for support and advice on any aspect of your treatment and recovery.

What treatment will I have?

Because the treatments for PPC and ovarian cancer are similar, take a look at our website for the most up-to-date information on different types of treatment including surgery and chemotherapy - targetovariancancer.org.uk/treatment.

You can also find out more in *What happens next?*, our guide for women with a recent diagnosis. Order your copy for free online at targetovariancancer.org.uk/guides or by getting in touch with us.

Before any treatment you will be asked to sign a consent form to confirm that you understand the procedure. This is an opportunity for you to ask any questions of your surgeon or oncologist.

"I agreed to a course of chemotherapy which I was assured was very effective and indeed it was! My oncologist said I had had a 'remarkable' reaction to the treatment. I was also offered surgery, which I accepted, being a 'belt and braces' kind of person!" Dorothy

Will I have any side effects?

It is common to experience side effects as a result of chemotherapy and/or surgery. Before your treatment starts your oncologist or CNS will explain some of the potential side effects that you might experience. Most will only affect you during your treatment but occasionally some people develop longer term side effects which they learn to manage day to day.

"During my treatment I kept notes every day on how I was feeling, which was really useful at hospital check-ups." Dorothy



How you might feel

Being told that you have cancer can be a shock, even if you were expecting your diagnosis. It is very normal to experience many different emotions throughout your diagnosis, treatment and beyond.

Women diagnosed with primary peritoneal cancer often experience emotions and feelings associated with their cancer type. Some of the women we spoke said that they feel “invisible” because “no one has heard of primary peritoneal cancer”. If you feel this way, you are not alone.

“After the sadness you feel when you get your diagnosis, stand tall and be positive. You will face some dark times, but you can get through them.” Hilary

“I feel invisible.”

You find yourself being looked after by a gynae-oncology team and being treated like you have ovarian cancer yet you have been told that you have something with a different name. You may have been offered the same information as women living with ovarian cancer. Looking around you may feel that nobody acknowledges that your cancer is different which may make you feel a bit invisible.

“No one has heard of primary peritoneal cancer.”

Many people find it very difficult to tell their close family and friends that they have been diagnosed with cancer. Being diagnosed with primary peritoneal cancer can bring with it extra challenges when talking to family and friends because they might not have heard of this type of cancer. This can make you feel very alone with your diagnosis.

“I don’t really understand my diagnosis.”

After reading this information you may find that you still have questions or perhaps even new concerns. Your CNS or oncologist will be happy talk to you and explain your diagnosis in as much detail as you need. Don’t be afraid to ask them to explain things again; it can be very difficult to absorb all of the information they give you the first time. Don’t worry, they will be very used to this.

“I was very open about my cancer diagnosis with my family and friends as I didn’t want anybody to feel awkward when we met, or worry about what to say. This meant that I had wonderful support.” Dorothy

“The best support was from my Clinical Nurse Specialist; I could phone up any time and know that she would reassure me. It’s important to feel able and entitled to seek out great support, even if it isn’t always offered.” Hilary



Back to everyday life after treatment

It will take time to get back to everyday life after treatment. Be kind to yourself. Take some time to work out what support you might like to access. We have lots of practical advice and information about how you might feel at this time, both on our website at targetovariancancer.org.uk/support and in our guide, *What happens next?*, which you can order for free by getting in touch with us.

“Friends have been a huge source of strength. Eventually, cancer takes a back seat. You continue to be the person you have always been and people relate to you in the old familiar way.” Hilary

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This information is approved by the Information Standard scheme to ensure that it provides accurate and high-quality information.



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