A guide for women with a recent diagnosis of primary peritoneal cancer

This information is for women who have been diagnosed with primary peritoneal cancer (sometimes referred to as PPC). Throughout this information Jill and Ann share their insights into their primary peritoneal cancer experience.

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. You may be wondering “What is the peritoneum?”, “Will I have chemotherapy?” and “Why am I being treated in the gynae-oncology department?”

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 a different part of the body.

We hope that this information will help you to understand more about primary peritoneal cancer. We also include support information and details of other guides that you might find useful.

About 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 ‘clingfilm’ 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. It allows them to move smoothly when you are active.

"Honestly, I don't think till my diagnosis I even knew I had a peritoneum." Ann

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.

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.
**Treatment**
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 him/her for support and advice on any aspect of your treatment and recovery, this might include: symptoms and side effects; day-to-day life; emotions; and resuming your sex life and intimacy.

A team of doctors which includes oncologists, who organise chemotherapy or other treatments, and surgeons, who are in charge of your operation, will discuss your test results. The clinical team will recommend a treatment plan that they feel is best for treating your particular cancer. Primary peritoneal cancer is usually treated with a combination of chemotherapy drugs and surgery; however the order in which you receive these treatments will depend upon your individual clinical needs and preferences. In some cases, surgery is considered too risky, in which case chemotherapy will act as your main treatment.

**Chemotherapy**
You will usually be treated with chemotherapy drugs; these are often carboplatin or cisplatin in combination with a drug called Taxol® (paclitaxel). Some women are given chemotherapy before surgery to help shrink the tumour, making it easier for the surgeon to eliminate as much cancer as possible during your operation. In this case, your chemotherapy will continue once you have recovered from surgery. If you are given your chemotherapy after your surgery, it is designed to eliminate any cancer cells that may be still be in your body but not visible to the naked eye.

**Surgery**
The aim of surgery is to remove as much visible tumour as possible from your body. Surgery will often include removal of your reproductive organs including your womb, ovaries and fallopian tubes, and a tissue known as the omentum which stores fat and hormones.

**During treatment**
It is common to experience side effects as a result of chemotherapy and 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 long term side effects which they live with day-to-day.

“During chemotherapy my work colleagues were hugely supportive. The patients at the chiropractic clinic where I worked had no idea. Some even admired my new ‘hair do’ when hair loss necessitated a wig!” Ann

**Your feelings**
Being diagnosed with 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.

“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.” Jill
Women diagnosed with primary peritoneal cancer often experience emotions and feelings associated with their cancer type. We have spoken to women diagnosed with primary peritoneal cancer who have told us they have experienced the following:

**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.

“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.” Ann

**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 friends and family because few people have heard of primary peritoneal cancer. This can make you feel very alone with your diagnosis. You will need to decide how you describe your cancer to your friends and family. It may help to show them this information.

“Telling my three grown-up daughters was one of the most daunting aspects of dealing with my diagnosis. I’d concealed the whole diagnostic process from them in an endeavour to protect them. Retrospectively, I think that was probably wrong as the news came out of the blue.” Ann

**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.

“The best support was from my Clinical Nurse Specialist; I could phone up any time and know that she would reassure me. She was my rock.” Jill

**How do I know my treatment is working?**
It is common to worry that treatment is not working. Your medical team will monitor your progress very carefully, both during your treatment and in the months and years following the end of your treatment. If you have any questions or concerns about your treatment, symptoms or side-effects you should contact your CNS or consultant for help or advice.

**Back to your ‘new normal’**
It will take time to get back to everyday life after treatment. You may need to ask for some help until you have got more energy. Try not to feel bad about doing less or asking others to help you. People really want to be helpful and doing the odd bit of ironing or cleaning might make them feel useful.
Going back to everyday life can make you feel very alone, even if you live with a partner or family. You got through the treatment but now you are left with the challenge of getting on with life again. For some women this is the most frightening part. If you have a day when you feel weepy and miserable try not to be hard on yourself. Trying to get back to some kind of routine will help, though this can be daunting and everyone will have different expectations about what they want their life to be like now. If these feelings persist, speak to your CNS about professional support.

I have symptoms. Does this mean my cancer is back?
It is completely normal to feel worried about new or unexplained aches, pains or symptoms after receiving a cancer diagnosis. If you develop any symptoms which cause you concern you should contact your CNS or GP immediately. You do not have to wait for your next appointment. They will discuss your concerns with you and either set your mind at rest or arrange for some tests.

Symptoms that you should be particularly aware of and report to your CNS or GP include:
- Persistent pelvic or abdominal pain.
- Increased abdominal size/persistent bloating – not bloating that comes and goes.
- Difficulty eating or feeling full quickly.
- Urinary symptoms (needing to wee more urgently or more often than usual).

Alongside these symptoms you should contact your GP if you have any unexplained changes in weight, persistent changes in bowel habits (either constipation or diarrhoea) or unexplained and extreme tiredness.

Sources of support
Target Ovarian Cancer events
Target Ovarian Cancer runs a programme of events across the UK to support women living with and beyond ovarian or primary peritoneal cancer, including our Being Together days. They offer an opportunity to meet other women outside of medical settings and provide support and information. All are free of charge. Visit targetovariancancer.org.uk/support-events or ring 020 7923 5475.

Target Ovarian Cancer website
Our website targetovariancancer.org.uk brings you insights from women who have had a diagnosis of ovarian cancer and how they feel. You might want to become a guest blogger too and write about your experience.

Support groups
Simply being around people who understand what cancer involves can help. Some groups like to share fears and worries or arrange talks about cancer from different professionals. Some groups arrange lunch or outings to boost spirits. Often groups are general, with members who have had different types of cancers, but there may be a group specifically for women with gynaecological cancers. Your CNS may run a support group locally or you can visit targetovariancancer.org.uk/support-groups to find a group near you.
Online communities

- Facebook pages such as facebook.com/TargetOvarianCancer offer you the opportunity to keep informed and connect with other people. Facebook groups are a smaller forum allowing people to come together around a common cause that can be created by anyone and you can choose to make it publicly available or keep it private and members can only join by invitation.

- POW Health is a unique digital health platform allowing you to manage your health information in one place and provides you with useful tools and communities to help you compare and learn from other people’s experiences: powhealth.com

- Macmillan Cancer Support’s Online Community can also give invaluable support at the click of a button: community.macmillan.org.uk

- Maggie’s Cancer Caring Centres have an online centre where you can meet others and access online support groups: maggiescentres.org

- HealthUnlocked is an online forum with hundreds of health communities. There is an ovarian cancer specific chat that includes members with primary peritoneal cancer forum run by Ovacome: healthunlocked.com/ovacome

Further information

If you have recently been diagnosed with primary peritoneal cancer you may find it useful to read our detailed guide for newly diagnosed women, What Happens Next? which deals with each aspect of getting back to everyday life. You can order a copy by contacting us, or you can download it directly from targetovariancancer.org.uk/guides

For more information on treatments and side effects visit the Target Ovarian Cancer website

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