

If your care needs increase Symptom control and palliative care Ovacome is a national charity providing support and information to anyone affected by ovarian cancer.

We run a free telephone and email support line and work to raise awareness and give a voice to all those affected by ovarian cancer.

This information is part of our *If your care needs increase* series. It looks at symptoms of advanced ovarian cancer and how they can be treated. It also describes palliative care services.





Symptom control and palliative care

Palliative care manages symptoms and side effects. It can be given alongside active treatment.

Advanced ovarian cancer is when your illness has reached a stage when a cure is not possible. You may have lived alongside your illness for many years having treatments if, and when you needed them. Advanced ovarian cancer can also mean that the cancer can no longer be controlled by treatment, or you may no longer be well enough to have more chemotherapy or other treatments.

Reaching the point in your life when further active treatment is less likely to be recommended, as its risks may now outweigh its benefits to you, means the aim of your care will now be to keep you well for as long as possible. This will mean managing symptoms and side effects through palliative care only.

Improving your quality of life

Palliative care is given to improve the quality of life. It addresses the needs of the whole person, not just the diagnosis.

It aims to treat symptoms and treatment side effects as early as possible. It is sometimes called supportive care, comfort care and symptom management.

You can receive this care in hospital, at home, in a hospice as an inpatient or at an outpatient clinic, or in a long-term care setting.

Palliative care can be given at any point in your ovarian cancer, from diagnosis to the end of life. You can receive palliative care while you are having active treatment.

Accessing the care you need

You can ask your GP, CNS (clinical nurse specialist) or your clinical team to refer you to a palliative care team. You may also be able to self-refer to your local team. This may include doctors, nurses, occupational therapists and physiotherapists. They will assess your needs and circumstances and the needs of your family so that they can give you all the best possible care and support.

The palliative care team will treat and manage the symptoms you may experience and alongside this they will give emotional support. You can receive this care at home, in hospital or in a hospice.

Symptoms of advanced ovarian cancer

Physical symptoms can include fatigue, nausea and vomiting, pain, constipation, bowel obstruction, heartburn and shortness of breath. Your palliative care team will aim to control the symptoms you experience at the earliest possible stage.

Managing fatigue

Fatigue is an exhaustion that seems to affect you a lot of the time. It can stop you doing routine tasks and affect your enjoyment of life. It is not the tiredness that we all experience at times.

Fatigue can be caused by anaemia (too few red blood cells) or kidney impairment which can be treated. It can also be caused by treatments such as chemotherapy, and by the cancer itself. Your energy may also be affected by the emotions and stress you may be experiencing at this time.

Gentle exercise can help, and your CNS or occupational therapist should be able to suggest activities and exercises, and ways to adapt to lower energy levels. You may find a level of activity that works for you. Some medicines can be used as stimulants and increase energy and alertness so you can enjoy your life more.

You can find out more from Ovacome booklet 24 *Managing fatigue* here: www.ovacome.org.uk/fatigue

Ascites

This is fluid in the abdomen that is caused by the cancer. Some people experience this as abdominal bloating when they are first diagnosed.

Ascites can cause many of the symptoms of advanced ovarian cancer including, abdominal bloating, breathing problems, indigestion, fatigue, nausea and vomiting and loss of appetite.

Abdominal ascites is detected by using an ultrasound scan. The fluid can be drained away using a procedure called paracentesis, when a thin, soft tube is inserted into the abdomen using local anaesthetic. The fluid drains through the tube, which is then removed. This process can be carried out as a day case, or with an overnight stay in hospital. Some hospices offer this treatment. The fluid may develop again, and you could then be offered an indwelling drain, known as a Pleur -X drain, that is inserted into your abdomen and stays in place. This allows you to drain the fluid in small amounts at home yourself or with the support of the district nurses.

Constipation

Constipation is a change to your usual bowel habit which may mean passing bowel movements less often; or having bowel movements that are hard and painful to pass.

It can be caused by the cancer spreading to the bowel and restricting it. Ascites can also cause it as the fluid build-up is heavy and can slow down the bowel. Opioid medicines such as morphine can also cause constipation. It may occur or be made worse if you don't drink enough fluids, have a poor diet or are inactive.

You can try to help yourself by drinking more water throughout the day, taking exercise and eating more fruit and vegetables to get your bowel working properly unless you have been advised not to eat these foods.

If you still have problems then speak to your CNS, palliative team or GP. They may suggest using laxatives. These are medicines that stimulate the bowel, bulk up the stool, soften the stool or draw water into the bowel. They usually come in pill form. If one type doesn't work, you can try a laxative that works in another way.

You can try using laxatives in the form of suppositories and enemas which you insert into the rectum yourself. These work by softening the stool and stimulating the rectum. A nurse may be needed to help with this.

Feeling sick

Nausea and vomiting can have many causes, but there are medicines that can help, so ask your palliative care team or GP for this. The causes include ascites, constipation, indigestion, chemotherapy, some medications, especially pain medicines, and some antibiotics.

You can help yourself by eating light meals and staying away from cooking smells. Using remedies for sea sickness and travel sickness may help.

If you find it difficult to keep food down, tell your doctor or nurse as this can make you dehydrated and unwell.

Some complementary therapies can help. You could try acupuncture (using fine needles to stimulate nerves) or aromatherapy (gentle massage using oils from flowers, roots and leaves).

You can find out more in Ovacome booklet Living with ovarian cancer: Complementary therapies: **ovacome.org.uk/complementary-therapies**

Bowel obstruction

Bowel obstruction, or a blocked bowel, needs to be treated by your team. Constipation, feeling and being sick, experiencing pain and abdominal bloating can be symptoms of bowel obstruction.

The bowel can be blocked by the cancer, or scar tissue from previous surgery. The cancer, or sometimes ascites produced by it, may be pressing on the bowel wall, or there may be damage to the nerves around the bowel which stops it working properly.

A blockage of the bowel is a medical emergency which sometimes needs surgery although there are other treatments that can help.

The bowel may need to be rested with a break from eating or drinking for a short time. Sometimes doctors insert a tube into the stomach via the nose to deflate the swollen bowel and reduce its contents. It may also be treated by using laxatives, draining the ascites or by using steroids to relieve inflammation around the blockage. You will be given treatment to relieve any pain or sickness caused by the blockage.

You may be advised to use a low-fibre diet which can reduce the risk of a blocked bowel. You can get more information about this from Ovacome booklet *Diet for a blocked bowel* here: www.ovacome.org.uk/blocked-bowel

Controlling pain

Not everyone experiences pain. If you do your team will use the weakest painkiller available that works for you and keeps your pain controlled. This might be a non-opioid painkiller such as paracetamol, a mild opioid painkiller such as codeine or strong opioids like morphine. Opioids control pain by interfering with pain receptors, usually in the gut or central nervous system.

Pain relieving medicines will be given in the easiest way for you. This may be by mouth, or patch; if this is not possible then by injection under the skin (subcutaneous), or into a muscle (intramuscular) or into a vein (intravenous).

A small battery-operated pump called a syringe driver can be used to give a continuous dose of pain reliever under the skin. This may be useful if you can't take it by mouth. Other pain-relieving medicines can be used alongside non-opioid and opioid drugs. These include medicines which are used for other conditions, but which are effective for controlling certain types of pain, such as nerve pain.

Heartburn and reflux

This is caused by stomach acid coming up into the gullet. It can be painful and might put you off eating.

Some drugs cause heartburn, such as steroids and anti-inflammatory drugs. Ascites can also be a cause, and the fungal infection thrush (candida) when it is present in the mouth or gullet. Thrush can be treated with anti-fungal medicines in the form of gels or liquids, or tablets.

Some causes of heartburn may be helped by over-the-counter medicines such as Gaviscon.

You may be able to help yourself by sitting up straight when you eat, having small amounts of food more often and avoiding spicy food, hot drinks and alcohol.

If this doesn't help, then ask your team or GP to give you medicine that will reduce stomach acid.

Breathing problems

Advanced ovarian cancer can cause shortness of breath as ascites pressures the diaphragm, or if fluid collects in the lungs (called pleural effusion), which makes it harder to breathe. This can be treated by draining the fluid (see the section on ascites above). Anaemia can also cause breathing difficulties, so you may be offered a blood transfusion to increase your level of red blood cells.

Anxiety can make you short of breath so relaxation techniques may help you. You can try sitting next to an open window or a fan and let the air movement relax the breathing.

Some hospices have special clinics for people with breathing problems, so you could ask your GP or palliative care nurse to refer you there. Your GP might also prescribe you low dose morphine syrup or other treatment for anxiety which could make you feel calmer and more able to breathe.

If you experience a new cough or chest pain as well as breathing difficulties tell your GP or nurse as this could be a chest infection, fluid in the lungs or a blood clot which can all be treated.

Your feelings and emotions

Your mental health is as important as your physical health at this time in your life. You may be shocked that your cancer is now incurable, or this may be a stage in your illness that you have anticipated and expected for some while.

Sometimes other people can find it hard to accept that the appropriate care for you is no longer active treatment focussed on curing the cancer. They may try to persuade you to resume former treatment and not to give up – in their eyes. Your needs should be the priority and your decisions should be respected. Mental unrest and worry can exacerbate any physical symptoms you are struggling with, so it is important that your feelings are shared. If you have depression or anxiety or other mental health concerns and need more help and support, talk to your palliative care team or your GP who will be able to prescribe medication for you.

Your palliative care team is trained to support you emotionally and spiritually and can support your friends and family members too and help them to come to terms with their concerns about you. It is important for you to be able to enjoy your relationships with the people who love you and are closest to you.

Changing your care and treatment can be a time of anxiety. Tell your palliative team if this is affecting you. You can find advice and some coping strategies in the Ovacome *Living with ovarian cancer* booklet available here: www.ovacome.org.uk/coping-with-anxiety

It may be helpful to get support from other people experiencing palliative care. Your local hospice may have a group that would suit your needs, it may be online. Ovacome has an online forum which is for everyone affected by ovarian cancer. You can access it here: www.ovacome.org.uk/forum.

Useful links

www.patient.info/news-and-features/self-care-cancer-treatment-chemo

www.macmillan.org.uk/cancer-information-andsupport/treatment/coping-with-treatment/cancer-and-your-emotions

www.cancerresearchuk.org/about-cancer/coping/emotionally/cancerand-your-emotions/depression/resources-and-organisations This booklet is one in four in the series If your care needs increase, funded by the James Tudor Foundation.

We welcome your feedback on this booklet. Please email ovacome@ovacome.org.uk or call 0800 008 7054. If you would like to discuss anything about ovarian cancer, please phone our support line on 0800 008 7054 Monday to Friday between 10am and 5pm. You can also visit our website at www.ovacome.org.uk. This is one of a series of information booklets produced by Ovacome. You can see them here: ovacome.org.uk/information.

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Disclaimer

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Version 1 | Date published October 2021 | Date for review October 2024



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Charity number 1159682