

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 discusses options for care. making choices and what to expect from a palliative care team.







What services are there for me now?

Your care and treatment needs may be changing during your illness. It may be that your cancer is no longer responding to active treatment such as chemotherapy or maintenance drugs. You may find that the side effects of your treatment are starting to outweigh its benefits to your health. This can happen if your illness is progressing, or if you were diagnosed when your cancer was at a later stage.

Your clinical team might suggest that it is time to review your care and may discuss whether to focus on symptom control with the aim of giving you the best possible quality of life. Your GP may also help you to choose this type of care. They can refer you to the services you need. You can also make a referral to the palliative care service yourself.

What is palliative care?

Palliative care is given to improve quality of life. It aims to keep you as well as possible for as long as possible by treating your symptoms and any treatment side effects as early as possible. You can receive palliative care while you are still having active treatment.

Palliative care can also be called supportive care, symptom management or comfort care. You can have this type of care at home, in an outpatient clinic, in hospital and at a hospice as an outpatient or an inpatient.

Your condition may stabilise when you are receiving palliative care. You could then be discharged from the service, but you can always return if you need to.

Palliative care aims to manage symptoms rather than cure the cancer. For instance, it can aim to improve symptoms of pain, shortness of breath, loss of appetite, fatigue, or difficulty sleeping.

It aims to deliver care and treatments that address problems that prevent you from being able to live your life to the full. These may not always be physical problems. Palliative care also supports people's emotional and spiritual needs, supports families, and can provide help with financial and legal issues.

Will I have to use a hospice?

Most palliative care is given in the community. It is usually delivered by hospices and their staff alongside other professionals who work with them, such as district nurses and GPs.

Hospices are mostly known for the inpatient end of life care they provide, and this is still an important and valued service. However, around 40 per cent (40 in 100) of hospice inpatients come for a short stay to get more complex physical or psychological symptoms under control before returning home again.

You may be able to have all the care you need given to you at home. However, hospices also offer opportunities to take part in activities such as music and art projects and other social events. Some of these activities may be provided online.

Hospices also offer rehabilitation programmes to improve your strength and keep you as mobile and independent as possible. They can also organise help with personal care.

The hospice community care teams have a telephone service to deal with medical emergencies that occur overnight or at weekends.

Diane is a former palliative care nurse specialist. She uses services at her local hospice to help with her ovarian cancer.

"I felt a huge sense of relief to be referred, because I knew that I would be able to access the most amazing support and resources.

"Hospices are all about helping people to live their best life.

"When most people think of hospice care they think of a building where people are admitted for end of life care...but this is only a part of the specialist care they provide.

"Most of the work they do is about promoting life and living at home. They do this through treating any distressing symptoms, listening to difficulties and finding solutions. Hospices give advice and support to services that can support you at home and provide specialist care to meet your needs. Hospice staff can be there for you at the end of the phone on bad days.

"Most in-patient admissions are to relieve complex symptoms that can be hard to manage at home because they need continuing assessment and adjusting treatments as necessary. When this is achieved, the patients go back home. The aim is to stabilise people's conditions so that they can live the best life possible in their own home.

"I know that when I need more support the local hospice will be a sanctuary for me whether their help is given through community services or as an inpatient."

What can I expect from palliative care at home?

If you want to receive your care at home, let your GP and medical team know.

The community palliative care team will be able to visit you at home. This specialist care will be given by doctors trained in palliative medicine, specialist nurses plus occupational therapists, physiotherapists and social workers.

This team of health professionals will co-ordinate your care alongside your GP and community nursing team.

Your local authority social services can provide a range of services, equipment and home adaptations that will help you to retain your independence and remain at home. Sometimes the hospice community team can organise equipment, adaptations and personal care more urgently, if necessary,

Doulas

Palliative care doulas (death doulas) offer non-medical support to people coming to the end of their lives. They can give companionship and support with care appointments and practical planning for the end of life. They usually work within a healthcare organisation and are usually self-employed. Some work on a voluntary basis, others charge for their services. You can find out more here: www.eol-doula.uk

Finding more support

You may want the support of other people who are receiving palliative care. The Ovacome support line can let you know more about groups and peer support for those with advanced ovarian cancer. Your local hospice and other community organisations might have social groups where you feel supported and comfortable to share your experiences.

What services are there for me now?

Useful information

Macmillan Cancer Support 0808 808 0000

Marie Curie Cancer Care 0800 090 2309 Their website also has a lot of useful information: ww.mariecurie.org.uk/information

www.hospiceuk.org

www.england.nhs.uk/eolc

www.palliativecarescotland.org.uk

www.nidirect.gov.uk/conditions/end-life-care-and-palliative-care

This booklet is one in four in the series If your care needs increase.

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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