

ovacome..
ovarian cancer

Living with ovarian cancer

Getting the support you need



Ovacom 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 booklet is part of our Living with ovarian cancer series. It looks at how Ovacom can support you, information on support groups, other sources of support, and links to various support organisations.



Patient Information Forum



Getting the support you need

Ovarian cancer is uncommon with around 7500 people diagnosed for the first time every year in the UK. Some of them never meet another person who has the same diagnosis, so having ovarian cancer can be a very isolating and frightening experience.

This booklet is an introduction to sources of support you may want to explore. The support you need may change over time. You can contact Ovacome to discuss the types of support available to you.



Ovacome's support for you

Ovacome's support service is open on weekdays from 10am to 5pm.

The Ovacome support team are here to talk things through when you're feeling overwhelmed. We're here to support you, provide information or just to have a friendly chat.

You can contact our support team if you're worried about symptoms, your risk of ovarian cancer or if you would like more information about some of the common signs of ovarian cancer.

We support anyone affected by ovarian cancer - this includes family members and friends. When you're caring for someone with cancer it's important that you're supported too.

- Call the Ovacome support line on free phone 0800 008 7054
- Email support@ovacome.org.uk
- Text/ WhatsApp on 07503 682 311
- Instant message through our website www.ovacome.org.uk
- Arrange a videocall (www.ovacome.org.uk/forms/1-to-1-videocall)

Support line calls can be interpreted so that you can discuss your concerns in a personalised way that is understandable. Ovacome can provide translation of our support materials into any language.

We also have an online discussion forum which is available 24 hours a day. See page 9 for details.

Ovacome also offers a whole programme of online activities and events. This includes online support groups for those diagnosed aged 45 or under, people with rarer forms of ovarian cancer, a family and friends group, a bereavement group, and a stoma group.

We also have workshops, craft sessions and gentle exercise sessions which run online. These sessions offer an opportunity to meet others while taking part in an activity.

You don't need to have tried any of the activities before - new attendees and beginners are always welcome.

The programme varies, so to stay up to date you can join Ovacome as a member to receive our monthly community news <https://www.ovacome.org.uk/membership-benefits> or regularly check our events page <https://www.ovacome.org.uk/Pages/Events/Category/come-to-our-events>

See Links to Ovacome services on page 9.

Support groups

Meeting other people in a similar situation can be reassuring. It can powerfully demonstrate that those living with ovarian cancer can respond to treatment and continue to lead fulfilling lives.

Support groups are a place where you can share knowledge and experience which can be very comforting.

Who runs the groups?

You may have an ovarian cancer support group near you. It may be organised and run by a local cancer nurse specialist (CNS) and take place in hospital. Other groups are started by people with ovarian cancer and do not have formal input from health professionals. They might be at someone's home, in a community space or online.

You may have a cancer support centre near you, such as a Maggie's Centre. Maggie's offers support groups, complementary therapies advice and information for anyone affected by cancer, which includes friends and family. See the link on page 11.

Choosing a group

Support groups take many forms. Some are very general and open to people diagnosed with different cancer types. Others are more specialised and focus on specific groups such as people with gynaecological cancers. You may be looking for a group focussed on ovarian cancer.

Groups may meet face-to-face, online or a combination of both.

Online meetings can be for people across the country and even across the world. This can work well for people with rarer forms of ovarian cancer who seldom meet other people with the same diagnosis.

Meeting online can also mean being able to take part in your own home, without having to travel, even if you are unwell.

However, you may need to be confident in using technology and need equipment and some training. It can be harder to get to know people without meeting them in person. Ovacome can help you practise with unfamiliar technology if you would like to attend one of our online groups.

What are the pros and cons?

Ovacom members tell us that the benefit they value most is being able to talk openly about their cancer with others who share the experience.

Support groups can give you confidence, shared knowledge and experience. This can help you learn to manage your cancer, communicate with health professionals, and get the best out of your treatments.

Joining a support group can reduce feelings of isolation and give you the experience of belonging in a safe space.

However, as well as getting support yourself, there may be an expectation of giving it to others as well. Also, while you will meet people who are coping well and maintaining good health, you will at some point meet those who are not. It can be difficult to see people experience recurrences and further treatment.

Tips for attending a support group

- You can find out more before you go along by contacting the organiser who can tell you about the size of the group and the format of meetings – for instance whether they have speakers or whether members are invited to talk about their experiences.
- If you feel nervous about attending, ask if you can bring a friend or family member to support you. Let the organiser know if you prefer not to speak.

Support lines

Support lines can offer emotional support where you can talk about any worries in a safe, confidential space. They can provide specialised information and details of any further services that may be helpful.

As well as the Ovacome support line, you can call Macmillan cancer support on 0808 808 00 00 which is open 8am - 8pm seven days a week; or the Samaritans on 116 123 which is open 24 hours seven days a week.

Online communities

Online communities such as discussion forums or Facebook groups can offer friendship and shared experiences which can be positive and helpful. Some people like to use these when they need support with problems caused by their cancer, and then have less contact when the situation feels more manageable. This means forums can sometimes be less likely to include positive experiences of being well.

Online communities have the advantage of being available at all times. Look for a community that is moderated and protects its members.

My Ovacome forum

My Ovacome is an online community for anyone affected by ovarian cancer. It is a safe, supportive space for people with ovarian cancer and their friends and families to share their experiences and offer each other encouragement, knowledge, understanding, and friendship. You can choose an anonymous username when you register, meaning that you can share your experiences and ask your questions in a more private way if you would prefer.

The Ovacome support and information team monitor the forum during office hours (Monday to Friday, 10am to 5pm) to ensure that all information posted by members is accurate and the forum remains a safe space. If you have a question or concern about a particular post or comment, you can message our team about it through the forum.

The Ovacome team also regularly post information to help support you through ovarian cancer treatment and beyond.

The web address for the My Ovacome forum is listed below.

Links to Ovacome services

Our online forum

www.ovacome.org.uk/forum and healthunlocked.com/ovacome

Online support groups and events

www.ovacome.org.uk/staying-connected

Ovacome's list of local ovarian cancer support groups

www.ovacome.org.uk/local-support-groups

Other forms of support

You may want to look at other sources of support such as counselling, or psychotherapy. Your GP or clinical team will be able to refer you to these services.

Counselling involves talking to a trained therapist, either one-to-one, in a group, or with your partner or family. It allows you to look deeper into your worries, and manage mental health issues, such as depression and anxiety.

Psychotherapy usually involves talking to a therapist in the longer term, often looking at deeper-rooted thoughts, emotions and behaviours. Sometimes other methods may be used, for example, art, music, drama, and movement. Sometimes couples or families can be offered joint therapy sessions together.

You will usually meet your therapist regularly; this can be in-person, online or over the phone. Individual sessions usually last about 50 minutes.

There are many different approaches to counselling and psychotherapy. For more information see the links on page 11.

Other helpful links

Maggie's Centres: www.maggiescentres.org/

The following three organisations all provide searchable registers of accredited counsellors and therapists:

- British Association of Counselling and Psychotherapy (BACP)
www.bacp.co.uk/search/Therapists
- National Counselling and Psychotherapy Society (NCPS)
www.ncps.com/
- UK Council for Psychotherapy (UKCP) www.psychotherapy.org.uk/

Mind provide a range of mental health information and support:
www.mind.org.uk/

Relate provides relationship counselling, family counselling, mediation, children's counselling, young people's counselling and sex therapy:
www.relate.org.uk/

Carers UK provide information and support for carers: www.carersuk.org/

Some people find complementary therapies very supportive, and there are more details on this in our complementary therapies booklet.
www.ovacome.org.uk/complementary-therapies-booklet For a paper copy call 0800 008 7054.

Penny Brohn UK (integrated cancer wellbeing support):
www.pennybrohn.org.uk/find-help/

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.

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Disclaimer

Ovacome booklets provide information and support. We make every effort to ensure the accuracy and reliability of the information at the time of publication. The information we give is not a substitute for professional medical care. If you suspect you have cancer, you should consult your doctor as quickly as possible. Ovacome cannot accept any liability for any inaccuracy in linked sources.

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Support line: 0800 008 7054
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Ovacome is a charity. We receive no government funding and most of our funding is provided by our community of supporters. We want to continue providing free support and information to people when they need it most. If you can, then please help us by making a donation. You can scan the QR code to the right or visit www.ovacome.org.uk/donate.



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