

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 booklet is part of our Living with ovarian cancer series. It looks at the issues raised among family members, children and friends when someone is diagnosed with ovarian cancer. It also gives sources of help and support.



Your family

If you have been diagnosed with ovarian cancer and have close friends and family, they will often want to help and support you. It is important to know that everyone will react differently to the news that you have cancer.

For some family members, your diagnosis may not be a surprise if you have gone through a long process of tests and investigations. But it may still be a shock for them to hear you have ovarian cancer. Others may not react immediately; they may find it hard to take in or they may withhold their feelings so as not to upset you.

If you can, find a time and a quiet place where you can sit down together to talk about what is happening, share information, answer questions and express your thoughts and feelings. They may feel afraid, or sad and angry. You may be feeling the same and thinking, "why me?" This is common and understandable.

Sharing the experience of a cancer diagnosis with those closest to you can help you share the burden, but it can also create other pressures.

You may feel responsible for your family's emotions which can lead to you minimising or covering up the effects of your illness. Try to be as honest as you can and remember that it is normal and understandable for others to be upset.

If you think those close to you might be hiding their true emotions, then you could talk to them about how it would help you to know how they really feel. It can help to check in with each other regularly and be open about what you are going through. However, it is also fine if everyone needs some time to process the news before it is discussed in detail.

Talking with your partner

A cancer diagnosis changes the lives of everyone in a family or relationship. A partner may feel overwhelmed by what has happened.

In the early stages following diagnosis you might both have concerns about whether your relationship will change, or whether your roles will alter. You may have different thoughts on this, so it can be helpful to talk together to ensure you understand each other's perspective and emotions.

You will get lots of information about clinical appointments, surgery and treatment dates. Going through this together can be a way of starting new conversations about what your diagnosis means for you both and the impact on your lives.

Your partner may want to come to your appointments. It can be very useful to have your partner there to take notes, remember the questions you wanted to ask and simply to share the experience with you. However, it may be that your partner finds it difficult to attend these appointments or is unable to due to other commitments. This can sometimes be hard but seeing if you can understand each other's perspectives can be helpful.

If your partner is unable to attend, perhaps see if there is someone else you trust who can support you. You may prefer to go to appointments on your own or with someone else you are close to. How you manage your appointments is up to you.

Serious illness can bring people together, but it can also put pressure on relationships. Your partner will have a variety of feelings about what has happened. They may have very different ideas about what their role should be during your illness. They may cope with their own feelings by distancing themselves from you; or wanting to do everything for you and protect you, which can leave you feeling that you are losing your independence.

What you need from your partner will be individual to you and will change over time as you progress through different stages of treatment. They may not always know what you need at different times, so it can help to explain to them what your needs are and keep having those conversations as things change.

Physical contact between you and your partner can be a great comfort. It can help to feel connected to your partner during this difficult time. There are many ways in which you can be intimate, including simply spending more time together, light touch such as hugs or holding hands. You may also want to think about sexual intimacy if this is important to you both. Having Ovarian cancer can lead to changes in how you feel about your body and your desire for sexual intimacy. Ovacome's information booklet Ovarian cancer and your sex life may be useful. You can see it here:

www.ovacome.org.uk/ovariancancer-and-your-sex-life-booklet

There is no one way of talking about cancer and the profound changes it can bring. Each relationship is unique, and you will find your own ways of expressing what you both feel and need.

Speaking to your children

Whatever age they are, your children will soon know something serious is going on that affects the family, even if they are too young to say so, which means it is important that you talk to them.

You may want to protect them from upsetting news, but if they sense something is wrong but have no explanation for it then this is likely to be frightening. If they are older, it is possible they may work it out for themselves or find out from someone else. It is difficult for a child to discover that someone else knows more about their family than they do.

Telling children about your cancer diagnosis will be hard but it will help prevent possible misunderstandings. It will also allow children to know what is happening and so feel less anxious. Talking with children about your cancer shows that you trust them, and that they can trust you, which can bring you closer together.

Children will need different levels of information depending on their age. A younger child only needs basic facts to help them make sense of the changes to normal life. Plan what you are going to say and be honest and use simple language. If you have a partner or another family member/friend who your child is close to, it can be useful to talk to children together ensuring you are both sharing the same information. There are resources below that can help you figure out what level of information is right for your child.

Teenagers or older children will often know what cancer is. They may have heard about it at school or have a friend with cancer. They may use the internet for further information, so you can support them in understanding whether the information they find is accurate and relevant.

Start by finding out what they already know. Explain what ovarian cancer is, where it is in your body, that the child can't catch it and, that it isn't their fault. Answer all their questions as honestly as you can.

You may want to say your doctors have told you that your cancer will be treated, and this will take some time and then you will feel a lot better. If you know it is possible that you will not get better, it is best not to promise children this.

Also explain about the treatment and what to expect. You may look different and some of their routines may have to change for a while. Think about the questions your children might ask so you can feel more prepared and able to answer them.

Say that you will try to tell them truthfully what is happening to you. Ask them to tell you when they feel worried, sad, angry or any other feelings, so you can share those feelings together. Younger children may find it easier to talk to you while they are playing.

At the end of your treatment, it is important to prepare your children for your recovery and let them know it may take some time for you to get back to the usual routines. If treatment is ongoing, it is important to let them know and explain what this might look like and mean for them and you, day-to-day.

Children will respond very differently depending on their age. Underfives will notice changes in their parents' emotions and changes to family routine. They may become clingy, go back to much younger behaviours and need a lot of reassurance. This is common so try to be patient and seek support for yourself too. Teenagers may spend more time away from home, or in their room.

Talking to your children and showing your feelings gives them permission to show theirs. Cry if you need to and voice how you feel about your ovarian cancer. Being honest and allowing everyone to express feelings can relieve tension and build trust.

Visiting you in hospital

You may not want your children to see you in hospital, but they may find being away from you even more stressful so ask them what they want to do.

Young children may only need a short visit, but older ones may want longer and want to spend some time alone with you. Plan the visits and make sure your children are prepared and know you may be connected to drips and be in a ward with people who are also unwell. If it is possible, you may want to meet in a hospital lounge or café or garden space.

While you are in hospital your children may be comforted by finding little notes and pictures of you at home. It can be nice for you and your child to have a similar toy or object that you both have whilst you are in hospital, to help them feel connected to you. You could also fix a special time each day for phone calls and messaging.



Telling your parents

You may not want to tell your parents about your diagnosis. Often this is because you want to protect them. It is your decision who you share information with. Talking to your parents can be hard as they are likely to be upset and they may wish it was them who are ill, not you. It may help to remember that they will have a long life's experience that may well already include facing serious illness.

Be honest with loved ones where possible and allow time for further conversations and questions. However, also remember that you don't have to share more information than you feel comfortable with. Some relationships are complex and talking to your parents might not be the right thing for you.

If you decide not to tell your parents, think about how you will manage this and be prepared for their reactions if they learn about your diagnosis from other people.

Talking to friends

After you have been diagnosed, you may want your close friends to know what has happened so that they can support you. You don't have to tell everyone; you can tell other people later if you want to.

It can be exhausting to explain what is happening to you again and again. It may be easier for you to decide what information you want to be known and to ask someone you trust to give it to the people you choose.

Sometimes people start a blog or send group emails or messages to share information with friends and family so that everyone can be updated at the same time, when you want to.

You can decide how much information you want to give people; you don't have to answer questions, no matter how well meaning. You can put it off until you feel better and say that you don't feel able to explain more right now.

Your friends can be a potential source of comfort and support so it can be helpful try to stay in touch. Talking with trusted friends about your diagnosis can help you to understand your feelings and help with decision making.

If a friend offers you help and support it can be helpful to ask for something specific like cooking a meal for you, help in the house, childcare, pet care and other tasks you need doing.

You may want emotional support which may mean talking about what you are going through or other things unrelated to cancer. Let them know what helps you.

While some people are wonderfully sensitive and supportive, others find it difficult to talk about cancer. You may find that some of your friends have no experience of talking about serious illness. They may be embarrassed and unsure and afraid of upsetting you. Perhaps gently reassure them that there isn't a right or wrong thing to say or guide them in the sorts of things you want to talk about – this might be about other things going on in your lives.



Even though you may have been friends for years, you can find that some people want to talk about others they have known with cancer which can feel inappropriate. They may be keen to share stories with you that are unhelpful, or they may just not know what to say. Remember it is fine to be clear about what you do and do not find helpful to talk about.

Some people may be in denial or insist on talking only of positive things. Occasionally people who feel like this will avoid you, which can be very hurtful.

Remember that a serious life event like a cancer diagnosis is likely to change relationships, but over time these people may relax and become more comfortable talking.

When your treatment ends

Some people have found that the time when their treatment has ended can be the most difficult for their relationships with close family and friends. They may assume that your problems are over, that the cancer has gone, and your life before your cancer diagnosis can be resumed.

But you may be struggling to cope with life after cancer treatment. You may miss the security and reassurance provided by hospital care. You may be tired, depressed and worried in case your illness comes back. You will probably be going for regular check-ups, which may make you anxious.

Your family and friends may need to know that even though you look well and seem to be back to your old self, your life has changed, your body is different, and you may feel uncertain about the future.

You could ask a member of your family or a trusted friend to explain your situation to others if you don't feel able to talk about it yourself. They can remind everyone of what you have been through and that you still need their ongoing support, kindness and patience.

You can get more support from:

The Ovacome support line is available for anyone affected by ovarian cancer, which includes family and friends. The number is **0800 008 7054** or you can email **support@ovacome.org.uk**

Macmillan Cancer Support provides information on talking about cancer and for those supporting people with cancer at www.macmillan.org.uk

Maggie's centres are for anyone affected by cancer. You can find out if there is one of their centres near you: www.maggies.org/cancer-support/managing-socially

Hope Support Service is for children whose parent has a serious illness: www.hopesupport.org.uk

The FruitFly Collective runs workshops for children and families on understanding cancer and have age-specific materials you can buy for children: www.fruitflycollective.com

You, your family and friends can also seek support from specialist cancer psychology or counselling services if your hospital offers these. Some cancer charities also offer talking therapy. You can also ask your GP about local talking therapies services that can help you.

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

Reviewed by: Dr Jo Ashcroft, Consultant Clinical Psychologist and Team Lead, Cancer Psychological Support Service, St George's Hospital

Disclaimer

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Support line: 0800 008 7054 Office phone: 0207 299 6654 Website: www.ovacome.org.uk Email: ovacome@ovacome.org.uk

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