

ovacome..
ovarian cancer



Preparing for remote
appointments

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 describes how to prepare for remote appointments, which may be over the telephone or over the internet.



Preparing for a telephone or internet consultation

This is information for ovarian cancer patients who are preparing for remote hospital clinic appointments taking place by telephone, or using the internet.

This booklet aims to help you get the most from your appointment. It suggests questions you may want to ask, and tells you what to expect from the clinical staff you speak with.

It is important to remember that your clinical team is still available to support and advise you between appointments. If your condition changes or you experience side effects from your treatment, contact them straightaway. Don't wait until your next routine appointment and don't worry that you are bothering them. They will want to be kept informed.

Before your consultation

Before your appointment your clinical team should let you know how you will be contacted. This may be by phone, or using an internet video call service like Attend Anywhere, Skype or Zoom. Make sure that it is suitable for you, and you feel confident using the technology.

If you don't have the equipment you need, such as a smartphone or laptop computer, make sure your team knows this. If this is the first time you have used this technology it might help to practice beforehand. Ask a family member, friend or support charity to talk you through.

Allow yourself time to prepare. Around 10 minutes before the appointment time find a quiet space with good wifi that is private and where there will be no interruptions. It can be useful to have a list of questions you want to ask.

You may want to have someone with you to take notes and support you. Make sure you can use the speaker on your phone so they can listen and take part if you want them to.

If you want to you can have someone else to take the call and speak for you, but do let the clinic know if you are planning this.

Be prepared for a delay. Clinics can be very busy and timings can change on the day.

You can call the free Ovacome support line on 0800 008 7054 if you want to talk about your appointment or any issue concerning ovarian cancer and your care.

Questions you may want to ask

What are my treatment options?

What is the team's recommendation for my treatment?

What are the risks and benefits of the treatment?

How long will it go on for?

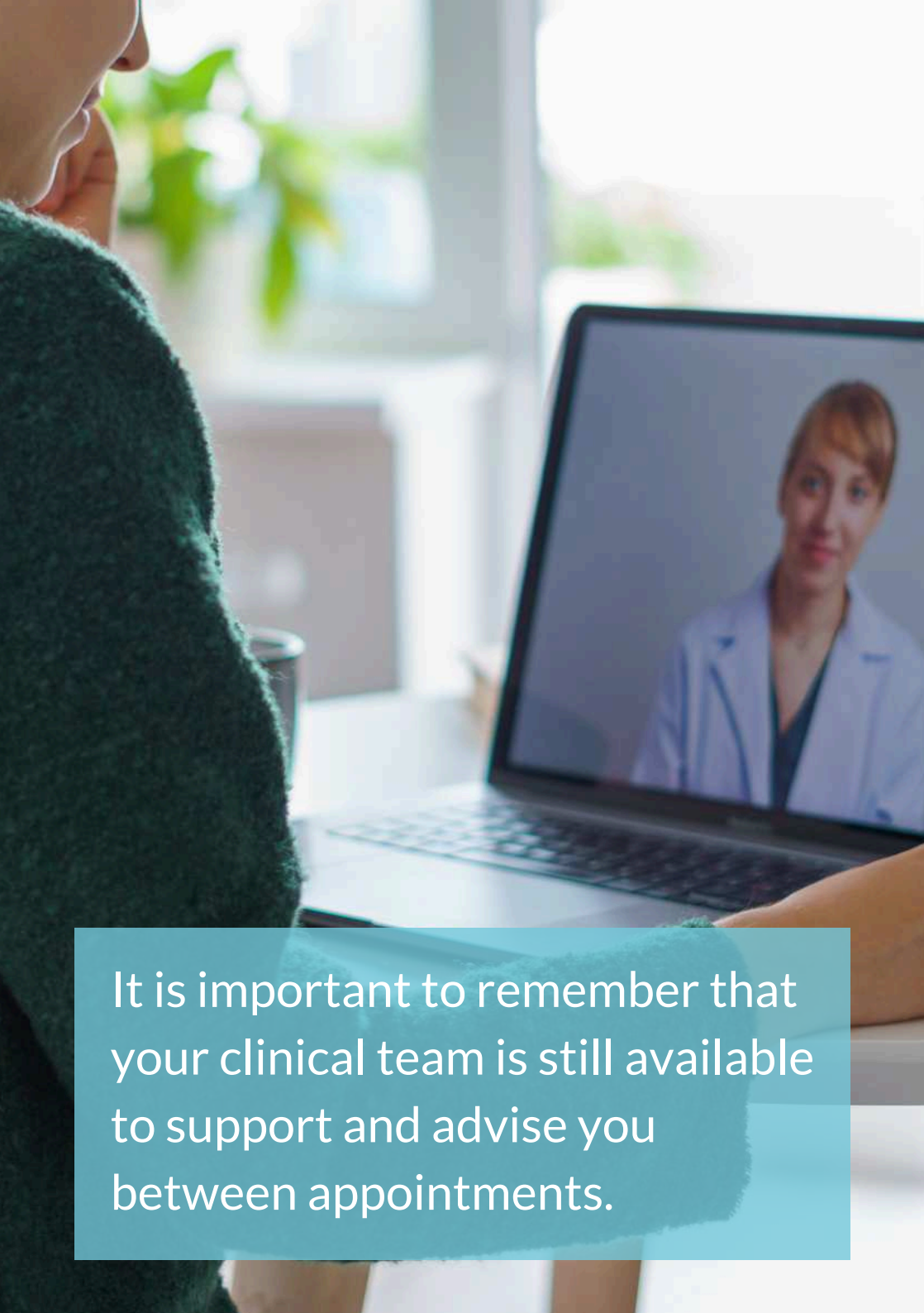
How often will I need to attend hospital?

Will you be able to remove all of the cancer?

What will happen if I don't have treatment?

Can my fertility be preserved?

Will my treatment have side effects? How do I get support to manage these?



It is important to remember that your clinical team is still available to support and advise you between appointments.

Dr Susana Banerjee, Consultant Medical Oncologist at The Royal Marsden NHS Foundation Trust explains:

"We have received positive feedback about telephone and video consultations from patients and families. It has allowed loved ones to be part of important consultations where otherwise they may not have been able to be present for the appointment."

What to expect from clinicians

During a remote consultation, clinical staff should reassure you that they are fully informed of your diagnosis and treatment.

They should say they attend the multi-disciplinary team (MDT) meetings that discuss your treatment and they can provide the support and information you need.

Remember that the meeting is an opportunity for you to get the information you need. The clinician is there to listen to you as well as to speak with you.

Patients say:



“I wasn’t worried. I had written out my questions and was assured that I would get the same amount of time as I would in a face to face meeting. I have found it very efficient and it saves me the stress of travel. I put it on loud speaker so my husband could take part.”

“It does add anxiety to an already anxious situation. There you are sitting waiting but no one can see that. I had to receive news I didn’t want to hear over the phone. It is hard not to see someone’s face and how they are reacting.”

If this is your first hospital appointment

Your first hospital appointment with your oncology team is usually after tests have shown that you may have ovarian cancer. You may be expecting to talk to your consultant to get more details about what will happen next. This is often surgery to confirm the diagnosis and remove as much of the cancer as possible, or chemotherapy to shrink the cancer before you have surgery.

You may be able to see your consultant face to face for this important first appointment. Your consultant might want to see you to assess you. They might need to meet you in person to begin your doctor/patient relationship.

Clinicians say:

"If patients do see the doctor or nurse face to face, then they may have to visit alone so may want to prepare questions with a family member/carer in advance. The healthcare professional may not be able to hold their hand or comfort them physically but they are there to support and treat the patient in the best way possible."

Planning your treatment

You may have further appointments to plan your treatment and these may be conducted remotely by telephone or using the internet. The hospital should let you know how the appointments will be arranged.

You may not be able to speak with your consultant and will instead be meeting with another member of your clinical team. This may be a specialist registrar, a clinical nurse specialist or other clinician who is a member of your multi-disciplinary team that attends the MDT meetings and helps to plan your care and treatment.

It may be someone you have not met before. They will still know about you and your treatment and will be able to discuss this with you on behalf of your consultant.

These appointments are to discuss your treatment which may be surgery followed by chemotherapy. You may be recommended to have some chemotherapy before surgery, or you may be treated using surgery alone or chemotherapy alone.

Chemotherapy and other drug treatments

To plan chemotherapy or other drug treatments, such as Avastin (bevacizumab) or PARP inhibitors such as olaparib and niraparib, you will need to meet your oncologist, or members of the oncology team.

This may be the first treatment following your diagnosis of ovarian cancer (with or without surgery) or it may be treatment when your ovarian cancer has come back.

This may be an appointment that is conducted remotely. Your hospital will tell you if this is the case.

If a face to face meeting is not possible, you should still be able to discuss your treatment, ask questions and make decisions with your oncology team.

Decisions about your treatment will take into account your diagnosis, your individual circumstances and any risks.

Questions you might want to ask

How will I know if the treatment is working?

What side effects should I expect? How do I manage these at home?

How often will I have to visit the hospital?

How long does each chemotherapy session take?

Who do I contact if I have problems when I'm at home?

Will I lose my hair?

Will I have to shield or self- isolate during my treatment?

Patients say:

“If you have physical symptoms it is hard to explain over the phone. In a face to face meeting the clinician can feel your body and see it, you can just point. When the doctor can see your face they can read you and see that you might need a little more time for things to sink in.”

“I am very happy to stay in the comfort of my home. In the end the appointment depends on the relationship you have with your clinicians. I have faith in mine and the telephone consultations have been relaxed.”

Follow-up appointments

When you have finished the main part of your treatment (such as surgery and chemotherapy), you will be invited to follow-up appointments. These may be face to face or remote appointments. At this time you may be taking medication at home.

When you are preparing for your follow-up appointment remember that any blood tests need to be done at least 24 hours before the appointment so that the results are available to be discussed. Your hospital will let you know how they are arranging this.

The questions you ask will depend on your individual circumstances as well as how long you have been having follow-up appointments.

Although hospitals tend to have their own follow-up programmes ovarian cancer patients are commonly followed up for five years beginning with appointments every three months to four months.

Remember that the meeting is an opportunity for you to get the information you need. The clinician is there to listen to you as well as to speak with you.

Questions you might want to ask

Your follow-up appointment gives you the chance to ask questions and get the information you need. Ask for anything you don't completely understand to be fully explained.

Here are some questions that ovarian cancer patients often ask at follow-up appointments. They may help you decide what you need to ask.

How long am I being followed up for?

How will I know if the cancer comes back?

Can I have CA125 tests and CT scans?

Who can I contact when I am at home?

Is my treatment still intended to cure the cancer?

Is my cancer now being managed rather than cured?

If I stop having active anti-cancer treatment can my symptoms be controlled?

I am feeling very anxious, is there support available?

Where can I find more information?

By the end of your appointment you should know the time and date of your next follow-up appointment and whether it is face to face, by phone or online.

You should also be clear about any action you need to take with regard to your cancer and what to do if your condition changes.

If you are using treatment that requires blood pressure monitoring your clinician may suggest that you buy a monitoring device to use at home.

You should be given contact details for the appropriate points of contact for you within the hospital trust.

After the appointment you will be sent a letter recording the consultation and a copy of this will be sent to your GP.

Clinicians say:

"Patients need to be clear and honest about any side effects they are experiencing so the clinician can manage them when they occur. If left these side effects can become severe and more difficult to treat."

Patients say:

"My experience so far has been really positive."

For more information about ovarian cancer treatment, see our other information booklets:

Chemotherapy:

ovacome.org.uk/chemotherapy-booklet

Targeted therapies:

ovacome.org.uk/targeted-therapies-booklet

Treatments for relapsed ovarian cancer:

ovacome.org.uk/treatments-for-relapsed-ovarian-cancer-booklet

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.

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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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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