

Fact sheet 4

What should I ask my doctor? How can I help myself?

We, Ovacome, are a support network for people affected by ovarian cancer in the UK. We provide information and support, raise awareness and put you in touch with others who are suffering from ovarian cancer.

What if my doctor thinks I have ovarian cancer?

You have been referred by your GP to a specialist, as there is a possibility that you have ovarian cancer. The specialist should be a gynaecological oncologist, who is a gynaecologist with extra training and skills in surgery for women who have or may have cancer.

This can be a very stressful time and this fact sheet is designed to help you find any information you need.

What can I expect to happen now?

- You should quickly be referred by your GP to a gynaecological oncologist.
- You should have a firm diagnosis within 31 days of cancer being suspected.
- You should be able to get information about the operation and what to expect. This must include a full explanation about the aim of the surgery and any treatment afterwards, including chemotherapy.

- You should be told about the risks and benefits of treatment, including any possible side effects.
- You must be given time to think about the treatment options and information about support services.

At your appointment

It can be helpful to take someone with you to these appointments for a 'second set of ears'. They may remember information that you have missed. Most consultants are happy for you to take notes and others may even be happy for you to tape the consultation.

At the first appointment, you may want to ask some of the following questions.

- Are you a gynaecological oncologist?
- What treatment is recommended for me?
- Are there any trials I could be involved in?
- If I need surgery, what exactly will be done?
- What are the risks?
- Is there any way to find out if it is cancer before carrying out major surgery?
- Will my fertility be affected? Is there any way I can preserve my fertility?
- Are there any other tests I need beforehand?
- If so, is there any information about these?

- How long will I be in hospital?
- How soon will I be able to get back to normal – before I can drive or have sex?
- Will the surgery cause an early menopause? If so, what can I have to help me cope with any symptoms I may experience?
- When will I get the results of the surgery?
- What will happen following surgery?
- Is there someone I can speak to before going into hospital if I have any questions?
- What treatments are available to help me with any side effects I experience?
- Are there any other ways of helping myself during treatment?
- Will I be able to carry on working?
- Are there any clinical trials that I could be involved in? What would be the advantages and disadvantages of taking part in these?
- How often will I go for follow-up appointments and what will this involve?
- Who will I be able to contact if I have any questions or problems?

You may have other questions and might find it helpful to write a list to take with you.

What if I have ovarian cancer?

If you have ovarian cancer, it is very likely you will be seen by (or have your case reviewed by) an oncologist. This is a specialist who deals with the treatment of cancer.

Members of the medical team involved in your treatment regularly hold a multidisciplinary team (MDT) meeting to discuss the care of their patients.

If you have been diagnosed with ovarian cancer, you may want to ask some of the following questions.

- What treatment is recommended for my particular situation?
- Do I have a choice in my treatment?
- Has my case been reviewed at a MDT meeting?
- What is the aim of my treatment?
- What side effects might I experience and how long are they likely to last?

My treatment has finished. Now what?

It is not unusual to feel that the end of treatment is a bit of an anticlimax. There may be some questions you still want answered. You may want to talk through your feelings with your nurse or phone our support line. You may want to ask the following questions.

- Who can I contact if I have ongoing problems or questions, especially if I am between hospital follow-up appointments?
- How long am I likely to experience side effects from the chemotherapy?
- Should I be looking out for anything?

Is there anything I can do to help myself?

If you have just been told you have cancer, you are likely to feel very frightened, uncertain, alone and angry. This is a very normal and understandable reaction. These feelings may sometimes overwhelm you and stop you from carrying out your normal activities, such as sleeping, eating or working.

If this is happening to you, it is very important to know that you do not have to cope on your own and there is help available. Remember this is not a sign of weakness. This is a very difficult situation and you need all the help you can get.

Communication

Talking to someone about your feelings may be helpful. You may be reassured or pointed in the direction of someone who could help. Talking through some of your worries may stop you feeling so helpless.

Other people's reaction to your news may vary. It might seem that some people avoid you. Others may be over cheerful and not realise how difficult things are for you. Sometimes this may even be those closest to you. This is usually because they don't know what to say and are afraid of saying the wrong thing and upsetting you. They may be feeling frightened and confused themselves.

You could say something simple like 'I feel very angry about what has happened. Can we talk?' or 'Things are very difficult but I don't want to talk about it at the moment'. This gives others some idea of what you would find helpful from them. It is quite normal to want to talk about something one moment and not a few hours later.

Some people might tell you that you have got to stay positive. You might find this helpful, you might not. You should not feel guilty if you are not able to feel positive all the time. It would be very unusual if you did not have some low points.

Support groups

No matter how close your friends and family are, you may find it helpful to talk to someone going through a similar experience. It may be very reassuring to speak to someone 'who has been there'. It can be a chance to talk through some of the worries you might not want to talk to your family about, in case you upset them.

Some support groups are run locally and are made up of people with cancer who meet regularly to talk about their experiences and learn from each other. Some support groups are set up by patients themselves, others by nursing staff.

There are some groups that are just for women with ovarian cancer, but most are for women with gynaecological cancers or for people with a range of cancers. Your clinical nurse specialist (CNS) should know if you have a support group in your area.

Other support groups are run nationally. We offer a range of services including a phone support line, website, newsletter and fact sheets. We also provide a 'fone friends' service, where we can put you in touch with someone in a similar situation. We aim to support sufferers, their families and their friends.

Other organisations such as Cancerbackup, which is now a part of Macmillan Cancer Support (phone 0808 808 2020 or visit www.macmillan.org.uk), may also be able to tell you about local support groups and give you general support about many issues related to cancer.

You may find it helpful to look at the Heathtalk website (www.healthtalkonline.org). Over 40 women who have been treated for ovarian cancer have been interviewed and their experiences can be found here.

Counselling

When life becomes very uncertain and stressful, it may help to talk to someone who is outside of your family, friends and carers. This may happen at different times for different people. Sometimes it may be months or even years later that people want a chance to talk through what has happened. Counsellors are trained to listen and to help you understand your thoughts and feelings.

Your GP or CNS may be able to put you in touch with a counsellor in your area. The Cancer Counselling Trust provides

counselling over the phone for you and your family, friends and carers.

(Phone 020 7704 1137 or visit www.cctrust.org.uk.)

Self-help

Self-help can involve relaxation, complementary treatments, such as reflexology and massage, or changing your diet. You may be keen to make changes straight away. However, there is a lot to cope with when having cancer, so it is important not to feel pressurised into making changes.

You can get more information about complementary therapies by phoning The Penny Brohn Centre on 0845 1232310, or by visiting their website at www.pennybrohncancercare.org.

If you would like more information or you would like to discuss anything to do with ovarian cancer, phone our support line on 0845 371 0554, Monday to Friday from 9am to 4pm. Or, you can visit our website at www.ovacome.org.uk.

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