



Your guide

to cervical cancer

Jo's cervical
cancer trust



Who is this guide for?

You will be reading this guide because you or someone you care about has recently been diagnosed with cervical cancer. Around 3,000 women each year in the UK receive this diagnosis. Finding out you have cancer can be an emotional and scary time. You'll probably have been given lots of information from the hospital, but it can be difficult to digest and remember what you've been told when possibly the only word you'll have heard is 'cancer'.

This booklet has been designed to support the information you've already been given and answer some questions you may have been left with. It is not intended to replace any support and guidance you may need from your medical team and they should be the first port of call to discuss your individual situation.

The booklet offers an overview of what cervical cancer is, the treatments you may be offered and the impact of a diagnosis. We've included stories from other women to try to help you understand your experience and give you direction on where you can get continued help and support.

Content

| | | | |
|---|----|---|----|
| What is cervical cancer and how is it caused? | 3 | The impact of cervical cancer . . . | 11 |
| Being diagnosed | 4 | Finding support for you | 14 |
| Stages of cervical cancer and treatments | 5 | Jo's Cervical Cancer Trust's Support Services | 14 |
| Having a trachelectomy | 7 | How your cancer team can support you. | 17 |
| Having chemoradiotherapy. | 9 | Summary | 18 |
| Having a hysterectomy. | 10 | Further information | 19 |

The cervix

The cervix (or neck of the uterus) is the lower, narrow part of the uterus which joins to the top end of the vagina. The opening of the cervix is called the os. The cervical os allows menstrual blood to flow out from the vagina during menstruation. During pregnancy, the cervical os closes to help keep the unborn baby in the uterus until birth and during labour, the cervix dilates, or widens, to allow the passage of the baby from the uterus to the vagina.

What is cervical cancer and how is it caused?

Our bodies are made up of millions of cells. New cells are constantly being developed to replace older cells when they die or become damaged. This happens in a controlled way so if you cut your hand, for example, your body will send a message for new skin cells to be produced until the cut is healed and then the message stops.

Most types of cancer begin when normal cells change and grow uncontrollably. In cervical cancer the cells on the surface of the cervix change and grow forming a mass; also known as a tumour. Tumours can be malignant or benign. A malignant tumour is also called cancer and it is malignant because it can spread to other parts of the

body. A benign tumour means the tumour is not cancerous and will usually not spread.

Cells become abnormal for many reasons, but the majority of cervical cancers are caused by infection with certain types of the human papillomavirus (HPV). HPV is a common virus that is contracted through any kind of skin-to-skin contact, including genital-to-genital contact, anal, vaginal and oral sex. It is very common, four out of five (80%) of all sexually active people will come into contact with the virus at some point in their lives and for most people it will not cause any harm. HPV can damage the cells in the cervix causing changes to their structure. Usually the body can fix this on its own, however, persistent high risk HPV can lead to changes in the cells of the cervix (called cervical abnormalities) and in some cases these changes can turn into cancer. Cervical cancer usually develops from abnormal cells that have been present for many years.

There are other factors that increase the risk of developing cervical cancer. The most common include smoking, a weakened immune system (such as women who have HIV or have had an organ transplantation) and taking the contraceptive pill for more than five years. These factors are thought to be linked with how your body fights off the HPV infection.

Being diagnosed

Kirsty's story (43, Staffordshire)



“ I remember the day I sat in hospital waiting for my appointment; there were three other women waiting in the room, each one of them were greeted by a young looking registrar, I was greeted by a registrar in a grey suit and grey hair. You could tell he was one of the more senior doctors and it hit me that the news I was about to be told wasn't going to be good. He came over with a nurse and pulled the curtain around my bed and sat down on the end of my bed. “It's cancer”, he said. They would have to do an operation and scans to see how far the cancer had spread.

I was in absolute shock and I didn't even look at him. I was looking down at the floor and I remember that he

tried to get me to look at him but I just couldn't... That's really the last thing I remember. All the other things he explained to me afterwards went in one ear and out the other. I was assigned a Macmillan nurse that day but all I wanted was to ask her if I would lose my beautiful blond hair. ”

Kirsty lost her hair, which only occurs with the intensive type of chemotherapy she received. However, the majority of cervical cancer patients who have chemoradiotherapy do not lose their hair. She has finished treatment and is currently cancer free. Kirsty has now started a new job as Cabin Crew, enjoys being mum to her two sons (and is in love with her new hair which has grown back curly).

Stages of cervical cancer and treatments

All cancers are **named, graded** and **staged**. For this to happen you will have had some investigations, including biopsies and scans (MRI, CT or ultrasound). Your medical team will provide you with information on what happens during these scans. The results and your case will be discussed in a multidisciplinary team (MDT) meeting to decide what treatment options are available, this is very important because your medical team needs to ensure they get the best treatment option for your cancer.

Naming the cancer

Cancer is named by the cells in which it started.

The most common cervical cancers are:

- Squamous cell - eight out of 10 (80%) cervical cancers are diagnosed as squamous cell. Squamous cell cancers are composed of the flat cells that cover the surface of the cervix and often begin where the outer surface joins with the cervical canal.
- Adenocarcinoma – more than one in 10 cervical cancers are diagnosed as adenocarcinoma (15 - 20%). The cancer develops in the glandular cells which line the cervical canal. This type of cancer can be more difficult to detect with cervical screening tests because it develops within the cervical canal.

Less common types include neuroendocrine tumours, clear cell carcinoma or small/large cell.

Grading the cancer

Tumour **grading** helps the doctor predict how cells may behave. Cells are graded from 1 to 3 depending on how different they look compared to normal cells under the microscope. Grade 1 tumours tend to be slow growing and don't look as abnormal as higher grade tumours.

Staging the cancer

The **stage** describes where the cancer is, if or where it has spread and if it is affecting other parts of the body. The presence of cancer in the lymph nodes does not alter the way cervical cancer is staged, but it may change the way the cancer is treated.

Stage 1

Cancer is only in the cervix. If it can be seen only under the microscope it is stage **1A**, larger tumours are stage **1B**.

Stage 2

Cancer has started to spread to nearby tissues. To the top part of the vagina (**2A**) or to the tissues around the cervix (parametria) (**2B**)

Stage 3

Cancer has spread to the lower vagina (3A) and/or the tissues at the side of the pelvic wall, it may also press on the ureter (the tube that takes the urine from the kidney to the bladder) causing a blockage (3B).

Stage 4

Cancer has spread to the bladder and/or bowel (4A) or to distant organs (e.g. liver, lung or bone) (4B).

Treatment

Treatment depends on several factors. The type and stage of cancer, potential side effects, your general health and your preferences all need to be taken into consideration. Your team will consult with you regarding your treatment and you can also talk to your team about all the treatment options available. Surgery or radiotherapy are equally effective at treating early stage cervical cancer. The aim of any treatment is to give you the best possible outcomes with the least side effects.

Surgery

- **Large loop excision of the transformation zone (LLETZ) or cone biopsy** - the area containing the cancer cells is removed leaving a clear margin where cancer cells are not present
- **Radical trachelectomy** - the cervix, the tissues surrounding the cervix (parametrium) and the top of the vagina are removed. The womb is left behind to try to maintain fertility
- **Hysterectomy** - the uterus (womb), including the cervix, is removed
- **Radical hysterectomy** - as with hysterectomy plus the parametrium and top of the vagina are also removed. Ovaries are not routinely removed as part of surgery for cervical cancer
- **Pelvic lymphadenectomy** - a sample of lymph nodes are taken to check the cancer has not spread into the lymph node system
- **Exenteration surgery** - removal of the uterus, vagina, lower colon, rectum and/or bladder. This is only offered after radiotherapy if your cancer has come back.

Hysterectomy and removal of lymph nodes can be done laparoscopically (using keyhole surgery) which helps to have a quicker recovery and less scarring.



Having a trachelectomy

Kate's story (30, Leicestershire)

“ The day I was diagnosed with high grade cell changes I sobbed because I thought I would lose the chance to have my own children. I went on to be diagnosed with stage 1b cervical cancer but luckily I soon found out that I could have a trachelectomy operation which meant my fertility would hopefully be preserved; my husband and I felt such a relief.

Eighteen months later I fell pregnant which was fantastic. I was closely monitored throughout my pregnancy and received progesterone. I was fortunate enough for the pregnancy to be quite uncomplicated and I tried to enjoy it as much as possible despite the worry at the very back of my mind. Our son Freddy was delivered at 34 weeks and 5 days by C-section. Freddy is doing fantastically well and we couldn't be happier. We feel so lucky that what started with a cancer diagnosis ended in us becoming our own little family. ”

A combination of chemotherapy and radiotherapy is used in larger tumours or those where the cancer has spread to cells close to the cervix. It is better to use chemotherapy and radiotherapy when the tumour shape means surgery could cause damage to nearby organs. Radiation and chemotherapy can also be used after surgery when the patient is at a high risk for the cancer coming back or if the cancer has spread.

Radiotherapy

Radiotherapy uses radiation to destroy cancer cells, it can be given externally and internally. Chemoradiotherapy is when chemotherapy is given alongside radiotherapy.

- External beam radiotherapy is usually given daily for about five weeks as an out-patient
- Internal radiotherapy (brachytherapy) requires hospital admission for a few days. This will depend on how your hospital delivers the treatment.

Chemotherapy

Chemotherapy uses drugs, normally through a drip, to destroy cancer cells; it stops them growing and dividing. It is given either with radiotherapy to increase the effectiveness of the radiation, or alone to help control cancer in advanced or recurrent disease. In some cases other drugs might be used with chemotherapy to stop the growth of new blood vessels to the tumour, these are known as targeted therapies.

Having a hysterectomy

Laura's story (43, Manchester)

“After an abnormal smear and LLETZ treatment I was told my biopsy showed I had cervical cancer and after further scans I was told the cancer was stage 1b1 and I needed a hysterectomy.

I was quite nervous about being put to sleep and going in for such a big surgery but I had to go through it to get better.

When I woke up from my surgery, I was wheeled out of ICU to my own room on the ward where I would spend the next few days recovering. I had the strangest most uncomfortable pain I had ever experienced, turns out that was trapped wind and as soon as that was gone so was the pain.

I had to stay in hospital for five nights and even though I would have loved to be home those days in hospital

were crucial; recovery is just so much quicker when you're in hospital and can do nothing, with every day of rest I could feel the pain gradually getting less. The main reason I was kept for a full five nights was so that my bladder could fully recover before they removed the catheter.

A week after being discharged from hospital I had another check up and went in to discuss the results. I was told they were able to remove all of the cancer and there was no cancer in the lymph nodes so no further treatment was needed. I was so relieved. ”

Laura stayed in hospital for five days but each hospital has its own procedure after hysterectomy surgery. Typically most will now encourage you to return home as soon as possible. Your health care team will advise you on how long you need to stay in hospital for.

Having chemoradiotherapy

Catherine's story (36, West Sussex)

“ When I was diagnosed with cervical cancer I was told it was early stage, 1b. I went in for an operation to double check that my scans were correct in saying that it hadn't spread and to also remove my lymph nodes. Unfortunately, my lymph nodes came back with some positive signs of cancer which meant I had to have six weeks of radiotherapy and chemotherapy along with three rounds of brachytherapy and I was informed that I would lose my fertility as the radiation would destroy the uterus (womb). I had surgery, prior to starting chemoradiation, to move my ovaries up into my back to hopefully preserve their function so I wouldn't go through early menopause.

Once a week and for eight hours straight I would have chemotherapy which can be quite tiring and boring. For radiotherapy I went into hospital every day. I was lucky in that I didn't suffer too badly with side effects from the chemo radiotherapy; I was incredibly fatigued and didn't move much for six weeks. I advise anyone about to go through the same to just listen to your body and not push yourself after treatment, you need time to recover but set yourself little goals you can slowly work towards.

I received the all-clear in January 2013. I went from 3-monthly to 4-monthly checkups with my surgeon and oncologist and I am happy to say all is looking good. ”

The impact of cervical cancer

Being diagnosed with and treated for cervical cancer can have both an emotional and physical impact on you. There is no right way to feel or to predict how you will react. In these pages we look at what might happen **NOT** what will happen. These are things you may want to consider when discussing your treatment options.

Emotional impact

It can be difficult to cope with your emotions; they may include numbness, shock, anger, guilt, disbelief and sadness. You may feel out of control, withdrawn, isolated, and fear for both now and the future. You probably feel like you're on a rollercoaster and can't get off. It's often harder to deal with the unknown than the known, so having the right amount of information and support may help you feel more in control. Don't be afraid to ask for more if you need it.

After treatment you may feel relieved but also nervous about your future; it's normal to feel worried and anxious that the cancer may come back. Knowing the risks and what options will be available if this happens can help you cope with your fears.

Physical changes

Almost all treatments will have side effects. Some may only last a short time or be temporary, others may be permanent.

Long-term complications following surgery are unusual. Occasionally some women have problems with their bowel or bladder but this is rare. You may have scars depending on the type of surgery you've had; these should fade with time.

Both surgery to remove lymph nodes and radiotherapy increase your risk of developing lymphoedema. If this happens your leg(s) and/or pubic area will be swollen with fluid that can't drain away on its own. There are things you can do to reduce the risk of this happening and to manage it if it does.

You will probably be tired and fatigued, which should pass following surgery. However, if you've had radiotherapy or chemotherapy some people find that this fatigue can linger.

Other possible side effects from radiotherapy include changes in how your bowels and/or bladder work; this can be temporary and may go away soon after treatment. In some it can continue or develop after treatment; this is known as 'late effects'. The tissues in your vagina can be affected by radiotherapy

and you may need to use dilators to prevent problems in the future. Dilation therapy can help to maintain vaginal function, it involves the use of a dilator, a cone shaped object that you put into your vagina. Not every woman will want to or need to use this type of therapy, your medical team will help you manage these decisions. It is important to remember that your medical team are there to support you through any side effects that you may experience after treatment.

Some treatments for cervical cancer will mean that you will not be able to become pregnant naturally in the future. For many women infertility can be devastating and really difficult to come to terms with. Sometimes it's later that the sadness and pain hit when life seems to be getting back to normal after your treatment. Support is available and it is important you explore your options if this is an issue for you.

Having radiotherapy may mean that you will more than likely go through the menopause. Having your ovaries removed means that if you haven't already, you will go through the menopause. Hot flushes, dry skin, mood changes and changes in your sex life are all things that might be experienced. Various options will be available including hormone replacement therapy and you can discuss this with your medical team.

You may find that your sex life changes, this can be due to emotional and psychological factors, including how you feel about yourself or your body image, and how your relationships are with the people in your life and if they've changed. Physical changes such as the menopause, shortening of your vagina from surgery or radiotherapy changing the tissues in your vagina may also have an impact.

With all these side effects things can be done to help so make sure you discuss changes with your cancer team, do not suffer in silence because you are embarrassed or afraid to ask, they are there to help.

Impact of diagnosis

Yoshie's story (51, North Yorkshire)



“ I was diagnosed with stage 1b1 cervical cancer after a routine smear test. I had to have chemotherapy and radiotherapy. Treatment was gruelling and made me feel very sick and exhausted and I finished it in 2014 having successfully beaten the cancer. I still have side effects from the treatment such as changes in my bowel movement. These changes meant that I had to change my diet.

My bowel is basically less able to absorb the acid that is released when having fat in the food, which gives you diarrhoea. I saw a specialist for this problem and they prescribed me medication and suggested a special diet for me that helps me cope with

these side effects. My special diet is a low fat diet, and I try to eat as little as 40g of fat a day. I was given the dietary information by the hospital dietician, and there are a lot of websites where you can find the information about the amount of fat in food. Also, most of all food at a supermarket show how much fat it contains. The most obvious things I had to stop eating are cakes, biscuits, chocolate, ice cream, Thai curry, Indian curry, anything that contains fat. Luckily, Japanese food is naturally low in fat, so it is not a big problem for me. With the medicine and the diet, I have managed to control my bowel conditions and since then it has really improved which is great for my quality of life.”

Finding support for you

Knowing what help is available can be confusing and what works for one person won't be right for another. Some of you will just want to get on with your lives and not feel the need for anything else whilst others will want to access as much support and help as possible.

Your health care professional, the team here at Jo's Cervical Cancer Trust and other voluntary organisations are all available to enable you get the information, support and help that you and your family need now at diagnosis, and in the future. You may want to know about your cancer and treatments, the long-term effects of your treatment and how you can reduce the risks or manage them, where to get support and help with financial and work issues, or maybe just to talk to someone else who knows what it's like.



Jo's Cervical Cancer Trust Support Services

Support groups

Our support groups offer you the opportunity to meet other women who are living with or beyond cervical cancer. They are led by trained volunteers who have personal or professional experience of cervical cancer or cervical abnormalities.

The groups meet locally and you'll be able to get information, make friends and support each other through the challenges cervical cancer brings. It's a safe place to talk and express how you feel knowing that others may have similar experiences and feelings. It might help you to cope and move forward.

“At times when I was going through my own journey with cervical cancer, I felt alone and scared. Having a local support group to go to, knowing you're not alone, really helps in difficult times.”

Maria, Brighton support group leader

Online forum

The forum can be used by anyone affected by cervical cancer including partners, family and friends, and supporters. It is a space to join online discussions with other forum members and there are guidelines to ensure a safe and supported environment so you can post freely about your condition.

There are two private forums; one for partners of women with cervical cancer and the other specifically for those who are living with or beyond advanced cervical cancer only (stage 4). If you are affected by pelvic exenteration/pelvic clearance surgery, ongoing chemotherapy/ trial drugs, an incurable diagnosis, or are living with or beyond an advanced stage cervical cancer and are seeking friendship and support from others in a similar situation, you can discuss your situation openly here without fear of upsetting those in our other categories.



“ The more I'm on the forum, the more I think it's an amazing place. Cancer can be very isolating emotionally. Having somewhere like this makes it a bit less so, and that's invaluable. ”

Annabel, forum user

Ask The Expert

Our Ask the Expert service has a panel of medical experts who volunteer their time to help. You can submit your question online and we will pass it on to the appropriate expert to answer your question. The service is totally confidential.

“ The expert panel reassured me about what I should have been told and what I should expect. They were very clear and easy to understand, and it's good to know that they are there should I need them again. ”

Isobel, Ask The Expert user



Helpline

Sometimes you want to talk to someone who understands what you are going through or have a question you want answering. The helpline is manned by volunteers who have had personal or professional experience; they are trained in listening, support and giving information and also know what it is like to be on your side of the call. It is free to call on 0808 802 8000 opening times are on the website.

“ Just needed to pass on my thanks, I have just spoken with a lovely lady on the Helpline, she has made me feel more confident and calm about the whole process and gave me some great information. Thank you, I wouldn't have known where else to go! ”

Tracie, Helpline caller

Let's Meet – information days

Every year we organise an information day for women from all over the country to get together to meet other women in similar situations. You can come alone or bring a partner or friend with you. It is a good opportunity for your partner to meet other partners, share their experiences and have some support.

Throughout the day there are several workshops on life after cancer for you to choose from and you have lots of opportunity to talk to other people attending.

“ Thank you so much for a lovely day. Everything was so well organised and you were all so welcoming, would definitely recommend it. Please pass on my thanks to the team. ”

Claire, Let's Meet attendee





How your cancer team can support you

Helen's story (Macmillan Gynaecology Cancer Nurse Specialist, Manchester)

“ As a Cancer Nurse Specialist at the Christie Hospital, I support all gynae patients who are referred here for surgery or radiotherapy treatment. I am the first port of call after diagnosis, and I am often called upon to be with women when they are told they have cancer.

Once diagnosed, Cancer Nurse Specialists have a pivotal role supporting women as they commence their journey through treatment. We ensure that their journey runs as smoothly as possible and are here to answer any questions or worries they might have. This includes before treatment commences chasing up appointments and alleviating fears, as well as making sure everything is adequate during treatment such as pain relief.

Once a patient is at home we encourage them to call with any

question, no matter how small or trivial it may seem. A cervical cancer diagnosis can be overwhelming and I know that many patients only take in 50% of the information being given to them at the time. Some might have practical or emotional questions and we encourage them to seek support. We can signpost to services like counselling, complimentary therapies and give information on financial help. Some patients benefit from attending a local day hospice in their area. These can offer wonderful support locally and enable cancer patients, no matter what stage of diagnosis, an opportunity to meet others, make friends and take part in activities.

I thoroughly enjoy meeting patients and their families, helping them through their cancer journey. No one day, or phone call is the same and some patients stay in touch long after treatment finishes. ”

Summary

We hope that the information in this booklet has helped you make sense of where you are and what you might expect. Please remember it is not meant to replace the information given to you from your health care team. Whilst we have covered the 'norm' of how cervical cancer is treated and some of the feelings and experiences that are commonly reported, we recognise you are an individual and your needs will reflect this.

Please use the links and sources of other information and support to ensure your needs are met. Don't be frightened to ask for help either locally from your medical team who provide your treatment or from us here at Jo's Cervical Cancer Trust.

If you are reading this booklet because someone you care about has been diagnosed with cervical cancer, remember that support is available for you too. Having an understanding of what is happening can help you to talk with each other and be prepared for the next steps.

Make your notes here...

For further information:

For more on cervical cancer, staging, treatment and impact:

jostrust.org.uk/cervical-cancer

Finding support for you

Jo's Cervical Cancer Trust:

jostrust.org.uk/support - 0808 802 8000

Macmillan Cancer Support:

macmillan.org.uk - 0808 808 0000

Marie Curie:

mariecurie.org.uk - 0800 090 2309

Pelvic Radiation Disease Association (PRDA):

prda.org.uk - 01372 744338

The Lymphoedema Support Network:

lymphoedema.org - 020 7351 4480

Finding support for partners

Jo's Cervical Cancer Trust:

jostrust.org.uk/being-a-partner - 0808 802 8000

We also have a private online forum for partners supporting a woman with cervical cancer.

Join here:

jostrust.org.uk/join-private-forum-categories



The information included in this publication was correct at the time of going to press. We plan to review publications after two years, however updates may happen more frequently. For updates or for the latest information, visit jostrust.org.uk.

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Call our helpline:

0808 802 8000

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