Your guide to cervical cancer

About this guide

If you or someone you care about has been diagnosed with cervical cancer, this booklet is for you. We developed it with people affected by cervical cancer to offer an overview of what cervical cancer is, its treatments, and the impact of a diagnosis.

We've included stories from others affected. These stories may help you understand your experience and offer ideas of where to get continued help and support. We hope it answers any questions you have and reminds you that we are here for you.

This information does not replace the advice and support from your healthcare team. They know your full medical history and can discuss your situation.

"After I was diagnosed, I weirdly felt relief and then curiosity at how it was going to be dealt with. At first, I only told my immediate family and very close friends. My line manager asked for permission to tell my team, as I was going to be off work for some time. Once they knew, I decided to put a message on social media, as I was getting some questions and losing track of who knew and who didn't.

The actual diagnosis didn't sink in for ages. In fact, 2 and a half years later I still feel it hasn't sunk in fully. Initially, I got support from the Jo's Cervical Cancer Trust forum. It was there at 3am when I was freaking out – there was always some lovely lady online giving advice and support. After I had my surgery and was recovering, I accessed counselling through a local cancer charity.

For anyone who's been diagnosed with cervical cancer, I would say find someone to talk to and never bottle it all up. Don't try to be superwoman – be kind to yourself and be selfish. If dishes in the sink are left until the next day, the world won't come to an end! Just work on finding whatever helps give you peace."

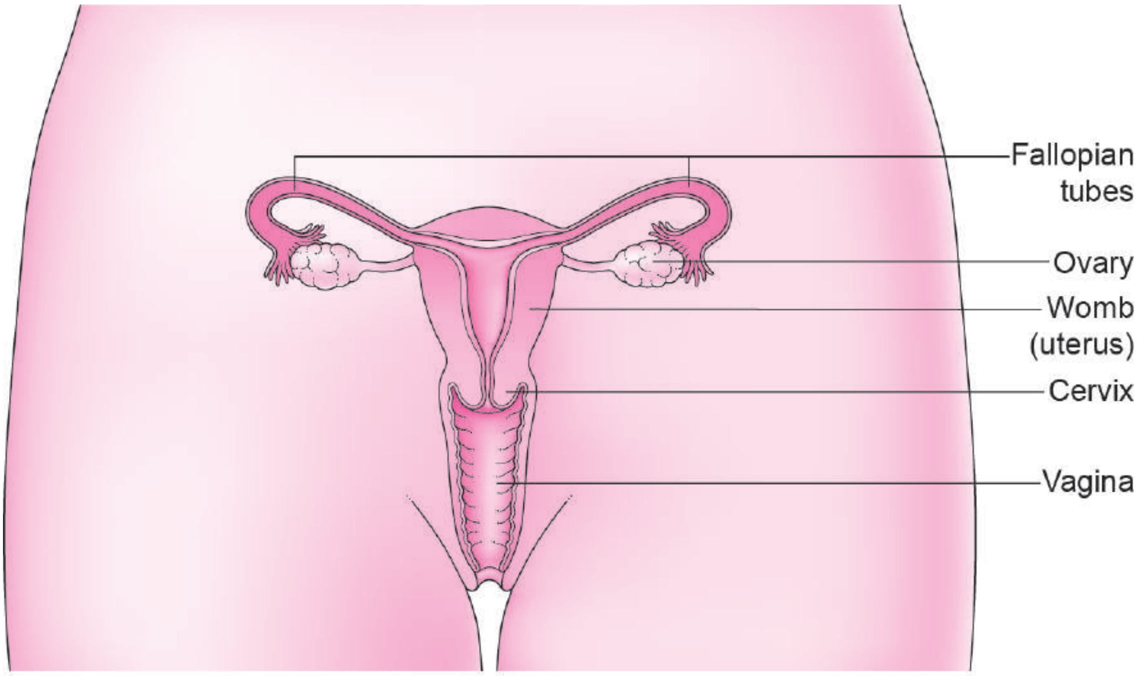
Sharon, diagnosed with stage 1b1 cervical cancer at age 46.

About cervical cancer

The cervix is the lower part of the womb (uterus). It joins to the top of the vagina.

If you looked up at the cervix, it is round with a small hole in the middle. This hole is called the os. It lets blood out of the vagina during periods, closes to keep the baby in the womb during pregnancy, and dilates when the baby is ready to be born.

The female reproductive system



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How does cancer develop?

Your body is made up of lots of small parts called cells. You are always making new cells to replace old ones when they die or are hurt. This happens in a controlled way. For example, if you cut your hand, your body sends a message that new skin cells should be made until the cut is healed.

Most cancers start when cells change and grow uncontrollably. Eventually, this forms a lump (a tumour). Tumours can be malignant or benign:

- A malignant tumour is also called cancer and can spread.
- A benign tumour is not cancerous and does not usually spread.

How does cervical cancer develop?

Most cervical cancers (99.7%) are caused by high-risk human papillomavirus (HPV). HPV is a common virus that 4 out of 5 (80%) of us will have at some point in our lives.

There are over 200 types of HPV. Most don't cause any problems, but about 13 types are linked to cancer – these are called high-risk HPV. It can be passed on through skin-to-skin contact in the genital area, including vaginal, anal and oral sex, touching in the genital area, and sharing sex toys.

Your immune system usually gets rid of HPV within 2 years. But if high-risk HPV stays in your body, it may cause the cells of the cervix to change. Cell changes are not cancer, but some may develop into cervical cancer if not monitored or treated. Read more about HPV at **jostrust.org.uk/HPV**

Other risk factors

There are other factors that increase the risk of developing cervical cancer, including smoking, and having an autoimmune condition like HIV. These affect how well your immune system can get rid of HPV.

Types of cervical cancer

There are different types of cervical cancer. The 2 most common types are:

- **Squamous cell cervical cancer.** Between 7 and 8 out of 10 (70% to 80%) cervical cancers are squamous cell. These are the flat cells that cover the outside surface of the cervix (ectocervix).
- **Adenocarcinoma.** More than 1 in 10 (more than 10%) cervical cancers are adenocarcinomas. This type of cancer affects the cells that line the cervical canal (glandular cells).

Less common types include mixed adenosquamous cancers, neuroendocrine tumours, clear cell cancers, and small or large cell cancers.

Staging cervical cancer

The cancer stage helps decide the treatment and longer-term outcome. You will have some tests and scans to find the stage out, including:

- a biopsy, that takes a small piece of tissue from the tumour or affected area
- magnetic resonance imaging (MRI) scan, that creates a picture of your body using radio waves
- computerised tomography (CT) scan, that uses x-rays to take detailed pictures of the inside of your body
- ultrasound scan, that uses sound waves to build up a picture of the inside of your body
- positron emission tomography (PET)/CT scan, that looks at whether the cancer has spread.

A multidisciplinary team (MDT) is a group of cancer specialists. Once your results are back, the MDT look at them to help decide what treatment to recommend and the next steps of your care.

Your key worker (usually your cancer nurse specialist or CNS) will discuss all steps with you. The MDT will also talk with you about the options, so you can decide what is best for you.

Staging results

The stage of the cancer goes from 1 to 4. There are also sub-stages – a, b or c and 1, 2 or 3. For example, you may have stage 1a1 cancer. The stage describes the size of the cancer and if it has spread to other parts of the body.

You may also hear your doctor talk about the grade of the cancer. It goes from 1 to 3 and predicts how quickly the cancer may develop. You can read more about staging and grading cervical cancer at **jostrust.org.uk/staging**

Treating cervical cancer

Your treatment options will depend on the type and stage of the cancer, your general health, the potential side effects, and your preferences.

You need to feel comfortable with any treatment you have. There may be certain things that are important to you, like still being able to have children.Your healthcare team will talk through any options with you, so you are involved and can make the decision that is right for you.

Surgery

Surgery is the most common treatment for early stage cervical cancer. Your healthcare team can explain more about the surgeries mentioned here and any others you may have.

LLETZ or cone biopsy

Large loop excision of the transformation zone (LLETZ) and cone biopsy both remove the area of the cervix where cancer cells are present. You can have both surgeries under local anaesthetic and won't need to stay in the hospital overnight.

"My consultant gave me various treatment options. I was 25 and mum to a 6-month-old baby, so I wanted to keep my fertility options open if it was possible.

There was a chance I could be considered for a trachelectomy, so I was referred to a specialist hospital and had one about 3 months later. I was extremely nervous, but the staff were incredible. I feel so lucky to have had the surgery and care I did.

Afterwards, I did feel different. Your cervix is removed, so that is a big deal and it hasn't been easy – but with time and some help I am getting there. I am completely happy that I had a trachelectomy and can be around for my son and, perhaps in the future, be lucky enough to have another baby.

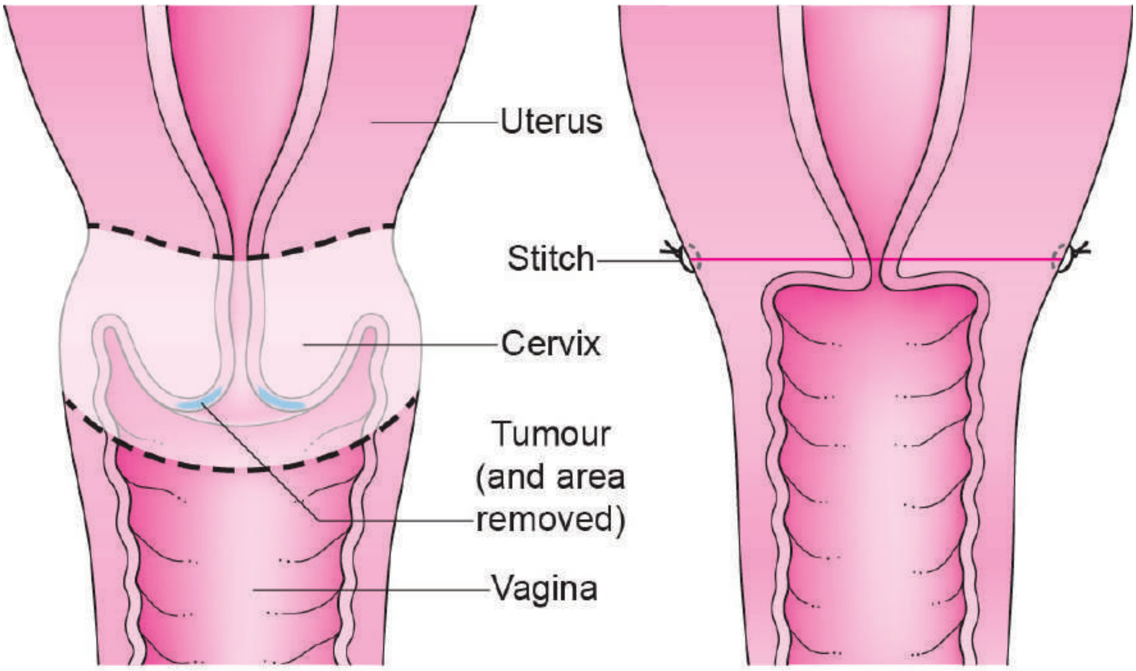
My husband and little boy have been my absolute rocks. I'm having counselling and therapies like reflexology, which has been a big help. My advice would be to give yourself time to heal and don't overdo it. I think the effects of cancer will always be with me, but I am dealing with that and learning there is life after cancer."

Chloe, diagnosed with stage 1b1 cervical cancer at age 25.

Trachelectomy

A trachelectomy removes the cervix, the tissues (parametrium) around the cervix and the top of the vagina. It leaves the womb to try to preserve fertility.

A trachelectomy (before and after)

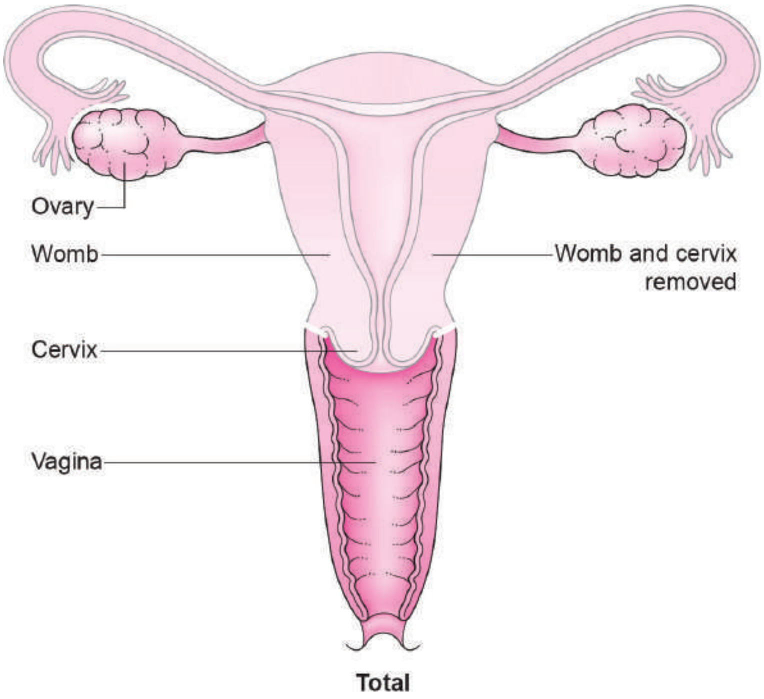


Hysterectomy

There are different types of hysterectomy:

- **Total or simple hysterectomy.** The womb and the cervix are removed. The ovaries are not removed, unless you are close to or have already gone through menopause.
- **Radical hysterectomy.** The womb, cervix, tissues around the cervix, and the top of the vagina are removed. The ovaries are not removed, unless you are close to or have already gone through menopause.

A total hysterectomy



Pelvic lymphadenectomy

This is when a sample of lymph nodes are taken to check the cancer has not spread into the lymphatic system. If you are having another surgery, such as a hysterectomy, this is usually done at the same time.

Pelvic exenteration

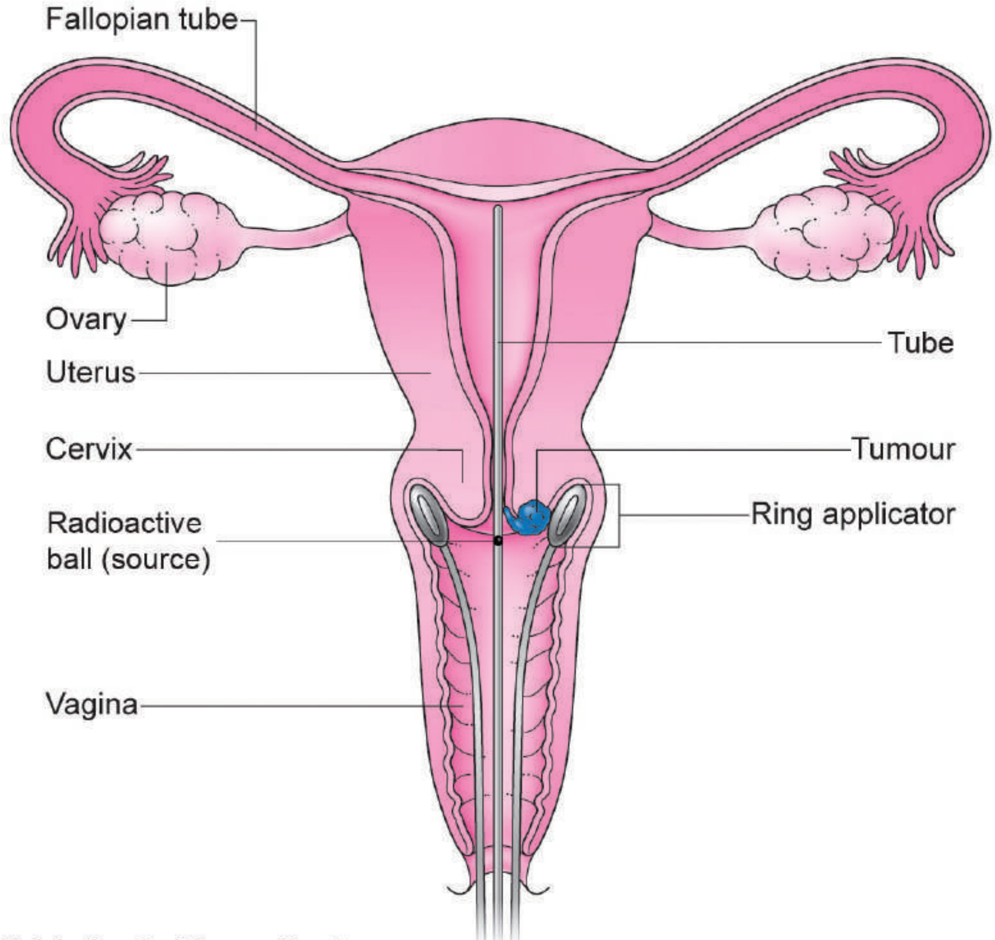
This treatment removes the womb, vagina, lower colon, and the rectum, bladder, or both. It is only offered after radiotherapy (see page 10) if your cancer has come back.

Radiotherapy

Radiotherapy uses radiation to destroy cancer cells, it can be given externally and internally. It takes about 30 minutes each day.

- External beam radiotherapy is usually given daily for about five weeks as an out-patient
- Internal radiotherapy (brachytherapy) usually requires hospital admission for a few days. Sometimes it is offered as an outpatient treatment over 3 sessions. This will depend on how your hospital delivers the treatment.

Brachytherapy



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Chemotherapy

Chemotherapy uses drugs to destroy cancer cells. It is usually given through a drip attached to your arm and takes a few hours for each drug.

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.

Chemoradiotherapy

Chemoradiotherapy is when low-dose chemotherapy is given alongside radiotherapy. It is usually used in larger tumours or if the cancer spreads to cells close to the cervix.

Chemoradiotherapy may be used when the tumour shape means surgery could cause damage to nearby organs.

It may also be used after surgery, if there is a high risk that the cancer may come back or if the cancer has spread.

"About a month after my diagnosis, I had a laparoscopic radical hysterectomy. I didn't have too much time to think about the emotional side effects that I might have and I wasn't really expecting many physical side effects afterwards.

Physically, I recovered quickly and was back to work after a month, but I was struggling quite a lot emotionally. I am still struggling to come to terms with the fact I've lost my fertility at a young age and before I was able to meet anyone I saw myself ever wanting children with. I think this is something I will grieve for a long time, especially seeing a lot of people my age starting families.

My friends and family have all been incredibly supportive. I saw an NHS therapist who told me I was suffering from PTSD, as well as increased anxiety and depression, which I've suffered from for a long time. She taught me some useful techniques for dealing with my emotions. I also found it very helpful reading the posts on the Jo's Forum from women who have been through cervical cancer. It's not always something I want to talk about, so it's reassuring being able to read people's stories and advice in a more anonymous way."

Ellie, diagnosed with stage 1b1 cervical cancer at age 26.

Follow-up after treatment

Once you have finished treatment, you will have follow-up appointments with your healthcare team. This is usually in person, but you may be offered a telephone appointment to discuss your continuing care.

At a follow-up appointment, you may be asked some questions about your health or offered a pelvic examination. If you need other tests or scans, your healthcare team will tell you.

Depending on your hospital's policy, these follow-up appointments may continue for 3 years or longer.

If you have problems or are worried about anything, remember you don't have to wait for your follow-up appointment – contact your healthcare team straight away.

Some people feel isolated after treatment, because the amount of contact they had during treatment has ended. But your keyworker or CNS can talk through these feelings with you and work out how best to manage them.

If cervical cancer comes back

Sometimes cervical cancer comes back after treatment. If it does come back, it can be even harder to cope with, especially when you have put time and energy into getting better.

Remember, the support you had before is still there for you. Your healthcare team can discuss treatment and care options with you.

"Before I started chemoradiotherapy, my doctor explained the possible side effects. I found the radiotherapy quite easy, but the chemo was much tougher. I was very ill for the first few sessions and tried different anti-sickness tablets until we found one that worked.

I wanted to be strong for my 2-year-old son, but when I was on my own I would cry and wonder, 'Why me?'. I was helped enormously by my friends and family. They visited a lot while I was recovering, and my mum would look after my son if I needed to clear my head.

After radiotherapy, I went into early menopause, which has had a massive impact on my life. I can't conceive another child or use the eggs I had frozen, which I've found very difficult to deal with. I find anti-depressants helpful, as well as alternative therapies, like holistic healing and reflexology therapies.

I would say accept help from family and friends, and keep talking. Remember, life does not end with this diagnosis."

Roisin (pictured with partner), diagnosed with stage 3 cervical cancer at age 25.

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 or wrong way to feel or react.

In this section, we talk about some of the ways you may feel or things that might happen. It may give you more ideas of what to discuss with your healthcare team when looking at treatment options.

Emotional impact

Coping with a cervical cancer diagnosis and treatment can be hard. You may have lots of different emotions, from numbness, shock, or fear, to anger, guilt, or sadness. It may leave you feeling out of control of your life and future.

It's often more difficult to deal with the unknown, so having the right amount of information and support may help you feel more in control. Your CNS or keyworker will share their contact details, so you can talk through any concerns or questions when you have them.

Remember, if you need more help, don't be afraid to ask for it. You are not needlessly taking up anyone's time – that is what your CNS or keyworker is there for. Your healthcare team want to support with any concerns or questions, no matter how big or small.

After treatment, you may feel relieved that it's over but also nervous about the future. It's common to feel anxious that the cancer may come back. Knowing the risks and what options are available if this happens can help you cope with any fears.

Read more about cervical cancer and mental health at **jostrust.org.uk/information/living-with-cervical-cancer/mental-health**

> "Cancer will take your mind on a dark journey, but remember there is light at the end of the tunnel. Ask as many questions as possible, so you are always in the know. Let your family and friends be your support system, but also find others who are going through the same thing."
>
> Lisa, diagnosed with stage 2b cervical cancer in 2013

Physical changes

Almost all treatments will have side effects. Some may last a short time, others for a longer time, and some may be permanent. This may be worrying, but there are ways to improve side effects and get the right support.

Feeling very tired (fatigue)

You will probably feel very tired (fatigued) after surgery, radiotherapy or chemotherapy:

- After surgery, this feeling may last for a longer time than you expect, but usually gets better within 2 to 3 months.
- After radiotherapy or chemotherapy, you may feel this way for longer, but it should eventually get better.

Scars

Depending on the type of surgery you have, you may have some scars. These should fade with time. Some scars may have a numbness above them, that gets better after a few months. If you have any problems with scars, let your healthcare team know so they can make sure you get the right care.

Lymphoedema

Lymphoedema is more likely to develop after surgery to remove the lymph nodes followed by radiotherapy. It is when your leg or legs, pelvic area, or both swell with fluid that can't drain away on its own. There are ways to reduce the risk of lymphoedema and to manage it.

Changes to your bowel or bladder

After treatment, some people have changes in how their bowels, bladder, or both work. This is rare after surgery.

Sometimes bowel or bladder changes only last for a short time and eventually get better. But in some people these changes can last for a long time. The changes may get worse after treatment or only develop a while after treatment, which is called a late effect.

If you have bowel or bladder changes, it is important that you speak to your healthcare team so they can help you get the right support.

"After chemo and radiotherapy, I was physically intact and thought nothing could stop me – until I realised the treatment that saved my life would place me on another journey filled with emotional and physical side effects.

As well as dealing with early menopause, my whole digestive system changed – food that was my best friend became an enemy. My tolerance for anything too hot or spicy was really low. I relied on medicines and this settled as I learnt the triggers.

Once my hair and eyebrows grew back, I regained some confidence and decided it was time to restart my sex life. Attending the dilator clinic helped, but did not fully prepare me. There was pain and a bit of bleeding that got better in time – but there was also that feeling of trying to please my partner and be accepted with my flaws, which I really struggled with.

Take one day at a time and accept the bad days in the same mind frame as the good. It's a daunting process that can have life-changing effects, but nothing in life stays the same. It's about making certain adjustments to your mindset so you can discover that life after cancer can be brilliant."

Lisa, diagnosed with stage 2b cervical cancer at age 37.

Changes to your vagina

Radiotherapy may tighten or shorten the vagina (vaginal stenosis). If this happens, it may affect different areas of your life.

You may need to use a dilator, which is a tube-shaped object that you put in your vagina to help stop the stenosis getting worse. Not everyone wants or needs to use a dilator, so your healthcare team can support you in making this decision.

Menopause

If you have not already gone through menopause, it may be triggered by surgery that involves removing your ovaries. Having radiotherapy may also mean you are more likely to go through the menopause early.

Menopause can cause side effects including hot flushes, dry skin, mood changes, and changes to your sex life. There are things that may help manage these side effects, such as hormone replacement therapy (HRT) as well as non-hormonal alternatives. Remember, your healthcare team are there to support you and figure out the best way to help.

Read more about menopause at **jostrust.org.uk/information/living-with-cervical-cancer/menopause**

Changes to your fertility

After some treatments, you won’t be able to become pregnant. This may be very distressing, especially if you want children. Before your treatment, you may want to discuss options for preserving fertility with your healthcare team.

Many people have, at some point, imagined what their future family might look like, and coming to terms with a different future is not easy. Sometimes this hits you when life seems to be getting back to normal. Try to remember that there are other ways to have children and support is available to help you navigate these options.

> “No matter what, you make the best decision that is right for you at the time. There are days where I still think about my choice – it’s a confusing topic even 3 years down the line for me. I think it’s important to know that it’s also okay to change your mind throughout the years. Although the timing might not be right for me to have children by fostering or surrogacy now, that doesn’t mean that will always be the case.”
>
> Debs, diagnosed with stage 2 cervical cancer in 2015

Changes to your sex life

Your sex life may change because of physical or emotional factors. If treatment has triggered menopause or caused vaginal stenosis, sex may be uncomfortable. You may also feel differently about yourself or your sexuality, which may impact on your relationships with people.

All of these things can cause a loss of sexual desire (libido) – a common effect of treatment and one you can discuss in private with your keyworker or CNS. They will be able to give you advice and support.

How we can help

There are different types of support available, so it may take some time to figure out what works best for you. Remember, there is no right or wrong way to approach getting support. Some people just want to continue with their lives without much help, while others want to access as much support as possible.

Your healthcare team, our team at Jo's Cervical Cancer Trust, and other voluntary organisations are all here to offer the information and support you and your loved ones need.

Ask the Expert

You can use our online Ask the Expert service to confidentially submit your medical questions and get answers from a healthcare expert within 7 working days. Visit **jostrust.org.uk/ask-expert**

Helpline

Whether you have a question or just want to talk, our Helpline is there for you. Our trained volunteers all have personal or professional experience of cell changes or cervical cancer, so they know what it's like to be on your side of the call. They can listen, offer emotional support and give information. You can call our Helpline free on **0808 802 8000.** Visit **jostrust.org.uk/helpline** for opening times.

Online forum

Our online forum is for anyone affected by cervical cancer, including partners, family and friends. It is a safe space to talk with other members, ask questions, and get and give support. You can choose how much to share and whether you want to be anonymous. Visit **jostrust.org.uk/forum**

We have a private forum for people living with advanced cervical cancer (stage 4) – visit **jostrust.org.uk/forums/living-advanced-cervical-cancer**

> "I am so glad to have found the Jo's forum – seeing the stories and conversations between other women is really helpful."
>
> Ellie, diagnosed with stage 1b1 cervical cancer in 2018

Let's Meet

Every September, we organise an information and support get together in London for those who have or have had cervical cancer. It's an opportunity to meet others in a relaxed, supportive environment.

Throughout the day, there are workshops on living with and after cancer for you to choose from – as well as lots of time to chat with others. You can come alone or bring a loved one with you. If you bring a partner, we run a workshop just for them, which is a good way to meet other partners, share experiences and get some support.

For more information or to sign up, visit **jostrust.org.uk/letsmeet**

Mini Meet

Throughout the year, we organise smaller Mini Meets for those who have or have had cervical cancer in different areas across the UK. To find out more, visit **jostrust.org.uk/minimeet**

Other useful organisations

Support with symptoms and effects

Bowel and Bladder Community
Supports everyone with a bowel or bladder condition. Has a free 'Just can't wait' card to help people access toilets quicker.
www.bladderandbowel.org

College of Sexual and Relationship Therapists (COSRT)
Find an accredited therapist specialising in sexual and relationship issues.
www.cosrt.org.uk/information-for-members-of-the-public/find-a-therapist

The Daisy Network
Provides support to women, along with their families and partners, who experience premature or early menopause.
www.daisynetwork.org.uk

Fertility Network UK
Provides free and impartial support, advice, information and understanding for anyone affected by fertility issues.
www.fertilitynetworkuk.org
Info Line: 01424 732361

Lymphoedema Support Network (LSN)
A patient-led organisation that supports people with lymphoedema.
www.lymphoedema.org
Phone: 020 7351 4480

Pelvic Radiation Disease Association (PRDA)
Provides information and support to people affected by pelvic radiation disease (PRD).
www.prda.org.uk
Helpline: 01372 744338

Surrogacy UK
Offers help and support through all the stages of surrogacy.
www.surrogacyuk.org

General cancer support

Hospice UK
Has more than 200 member organisations offering care and therapies across the UK.
www.hospiceuk.org

Macmillan Cancer Support
Provides information and support to everyone affected by cancer.
www.macmillan.org.uk
Support line: 0808 808 0000 (Monday to Friday, 9am to 8pm)

Maggie's Centres
Provides information about cancer, benefits advice, and emotional support.
www.maggiescentres.org
Phone: 0300 123 1801

Marie Curie
Supports people with a terminal diagnosis and their loved ones. **www.mariecurie.org.uk**
Support line: 0800 090 2309

Support with finances and work

Citizen's Advice
Offers financial and work support relevant to where you live.
www.citizensadvice.org.uk

Department for Work and Pensions (DWP)
Manages state benefits in England, Scotland and Wales.
www.gov.uk/browse/benefits

Thanks and references

Thank you to everyone affected by cervical cancer who helped us develop this booklet and who shared their stories in it.

All of our information is reviewed by experts for clinical accuracy – thanks to those who reviewed this. For references, email **info@jostrust.org.uk**

Version 2.0. Updated March 2020. Next planned review 2022. This information was correct at the time of publication.

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