



Radical Trachelectomy

A guide for patients and their carers



Contents

Introduction	3
What is a radical trachelectomy and why is it necessary? .	4
Agreeing to treatment	5
The operation	9
After the operation	12
Leaving hospital and coping at home	14
Follow up treatments and appointments.	17
Staging and grading of cervical cancer explained.	19
Contacts and further information	20
Support groups and useful organisations	20

Introduction

This booklet has been written to help answer some of the questions you may have about radical trachelectomy.

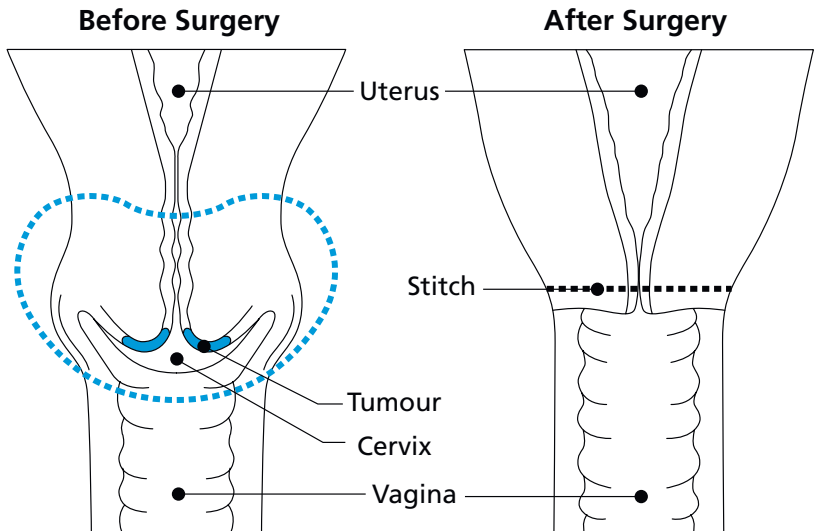
If you have recently been diagnosed with cervical cancer, it is normal to experience a wide range of emotions. For some women, it can be a frightening and unsettling time. Whatever you may be feeling at present, try talking about it with someone who specialises in dealing with this condition such as your consultant or the gynaecology cancer nurse specialist (CNS). They will listen, answer any questions you may have and can put you in touch with other professionals or support agencies if you wish. Some useful contact numbers are also listed at the back of this booklet.

What is a radical trachelectomy and why is it necessary?

A radical trachelectomy is an operation to treat cervical cancer. It may be offered to women who wish to keep their womb (uterus), because they still wish to have children.

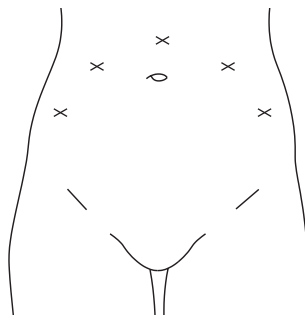
Most of the time, the procedure is carried out through the vagina. It involves removing the whole of the cervix, the top 2-3cm of the vagina, and tissue from around the cervix. A large permanent stitch is then inserted around the opening of the remaining uterus, strong enough to withhold a pregnancy.

Sometimes a trachelectomy can be performed through a cut on the abdomen (tummy), although the vaginal route is the more common.



Taken from CancerHelp UK, the patient information website of Cancer Research UK; www.cancerhelp.org.uk

The pelvic lymph glands are also removed (known as pelvic lymphadenectomy). This is because the cancer can spread to these glands first. The lymph glands are usually removed by keyhole surgery (laparoscopically) through 3 or 4 small cuts on the tummy. However, for technical reasons this is not always possible, and a larger incision (cut) is needed.



Incision sites for laproscopic surgery

(the surgeon will use one of these)

The aim of the operation is to remove all of the cancer. If there is any evidence that the cancer has spread, or if the results of the operation suggest that you may be at an increased risk of recurrence of the cancer (your cancer returning), you may be offered further treatment, such as further surgery, chemotherapy or radiotherapy. This will be discussed with you when all the results are available.

Agreeing to treatment

Consent to treatment

We will ask you to sign a consent form agreeing to accept the treatment that you are being offered. The basis of the agreement is that you have had a written description of the proposed treatment and that you have been given an opportunity to discuss any concerns. You are entitled to request a second opinion from another doctor who specialises in treating this cancer. You can ask your own consultant or your GP to refer you. Your consent may be withdrawn at any time before or during this treatment.

Should you decide to withdraw your consent then a member of your treating team will discuss the possible consequences with you.

What are the benefits of this operation?

The aim of operation is to remove all of the cancer and so that we can assess the extent of the disease. This is known as staging. This will enable the team to know whether further treatment is recommended.

Are there any alternatives to this operation?

Yes, but these vary from patient to patient. The cancer team will discuss the options available to you. The options will depend on the stage of your disease. For some women the options are:

- **Radical hysterectomy:** this is the removal of the uterus and fallopian tubes along with the cervix, top 2-3 cm of the vagina, the tissue around the cervix and the lymph glands. This operation is carried out through an incision (cut) on the abdomen.
- **Radiotherapy:** this is as effective as surgery. This tends to be offered to women with larger tumours or women who are not medically fit enough to have major surgery. Chemotherapy is also often given to women who have radiotherapy.

However these options will affect your fertility, whereas the aim of radical trachelectomy is to treat the cancer but still enable you to carry a pregnancy.

What happens if I have no treatment?

Your wishes about treatment will be respected at all times by your medical team. If you choose not to have treatment,

your cancer will progress and your health is likely to deteriorate. At this time you may wish for us to transfer your care to the supportive care team. The team will discuss with you what will happen next and help you to manage your symptoms and support you, either in hospital, at home, or in the local hospice.

Are there any risks?

As with any operation there are risks but it is important to realise that the majority of women do not have complications.

The risks associated with having a general anaesthetic and major surgery include:

- Bruising in the wound. Internal bruising (inside your tummy) may occur. A blood transfusion may be needed to replace blood lost during the operation. Very occasionally, there may be internal bleeding after the operation, making a second operation necessary.
- Infection in the wound or internal infection may occur needing treatment with antibiotics. Occasionally, a second operation may be necessary.
- Deep vein thrombosis or DVT (blood clots in the leg or pelvis). This can lead to a clot in the lungs (pulmonary embolism or PE). Moving around as soon as possible after your operation can help to prevent this. We will give you special surgical stockings (known as 'TEDS') to wear whilst you are in hospital and injections to thin the blood. You may have blood thinning injections for four weeks following discharge. The physiotherapist may visit you and show you some leg exercises to help prevent blood clots.
- Your bladder and bowels may take some time to begin working properly after your operation. Some women

have loss of feeling in the bladder that may take some months to get better. During this time, you may need to take special care to empty your bladder regularly.

Occasionally, a hole may develop in the bladder or in the tube (ureter) bringing urine to the bladder. If this happens it is generally identified at the time of surgery. If not, it results in a fistula (leakage of urine into the vagina). The hole may close without surgery, but another operation may be necessary to repair this.

- Some women may have pain on intercourse or pelvic pain. Sometimes there can be irregular vaginal bleeding and/or bleeding after sexual intercourse. Occasionally the entrance to the womb can become too tight, which may require further surgery.
- The laparoscope (the instrument used for the keyhole surgery) can puncture the bowel or bladder. If this happens then you will need an operation to repair the damage. This will involve a larger incision (cut) on your abdomen and a longer stay in hospital.
- You may also need to have a larger cut if the surgeon cannot remove your lymph nodes using a laparoscope.

Are there any long-term complications?

The skin around the wound is usually numb for several months until the small nerves damaged by the incision grow back. Sometimes the numbness may affect the tops of the legs or the inside of the thighs. This should get better in 6–12 months.

There is a small risk of swelling, called lymphoedema, of the legs or lower abdomen. If this occurs please tell your GP or cancer team. Normally, lymphatic fluid circulates throughout the body draining through the lymph glands. The pelvic lymph glands are removed during the operation to prevent

the spread of cancer cells. The lymphatic system may then become blocked, resulting in a build up of fluid in one or both legs or in the genital area. Preventative measures can be taken to reduce the risk of it developing and you will be given information about this.

However, if you do develop lymphoedema the problem can be treated and you will be referred to a specialist to manage the swelling.

Occasionally you may develop a lump or cyst in your abdomen (called a lymphocyst) which contains lymphatic fluid. Often it will be left to settle on its own.

Some women have problems emptying the bladder after surgery. This usually settles with time but a small number will have long term problems. Occasionally it is necessary to show you how to put a catheter tube into the bladder to make sure it is emptying completely. This does not mean wearing a catheter permanently and is known as intermittent self catheterisation. It affects only about 1 in 50 of women having radical trachelectomy.

The operation

What is removed during my operation?

- Cervix (neck of the womb)
- Tissue around the cervix
- Top 2-3 cm of the vagina
- Pelvic lymph glands.

Is there anything I should do to prepare for my operation?

Yes. Make sure that all of your questions have been answered to your satisfaction and that you fully understand

what is going to happen to you. You are more than welcome to visit the ward and meet the staff before you are admitted to hospital. Just ask the gynaecology CNS to arrange this for you.

You may take part in the Enhanced Recovery Programme (ERP). The aim of this programme is to improve the quality of your care and get you back to full health as quickly as possible after your surgery.

You should also eat a **healthy diet** and if you feel well enough, take some gentle exercise before the operation, as this will also help your recovery afterwards. Your GP, the practice nurse at his/her surgery or the doctors and nurses at the hospital will be able to give you further advice about this.

If you are a smoker, it would benefit you greatly to **stop smoking** or cut down before you have your operation. This will reduce the risk of chest problems as smoking makes your lungs sensitive to the anaesthetic. If you need further information about stopping smoking please contact your GP or Smokefree NHS on **0300 123 1044**. A specialist adviser is available Monday to Friday from 9am–8pm and on Saturday and Sunday from 11am–4pm.

Before you come into hospital for your operation, try to organise things ready for when you come home. If you have a freezer, stock it with easy-to-prepare food. Arrange for relatives and friends to do your heavy work such as changing your bedding, vacuuming and gardening and to look after your children if necessary. You may wish to discuss this further with the gynaecology CNS.

If you have any concerns about your finances whilst you are recovering from your operation, you may wish to discuss this with the gynaecology CNS.

What tests will I need before my operation?

Tests will be done to ensure that you are physically fit for surgery and help your doctor to choose the most appropriate treatment for the type and extent of your disease. Recordings of your heart (ECG) may be taken as well as a chest x-ray. An MRI or CT scan of your pelvis and abdomen will be needed.

We may take swabs from your nose, throat and groin to find out whether or not you carry the bacterium known as MRSA. This is so we can identify whether you will need any treatment for this infection during your stay in hospital. Do not worry, if you are carrying the bacterium this will not cause your operation to be cancelled.

You will also have the opportunity to ask the doctor and the specialist nurse any questions that you may have. It may help to write them down before you come.

Why do I need to attend the pre-operative clinic?

Before your admission to hospital, you will be asked to attend the pre-operative clinic to make sure that you are fit for the operation. During this visit the staff will discuss your operation with you and what to expect afterwards. You will have the opportunity to ask any questions.

Your temperature, pulse, blood pressure, respiration rate, height, weight and urine are measured to give the nurses and doctors a base line (normal reading) from which to work.

A blood sample will also be taken to check you are not anaemic and to identify your blood group in case you need a blood transfusion.

When will I come in for my operation?

You will usually be admitted on the day of your operation or the day before if necessary. Any further questions you have can also be discussed at this time.

What happens on the day of my operation?

Each hospital has slightly different fasting times and the ward staff will tell you more about this. Before going to the operating theatre, you will be asked to change into a theatre gown. All make-up, nail varnish, jewellery (except your wedding ring), dentures and contact lenses must be removed.

After the operation

What happens after my operation?

After your operation you will wake up in the recovery room before returning to the ward. You may still be very sleepy and be given oxygen through a clear face mask to help you breathe comfortably immediately after your operation. You will be encouraged to take a few sips of water once you feel up to it. An intravenous infusion also known as a 'drip' will be attached to your hand or arm to give you fluids and prevent dehydration until you are drinking enough.

You may also have a drain (tube) in your abdomen that is inserted during your operation. This is so that any blood or fluid that collects in the area can drain away safely and will help to prevent swelling. The drain will be removed when the drainage has reduced, which could take several days, or until your consultant advises it should be removed. You may have a special dressing, called a pack, placed in your vagina. This will be removed around 24-48 hours after your operation.

During your operation a catheter (tube to drain urine away) will be put into your bladder. As the bladder is positioned close to the cervix, uterus and vagina, where the surgery has taken place, the catheter will allow the area to recover and heal. The catheter will need to stay in for approximately 3-10 days. Once it has been removed we need to make sure that you have emptied your bladder completely. We can do this by inserting another small catheter or by scanning your bladder to see if it is completely empty.

Occasionally, the catheter will need to remain in place for a little longer or you may need to insert the catheter at regular intervals (known as 'intermittent self catheterisation') to enable your bladder to return to working normally. This varies from woman to woman and will not necessarily prevent you from going home. If needed, a district nurse can visit you at home to help you care for your catheter.

You may also have trouble opening your bowels or have some discomfort due to wind for the first few days after the operation. This is temporary and we can give you laxatives and painkillers if you need them.

How will I feel after my operation?

You can expect to be extremely sleepy or sedated for the first few hours. This will allow you to rest and recover. Please tell us if you are in pain or feel sick. We have tablets/injections that we can give you as and when needed, so that you remain comfortable and pain free. You may have a device that you use to control your pain yourself. This is known as a PCA (Patient Controlled Analgesia) and the staff will show you how to use it.

Alternatively, an epidural may be inserted in your back for pain relief. The anaesthetist will discuss these choices (PCA or epidural) with you before surgery.

You may have some vaginal bleeding or a blood-stained discharge for up to 6 weeks after the operation. The incisions will have dressings to keep them clean and dry.

We will encourage you to do gentle leg and breathing exercises to help your circulation and prevent a chest infection.

Is it normal to feel weepy or depressed afterwards?

Yes. It is a very common reaction to your diagnosis and the operation. Also sometimes being away from your family and friends can make you feel weepy. If these feelings persist or develop when you leave hospital, the advice and support of your friends, family, GP, or gynaecology CNS may help. There are also a number of local and national support groups. (See page 20).

Leaving hospital and coping at home

When can I go home?

You will usually be in hospital between 2-3 days, depending on the type of operation you have had, your individual recovery, how you feel physically and emotionally and the support available at home. This will be discussed with you before you have your operation and again whilst you are recovering.

When can I get back to normal?

It is usual to continue to feel tired when you go home. It can take up to 4-6 weeks to fully recover from this operation, sometimes longer.

However, your energy levels and what you feel able to do will usually increase with time. This is individual, so you should listen to your body's reaction and rest when you

need to. This way, you will not cause yourself any harm or damage.

We suggest you shower and do not have a bath for the first 3 weeks to minimise the risk of vaginal infection.

Avoid lifting or carrying anything heavy (including children and shopping) for a minimum of 3 weeks, and then only once you feel comfortable. Vacuuming and spring-cleaning should also be avoided for at least 3 weeks after your operation.

Rest as much as possible, gradually increasing your level of activity. Generally, within 6 weeks you should be able to return to your normal activities but you can discuss this further on your return to the follow-up clinic.

When can I start to drive again?

We advise you not to drive for at least 2 weeks after your operation. However, this will depend on the extent of your surgery and your individual recovery. You will be able to discuss it further with your doctor at your follow-up appointment.

We advise you to contact your car insurers for advice on driving following surgery.

What about exercise?

It is important to continue doing the exercises shown to you by the physiotherapist for at least 6 weeks after your operation. Ideally, you should carry on doing them for the rest of your life, particularly the pelvic floor exercises. Avoid all aerobic exercise, jogging and swimming until advised, to allow the muscles cut during your operation to heal. The physiotherapist or gynaecology CNS will be happy to give advice on your individual needs.

When can I have sex?

To allow the top of the vagina to heal, full penetrative sex should be avoided for 6 weeks. You may have a small amount of brown vaginal discharge from the stitches at the top of the vagina. If this discharge becomes offensive, please contact your GP.

You will be advised to use contraception. You will have an MR scan within the first year after your operation to check for any signs of recurrence of the cancer. After this you will be informed of the results of the scan and whether you can try and get pregnant.

During this time, it may feel important for you and your partner to maintain intimacy, despite refraining from sexual intercourse. However, some couples are both physically and emotionally ready to resume having sex much sooner and this can feel like a positive step. If you have any worries or concerns, please discuss them with the gynaecology CNS.

It can be a worrying time for your partner. He or she should be encouraged to be involved in discussions about the operation and how it is likely to affect your relationship afterwards.

If you do not have a partner at the moment, you may have concerns either now or in the future about starting a relationship after having a radical trachelectomy.

Please do not hesitate to contact the gynaecology CNS if you have any queries or concerns about your sexuality, change in body image or your sexual relationship either before or after surgery.

Follow up treatments and appointments

Will I need to visit the hospital again after my operation?

Yes. It is very important that you attend any further appointments arranged.

An early appointment, in the outpatient clinic, will be made to discuss the histology (tissue analysis) results and any further treatment options if necessary. This is usually within 3 weeks following discharge from hospital.

You will need to attend for regular follow-up appointments once your treatment is complete. These follow up appointments will be arranged for every 3-6 months for the first 2 years, then every 6 months up to 5 years. At these appointments you will be seen by a member of the cancer team. This may be a doctor or gynaecology CNS who works closely with your consultant.

After your first follow up appointment, your subsequent appointments may be at your local hospital if no further treatment is necessary.

Why do I need to be followed up in the clinic for so long after my operation?

By having frequent appointments during the first 2 years any problems can be detected early. On occasion, cervical cancer may return and if this should happen it is usually within the first 2 years after your first treatment. These appointments are not only to look for medical problems, a diagnosis of cancer can affect any aspect of your life. You can discuss these issues with your gynaecology CNS.

Will I need further treatment?

You may need further treatment if cancer is found in the lymph glands or close to the edge of the tissue which has been removed. If the histology results show that you need further treatment, an appointment will be made with the clinical oncology team (radiotherapy) to discuss this with you.

Should I continue to have cervical smears?

Yes. You will need to have regular smears and colposcopies from the isthmus (the lower part of the womb) and the top of the vagina. These will be carried out 6 months, 12 months and then 24 months following surgery and then yearly at hospital.

What symptoms should I report or be worried about?

If you have any of the following symptoms, please contact your gynaecology CNS, GP, or hospital for an earlier appointment:

- bleeding or discharge from the vagina
- lower tummy pain lasting for 2-3 weeks particularly if it keeps you awake at night
- swelling in one or both legs (if lymph glands removed).

After you have had treatment for cancer it can be a worrying time. Please remember that you will have the same aches and pains that you have always had. If you develop a new health problem, this may not be related to your cancer and its treatment.

Staging of cervical cancer explained

The **STAGE** of a cancer describes its size and extent.

Stage 1. The cancer cells are found only in the cervix.

Stage 2. The cancer has spread into nearby organs and tissue, such as the upper vagina or tissue next to the cervix.

Stage 3. The cancer has spread further to the lower part of the vagina, nearby lymph nodes, and / or tissue at the sides of the pelvis.

Stage 4. The cancer has spread to the bladder or bowel and / or outside the pelvic area. This stage includes cancer that has spread to the lungs, liver or bone although these are less common.

Grading of cancer explained

Tumour cells arise from normal cells within the body. If the tumour cells are very similar to normal cells then the tumour is described as being **well differentiated or grade 1**. If there is less similarity then the tumour is described as being **moderately differentiated or grade 2**. If the tumour bears little resemblance to the normal cell then the tumour is described as being **poorly differentiated or grade 3**.

Contacts and further information

We hope that this booklet answers most of your questions but, if you have any further queries or concerns, please do not hesitate to contact your key worker or gynaecology CNS. If your query is urgent and your CNS is not available to take your call you should contact the ward you were admitted to for your operation, or your GP. Please note that the gynaecology cancer nurse specialists are not available evenings or weekends.

Support groups and useful organisations

Macmillan Cancer Support

89 Albert Embankment, London, SE1 7UQ.

Freephone: **0808 808 0000** Monday-Friday, 9am-8pm.

You can get:

- Answers to any questions about cancer
- Emotional and practical support
- Signposting to other organizations and services
- Access to specialist information, nurses and specialist welfare rights advisors
- If you are a non English speaker, there are interpreters available

If you are hard of hearing, use the textphone on **0808 808 2121** The website **www.macmillan.org.uk** has information about cancer treatment, living with cancer and Macmillan services, along with support through online communities.

Jo's Cervical Cancer Trust

Helpline: **0808 802 8000**

Website: www.jostrust.co.uk

Email: info@jostrust.co.uk

A charity dedicated to women, their families and friends affected by pre-cancer and cancer of the cervix. Web-based support group.

The Lymphoedema Support Network

St. Luke's Crypt, Sydney Street, London, SW3 6NH.

Telephone: **020 7351 4480**

Website: www.lymphoedema.org

Email: adminlsn@lymphoedema.freemove.co.uk

A charity that aims to ensure that every patient with lymphoedema has the condition correctly diagnosed and gets a suitable level of care.

NHS Choices

Website: www.nhs.uk

Information from the National Health Service on conditions, treatments, local services and healthy living.

Eve Appeal

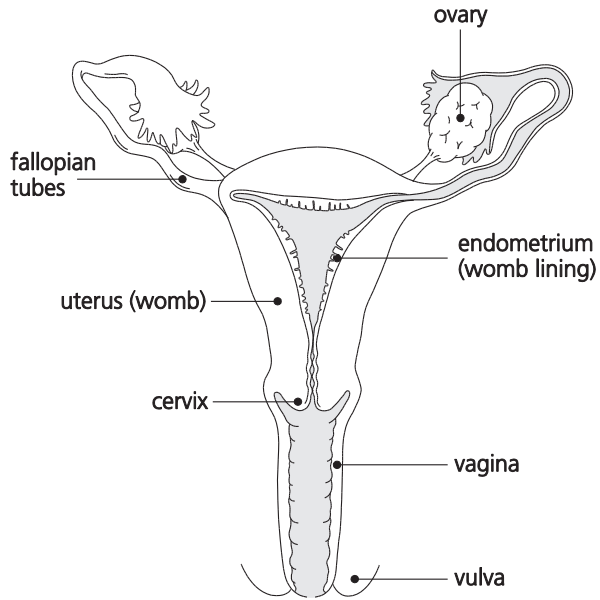
15B Bergham Mews, Blythe Road, London, W14 0HN.

Telephone: **020 7605 0100**

Website: www.eveappeal.org.uk

The only UK national charity raising awareness and funding research into gynaecological cancers.

My cancer is _____



My gynaecology oncology surgeon is _____

My key worker is _____

We hope that you have found this booklet helpful. Please feel free to ask us any questions you may have. We have suggested below some questions you may want to ask.

How quickly will I be seen by the team who will do my operation?

Will you let my GP know about my diagnosis?

How soon will I have my operation?

If I need chemotherapy or radiotherapy do I have to go to The Christie for this?

Who will I contact if I have questions or concerns, once my treatment has finished?

If you need information in a different format, such as easy read, large print, BSL, braille, email, SMS text or other communication support, please tell your ward or clinic nurse.

We try to ensure that all our information given to patients is accurate, balanced and based on the most up-to-date scientific evidence.

If you would like to have details about the sources used please contact patient.information@christie.nhs.uk

Written in collaboration by The Christie NHS Foundation Trust
and Manchester University NHS Foundation Trust.

Visit the Cancer Information Centre

The Christie at Withington **0161 446 8100**

The Christie at Oldham **0161 918 7745**

The Christie at Salford **0161 918 7804**

Open Monday to Friday, 10am – 4pm.

Opening times can vary, please ring to check
before making a special journey.

The Christie NHS Foundation Trust

Wilmslow Road
Manchester M20 4BX

Switchboard 0161 446 3000

The Christie Hotline 0161 446 3658

www.christie.nhs.uk

The Christie Patient Information Service
December 2017 – Review December 2020

