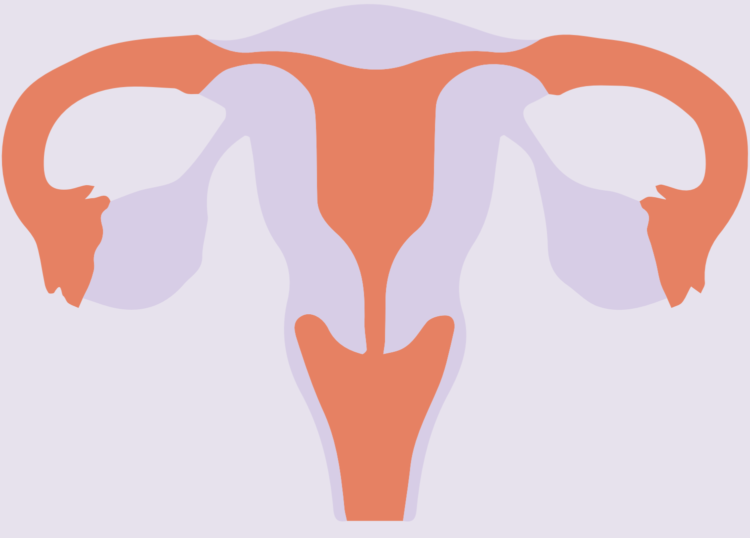
Cervical Cancer Guide

talk peach
GYNAECOLOGICAL AWARENESS



Letter to all those affected by cervical cancer

If you, a member of your whānau, or someone close to you has been diagnosed with cervical cancer, you are probably in shock and experiencing a wide range of emotions. Talk Peach was founded by gynae cancer survivors, we know first-hand the devastation and loneliness of a cancer diagnosis, and that is why we are here to help.

Cervical cancer can be a difficult journey, it is imperative that you have all of the information and support that you need at your fingertips — which is what this guide is for. We hope that it will assist you in processing the news of your diagnosis, support you through the challenges ahead and empower you to ask questions, build support, and advocate for your health.

Not all of the information in this guide will apply to everyone, but it should give you and your close ones the answers to many of your questions, as well as help you form questions you may not have thought to ask.

To all those scaling mountains, we are with you.

Ngā mihi nui,

Tash Crosby and team Talk Peach

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About Talk Peach

Talk Peach is a registered Gynaecological Charity in Aotearoa, New Zealand.

We raise awareness with evidence-based, body positive, inclusive gynaecological education and support.

Our Story

We are here to educate the public on the early and often subtle signs of gynaecological cancers and to empower people to take ownership of their gynaecological health. We advocate for better funding into: education and awareness, research, clinical trials, access to medications, and better pathways to diagnostic testing.

> *“When I was diagnosed...I had heard of breast and other cancers but not cervical cancer. Not knowing my body well enough to understand if there were any changes or things that needed to be checked. I never got regular checks as it wasn’t something I was ever really encouraged to do, friends didn’t talk about it either.”*
> *— Kate*

We're also here to connect and support those who are diagnosed, to help those who have been diagnosed ask the right questions and to advocate for themselves if they aren't being listened to.

> *"I think Talk Peach is a wonderful organisation raising awareness for gynae cancers. We shouldn't be embarrassed by our bodies. I think there is still a stigma attached to gynae cancers. I want to help break this taboo." - Laura*

Talk Peach sees Breast Cancer awareness as a great model to aspire to. It's taken some years and hard work, but now men talk about it, rugby teams wear pink shirts and monuments are lit up to honour the fight against it. It has a strong presence and the public are more aware than ever before. Talking about a mammogram or your breasts is socially okay; now we have to start using words like vagina and vulva in public. We don't usually dive into that conversation, but we need to start talking about our gynaecological health, honestly and openly.

It's time to Talk Peach.

You can access further information regarding Talk Peach, cervical cancer, and support available through our website: https://www.talkpeach.org.nz/

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PART ONE:
Diagnosed

> *"They examined me and took a biopsy. I was told that I was to be booked in to have surgery within 2 days to remove what they strongly believed to be cancer...I felt in shock and broken"* — Danielle

Talk Peach is founded and run by gynae cancer survivors, we know all too well the devastating shock and isolation of a cancer diagnosis.

> *"The day I was diagnosed was surreal. The surgeon sat us down and said I'm so sorry, you do have cancer. She said there's nothing that I did to get it and there is nothing I could have done to prevent it. I'm a mum, a business leader, I'm athletic and there was no cancer in my family. I thought I had this kind of get out of jail free card so it was total disbelief. I felt like the courier had left the package at the wrong doorstep."* — Rosie

Being told that you have cervical cancer will affect everyone differently. Some might feel frightened, anxious, sad or lonely, while others may be in disbelief, feel angry or even numb. You may also be worried about how those close to you will take the news. It is important to know that there is no right or wrong way to feel, and that it is completely normal to experience very strong, unsettling and highly changeable feelings during this time.

Just as there is no right or wrong way to feel, there are many ways one might deal with those feelings. Some take solace in finding out as much as possible about their condition, while others find the influx of information overwhelming. Some may want to surround themselves with loved ones, while others prefer to process the news on their own. Just know that whichever approach you take is valid.

Through sharing the experiences of others, providing important, easily accessible information and the tools to build support, we hope that this guide will help you to feel a little less overwhelmed, and to assist you (and those around you) through your rightful pathway of emotions.

> *"I was so shocked when I was diagnosed with a gynaecological cancer, I thought — why me!?" — Tash*

Pathway to diagnosis

Signs and symptoms

Signs and symptoms of cervical cancer can include:

- Bleeding or spotting between periods
- Bleeding or spotting after sex
- Bleeding or spotting after menopause (after periods have stopped)
- Unusual and persistent discharge from your vagina
- Persistent pain in your pelvis
- Pain during sex

Screening

Most cervical cancer diagnoses are identified through a cervical smear test. Other ways to check for cervical cancer include colposcopies, MRI scans, CT scans, and positron emission tomography (PET) scans. If you are diagnosed with cervical cancer following testing, more tests will then be needed to see the type and stage of your cancer.

Cervical Smear/HPV Screening

A smear test can detect abnormalities in the cervix, including cancer cells. During a smear your GP, nurse or gynaecologist scrapes and brushes cells from your cervix, these are then sent away to be tested for an HPV test. If the HPV test is positive – then the cervical smear will be processed.

You can choose to perform a self swab for HPV only. If this is negative – your next test will be in 5 years. If it is positive then you will need to see your GP for a smear test and/or be referred to a colposcopy clinic – the exact pathway depends on the type of HPV detected.

Colposcopy

A colposcopy procedure involves your doctor closely examining your cervix with a device called a colposcope for signs of anything unusual.
The colposcope is a combination of a microscope, light source, and still or video camera.

If an initial smear test reveals any abnormalities on your cervix, a colposcopy is often then recommended as a follow up. A sample of tissue might be taken during a colposcopy for lab testing.

MRI SCAN

An MRI scan is used to see how far cervical cancer has spread through the cervix, and its proximity to the bladder and bowel.

CT Scan

This scan is very good for looking at lymph nodes in the pelvis and the chest, which is where the cancer is most likely to spread first.

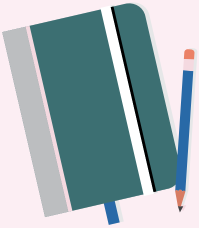
PET Scan

During a Positron Emission Tomography (PET) Scan you will be given a small amount of low-dose radioactive glucose. Rapidly dividing cells, such as cancer cells, ‘pick up’ the glucose, making the cells visible on the scan.

Waiting for results

The uncertainty and anxiety of waiting for your test results can be physically, mentally and emotionally exhausting. It can be hard to concentrate on other things, we often imagine the worst and may feel that our life is out of control. Some test results may come back within a couple of days, but others may take more than a week. Be sure to ask your doctor to explain each step and how long it will take to receive each result, as well as a contact number just in case you don't receive your results in the expected time. This information will mean fewer things to feel uncertain and anxious about.

Some tips that may be useful:



- Leave a notebook by your bed. We think a lot at night and often questions pop into our heads. Writing them (or anything else) down when you think of them makes it easier to relax and sleep.
- Keep up normal activities and routine as much as you can – working, going to the gym, or seeing friends.
- Many find learning more about cervical cancer and its possible treatments empowering, or a way to feel more in control of their situation. Focus on the sections of this guide that answer some of your questions, and look to our *'Support'* section for useful websites, support groups and cancer helplines.

If you are finding information online during this time, beware that the internet contains a lot of misinformation. Make sure that you are visiting the websites of reputable organisations. Again, refer to our *'Support'* section for some examples.

Even with the support of our friends and whānau, waiting for your results can be a very lonely time, you might like to give Cancer Society a call on 0800 CANCER | 0800 226 237, or contact us here at Talk Peach at www.talkpeach.org.nz for further advice and support while you wait.

Next Steps

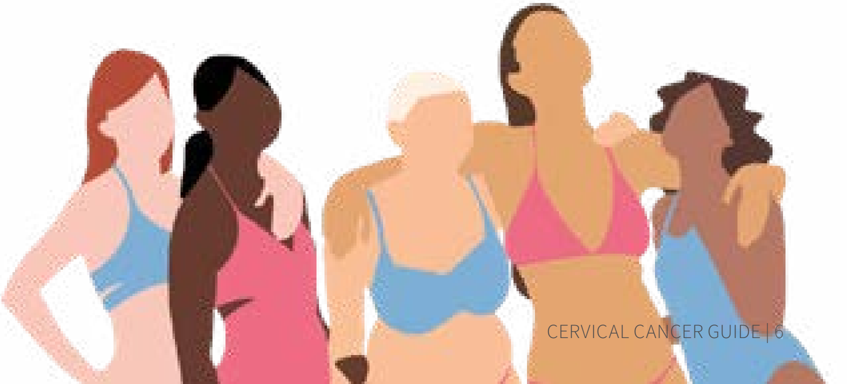
> *"Telling other people was almost worse than receiving the diagnosis — it was like repeating the whole experience over and over, and having to act like I wasn't petrified. I really felt like I had to prove that I was going to be okay." — Amy*

Letting people know

Share your diagnosis with others if and when you are ready, and at that point share as much or as little as you feel comfortable with. You can also choose not to tell everyone at once, or to ask a friend or family member to share the news for you. This is your information to give at your discretion, so go at your own pace.

Choose those you feel comfortable with and know that everyone deals with this kind of news differently, some reactions might not be what you would expect.

> *"Some of my friends, I think, felt weird or too sad to talk to me about my cancer. They didn't know what to say or how to help. Others were there for me at pretty much every turn, which really helped." — Tash*



Some tips that may be helpful:

- Think about how much you want to share the first time you tell someone.
- Telling people in person is often preferred for certain relationships, but sometimes it's not possible, and you shouldn't feel pressure to do so if it's too difficult. Making a list of those you want to tell in person can help.
- You might find it useful to take along a pen and paper (or just your phone) to write down any questions they ask that you don't know the answer to, so that you can ask your doctor.
- Sending a message via email or text can take the stress out of letting many people know at one time. It can also give those people time to process the news before replying.
- You don't have to tell everyone everything yourself. Ask someone close to you to be your messenger. Let them know what information you want them to share. Not only for telling others about your diagnosis, but to keep people updated via email, text or messenger. They could even set up a blog or Facebook page to document your progress, this is really great for connecting with others on the journey also.
- At work you can choose who you tell (if anyone). Sometimes, not telling colleagues helps people to cope by keeping at least one area of their lives as normal as possible. While entirely up to you, telling a colleague(s) that you trust gives them the chance to support you, to know what to expect, and to help you plan how to tell others. Your employer doesn't have to know until you want them to. If and when the time comes, you could ask a colleague, friend or family member to tell your employer for you if you don't feel up to it. Talk Peach is also available to run workplace educational sessions. Contact us for more details at info@talkpeach.org.nz.
- You could ask someone to coordinate visits or calls during your hospital stays and post treatment. This could include video calls for when you're not up to an in-person visit, or group calls for when you want to see a bunch of friendly faces at the same time without feeling overwhelmed. They could also schedule in 'contact free' times to ensure you get enough rest.
- Support from others is awesome, but sometimes it can be tiring! Let people know if you are not in the mood, too tired, or feeling too unwell for visits or to talk. They will understand.

Talking about it

Sharing how you are feeling and building support can help to relieve stress. While some may find this more difficult than others, remember that it is useful — not just because talking to others can be therapeutic — but when those around you have a clearer idea of what you are going through, they have a better idea of what you need and how they can help. Be sure to wait until you feel ready, and seek out those you feel comfortable with.

Do not be concerned about asking for or accepting help. For many this is key to coping with the news of their diagnosis and the challenges that lie ahead.

It can also be a good idea to look outside of your immediate support system (if and when you feel ready), as no one person can provide you everything you need and different perspectives can help you to accumulate ways of coping that best suit you.

> *"One of the most meaningful moments I had in a support group was at Look Good Feel Better (a free programme for anyone with cancer) when I took my wig off and everyone else followed suit. It was really empowering." — Tash*

Some examples of support available:

- Cancer support groups
- Cancer information helplines
- Talk Peach
- Psychologists or counsellors
- Physiotherapists
- GPs or specialist doctors (oncologist, surgeon)
- Cancer (oncology) nurses
- Dietitians

Please see the '*Support*' section for more information.

Looking after yourself & preparing for treatment

Now is the time to look after yourself. This includes putting your needs first and conserving your energy.

- **Don't be afraid to say no** to things you don't feel like doing — prioritise yourself and your own wellbeing.
- **Listen to your body** and rest as frequently and for as long as you need to.
- **Some light physical activity** here and there can help with sleep, mood and energy levels. Maintaining and keeping up with your physical health and fitness is an important way to prepare for treatment and surgery. It can feel odd to prioritise this after a cancer diagnosis, but being in good health can improve your recovery. When you feel unwell it can be hard to do any exercise, but even some light movement can boost your fitness levels. You could try some short walks, or some gentle yoga or stretching exercises. There are free videos online that can demonstrate these for you, so you can try them at home. Discuss this with your healthcare team though — it is possible that you are just too ill at this time.
- **Eat a variety of nutritious foods.** This helps with strength to manage treatments and their side effects. Consult with your doctor, a dietitian or others who have gone through similar treatments. See our *'Managing Symptoms and Side Effects'* and *'Support'* sections for more information.
- If you feel up to it, **some social activity** may help to take your mind off your worries, even if for a short time. Talk them out; get some advice or a fresh perspective. Invite a close friend over for a movie, go for a walk, or do something else you both enjoy. If you are feeling too ill or low for in-person visits or to leave the house, you could try a group call or chat.
- **Minimise stress** where you can. Stress can take a toll on your body and slow the healing process. Before you embark on treatment, think over the things that can cause stress in your life and how you might reduce them. It could be a matter of setting them aside to return to only when

HE ITI HOKI TE MOKOROA NĀNA I KAKATI TE KAHIKATEA

WHILE THE MOKOROA GRUB IS SMALL, IT CUTS THROUGH THE WHITE PINE.

THERE IS POWER IN SMALL THINGS

you're well again, or prioritising space for yourself. Keep in mind the people, activities, and things that help you to relax as well. A long bath, a phone call with a caring friend, or a good book could all help you unwind.

- **Stop smoking.** Smoking can lengthen your recovery time, worsen side effects, and increase the risk of complications. Smoking and vaping is also not allowed inside hospitals, which may put pressure on you while you undergo treatment. Although quitting is more easily said than done, as you may be using smoking as a coping method for stress, there are support and resources available for you to give up. *https://quit.org.nz/*
- **Financial Support.** You will be entitled to financial support during treatment and recovery. See our *'Support'* section for more information.
- **At Home.** Extra support with childcare, housework, and buying and cooking food can ease your time in treatment and recovery. See our *'Support'* section for services that can help with this. If you can, stock up your cupboards and freezer with easy-to-prepare foods that you can reheat later. Your healthcare team can tell you what food is best during treatment and recovery. Reach out to your friends and family and see how they can help. This may feel like a difficult thing to do, but your loved ones will want to support you and offer practical care if they can. They might be able to do some babysitting, drop off groceries, or wash your laundry. You could consider setting up a shareable calendar with treatment dates and errands to run so you can spread the support out. Cancer Society NZ has a free online tool you can use for this. See our *'Support'* section for more details.

Cervical Cancer: What is it?

When you or a loved one has been diagnosed, you're sure to have many questions. Over the next few pages we hope to answer some fundamental questions around what cancer is, and more specifically — what cervical cancer is.

> *"When I was diagnosed I didn't even know where my cervix was. I had no idea what cervical cancer was, I had never heard about it before..." — Kate*

Cancer

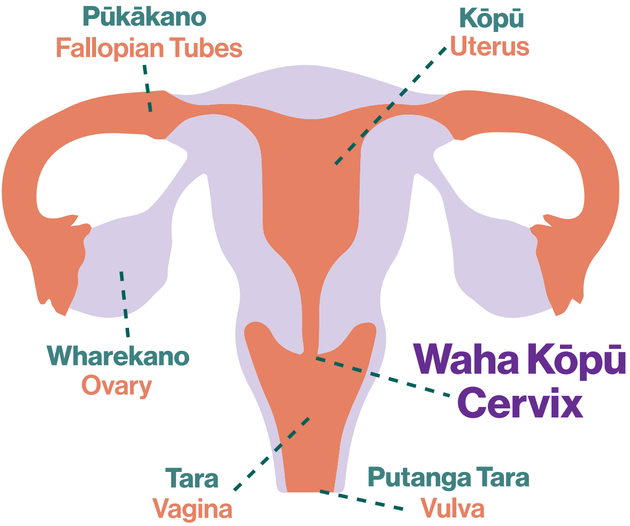
Cancer is an umbrella term for a range of related diseases. The type of cancer is named after the bodily location where it starts (primary cancer). For example, if cancer starts in the cervix, even if it spreads to, say, the liver (secondary cancer), it is still called cervical cancer.

There are many different types of cancer, but they all begin in the same way. The body is always producing new cells, they replace old or damaged cells and usually grow in a systematic way. Cancer occurs when there is an uncontrolled growth of abnormal cells, and this may form a growth or lump known as a tumour which can be either benign (not cancerous) or malignant (cancerous).

Benign tumours typically do not spread outside where they began. Malignant tumours can spread into nearby tissue — cells can sometimes spread from where the cancer began and move through the blood or lymphatic system to other parts of the body.

The cervix

The cervix is part of our reproductive system which also includes the vagina, the uterus (or womb), the ovaries and the fallopian tubes. The cervix is the lower part of the uterus that connects to the vagina (sometimes called the neck of the uterus). It is a small round organ, which has an opening called 'the os', forming a tunnel from the lower part of the uterus to the top of the vagina. You may hear this tunnel referred to as the 'endocervical canal'. The cervix is divided into two parts; the inside of the cervix (endocervix), and the outer surface (ectocervix).



Cervical cells and the transformation zone:

'Squamous' and 'glandular' are the two main types of cells in the cervix. Squamous cells, which are thin and flat, cover the outer surface of the cervix. Glandular cells look like columns and cover the inside of the cervix. The transformation zone, near the opening of the cervix, is where the glandular and squamous cells meet, where samples are taken from during a cervical screening, and where most cervical cancers develop.

But what does the cervix do?

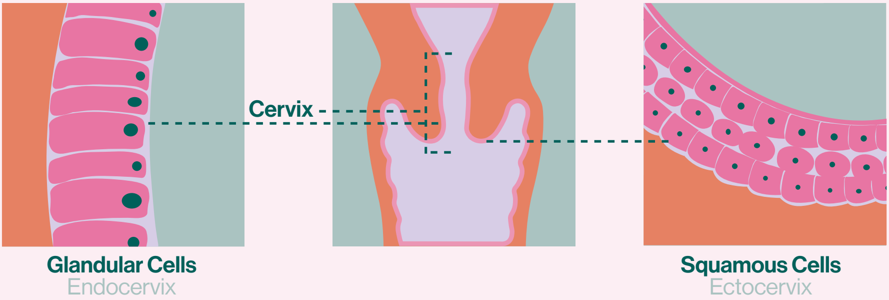
The cervix helps protect against infection, and plays an important role during the menstrual cycle (periods), and during pregnancy:

- The glandular cells in the cervix produce a fluid mucus, or cervical discharge, that protects the cervix and other reproductive organs from bacteria. The fluid is often clear or white in colour.
- When you have a period, the uterus will shed its lining, and the cervix will open up so blood can flow out into the vagina.
- ‘Ovulation’ is the word for the time when one of your ovaries releases an egg to be fertilised. It generally occurs once a month. During this time cervical discharge becomes thinner so that sperm can travel up the fallopian tube and reach the egg.
- During pregnancy the cervix closes up, forming a barrier to keep the baby inside the uterus. When it is time to give birth, the cervix becomes softer and stretches out so that the baby can move through it to the vagina.

Cervical cancer

There are five gynaecological cancers, and cervical cancer is one of them. It forms in cells inside the cervical canal, on the outer surface of the cervix, or the point where these parts meet (the transformation zone). Cervical cancer is caused by some strains of the human papillomavirus (HPV), which is a group of very common viruses (passed on by sexual contact) that infect about four out of five people at some time in their lives.

HPV causes cells to grow abnormally, and over time, these abnormalities can lead to cancer. However, it is important to know that having HPV does not automatically mean that you will develop cervical cancer, and you can develop cervical cancer without having contracted HPV — it can affect anyone with a cervix at any age.



Types of cervical cancer

There are two main types of cervical cancer:

Squamous Cell Carcinoma

This is the most common type of cervical cancer. It starts in the ‘skin-like’ cells that cover the outer surface of the cervix at the top of the vagina.

Adenocarcinoma

This is a less common type of cervical cancer. It is in the glandular cells in the cervical canal.

Risk factors

The most important risk factor for cervical cancer is persistent HPV infection. Other factors may contribute, including:

- HPV: Infection with the human papillomavirus is the most important risk factor for cervical cancer.
- Not having regular screening.
- Smoking: tobacco is a factor in causing many types of cancer, including cervical cancer. Those who smoke are twice as likely as non-smokers to develop cervical cancer.
- Genetics: some people are more likely to get cancer than others (family history).

PART TWO:
Treatment

Planning your treatment

Treatments for cervical cancer include:

- Surgery
- Radiation treatment
- Chemotherapy

or a combination of these treatments

Your team of healthcare professionals will consult with you and decide what treatment you need. Your individualised treatment plan will depend on factors such as the type of cervical cancer you have (squamous cell or adenocarcinoma), the exact location of the cancer within the cervix, the stage (the size of the tumour and how far it has spread) and grade (how abnormal the cell is) of your cervical cancer, your age, and your general health.

Your team of healthcare professionals

Your treatment will be managed by a multidisciplinary team (MDT) of doctors and other cancer healthcare professionals each specialising in a different area of care.

- **A gynaecological oncologist.** They will plan and manage your overall treatment and perform the surgery.
- **A medical oncologist.** A medical cancer specialist who will coordinate your chemotherapy if needed.
- **A radiation oncologist.** A specialist who manages radiotherapy (such as high energy X-rays) treatment for cancer.
- **A cancer nurse specialist.** A nurse who specialises in gynaecological oncology will manage and provide your care during your time in hospital. They are often the best point of contact for your team and a good source of support.

Almost all those diagnosed with cervical cancer require some type of surgery. For many, treatment will require a combination of surgery, radiotherapy and chemotherapy.

Surgery

The extent of surgery will be discussed with you by your surgeon. The timing, type and amount of surgery required will vary depending on the cancer stage. Surgery is a common way to treat small cancers found only within the cervix (stages 0-1). The extent of the cancer in the cervix will determine the type of surgery needed. For earlier stages surgery may be the only treatment needed, but radiotherapy, chemotherapy or a combination of the two are usually needed. For more advanced stages radiotherapy and/or chemotherapy are generally offered along with surgery.

Radiotherapy

Radiotherapy involves the use of high energy x-rays to destroy cancer cells. Your course of radiotherapy (the dose and exactly where you need it) will be discussed with you and administered by your radiation oncologist/ radiotherapy team. This may involve a planning CT scan in the radiation therapy department of the hospital which can take around 45 minutes.

External radiotherapy along with chemotherapy (chemoradiation) is the main treatment for stages two and above cervical cancer, and for locally advanced cervical cancer. External radiotherapy is often followed by internal radiotherapy (brachytherapy). See *'Treatment by Stage and Grade'* and 'Radiotherapy' sections for more detail.

Radiation therapy may also be administered after surgery to help destroy any remaining cancer cells, and to reduce the risk of the cancer coming back. This is known as 'adjuvant therapy'.

External radiotherapy is also called 'external beam radiation therapy' (EBRT). These treatments are fast and painless, each session requiring you to lie on a table under the radiation therapy machine for just a few minutes. You will most likely have daily treatments over a course of 4-6 weeks.

Internal radiotherapy (brachytherapy) is delivered inside of your body – directly to the tumour, using an applicator which is placed inside the cervix. You will most likely have 3-4 sessions of internal radiotherapy over a period of 2-4 weeks.

Chemoradiation

Chemotherapy uses drugs to kill or slow the growth of cancer cells. With cervical cancer, chemotherapy is most often combined with radiation (chemoradiation), as the chemo drugs help the radiotherapy work better. Chemotherapy is typically given as an injection into a vein (intravenously). You will usually have chemotherapy once a week, a few hours prior to your radiotherapy session.

Treatment by stage and grade

If cervical cancer is diagnosed, the next step is to identify its stage and grade. The grade describes how quickly the cancer might grow or spread. The stage indicates the extent of the cancer's spread throughout the body.

Grading

A doctor will look at your cells under a microscope to give the cells a grade from 1 to 3:

Grade	What this means
Grade 1	The cells look similar to healthy cells. They tend to grow more slowly than higher grades.
Grade 2	These cells look a bit like healthy cells and may grow a bit quicker.
Grade 3	These cells look very different to healthy cells. They tend to grow more quickly which means they are more likely to spread. Grade 3 cancers might need more intensive treatment than lower grades.

Staging

Stage	What this means
0	Abnormal cells are found in the first layer of cells lining the cervix.
1	The cancer is found only in the cervix.
2	The cancer has spread beyond the cervix to the upper portion of the vagina.
3	The cancer has spread throughout the pelvic area. It may involve the lower portion of the vagina, ureters and surrounding lymph nodes.
4	The cancer has spread to nearby organs such as the bladder or rectum, or to other parts of the body (e.g.: lungs, liver, bones).

Types of surgery

Not all the surgeries below will apply to you, it is just an overview of some possible operations. Your gynaecological oncologist will discuss what will happen during your surgery – the type of operation depends on where the cancer has spread to. The main types of surgery for cervical cancer are explained below.

LLETZ

LLETZ stands for ‘large loop excision of the transformation zone’, a type of surgery where a small part of the cervix is removed. LLETZ biopsy can be used to diagnose cervical cancer.

Cone Biopsy

Some very early cervical cancers may be treated with cone biopsy. During a cone biopsy, you will be anaesthetised as tissue is removed from the cervix. This is then sent to the laboratory to be studied. Cutting away the tissue also removes the abnormal cells. The tissue that grows back is likely to be normal, in which case no more treatment is needed. A cone biopsy takes less than an hour.

Trachelectomy

A trachelectomy involves the removal of the cervix. There are different types of trachelectomy depending on the type of cervical cancer you may have.

A simple trachelectomy means only the cervix is removed, while a radical trachelectomy removes the cervix as well as the tissue around the womb (parametrium), and part of the upper vagina.

Lymph nodes in your pelvis may also be removed during a trachelectomy. Removal of the lymph nodes is called a lymphadenectomy.

Hysterectomy:

Total Hysterectomy

In a total hysterectomy, the uterus and fallopian tubes are both removed, along with the cervix. When possible, the ovaries are not removed, to avoid early menopause.

Radical Hysterectomy

A radical hysterectomy involves the removal of the uterus and about two centimetres of upper vagina and tissues around the cervix.

When you have either type of hysterectomy (radical or total), you will also have a:

Pelvic Lymphadenectomy

The removal of lymph nodes within the pelvis.

Bilateral Salpingo Oophorectomy

The removal of both ovaries and fallopian tubes.

Cervical surgery can understandably be daunting, scary, or anxiety inducing. There is support available if surgery is recommended for you, provided by people with experience who want to help. You will not have to cope with the surgical process alone. Please see our *‘Support’* section for more information.

Post-surgery

Waking up

In most cases, you will wake up in a recovery unit at the hospital post-surgery — although if you had additional surgeries, you may wake up in the intensive care unit (ICU). After a day or so of monitoring, you should go back to your ward. At this point, you will be under the care of your surgeon, and maybe anaesthetist too if you had those additional surgeries. You might feel 'spaced out' and drowsy — this is a normal side effect of anaesthetic.

You will also probably have some tubes attached. These could be:

1. **A drip** (in your arm, providing essential fluids and pain medication)
2. **Abdomen tubes** (to drain excess fluids from the operation)
3. **A catheter** (to drain urine)
4. **A nose tube** (again, to assist with excess fluids)
5. **An epidural** (attached to your spine, to provide additional pain relief)

As your body recovers and you get into a regular eating and drinking cycle over the next few days, these tubes will be removed.

Pain relief

You'll be given a lot of pain relief to help with your recovery, as this is major surgery. While it might come through an epidural, it could also be through a patient-controlled analgesia (PCA). With a PCA, you'll get to choose how much pain relief you get, but if you continue to feel pain, let your nurse or surgeon know right away.

You'll also get painkillers to take home and use yourself when you leave the hospital. It's important to let your nurse know about any pain you're feeling as you recover, so they can make sure you get the right kind and amount of pain relief.

Your wound

Cervical cancer surgery will leave a wound, as most operations do. The type of wound you have will depend on the type of surgery. This will be confirmed by your surgeon/healthcare team.

The wound will possibly have a dressing, which the nurse should remove after a couple of days. You could also have stitches – hospital staff can let you know if these will dissolve naturally, or if they need to be taken out (which normally happens a week to 10 days after the operation). If you had keyhole surgery, your cuts may be closed with glue, which is also dissolvable.

After you go home, be mindful of your wound. Contact your GP or healthcare team at the hospital if the edges of the wound come apart or you have signs of an infection. These can include:

- The wound area feeling hot
- Fluid coming out of the wound
- Having a high temperature (fever)
- The wound area looking red and swollen.

Wound Healing

Although the visible parts of your wound may heal quickly you could have pain or discomfort in the area for a while after, while your muscles and nerves heal.

Having radiotherapy or chemoradiation after surgery may mean your wound takes longer to heal. These treatments can delay renewal of the cells that are needed to heal and close the wound.

Be aware that the skin around the wound may be numb for some time after surgery while your nerves recover. It should gradually get better, but it is important to speak to your GP or healthcare team if you are concerned.

Eating and drinking

You might not be able to eat or drink as normal for a few days after your surgery. Your drip will make sure you have all the fluids you need, and after a few days you should begin to resume a regular eating schedule. In some cases you might even be able to eat and drink a few hours after you wake up — your nurse will let you know.

Moving about

Movement is an important part of your recovery. It helps to prevent blood clots, relieves wind and generally helps the recovery process.

After your surgery, you'll have to stay in bed for a day or two. A physiotherapist will usually visit during this time and help you with breathing exercises, leg exercises and beginning to move about.

You may have to have a few injections in your stomach as you begin moving — these are to help with the blood clots. This could continue for a few weeks after you leave, and you can do them yourself or have a nurse help you at home. Another way of helping your recovery is wearing anti-embolic stockings, also known as TED stockings. These provide light compression to your legs, aiding blood circulation and mitigating the risk of clots.

Leaving the hospital

You're likely to be in hospital for between 3 and 7 days after your surgery. The length of this period depends on a few things, such as how your recovery is progressing and whether you are having your first chemotherapy cycle during your stay.

Before going home, your nurse and support team will make sure you have everything you need for a safe and comfortable recovery. They'll help you work out things to do at home to help you heal, as well as anything you should avoid.

Once you are home, there will be a healing period of 4-6 weeks. You'll gradually be able to do more and more over time, but check in with your medical team about keeping your recovery on track.

Possible complications

1. **Infections.** Tell your doctor or nurse if you have any high or low temperatures, are coughing or nauseous, generally feel unwell or have redness or soreness around your wound.

2. **Vaginal bleeding.** Similar to a light period, this can continue anywhere from a few days to a few weeks after your surgery. Talk to your doctor or nurse if the bleeding stops and then starts again, gets much heavier, smells, or is green or yellow in colour.

3. **Bleeding in the abdomen or pelvis.** There will be some blood loss during or after your operation, but in rare cases there can be a risk of internal bleeding. Your nurse will check you regularly for any signs of this. In rare cases, you may need a second operation.

4. **Bladder or bowel problems.** Your surgeon will usually notice this if it occurs, and it can require a second operation if there is damage to the bladder, bowels or ureters (a tube that carries urine from the kidney to the urinary bladder).

5. **Blood clots.** As mentioned above, blood clots can occur as you recover from surgery. While they begin in your pelvis or legs, they can spread to your lungs. Your doctors or nurse will help you move to prevent this. Let them know immediately if you cough up blood, have chest or upper back pains, swelling or redness in your legs, or are generally short of breath.

6. **Leg swelling.** If your lymph nodes are removed during your surgery, it can cause a buildup of fluids. It usually happens in the legs, but can rarely occur in the genital area. Let your doctor or nurse know if you notice any swelling in these areas.

7. You may experience **constipation** due to pain killers. Refer to the *'Managing Side Effects and Symptoms'* section for ways to help with this.

Radiotherapy

What is it?

Radiotherapy is used to treat cervical cancer at different stages. It destroys cancer cells via radiation (high energy x-rays) and may be internal or external.

External Radiotherapy

During external radiotherapy a machine delivers radiation from outside the body. There are various types of external radiotherapy that deliver the x-rays in different ways.

Types of external radiotherapy include:

Intensity Modulated Radiotherapy (IMRT)

IMRT is a treatment that reduces the risk of high doses of radiation to your bladder, back passage, parts of your colon and bowel. This may lessen side effects.

Extended Field Radiotherapy

In cases of locally advanced cervical cancer, you may undergo ‘extended field radiotherapy’ to include areas where cervical cancer may spread to – such as lymph nodes in your stomach (abdomen). There can be more side effects with this course of treatment.

Adjuvant Radiotherapy

You may have radiotherapy at the same time as a course of chemotherapy (chemoradiation) after surgery. This can reduce the risk of the cancer coming back. Chemoradiation after surgery is called adjuvant treatment. Not everyone will require this after surgery, but you can need it if the cervical cancer has spread to your lymph nodes, or the cervical cancer is larger and more likely to spread.

Radical Treatment

If you have locally advanced cervical cancer that can’t be treated with surgery, you may undergo chemotherapy. This is called radical treatment.

Palliative radiotherapy

You may have a short course of radiotherapy if advanced cervical cancer has spread to other parts of your body. This can help with symptoms such as pain or bleeding.

Internal Radiotherapy

Internal radiation therapy, also known as brachytherapy, involves radioactive material being placed into your vagina to give radiotherapy directly to the cervix and the area close by, destroying the cancer cells. It can be called ‘intrauterine brachytherapy’. It is usually done after you have already had chemotherapy, radiotherapy, and possibly surgery.

The type of brachytherapy you may have depends on the stage of your cervical cancer and what kind of treatments you’ve previously had.

- Brachytherapy is often paired with chemotherapy. When the two treatments are done in tandem, this is called chemoradiation.
- Brachytherapy can at times be administered after surgery to help reduce the risk of the cancer returning. This is referred to as adjuvant treatment. It is not always necessary and may only be recommended to you if the cancer has spread to your lymph nodes, or the cancer was larger and more likely to spread.
- If you have locally advanced cervical cancer that can’t be treated with surgery and receive brachytherapy, this is known as ‘radical treatment’.

Brachytherapy can feel invasive — your healthcare team is here to help you feel more comfortable and to guide you through the process.

What Are the Side Effects of Radiotherapy?

When you receive radiotherapy, you may experience side effects. These can be short-term and might only last for the duration of your treatment, or they could have a longer effect and last for weeks, months, or possibly years.

Keep in mind that not everyone will experience all possible side effects, and that side effects can be managed. Your healthcare team will guide you through what to expect.

Side Effects of Radiotherapy:

Short term:

- Your skin may be sore on the outside of your genitals (vulva) and the area around your bottom (anus). It's recommended that you avoid shaving, waxing, or using hair removal cream during radiotherapy.
- This sore skin may also cause pain (stinging) when you wee.
- Fatigue
- Nausea and vomiting
- Diarrhoea, wind, and cramps
- Pain
- Pubic hair loss
- Your vagina may change to become tighter, shorter and drier, (vaginal stenosis)

Long Term:

- Early menopause
- Bladder and bowel problems
- Changes to your sex life
- Swelling in your groin or legs (lymphoedema)
- Bone problems

There's more detail on the side-effects of radiation, and some useful tips to help you cope with them in our *'Managing Symptoms and Side Effects of Treatment'* section.

Thinking about Fertility

One effect of radiotherapy is that it can damage your ovaries. After a course of radiotherapy, it is possible that you won't be able to get pregnant and have children (or additional children). It is more than understandable to feel worried, scared, sad or angry about this effect of your treatment. Anything you may feel is valid.

There are some practical fertility options you might discuss with your healthcare team to see if they are right for you, before starting treatment for cervical cancer. You will need to take into account the risks of delaying treatment and weigh possible courses of action according to your specific needs.

You may be able to:

- freeze and store your eggs
- freeze and store embryos (eggs that have been fertilised)
- have an operation to move your ovaries (ovarian transposition).

Keep in mind that these options may not always be possible for everyone, and that such services are not available in every hospital. Please see our *'Fertility, Menopause, Sex'* section for more information and support.

Chemotherapy

What is it?

Chemotherapy uses anti-cancer drugs (most often cisplatin for early or locally advanced cervical cancer) which circulate throughout the body in the bloodstream to kill the cancer cells, or to slow down or stop their growth. Chemotherapy is usually combined with radiotherapy when treating cervical cancer. This is known as 'chemoradiation'.

Your oncologist will explain what happens during chemotherapy and at what point it will be administered: on its own, before, after, or alongside other treatments. They will discuss the risks and benefits and what to do if you have side effects. If there are things that don't make sense or you have questions, ask your oncologist or a member of their team.

There are different types of chemotherapy that might be administered to help treat cervical cancer:

Adjuvant chemotherapy

Having chemotherapy with or without radiotherapy after surgery is called 'adjuvant treatment'. You may only need it if the cervical cancer has spread to your lymph nodes, or the cervical cancer was larger and more likely to spread.

Radical Chemotherapy

If you have locally advanced cervical cancer that can't be treated with surgery, you may have chemotherapy with radiotherapy (chemoradiation). This is called 'radical treatment'.

Palliative Chemotherapy

Palliative chemotherapy might be offered to you if the cervical cancer is advanced and is causing symptoms, or the cervical cancer has come back after other treatments. You may have the chemotherapy on its own or alongside other drug treatments, such as Avastin (bevacizumab).

Neoadjuvant Treatment

Although this is not a common procedure, you may have chemotherapy with radiotherapy (chemoradiation) before surgery as part of a clinical trial. This is called Neoadjuvant Treatment and it may help shrink the tumour and make surgery easier.

How long does it take?

Usually, chemotherapy is administered once every three weeks. The treatment may take up to 5-6 hours, which is followed by a rest period in order to recover from the side effects. The time it takes to deliver the chemotherapy depends on how many drugs are being given and the type of drug being given. These three week periods are referred to as a ‘cycle’. Generally there are a total of 6 cycles, but this may vary — your oncologist will confirm the number of cycles you will have. Some treatments may require more visits to the hospital. Different drugs are often used if the cancer comes back.

How is it given?

Usually intravenously (IV) - A nurse puts a small tube into one of your veins and connects the drip to it. It’s possible that you will need a central line. This is a long plastic tube that goes into a larger vein, either in your chest or your arm.

So that your nurse doesn’t need to find a new vein each time, the device may stay in over the course of your treatment, which may be for a few months. It can also be used for blood tests. The nurses or your doctor will discuss this with you if it is needed. You can also ask your medical team about the pros and cons of having this.

Where do I go for the treatment?

Usually, your chemotherapy treatment will be given at an outpatient or cancer day-patient clinic at the hospital. Because you might be there for a good part of the day, you will be provided with a comfortable chair and you are welcome to take a friend or whānau member with you for support. It’s also a good idea to take along a book or an electronic device to help pass the time.

What kind of side effects does chemotherapy have?

Some common ones include:

- Feeling sick
- Tingling and numbness in hands and feet (neuropathy)
- Loss of appetite
- Weight loss
- Mouth ulcers
- Fatigue
- Rash/skin changes
- Hot and cold episodes
- A lowered resistance to infections
- Bleeding and bruising easily
- Diarrhoea or constipation
- Hair loss

Side effects may vary greatly over the course of treatment. Your healthcare team can help you to manage them. You can also have a look at our *'Managing Symptoms and Side Effects of Treatment'* section for information and some helpful tips.

How do the doctors decide on what treatment to give?

Your doctor will discuss the types of radiation and chemotherapy that could be used and the potential benefits and side effects. The types of radiotherapy and chemo drugs used depend on the type of cancer, stage of cancer, whether the cancer has come back and other treatments you've had in the past. Sometimes there will be more than one option that they will discuss with you. If it's not clear, ask your doctor to go over it again with you.

Getting Back in the Waka – Life after Treatment

There is no one way to feel after you have completed your treatment. Some may feel a great sense of relief and happiness while others may feel lonely or frustrated or lost. Don't feel pressure from loved ones to simply 'move on' after treatment; it's completely normal to have a range of confusing and overwhelming feelings as everything that has happened catches up with you. You may also experience lingering physical effects such as muscle pain, bladder and bowel problems, fatigue, and 'chemo brain'. See our *'Managing Symptoms and Side Effects of Treatment'* section for more information.

> *"You deal with cancer emotions well after you have been through the storm of it." — Danielle*

It can take much longer than one thinks for these to go away and sometimes they get tougher before they get easier. Remember that even though your treatment has finished you should still seek help whenever you need it. Your healthcare team will still be there for you if you need them and there are many other avenues of support available to you. It's very useful during this time to find a cancer support forum that best suits your needs, as friends and whānau might not understand what you are going through. See our *'Support'* section for more information.

E KORE AU E NGARO, HE KĀKANO AHAU I RUIA MAI I RANGIĀTEA

I CAN NEVER BE LOST, I AM A SEED SOWN FROM RANGIATEA

I HAVE A REASON FOR BEING

PART THREE:

Managing symptoms and side effects of treatment

Radiation and chemotherapy work to destroy, stop or slow the growth of cancer cells and make them less likely to grow back. However, they can also affect healthy cells, and this is what causes side effects. The side effects will vary - person to person, day to day, week to week, and cycle by cycle. Many find managing the inconsistency of their symptoms (not knowing what to expect), along with the symptoms themselves, the most difficult part of having cancer. Make sure you seek advice or medication from your healthcare team — the earlier the better in order to minimise discomfort.

Below is a list of some common side effects for radiation therapy and chemotherapy, along with some practical advice for how to manage them. It may take some experimenting to figure out what works best for you.

Eating problems

Taste changes

Cancer treatment can alter your sense of taste, texture and smell. Some food may taste unusually bland, others may be salty, metallic or bitter. Your mouth might also have increased sensitivity to bubbly, cold, hot or spicy food and drinks.

- If things are tasting metallic you could try sucking hard lollies or mints between meals, or having some juice or a small piece of fruit just before you eat. The ‘metallic’ taste of cutlery can also be off-putting! Some find using plastic cutlery instead can help.
- If your food tastes bland, experiment with or enhance the flavour with sauces and herbs like soy sauce, spices, relish, lemon juice etc.
- Some people lose their taste for meat; marinating it in a flavourful sauce before cooking can help with this. You could try honey or fruit juice, ginger or soy sauce. If this doesn’t work you could also try meat alternatives like lentils, eggs, cheese, nuts, legumes or tofu.
- Food can sometimes be overly salty, so avoid adding salt before you taste it.

Mouth care and swallowing difficulties

Sometimes treatment can affect the salivary glands causing dry mouth, or it can cause thick saliva or mucus that can make eating difficult. The following can help:

- Sip water regularly.
- Apply lip balm to keep your lips moist and prevent cracking.
- Ask your doctor about the different kinds of artificial saliva, oil mouth sprays or gels, and when they are safe to use.
- Stay away from food that is spicy or overly rough, dry or crunchy.
- Experiment with moist, minced and puréed foods like soups and stews, or moisten food with plenty of sauce like gravy, dressings, pasta sauce etc.
- For mouth ulcers, regularly use alcohol free mouthwashes and salt gargles to keep your mouth clean and moist.
- Dunk your favourite biscuits in hot tea/your preferred hot drink to soften them.
- Suck on an ice block if you don’t find it too cold, or some ice chips if the sweetness is a bit much.
- Have a dental check-up before you start treatment to make sure that you don’t have any infections that could complicate your treatment.
- Drinking through a straw can help you avoid any sore areas in your mouth.

Feeling sick and vomiting

- Anti-sickness medications (antiemetics) can help prevent sickness which is easier than treating it once it has started.
- See a dietitian for nutrition or dietary advice.
- Rest before and after meals, but try not to lay down after eating.
- Eat smaller, more frequent meals.
- Avoid cooking smells!
- Sometimes cold food is more tolerable than hot meals. Choose plainer foods that smell less.
- Stay away from overly fatty food, like things that have been deep fried.
- Salty foods like pretzels or salty crackers can help with nausea.
- Drink plenty of fluids.
- Ginger has anti-nausea properties. Try adding some to tea/water/any drink you can stomach, or try sucking on some hard ginger sweets.
- Some people find acupuncture can help with nausea.
- Try relaxation or mindfulness exercises — see our *'Staying Well'* section.

Loss of appetite and weight loss

It's very common during chemotherapy and/or radiotherapy to experience a lack or loss of appetite. It can be related to any number of symptoms including: taste changes, mouth and swallowing problems, fatigue, pain, nausea and depression, which affect your desire and ability to eat or keep food down, leading to weight loss. It's important to maintain your weight during treatment — even if the idea of losing a bit of weight doesn't sound like the worst symptom.

If you notice that you are losing weight, talk to your healthcare team about what kinds of medications or treatments may be appropriate, and also ask to speak to a dietitian (or ask your caregiver to do so). They can provide nutritional assessment, counselling around eating, and education about what kinds of high calorie, high-protein and nutrient rich foods are best when you're finding it difficult to eat.

Below are some tips to help you maintain your weight during treatment:

- If eating is made difficult due to nausea, taste changes, mouth or swallowing problems, see the advice given in the relevant sections above.
- Determine which times of day you are hungry and eat at those times. This may vary though and some find it helpful to carry around a snack bag or to have their favourite foods on hand just in case hunger suddenly strikes, or the thought of eating isn't unbearable.
- Choose nutritious snacks that are high in calories and protein such as meat, dried fruits, nut butters, yogurt, cheeses, eggs, smoothies, cereal, and protein or muesli bars.
- Ask your dieticians about what kind of supplements would be best for you.
- Increase the calories in your food by adding extra olive oil, butter, nut butter, avocado, gravy, sour cream or grated cheese to your meals.

Fatigue

Fatigue is one of the most common side effects of treatment. It is extreme and overwhelming tiredness or lack of energy which doesn't get better after rest or sleep. During treatment symptoms of fatigue will have varying levels of severity. Fatigue may be caused by chemotherapy, radiotherapy, or other medicines. The cancer itself may also cause fatigue or low red cells (anaemia). If fatigue is ongoing, talk to your healthcare team, as it may be treatable.

Below are some tips to help manage your fatigue:

- Dealing with pain associated with treatment can be very draining. Managing your pain can help with your fatigue. Talk to your healthcare team about what kinds of medication/treatment they think is appropriate and take a look at our *'Pain'* section below.
- Stress and anxiety can add to your fatigue. You may find counselling or support groups helpful with this — see our *'Support'* section for more info. Relaxation techniques can also help; see our *'Staying well'* section.
- Depression. Fatigue is a common symptom of depression. If your mood is low, and you have lost interest in things you used to enjoy, you may benefit from treatment for depression.
- Infection. Chemotherapy can weaken your body's ability to fight off infections. Fatigue may be one of the first signs of infection, especially if fatigue comes on quickly. If you have a body temperature of over 38°C or other fever symptoms, follow your treatment team's advice.
- Interrupted sleep often happens due to pain, nausea and worry/anxiety. Talk to your healthcare team about managing these symptoms and what supplements or treatment may be appropriate in aiding your sleep.
- Don't be afraid to say no to visitors if you need time to rest. They will understand.
- Talk to a dietitian about what kinds of food may help with your energy levels.

- Moderate exercise can help, but you should consult with your healthcare team about what kind of exercise (if any) is right for you.
- Don't be afraid to ask for help with things you just don't have the energy for! See our '*Support*' section — particularly 'day to day' — for more info.

Pain

Cancer pain can be caused by a number of factors including: a side effect of treatment, the spread of cancer to other organs, blockages in organs like the bowel, the cancer pressing on nerves, bones or organs, infection, and muscle aches or stiffness. For those that experience pain during treatment, there are many safe and effective options that may help. Cancer pain can almost always be reduced.

Below is some advice to help manage your pain:

- Talking to your doctor or healthcare team is the best way to manage your pain, they will prescribe the suitable pain relief for your situation. This may include pain killers, muscle relaxants or radiation, depending on the type and severity of the pain. Tell them where and when you usually feel the pain, what the pain feels like, whether it keeps you awake, and what makes it worse i.e. lying on your side, standing up or changing positions. The earlier you discuss this with them, the easier it will be to treat.
- Be aware of side effects. Ask your healthcare team about the side effects of your pain medication and how you can prevent them. Common side effects include constipation, nausea (feeling sick), vomiting (being sick) and drowsiness (feeling sleepy). Side effects vary with each person, so talk to your doctor about your experiences. Don't let any side effects stop you from getting your pain under control.
- Don't run out of pain medicine. Prescriptions are needed for most pain medicines, and pharmacies don't always have them in stock. It can take a few days to get some medicines, so allow time for delays.

- Feeling anxious can worsen your physical pain.See our *'Support'* and *'Staying well'* sections for advice to help manage this.

- If you are spending a lot of time sitting or lying down, ask your treatment team for advice. You can get special equipment, such as a V-shape pillow or cushions, that might make it more comfortable.

- Some complementary therapies can be helpful such as acupuncture, massage, TENS (transcutaneous electrical nerve stimulation) and relaxation techniques. It's very important to consult with your healthcare team about any form of complementary therapy so that it doesn't interfere with your treatment.

- After radiation therapy, you might have pain between your hipbones (pelvis), in your lower back, or your stomach. This may be because radiation can cause bowel changes leading to cramping in the stomach, or because it has damaged the muscles and tissue around the pelvic bones or the joints where the bones meet. Tell your healthcare team so that they can assess the problem and provide you with some options to relieve the pain.

- Adapt and adjust. Talk to your doctor about changing your pain control plan if it isn't working. If your pain isn't getting better or isn't going away, or if you are having breakthrough pain despite taking your pain medication as prescribed, or if the side-effects of your medicines are bothersome, tell your doctor. Small adjustments to your medication can make a big difference.

You may find it helpful to read the National Cancer Institute Cancer Pain Control booklet. Download a PDF copy here: *https://www.cancer.gov/publications/patient-education/paincontrol.pdf*

Diarrhoea and constipation

You may experience the following changes after cancer treatment:

- Change in consistency of bowel motions, softer or watery bowel motions or constipation
- Frequent bowel motions
- Difficulty in emptying the bowel
- Sudden episodes of diarrhoea
- Loss of control – incontinence of bowel motion (faecal incontinence)
- Bloating and farting (flatulence)

Your problems may be more severe if you're having a combination of treatments, such as surgery, radiation treatment and/or chemotherapy. This can be frustrating and embarrassing, but there are things you can do to improve your bowel function. Keep in mind that advice for people following cancer treatment may be different from the advice given to the general public.

It's important to let your doctor know if you are constipated, have diarrhoea, stomach pain or cramps.

Managing diarrhoea

Your doctor or nurse may recommend some or all of the following steps to help you manage diarrhoea that arises as a result of your chemotherapy or radiation therapy:

- Drinking lots of fluids every day. Your doctor can let you know the ideal amount for your situation.
- In intense cases, you may have to consume clear liquids or IV fluids for a short period of time.
- Eating smaller portions or meals — you may be asked to have 6-8 small meals instead of the usual three per day.
- Minimise food or drink that could cause further diarrhoea. This includes grains, nuts, seeds, raw fruit or vegetables, dairy and caffeine.
- Focus on potassium and sodium — you can lose a lot of these when you have diarrhoea, so replenishing with foods like spinach, broccoli, cured or canned meats, and potatoes can be a good idea.

- Stay clean — keeping your anal area clean and dry can help the situation.
- Check with your doctor about anti-diarrhoea medication that is available.

Managing constipation

- Keep up your fluid intake. Ideally about two litres of clear fluids daily.
- Increase fibre intake. This includes grains, whole grain breads or cereals, as well as fresh vegetables and fruit.
- Physical activity — simple tasks like walking around the block can help you manage constipation.
- Kiwi Crush ice blocks, which are available at most supermarkets.
- Check with your doctor if laxatives are right for your situation.

Sometimes your bowel can become blocked due to the cancer's growth or as a result of surgery, which is called a bowel obstruction. This can cause nausea, vomiting and abdominal pain. Please contact your doctor as soon as possible if you think this might be the case for you.

"Chemo brain" or "Brain Fog"

This is a common side effect of chemotherapy/chemoradiation where you may struggle with concentrating, processing details, and even your short-term memory.

It remains unclear if this is specifically due to treatment or if it includes stress-related factors or hormonal changes, but it can be incredibly frustrating as you recover — many who have undergone chemo/radiation have experienced the same thing.

Be gentle with yourself, give yourself the space to process this and speak with your doctor or healthcare team about it and any concerns you have.

Ototoxicity (changes to your hearing)

Ototoxicity is damage to the inner ear, which can mean you lose hearing for high pitched sounds or suffer from tinnitus – ringing in the ears.

This can happen with certain chemotherapy drugs, notably platinum-based ones like cisplatin which is often used for cervical cancer. Contact your doctor if your hearing changes, you feel dizziness, or you experience ringing in your ears.

Skin problems

Radiotherapy can have side effects for your skin, resulting in dry, itchy or red skin where the treatment occurs. Similarly, chemotherapy can cause dryness, itching, redness or breakouts.

You can manage this by taking gentle care of your skin with cleansers that don’t have soap, or moisturisers that contain fewer irritants. The classic “slip, slop, slap and wrap” is another way to take care of yourself, so make sure to use SPF30+ sunscreen. Your healthcare team should also recommend some creams to help you feel more comfortable.

Changes to your vagina

Vaginal Stenosis

Throughout treatment for cervical cancer your vagina may become tighter, shorter and drier — a condition called vaginal stenosis. This is because surgery and pelvic radiation can cause scar tissue to form in the vagina —making it drier and less elastic. Sex and internal examinations of your vagina can be painful if you experience this side effect. There are methods to help prevent/manage vaginal stenosis (such as vaginal dilators, topical oestrogen, topical testosterone and pelvic floor muscle exercises) which your healthcare team should go over with you.

A vaginal dilator is a tube-like object with a smooth surface, usually made of plastic, rubber, or silicone. It comes in various sizes and is inserted into the vagina to assist in keeping it open. Your healthcare team should run you through how to use them. It is generally advised to begin using dilators approximately 2 to 8 weeks after completing radiotherapy, but it is important to wait until any vaginal soreness has subsided. Dilators have been reported to improve sex after radiotherapy, and they are recommended by experts in the field.

Vaginal Dryness

Vaginal dryness can be reduced by using lubrication. These are liquids, gels or creams that you can buy from pharmacies, online, or receive for free with a prescription. Talk to your healthcare team about which lubricants might be right for you. When you have vaginal dryness, burning or itching, or your vaginal tissues are thinning, your healthcare team may also prescribe oestrogen creams which you apply using a special applicator (which measures the correct dose of cream and inserts it into your vagina), and oestrogen pessaries – a tablet which you insert into your vagina using your finger.

Hormone replacement therapy (HRT) is also often used to treat changes to your vagina/vaginal dryness. Talk to your doctor about whether HRT is right for you.

Infection

Vaginal infections (such as thrush) can sometimes occur due to vaginal dryness. Ask your healthcare team about the tablets, creams and pessaries that are available to treat infection.

For more information on sex/intimacy after cancer see our *‘Menopause, Fertility, Sex’* section.

Lowered resistance to infections

Radiation therapy and Chemotherapy can result in fewer neutrophils (white blood cells in your body) which can put you at higher risk of infections or bleeding. Your healthcare team will monitor your white blood cell count regularly, but it's important to seek aid right away if:

- Your temperature goes over 38 degrees (go to the emergency department)
- You have unusual symptoms that suggest infection (fever, shaking, diarrhoea, vomiting, burning sensations when passing urine, redness or swelling around your wound or chemotherapy device)
- You have a nosebleed or bleeding gums
- You are bruising very easily
- There's blood in your bowel movements

This means checking your temperature at home (it's very important to familiarise yourself with using a thermometer) and avoiding people with other infections.

Lymphoedema

If you have lymph nodes removed during surgery, over time (sometimes months or years) you may find swelling around this area or in your legs. This is called lymphoedema and can be a permanent condition.

It is important to seek help if you notice signs of swelling as soon as possible to address this. Lymphoedema is manageable in most cases, with compression stockings and regular gentle exercise able to assist with reducing the swelling.

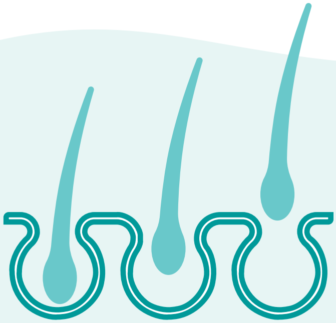
For more information visit the Lymph Info Trust website:
https://www.lymphinfo.org.nz/

Infertility after treatment

When cervical cancer happens at childbearing age it can affect your ability to have children and can cause infertility. You will discuss your options for preserving your fertility with your gynaecological oncologist - but it may not be possible for everyone. See our *'Fertility, Menopause, Sex'* section for more information, advice and support.

Hair loss

Chemotherapy/chemoradiotherapy for cervical cancer can often cause hair loss because of how it affects healthy cells involved in hair growth. If hair loss happens it will start about two weeks after the first treatment, is usually temporary, and will grow back after your final treatment. See our *'Wigs and Hair Loss'* section for lots of information and helpful advice. If you are having radiotherapy without chemo, you shouldn't lose the hair on your head. This is because radiotherapy only causes hair loss in the area that is being treated – which means you might lose your pubic hair. It generally starts to fall out around 2 to 3 weeks after treatment starts, but in most cases it grows back.



PART FOUR:

Wigs and hair loss

The Talk Peach guide to all things hair

Why does chemotherapy/ chemoradiation cause your hair to fall out?

How can I prepare for this?

How long until it grows back?

Are there any special tips for taking care of my hair during chemotherapy treatment?

For many individuals one of the most daunting things about chemotherapy is the thought of losing their hair. Understanding the process and being prepared for hair loss is a great way to minimise the anxieties around it. Below we have compiled and answered some frequently asked questions about hair loss and chemotherapy.

Why does chemotherapy cause hair loss?

Chemotherapy is an umbrella term for any cancer treatment using what are known as cytotoxics. Cancerous cells divide rapidly and cytotoxics drugs are drugs that set out to destroy these rapidly dividing cells or to delay their growth. Unfortunately, they also destroy other rapidly dividing cells such as the cells in our follicles that make our hair grow. This is why chemotherapy can also cause hair loss.

Why don’t all people experience hair loss during treatment?

Many cancer treatments differ, and all chemotherapy/chemoradiation regimens use different combinations of drugs depending on which kind of cancer you have. Some chemotherapy regimens will cause hair loss and others cause very little to no hair loss whatsoever. Some people experience their hair thinning or notice it becomes a lot duller or drier during treatment. Your medical team will know the likelihood of you losing your hair based on the type of chemotherapy treatment you have been prescribed.

If I don’t experience total hair loss what should I do to look after my hair during treatment?

During chemotherapy treatment it is advisable to be gentle on your hair and scalp, your skin can dry out and become more sensitive during treatment. Don’t wash your hair too vigorously and if you can it’s best to use a more gentle hair care range. If you use a hair dryer or styling tools it’s best to keep it at the lowest temperature setting, and go easy on the brushing. Try to source a softer bristled brush.

Can I dye my hair during chemotherapy treatment?

Dyes can dry your hair out even more, but you know your hair best and will have a better insight into how your hair is coping; you can always seek out the opinion of a reputable hair salon who can advise you. It's good to note that there are less chemical-heavy products out there that are kinder to your more fragile locks, and there are lots of great salons who are using and promoting these.

When will my hair start falling out?

This usually begins 2 to 3 weeks after your first chemotherapy treatment. Some people lose their hair gradually, and others begin to lose hair immediately. By the second round of treatment the majority of head hair will have fallen out.

Should I cut or shave my hair before I start chemotherapy?

Cutting or shaving your hair prior to chemotherapy is a personal choice. Some people find that it helps them with the transition from having hair to going bald, that it feels less abrupt and that they have some power or control over the loss of it. When your hair starts to fall out it is often easier to deal with if it is shorter locks falling rather than losing long strands. If it's shaved, you will only notice the stubble, and if it's short, you will only have to deal with shorter hair strands falling. This can be helpful when it comes to the shower, which a lot of people find this less confrontational. If you choose to shave off your hair we recommend using electric clippers and having someone help you as it can be an emotional time for some. Please note, if you are not used to using electric clippers, go to the hairdresser or ask someone with experience to help you out.

Is chemotherapy hair loss painful?

Some people feel some scalp pain when hair loss occurs, others feel an itching or a prickly feeling. It usually only lasts a few days when the hair loss first starts and symptoms will vary from person to person.

Will I lose body hair?

Yes, you may also lose your body hair, i.e. the hair on your legs, arms, armpits, pubic hair and your eyebrows and eyelashes. Please note that this depends on the type of chemotherapy regimen you are on, and it can vary from person to person.

Will my head get cold more quickly without hair?

Yes. Wigs, scarves and hats are key items for a chemotherapy hair loss sufferer to keep their heads warm. At night you will feel the cold a lot more, especially during the colder months of the year. It’s good to get hold of a nice soft cotton hat for wearing in bed at night time.

Will my hair look different when it grows back?

Hot topic! “chemo curls”.

Many people report that the colour and texture of their hair grows back different to what it was prior to chemotherapy. It may come back curly or, if it was already curly, it can end up growing back straight. People also note that their hair grows back thicker or more wiry. Your hair colour can also change and come back lighter or darker, some people report hair coming back a lot greyer than before. New hair growth usually appears after 3 to 6 weeks. How it grows back varies from person to person, and may change over the months as it grows back in. For some, the changes are permanent and for others only temporary. Chemotherapy drugs attack the follicles and it takes some time for these to get back to how they were prior to treatment.

Will I lose my eyelashes and brows?

This depends on the type of chemotherapy treatment you receive. Speak to your medical team about this, but generally if the chemotherapy regimen you are on is likely to cause extensive or total hair loss, then there is a very high chance that you will lose your eyelashes and brows too. In some cases, they become a little bit thinner, other people lose the majority of their hair and others temporarily lose all of their brow and eyelash hair. Eyebrows and lashes tend to take longer to fall out than head hair.

Will my eyelashes and eyebrows grow back?

YES, they will almost always grow back. It may take a little longer because you probably lost them at a relatively later stage in your treatment than your head hair. They may also grow back thinner or more sparse, however, some people report bushier brows. There are great treatments for speeding up the hair growth process and ensuring thick, strong hair growth.

What’s the best kind of wig?

This will vary depending on the person! Some people prefer synthetic, others prefer wigs made from real hair. Some prefer to find a wig that matches as close to their own hair as possible, others take the opportunity to experiment.

In terms of sourcing your wig, Google is your best friend. There are many local New Zealand wig suppliers and shops abroad who deliver internationally.

You don’t have to worry if you aren’t able to spend a huge amount of money on a real hair wig, synthetic wigs have improved a lot — some people actually find they prefer the way they look and fit, and can even find them less scratchy on the scalp; plus there are a huge range of styles and colours available. They are also lower maintenance, as unlike real hair wigs they don’t require styling and don’t go frizzy. There is also a wigs/hairpiece subsidy! See below!

Wigs and hairpiece subsidy

The Wigs and Hairpieces Service Payment is available to any eligible person who suffers from serious hair loss because of a medical condition or from certain cancer therapies. The payments are to reduce the cost of purchasing and maintaining a wig or hairpiece or other related products.

The Wigs and Hairpieces Service Payments notice sets out the terms and conditions on which the Ministry will:

- pay any provider for providing wigs, hairpieces or other headwear (‘the Services’) to any eligible person; or
- pay any eligible person for the purchase of the services by that eligible person from a provider.

https://www.tewhatuora.govt.nz/for-health-providers/claims-provider-payments-and-entitlements/wigs-and-hairpieces-subsidy

Who can claim this service payment?

You may claim for this service payment if you:

- are a New Zealand citizen, or are ordinarily resident in New Zealand; and
- have a medical condition that has caused you to lose your hair (like treatment for cancer, alopecia or other scalp conditions that cause hair loss). Your specialist or general practitioner (GP) needs to give you a current medical certificate with your NHI number, details of the hair loss condition and whether it is permanent or temporary.

What can I use the service payment for?

The service payment is available to cover the cost of the following items only:

- wig or hairpiece
- headwear (e.g. hats, turbans)
- eyebrow wigs and associated products.

Your entitlement

If you are an adult (18 years or over), the amount you are entitled to depends on whether your hair loss is permanent or temporary. If you are under 18, your entitlement is the same whether the hair loss is temporary or permanent.

For adults (with temporary hair loss), your entitlement is $408.88 GST inclusive (at the time of writing this document) over a 1-year period. You may claim all of or part of your $408.88 entitlement at any time over the 1-year period.

The service payment is available to cover the cost of the following items only:

- wig or hairpiece
- headwear (e.g. hats, turbans)
- eyebrow wigs and associated products.

PART FIVE:

Support

Support for those with cervical cancer

Dealing with cervical cancer presents a wide range of practical, physical and mental challenges, but you don't have to go through them all on your own. This part of the guide provides information about the different kinds of support available here in Aotearoa. It is for all those touched by cervical cancer: those with it, their whānau, friends and caregivers.

Support groups and services

> *"Joining a support group really helped to relieve my anxiety, it helped me to relax, feel less alone, more normal and more in control."*
>
> *— Margaret*

Many people with cancer find that looking outside of their immediate support system really helps. It's important to speak with a range of different people during this time, and often those best placed to give the kind of support you need are those who have gone, or are going through a similar situation. This is why being aware of and taking advantage of the support available to you is key. To help you with this, we've compiled a diverse set of support groups and networks, including in person one-on-one help, face-to-face group support sessions, over the phone services, and some useful websites and apps so that you can choose the format(s) that best suits you.

Talk Peach

We are here to help! For information or support contact us through our website: *https://www.talkpeach.org.nz*, or our instagram account: @talk_peach.

We can also connect you to someone with a similar diagnosis.

Cancer Connect NZ

A free over the phone support service. You are peered with a supporter – usually someone who has had a similar cancer experience.

Call: 0800 CANCER (226 237).

NCCC – National Cervical Cancer Coalition

An online cervical cancer support community – a space to feel empowered to ask questions, share stories and feel reassured that you are not alone. **To join visit:** *https://www.nccc-online.org/find-support/*

NCCC has also partnered with Imerman Angels to serve those in need of a mentor, providing personalised one-on-one support for cancer fighters, survivors and caregivers. The service is free and available to anyone touched by cancer living anywhere in the world.

To learn more about Imerman Angels and to request support, visit: *https://imermanangels.org/*

> *"When I found the right support group it really helped. My friends and family were definitely there for me, but it wasn't until I found people in the same situation - who really got what I was going through - that I felt understood and heard." - Tash*

Look Good Feel Better Charity

Offers support to people with any type of cancer at any stage. They'll connect you with others for support, and provide free classes to help you to face cancer with confidence.

Visit: *http://www.lgfb.co.nz/*
Call: 0800 865 432
Email: lgfb.co.nz/contact

The Adolescent and Young Adult (AYA) Cancer Network Aotearoa

This network for younger people with cancer connects professionals, patients and carers to provide support and information. Their website also has some excellent resources for coping with cancer.

Visit their facebook page: *https://www.facebook.com/ayacancernetwork*
Visit their website: *ayacancernetwork.org.nz*
Call: 021 819 486

Dove Hospice

Offering a variety of services to anyone with cancer, at any stage — including art therapy, massage, reiki and skin care.
Visit: *https://dovehospice.org.nz/access-our-services/*

Cervical Cancer Aust / NZ, Support Group

A supportive group of Australian/New Zealand women. Who have, or have had, cervical cancer. They provide understanding, love, humour, and friendship. Also open to carers, family and your support network: *https://www.facebook.com/groups/644503988935517*

The following link is run by the same admin team as the Facebook group above, but specifically for cervical cancer recurrence and/or a terminal diagnosis: *https://www.facebook.com/groups/2402052350116416/*

Financial support

The cost of cancer care may be a concern if you or a family member has been diagnosed. Having cancer may mean you earn less because you have to work fewer hours due to feeling unwell, or not work at all.

You might also have extra expenses, such as medical, travel, accommodation (if travelling away from home), hospital parking, petrol, childcare costs etc.

Financial worries can add to you and/or your family's stress, especially if the budget is already tight. Below is a list of some of the financial support services available to those undergoing cancer treatment:

Mortgage holiday

If you are paying off a mortgage you may want to consider taking a mortgage holiday. Some banks can offer a break from paying off your mortgage or have options to pay the interest only for a certain time period. For more information get in touch with your bank to see if this applies and/or what they can offer.

KiwiSaver – significant financial hardship or serious illness

If you can provide evidence that you are suffering from a serious illness and/or significant financial hardship, you may qualify to withdraw some of your KiwiSaver savings. Contact your KiwiSaver provider or visit the KiwiSaver website for more information. *https://www.ird.govt.nz/kiwisaver*

Work and Income Services

Check the website for a full list of support options provided by WINZ. *https://www.workandincome.govt.nz/eligibility/health-and-disability/index.html*

Take a look at the WINZ online eligibility tool, to see what kind of help you may qualify for. *https://www.workandincome.govt.nz/online-services/eligibility/index.html*

Accommodation

Contact Cancer Society to see what is available in your region, or for advice on how to access financial assistance to help pay for accommodation while going through treatment: *https://www.cancer.org.nz/*

If you are in Auckland, or travelling to Auckland for treatment:

The Domain Lodge functions like a motel, offering 'home away from home' accommodation for people who need to travel long distances for treatment in Auckland. Domain Lodge does not provide health or personal care. Domain Lodge can usually provide accommodation (one room only) free of charge for you and your supporter. Please contact Domain Lodge for more information. *https://www.domainlodge.co.nz/*

Day-to-day

Help from friends and whānau

Don’t be afraid to delegate or to accept help from those around you! Your friends and family might not fully understand what you are going through physically or mentally, but most of the time they are a good resource for practical support. Accepting their help with day-to-day activities — like laundry, transport, and meal preparation — helps them feel useful, and means that you can conserve more of your energy for getting through your treatment and recovery. If you don’t want to ask them to help you with something directly, you could ask them to help you organise services like those listed below. You might also like to direct them to the ‘Support for Friends, Whānau and Caregivers’ section of this guide.

Meals on Wheels

If you are too ill to cook, venture out for food, or money is tight, Meals on Wheels can deliver hot, nutritious meals to your door. Meals on Wheels is subsidised — it usually costs around $6.80 per meal. Talk to your GP or contact your local DHB to see if you are eligible to receive this service. It’s a good source of independence to those recovering from illness or hospital treatment, and it can also provide regular social contact if the recipient needs/wants it. *https://www.redcross.org.nz/what-we-do/in-new-zealand/meals-wheels/*

Talk Peach

Talk Peach Gynaecological Cancer Foundation may also be able to provide meals. Contact us on info@talkpeach.org.nz

Volunteer Driving Service

If you are finding it difficult to get to and from cancer-related appointments, Cancer Society volunteer drivers may be able to assist. They can pick you up from home and return you after your appointment. Please get in touch with Cancer Society for more information about this wonderful service. *https://www.cancer.org.nz/*

District Health Board

District Health Boards (DHB) can sometimes offer help with things like interpreters (for sign language or non-English speakers), palliative care, oncology dietetics, smoking cessation, and chaplains for spiritual support. Contact your local DHB to find out what services are available in your area. If they don't provide the kind of help you need, they may be able to point you in the right direction.

Support for LGBTIQ + community

Outline

Outline is a New Zealand based, all-ages rainbow mental health organisation which provides a nationwide support line. Their service is free and confidential for those wanting to talk to trained LGBTIQ+ volunteers. While their service is not specifically for cancer, we recommend contacting them if you need emotional support leading up to, during, or post-treatment.

Visit their website: *https://outline.org.nz/*
Call them: 0800 688 5463, 7 days a week from 6pm to 9pm!

Support for friends, whānau and caregivers

This part of the guide is for the friends and family members helping someone through their journey with cervical cancer. It provides tips for looking after yourself during this time, how to better understand what your loved one is going through, and how to support them.

KI TE KOTAHI TE KĀKAHO, KA WHATI; KI TE KĀPUIA, E KORE E WHATI.

IF A REED STANDS ALONE, IT CAN BE BROKEN; IF IT IS IN A GROUP, IT CANNOT.

Sharing the load

If you are the main support person for someone with cervical cancer, it's a good idea to ask for help from others. Whether it's help with cleaning, cooking, transport to appointments, providing company/social support, or going to the supermarket.

You could share a calendar/timetable of daily needs to coordinate assistance from family members, friends or people who have offered to help but don't know how. Be sure to try out the services outlined in our 'Support For Those With Cervical Cancer' section.

Support Crew

Support Crew is a free online support platform that helps you coordinate meals and support for family and friends in need.

Visit the website: *https://www.supportcrew.co/*

Financial support

Depending on the situation WINZ may provide financial support for carers. Visit their website for more information: *https://www.workandincome.govt.nz/eligibility/carers/index.html*

Looking after yourself

Make sure that you have your own support system. Don't be afraid to ask for help from others, or to take time for yourself, and don't feel guilty about it. Looking after your own wellbeing is just as important as looking after your loved one. Take time to relax, exercise, spend time with others and do the things you enjoy. Caregiving can be tiring and stressful, so looking after your physical and mental health is important in maintaining the strength needed as a primary carer.

- Talk about how you are feeling with your friends and family members, and seek counselling from a professional, or advice from other caregivers if and when the need arises. See services available at the end of this section.
- Learning about your loved one's condition, treatment, and side effects will help you to cope, and being informed will make you better equipped to provide support. Use the relevant sections of this guide to keep you informed throughout the different stages of the journey.
- Take a look at the *'Day To Day'* section of this guide for services that can help you with the everyday, practical side of things like transport and meal preparation, so that you can conserve your energy for other tasks, or take time to rest.

How to help

Don't underestimate the power of being there. Helping can be as simple as listening. Don't feel like you always have to 'fix' problems, there might not always be a solution. Being a stable sounding board or a shoulder to cry on is enough.

Sometimes your loved one will want to be alone. Don't take this personally, illness is exhausting, mentally and physically. Use the time to do something for yourself.

Your loved one needs to make their own decisions around their illness, there may be times where you need to accept that they aren't in line with your own.

If you accompany them to doctor’s appointments, help them make a list of questions to ask beforehand. Ask questions yourself, and take notes for your loved one, so that you both can remember what was said.

Offer to help with organising a visiting schedule for friends and family, and be prepared to cancel for them if they are feeling too ill, or when alone time is needed.

Advice for those caring for a loved one who is finding it difficult to eat.

As a caregiver, one of your roles may be to make sure that your loved one eats. However, cancer treatment can cause multiple symptoms that make eating and drinking unappealing and physically difficult. Seeing your loved one losing weight is stressful, and when they refuse to eat it can be frustrating or make you feel helpless:

- It’s not always a case of ‘trying harder’ to eat. Remember that loss of appetite may be out of your loved one’s control. It is also out of your control, don’t feel like a failure if you can’t get them to eat.
- Trying to force them to eat can make the problem worse. Have food waiting, or food that’s quick and easy to prepare as the feeling of hunger might not last for long.
- Consult *‘problems eating’* in our ‘*Managing Symptoms and Side Effects*’ section for a range of advice to encourage eating in response to particular side effects of treatment.

> *“Sometimes my partner would ask for food, I would feel so relieved and quickly whip something up for her, but by the time it was done she didn’t want it anymore. One thing that helped was keeping odourless snacks that I knew she liked in the bedside table so that they were right there when the mood struck” — Kevin*

Advice for those friends and whānau who aren't the main carer(s)

> *"One day I asked my friend how she was and if she wanted to catch up. She responded with 'I'm doing chemo', and nothing else. I don't really know why in retrospect, but I thought this meant she just wanted me to leave her alone. I stopped contacting her as much, and found out later that this really hurt her feelings." – Jennifer*

- Don't visit when you are sick! During treatment your friend/family member will be highly susceptible to infection.
- Don't feel offended if they cancel on you, or don't feel like visitors. They will need time to themselves, and will often feel too sick for company.
- Don't assume that if they don't want to see you one day, they won't want to see you the next. Don't badger them, but realise how important you are and that their needs will change day to day. Be consistent in checking in.
- Talk openly with them about their cancer, don't be afraid to ask questions, and most importantly — just be there to listen.
- Check in with their carer for updates and practical ideas for how to help.
- Many people find it difficult to accept help. Sometimes suggesting something specific, like offering to keep them company during a chemotherapy treatment, or cooking a meal is more useful than saying 'let me know how I can help'.

NĀ TE IHO KO TE KŌRERO, NĀ TE WHAKAARO NUI KO TE MŪMŪ

TALKING COMES NATURALLY, SILENCE COMES FROM WISDOM

LISTENING IS UNDERRATED

Counselling and support services for partners, friends, whānau and caregivers

If you are unsure how to help your loved one, or you need some support yourself, there is help available for you, talk to your medical team about counselling options.

Talk Peach

As gynaecological cancer survivors ourselves, we know first-hand the kinds of support from friends/family/carers that was the most useful and meaningful during this difficult time. We also know how tough it can be for the carers and loved ones of those suffering from cancer. If you don't know how to help, or just need to chat:

Contact us through our website: *https://www.talkpeach.org.nz* or email us atinfo@talkpeach.org.nz

Cancer Connect

Cancer Connect offers a free over-the-phone support service for people with cancer, and also for those caring for them. Let them know that you are a carer, or family member and they will peer you with someone who has had a similar experience.

Call: 0800 CANCER (226 237)

PART SIX:
Staying well

This section addresses interrelated aspects of wellbeing (e.g. emotional, physical, social) to help you feel better during this difficult time. Many people with cervical cancer find a new exercise, hobby or way to relax that really helps them cope. Keep an open mind and find what works for you.

> *"During treatment I was in too much pain to exercise and felt really anxious all the time. When my friend suggested meditation I was like I dunno... I think I thought I would feel bored or silly — which at first I did, but then it became my ritual every morning and it still is six years later. I think — don't be afraid to try something new, like if there's something that might help you, go for it." — Claire*

Important! Complementary treatments are used with conventional treatment. Always run any complementary treatments, exercise ideas or special diets by your healthcare team. They will tell you whether it's safe, if there is a better time (during or post treatment, for instance) to try it out, or they may suggest something else.

What is Te Whare Tapa Whā?

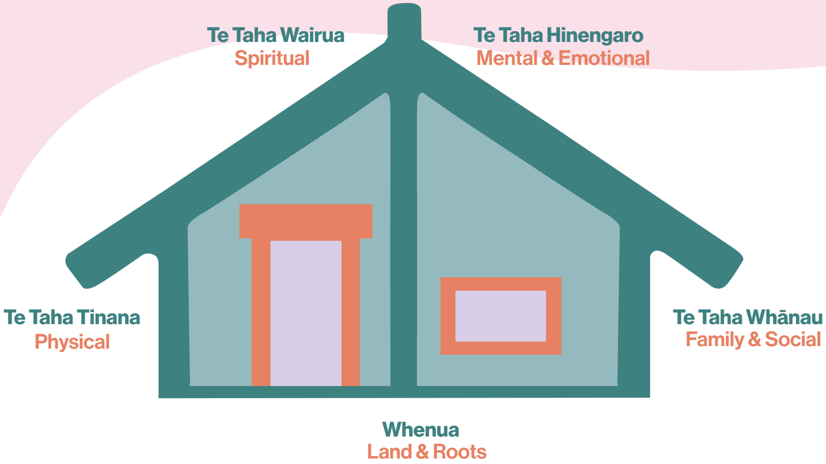
Created by leading Māori health advocate/ahorangi Sir Mason Durie in 1984, te whare tapa whā provides a model for understanding Māori health, but also a framework for anyone wanting to maintain or improve their overall wellbeing.

The model depicts health and wellbeing as a wharenui (meeting house) with four walls or pillars (pou). These four interconnected pou, along with the base, make up an individual's hauora (wellness), and represent the basic tenets of life:

taha wairua spiritual health	**taha whānau** family and social wellbeing
taha tinana physical health	**taha hinengaro** mental and emotional health

The wharenui sits on top of the whenua/land. Our roots — connection to the land and to whakapapa (ancestry) form the foundation of the four pou (pillars) or dimensions of health.

When all these aspects of our health are strong and in balance, we thrive. When one or more pou is weakened or the harmony between them is interrupted or imbalanced, it can result in poor health and wellbeing.



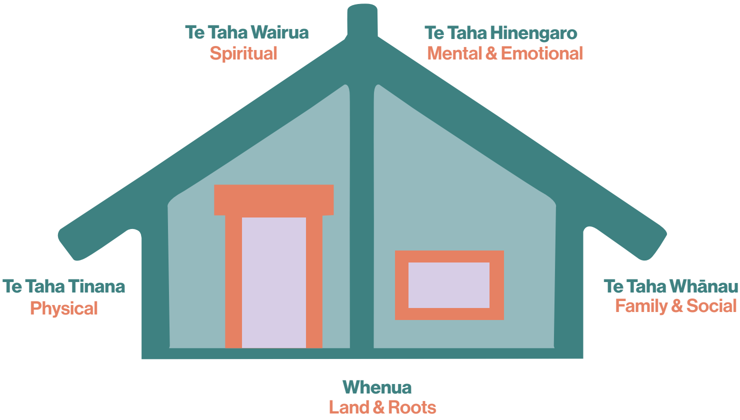
Te Whare Tapa Whā as a Framework for Coping with Cancer

Te whare tapa whā is a way to think about staying well with your 'whole self' in mind. Incorporating aspects of mental, physical, spiritual and family health, te whare tapa whā provides an holistic approach to your wellbeing that is beneficial for anyone on their cancer journey. Whether you are preparing for cancer treatment, undergoing treatment, in the process of healing, living with cancer, or going through palliative care, te whare tapa wha offers a framework for self-reflection at every step.

Rather than focusing on your cancer or on the individual parts of your body affected, te whare tapa whā places attention on all facets of you – such as your emotions, how you care for your body, the people around you, and the sources from which you draw strength. Often during challenging and stressful times all four pou or walls of the house can become depleted. A te whare tapa framework can remind you to take care of all the different dimensions of your life to support your wellbeing and cope with cancer.

POIPOIA TE KĀKANO KIA PUĀWAI

NURTURE THE SEED AND IT WILL BLOOM



The Parts of the Wharenui:

WHAT IT IS	HOW TO NURTURE IT
Taha Tinana (physical health)	
Taha Tinana is about your body's health, how your body feels, and how you nurture it. Our physical being supports our life essence and shelters us from the external environment. Tinana extends to physical activity, the food you prepare and eat, and tikanga around your body, especially bodily functions.	Cancer and treatment can affect things like your appetite, energy levels, and how your body feels inside and out. During this time your physical health may feel outside of your control — and that is okay, just do what you can! Finding small ways to take care of your taha tinana, such as: light physical activity, hydration, sleep/rest, spending time outdoors, healthy eating, physiotherapy, and avoiding alcohol and smoking, will also improve your wairua, mental health, and help strengthen connections — to your loved ones, to your environment, and to yourself.
Taha Hinengaro (mental/emotional wellbeing)	
Your thoughts and feelings fall under taha hinengaro. Healthy thinking, emotional resilience, keeping your mind refreshed and stimulated, and caring for your self esteem are all part of taha hinengaro.	As you cope with cancer, it is common to have difficult emotions and tough thoughts pass through your mind, it is important to acknowledge and accept these feelings and to then try and focus on the things you can control. Finding ways to calm your mind can also help; focussing on the present, using distraction or mindfulness techniques, thinking about things that make you laugh, taking time for self-care, and practising self-kindness. Many people find that learning about their cancer also helps with the mental load — we hope that this guide is useful for you on this journey.

Taha Wairua (spiritual health)

Taha wairua encompasses concepts like awe, strength, gratitude, hope, dignity, personal contentment, cultural identity and connection. It is our life force - what we are, where we come from, where we are going. When you have a healthy connection to wairua, it's easier to feel good, cope with challenges and build stronger relationships.

Wairua is complex and can mean different things for different people. While for many this will be in the form of faith or a belief in a higher power, it doesn't have to mean practising religion. It's about meaning and purpose, and can manifest in any practice that supports self-awareness, identity, and connectedness.

The challenges of cancer can weaken your wairua. At the same time, cancer can lead you to deeply contemplate life and look to things that are bigger than yourself for solace, a time to think about what wairua is for you and to find ways to strengthen it.

Some ideas could include; defining your values, connecting with your culture through your favourite customs or learning a traditional skill, visiting a place of cultural or spiritual significance (marae, family home, church or community centre, your favourite body of water), practising self-kindness and mindfulness, finding ways to connect with nature (e.g. a forest walk, time at the beach, gardening), and sharing food, stories or time with loved ones.

Taha whānau (family/social wellbeing)

Whānau refers not only to immediate relatives but to people who give us our sense of identity and belonging. These can be your family, friends, hoamahi/colleagues, iwi, or community – everyone in your network.

Your relationships with whānau and your wider community can be a support system throughout cancer treatment and recovery. Talk, connect, share, and don't be afraid to ask for help. Find ways to show your love, compassion or appreciation for those special to you; a hug, a chat, sitting in silence with each other, writing a letter or even just sending a cute emoji — whatever you have the energy for!

Whenua (land)	
The four pou of the wharenui rest on whenua – land – which creates the foundation for everything else. Whenua is a comforting connection between earth, nature, animals and people, and it links us to our tūpuna/ancestors. A strong foundation will help you keep balance and look after each of your pou.	Share stories with or experiences with your whānau, explore your whakapapa or family history. You could learn your pepeha and, if you feel up to it, visit your mountain or your river. Catch some rays or take a breath of fresh air, keep some greenery around you, take time to notice your breathing or what you can see and hear outside (the rustling of the trees, bird-song, or an insect going about it's business), keep some greenery around you, enjoy the night sky, or learn about Aotearoa's beautiful wildlife and natural wonders.

Ways to strengthen your pou (pillar)

As you can see, each of the pou have intertwined relationships with one another. For example, the fatigue and loss of appetite you may experience on your cancer journey impacts your taha tinana, but can also lead to feelings of loss or frustration — weakening your taha hinengaro. In turn, a weakened taha hinengaro to do with your cancer could limit your taha wairua, reducing connection with the world around you or even your taha whānau. We need to care for all of the pou, both on an individual and interconnected basis. We believe the below strategies are a useful starting point for exercising this care for all your pou, and building and maintaining your overall wellbeing.

Eating well

Chemotherapy, radiation and surgery increase your body's need for nutrients and energy. Eating a wide range of healthy foods leading up to, during and post treatment will help to enhance your overall wellbeing by improving energy levels, your emotional state, and your body's ability to fight infection and to recover from surgery.

Everyone's needs and preferences will be different, but generally speaking, try to eat a balance of fruits, vegetables, lean protein, legumes, whole grains and low-fat dairy. Stay hydrated! Drink plenty of water and find your favourite, caffeine free herbal teas. That being said, many people find it difficult to eat during treatment and what is most important (at least in the short term) is that you are taking in calories in order to maintain your strength — so if macaroni and cheese or a cookie is what you feel like — then eat it! Generally speaking, there are no specific foods to eat a lot of or to avoid.

To overcome obstacles to eating due to treatment side effects like nausea and sensitive/dry mouth, see 'eating problems' in our *'Managing Symptoms and Side Effects'* section.

Speaking to a dietitian can be very useful, so ask your doctor for a referral or find one here: *https://dietitians.org.nz/find-a-dietitian/*

Exercise

Keeping active is also important for your overall wellbeing. It can help to maintain your bone and muscle strength, to improve your tolerance to chemotherapy, and to relieve fatigue, stress and anxiety — even constipation! The amount and type of exercise you do will depend on your treatment type/stage, and the kinds of symptoms or side effects that you experience.

Don't overdo it, don't force yourself to move about if you are too unwell, and ask your healthcare team for advice about what kinds of exercises are best for you, and what precautions you should take. During treatment gentle exercise is advised, and this may increase in amount and intensity as you move through different stages or start to recover.

This could include:

- Walking
- Yoga, or flexibility exercises
- Tai chi
- Pilates
- Swimming (find a calm lake or pool)
- Strength/resistance training

Sometimes treatment can inhibit balance, so choose exercises that work to enhance balance rather than exercise that relies on it. You don't want to be dealing with any other injuries or pain during treatment!

Therapy

Talking through your illness will be so important for your wellbeing. Talk to your friends and whānau, people you feel comfortable with. Reach out to support groups - these will be filled with people who understand what you are going through, and importantly, don't be afraid to seek professional help from a psychologist or counsellor. Your doctor or healthcare team will be able to recommend a reputable therapist who is experienced in counselling patients through illness. However, you need to find a therapist that suits you as an individual, not just as a cancer patient. Don't be afraid to ask for someone else, or to look elsewhere.

Te Pou has a comprehensive guide on talking therapies, including the different types, why it is useful, and the costs involved.

Download it here: *https://www.tepou.co.nz/resources/a-guide-to-talking-therapies-in-new-zealand*

Or contact them for advice on where to find a therapist that suits your needs: *https://www.tepou.co.nz/*

The following websites provide search engines to help you find accredited counsellors or psychologists in your region:

New Zealand Association of Counsellors
https://nzac.in1touch.org/

New Zealand Psychological society
https://www.psychology.org.nz

Psychology Today
https://www.psychologytoday.com

For a range of free counselling or support see our '*Support*' section.

Complementary treatments

Used alongside conventional treatments, complementary treatments have been known to help manage the side effects of chemotherapy, to reduce stress, and to improve sleep quality.

Physiotherapy, massage and reflexology can help lower cancer-related or muscle pain, relieve nausea, reduce anxiety, and improve sleep which can lessen fatigue.

Pinc and Steel offer free physiotherapy to cancer patients: *www.pincandsteel.com*

Acupuncture can help relieve postoperative pain, fatigue, hot flushes, nausea and vomiting.

Meditation increases self-awareness and reduces stress and anxiety, which may help to control pain and improve sleep. Meditation doesn't just mean sit down and try not to think — there are actually many different kinds, including mindfulness, spiritual, focused, movement, mantra, transcendental, progressive, loving-kindness, and visualisation. Finding the right type may take some research and experimentation, and you could mix it up based on what you need from it at different times. For example, if it's to reduce anxiety, consider mindfulness meditation. To help with chemo brain, try focussed mediation.

Mindfulness practices (aside from meditation) can include: being aware of and controlling your breathing, journalling/writing out your feelings, focussing on the present to help with worries about the unknown, and active self-compassion — all of which can reduce stress and improve outlook.

Further Resources:

Health Navigator New Zealand provides a detailed description of the Te Whare tapa wha model along with some suggestions for nurturing each of your pou/aspects of wellbeing.
https://healthify.nz/hauora-wellbeing/t/te-whare-tapa-wha-and-wellbeing/

They also have some very helpful information on how to better connect with whenua, including their ‘top tips for letting nature in to strengthen your wellbeing’:
https://healthify.nz/hauora-wellbeing/l/let-nature-in-strengthen-your-wellbeing/

Connect with whenua, wairua and nourish your taha hinengaro with Dr Hinemoa Elder’s 2021 book of whakatauki: ‘Aroha – Māori wisdom for a contented life lived in harmony with our planet.’

Nourish your taha whānau with this **‘Create to Heal App’** which aims to provide stress relief for cancer patients and their families through music, art, inspirational messages and meditation: itunes.apple.com/us/app/create-to-heal/id882453467

Take a small step to look after you taha hinengaro (mental health), taha wairua (spiritual health) and taha tinana (physical health) with these mindfulness apps:

‘Headspace’ provides a meditation and mindfulness app: www.headspace.com.	**‘Smiling Minds’** provides a mindfulness app with some helpful guided exercises.	**‘Melon Health’** provides free activities to help with meditation, sleep and mindfulness.

Macmillan cancer support provides a guide to help you nourish your taha tinana (physical health) and become more physically active during your cancer journey: *https://cdn.macmillan.org.uk/dfsmedia/1a6f23537f7f4519bb0cf14c45b2a629/3045-source/mac13314e03move-morelowrespdf20190401?_ga=2.139408435.1698193227.1635287717-875706731.1631656604*

PART SEVEN:

Menopause, Fertility, Sex

This section is designed to inform those who are worried about their fertility options, early/surgical menopause, and how cancer will affect their sex lives.

Fertility

Treatment for cervical cancer can impair your ability to have children, often causing infertility. This is because you could have surgery to remove your uterus (a radical hysterectomy), or radiation therapy which can cause your ovaries to stop working. Some chemotherapy drugs can also affect your ovaries, bringing on early/surgical menopause.

Available options for preserving your fertility will depend on your age, the type and stage of your cervical cancer, and the kind of treatment(s) you will have. Your gynaecological oncologist will outline what is and isn't possible for you based on these factors. For some people, fertility preservation will not be an option.

If your cervical cancer is caught early (e.g. small stage 1) you may be able to have surgery to remove the cancer without removing the uterus so that you still have the possibility of becoming pregnant in the future. You could have a cone biopsy or LLETZ (see our *'Types of Surgery'* section for more information), which removes an area of cervical tissue. However, following these procedures there may be increased risk of low birth weight and premature birth.

Another stage 1 option is a radical trachelectomy where most of your cervix, along with the upper part of your vagina, are removed and a permanent stitch holds the internal opening of the cervix closed. It remains possible to get pregnant/carry your own baby after this treatment, but you will need to have a caesarean section (due to the stitching of the cervix) and again, there is increased risk of premature birth as well as miscarriage.

In vitro fertilisation (IVF) will increase the likelihood of successful pregnancy under these circumstances. However, it is also possible that radiotherapy or chemotherapy treatment after and/or before your surgery damages the ovaries, or causes an earlier menopause – further impairing fertility, or resulting in infertility. There is surgery to protect your ovaries from the effects of treatment, but this may not be suitable for everyone.

> ***"About a year after my treatment I went through IVF, it wasn't easy but I did eventually have a healthy pregnancy. My doctor was really clear and realistic about the likelihood of having a baby after treatment, and what that would entail — it really helped prepare me emotionally." — Jo***

Ovarian Transposition

In ovarian transposition surgery your ovaries are moved away from the targeted area of radiotherapy. This procedure may prevent early menopause, which means you may still potentially be able to have a child or more children through surrogacy.

If you have an ovarian transposition, this needs to happen before radiotherapy starts. The possibility of an ovarian transposition depends on:

- the stage of the cancer
- the risk of the cancer having spread to the ovaries.

Unfortunately, there is no guaranteed success for ovarian transposition. Even if you have the surgery there is a chance you will go through early menopause and be unable to have children.

When treatment involves the complete removal of your uterus, such as a radical hysterectomy, you will not be able to carry your own baby. However, prior to surgery, you may still be able to:

- freeze and store your eggs
- freeze and store embryos – eggs that have been fertilised
- have an operation to move your ovaries (ovarian transposition)

You will need to take into account the risks of delaying treatment, and weigh possible courses of action according to your specific needs.

Keep in mind these procedures are not always possible for everyone, and such services are not available in every hospital. Your healthcare team will be there to guide you through these decisions.

> *“One of the most devastating parts of my diagnosis was finding out I would never have my own baby. I was told that I could freeze my eggs, but that it would be safer to have the surgery immediately. After speaking to some close friends I decided that holding off on the surgery would be too risky. I do know of people who had a similar diagnosis and have had successful surrogacies...it just wasn’t the best option for me, but counselling has definitely helped and so has time” — Tash*

While it won't affect everyone in the same way, infertility after treatment can take a huge toll on your mental health. Many describe an emotional response similar to the grief of mourning a loved one, or a sense of profound loss. We recommend infertility counselling and support groups to help you through this very difficult aspect of your treatment.

Menopause

Usually menopause is a gradual transition occurring naturally with age (between 45 and 55) when periods stop and estrogen levels decline. Often, surgery for cervical cancer can cause early menopause, known as 'surgical menopause'. Your gynaecological oncologist will let you know the likelihood of this happening for you. Going through menopause is no easy feat, especially when its onset is sudden and earlier than expected. Learning about surgical menopause will help to prepare you for the possible changes to your body, and to feel more in control when those changes take place.

Surgical menopause can affect mood, cause fatigue, hot flushes, weight gain, and can weaken your bones and core muscles. Exercise is a fairly reliable means of controlling weight gain and to improve muscle and bone strength — resistance training is particularly good for this. Ask your healthcare team for advice on what kind, amount and intensity of exercise is right for you during and post treatment.

The hormonal changes associated with surgical menopause can also affect your sex drive, arousal and orgasm — see our *'Sex'* section for more info.

Surgical menopause will affect everyone differently. Talk to your health care team about any symptoms that you experience, as there is medication to help with some of them — like hormone replacement therapy (HRT) — otherwise they should be able to give you some advice or point you in the right direction.

Often symptoms will improve on their own, however, it can be hard to predict how long they will persist.

Some questions about HRT to ask your doctor:

- Is HRT right for me?
- Is it safe with my type of cervical cancer?

- What are the different kinds of HRT?
- When is it given and how long will I need it for?
- What symptoms will it help with?
- Will I be given a tablet, patch or gel?
- Are there any alternatives to HRT or treatments alongside it that would help with my symptoms?

For an inspiring, informative and frank discussion on menopause we recommend Dr Jen Gunter's book '*Menopause Manifesto*'.

Sex

Cervical cancer often comes with sexual side effects including lowered sex drive, vaginal dryness, and difficulty with arousal. It can change how you feel about your sexuality, affect your romantic relationships and potentially damage your self-esteem. We understand these can be difficult conversations to have with those close to you (let alone a medical professional) and we know that it is often skimmed over in relevant literature. We hope this section helps with questions you may not have been able to find answers for, or do not feel comfortable asking. For our comprehensive sex and intimacy guide *'Sex and Gynaecological Cancer'*, visit the Talk Peach website: *https://www.talkpeach.org.nz/*

Sex drive

The hormonal changes associated with surgical menopause can lower your sex drive. Often, even if treatment doesn't lead to menopause, other changes to your body and/or the emotional journey of cancer can reduce your desire for sex.

Hormone replacement therapy (HRT) is one of the most common and effective treatments for menopause-related side effects. It can improve your libido, sexual responsiveness and ease other physical and mental side effects that may be inhibiting your sex drive. Talk to your doctor about whether HRT is right for you, how long you will need it for, and which type is the best for your situation.

If your lowered sex drive is due to other changes to your body such as scarring, hair loss, weight gain or loss, or just not feeling like yourself, see our *'Self Image and Intimacy'* section for advice.

Vaginal dryness

The hormonal changes associated with surgical menopause can also cause vaginal dryness and/or itching - which can lead to painful or uncomfortable sex, and in turn this may lower libido and cause difficulty with arousal.

> *"Vaginal dryness is the worst — it made sex really unappealing for a while. I thought maybe my sex life was over — so depressing! At first I had trouble talking about it with my partner — it just ruined the mood because I felt so awkward about it. I think once I became used to having open conversations about menopause, and sought out some good advice, it all got a bit easier." — Sarah*

Luckily, vaginal dryness can be fairly easy to treat, and again HRT is the most common form of treatment. It assists your body in the production of fluid that helps your vagina to self clean, prevents infection and lubricates during sex. Talk to your doctor about whether HRT is right for you. Vaginal moisturisers and water-based lubricants can also be used to relieve dryness.

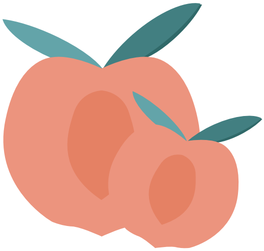
These can be used before/during sex or even on a daily basis — just like you would moisturise your legs if they were feeling dry! Make sure you use sensitive and non-irritant brands.

Self image and intimacy

Changes to your body during and after treatment can cause emotional distress, impact your self esteem, change relationships, and cause intimacy issues.

- If you think your partner is holding back, ask them how they feel. They might not be sexually responsive or want to initiate sex because they are worried about hurting or upsetting you, or they could be feeling confused or guilty about wanting sex while (or even after) you are sick.
- You may be worried about how current or future partners will perceive your illness, or changes to your body. It's important to be kind and patient with yourself. Remember that a lot of the time we are our own worst critics. Open communication with partners, talking with people who have been through similar situations, self-care and therapy will help you regain confidence, sexual or otherwise.
- Take it slow. It may take time and practice to figure out what feels good, or you may need to build up to sex over time with smaller acts of intimacy like cuddling, or a massage.
- Masturbate! Masturbation can help to improve libido, mood and sexual function. It also helps you stay in touch with your body. Experimenting with new positions and/or toys might also help.
- Pelvic floor awareness, exercises to strengthen pelvic floor muscles and relaxation techniques can increase your enjoyment of sex. Knowing what your needs are and being able to assert them can improve the quality of your sex life, and will help you to feel more in control. Learn more about your body and tell your partner what feels good.

- Talk to a counsellor or sex therapist — your doctor may be able to refer you to someone who specialises in sexuality and cancer. It can help to rebuild self esteem or sexual desire on an individual level, and/or the intimacy in a relationship. You could go alone if you want privacy, are worried about future relationships, or just want to work through your own feelings. If you have a partner, you could take them along or ask them to go on their own — it can help open up communication, or to educate them on how cancer can affect sexuality and relationships. If you don't feel comfortable talking about these issues in person, many therapists offer their services online and over the phone.
- It's also fine to just not want sex and be okay with that. If you find you have a lowered sex drive, or would prefer to be alone then absolutely don't feel pressured to do otherwise.



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Project Manager
Natasha Crosby

Author
Anna Langford

Editor
Nadine Ackermann

Design Lead
Zoë Hindle

Image Design
Jess Pressnell

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