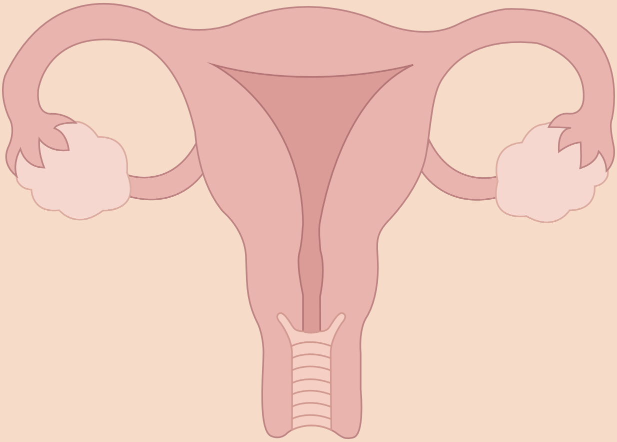
Ovarian Cancer Guide

talk peach
GYNAECOLOGICAL AWARENESS



Letter to all those affected by ovarian cancer

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

Ovarian cancer can be a difficult journey, it is imperative that you have all of the information and support that you need at your fingertips - that 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 battling and 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.

Raising awareness with evidence based, body positive, inclusive gynaecological education and support.

> *“For more than 2 years I was misdiagnosed.” - Kimberly*

Our Story

Founder, Tash Crosby, launched Talk Peach because she’s been there, and very nearly wasn’t here to tell the tale. Diagnosed in 2016 with ovarian cancer, Tash is among the 15% of those caught at stage one; 85% of those diagnosed are caught in the later stages of the disease when treatment options are more limited.

Because of this, 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.

> *“My knowledge of ovarian cancer was minimal, I had never considered it a possibility.” - Rosie*

We’re also here to connect and support those who are diagnosed, help those who have been diagnosed to 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, ovarian cancer, and support available through our website:

https://www.talkpeach.org.nz/

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PART ONE:
Diagnosed

Diagnosed

> *"[I was told] I would need surgery and chemotherapy once I had recovered. It is impossible to describe the feeling of being told this. It was a very emotional and exhausting time" - Charlene*

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

> *"I was so shocked when I was diagnosed, I thought - why me!?" - Tash*

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 whatever approach you take, it is valid.

> *"The day I was diagnosed I was handed a slip of paper from a charity that wasn't from New Zealand ..." - Rosie and Tash*

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.

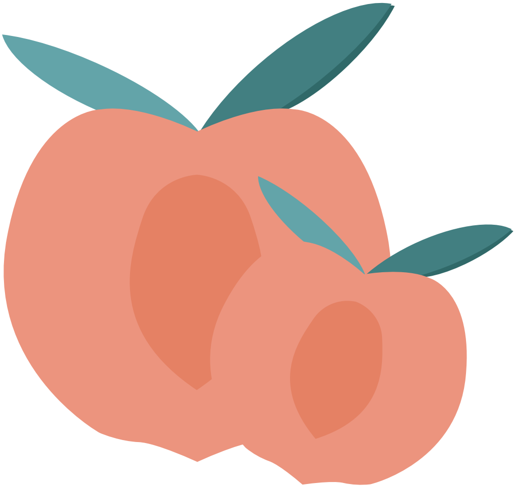
Pathway to diagnosis

Signs and symptoms

Ovarian cancer often has symptoms that are difficult to detect in the early stages. Later stages are associated with symptoms, but they can be non-specific.

They may include:

- Increased abdominal size/ persistent bloating – not bloating that comes and goes
- Fatigue
- Pain during sex
- Frequent need to urinate or an urgency to go
- Change in bowel habits (loose stools/constipation/painful bowel movements
- Abdominal or pelvic pain
- Back pain/aches
- Menstrual irregularities
- Indigestion
- Unexplained weight loss or weight gain



Screening

There has been a lot of research to develop a screening test for ovarian cancer, but there hasn't been much success so far. The 3 tests used most often to check for ovarian cancer are a pelvic examination, transvaginal ultrasound and a CA-125 blood test.

Pelvic Examination

A doctor or nurse examines your vulva and your internal reproductive organs — your vagina, cervix, ovaries, fallopian tubes, and uterus. This examination requires the doctor to place one or two fingers into the vagina and another over the abdomen to feel the size, shape, and position of the ovaries and uterus. Ovarian cancer is rarely detected in a pelvic examination and usually in an advanced stage if it is.

Transvaginal Ultrasound

A transvaginal ultrasound is a test used to examine the reproductive organs and bladder, and can often reveal if there are masses or irregularities on the surface of the ovaries and within cysts that form inside the ovaries. To administer the test, the doctor inserts a probe into the vagina. The probe sends off sound waves which reflect off body structures. The waves are then received by a computer that turns them into a picture. An ultrasound alone is not an accurate way to screen for ovarian cancer.

The CA-125 Blood Test

Measures the amount of a protein called CA-125 in the blood. CA-125 is a substance in the blood that can increase when a cancerous tumour is present; this protein is produced by ovarian cancer cells and is elevated in more than 80 percent of those with advanced ovarian cancers and in 50 percent of those with early-stage cancers.

Used alone it is not a reliable early detection test for ovarian cancer. In about 20 percent of advanced stage ovarian cancer cases and 50 percent of early stage cases, the CA-125 is not elevated even though ovarian cancer is present. This varies depending on the type of ovarian cancer. As a result, doctors generally use the CA-125 blood test in combination with a transvaginal ultrasound. CA-125 can be elevated by non cancerous conditions such as endometriosis and pelvic inflammatory disease.

CT Scan

CT scans take cross-sectional images of the tissues and bones within the body. CT scans help define the boundaries of a cancerous tumour and show the extent of tumour spread, helping a doctor determine where to operate.

None of the above tests are definitive when used on their own. They are most effective when used in combination with each other. To confirm the presence of ovarian cancer suspected by the tests, there will either be a surgical biopsy of the tumour tissue, or a CT guided or USS guided biopsy.

Surgery and Biopsy

This is the only definitive way to determine if a patient has ovarian cancer. Doctors will perform surgery after they obtain enough evidence from the above examination and test results and feel that there is sufficient evidence that ovarian cancer is present.

A laparotomy or laparoscopy is performed depending on what the CT shows/ how large the tumour is or how far the cancer has progressed.

A laparotomy is a surgical procedure involving a long incision in the wall of the abdomen to remove fluid and tissue, such as the ovaries, fallopian tubes, uterus and connecting tissue, depending on how far the cancer has spread.

Laparoscopic surgery is when a thin tube with a camera (a laparoscope) is used and that allows the doctor to see and remove tissue.

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 will 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, and for 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 ovarian cancer and its possible treatments empowering, or a way to feel more in control of their situation. Focus on 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 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 **Talk Peach 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. 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 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.

> *"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*

- 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 *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. 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
- GPs or specialist doctors (oncologist, surgeon)
- Cancer (oncology) nurses
- Dieticians
- Physiotherapists

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

Looking after yourself

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 - 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.
- Eat a variety of nutritious foods. This helps with strength to manage treatments and their side effects. Consult with your doctor, a dietician or people 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; or to talk them out, get a fresh perspective or some advice. Invite a close friend over for a movie, go for a walk, or something 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.

> *"Since my diagnosis my team of nurses, surgeons and oncologists have been incredible." - Lea*

Ovarian 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 ovarian cancer is.*

> *"I had never heard of ovarian cancer prior to this [diagnosis] and I did not know that cervical smears could not detect it" - Eve*

Cancer

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

The ovaries are about the size of almonds, one on each side of the uterus, near the ends of the fallopian tubes. The ovaries make the hormones oestrogen and progesterone. They also produce eggs which travel through the fallopian tubes to the uterus. During menopause the ovaries stop producing eggs and hormone production is reduced.

Ovarian cancer

There are five gynaecological cancers, and ovarian cancer is one of them. It arises from the cells in and around the ovary. Ovarian cancer is most common after menopause, however, it can affect anyone with ovaries at any age. There are several different types, depending on which part of the ovary they come from. The most common types are epithelial cancers, which arise in the lining of the ovary, fallopian tubes or the peritoneum (the lining that covers the organs inside your abdomen).

Main types of ovarian cancer

Epithelial Ovarian Cancer

This starts in the epithelium (the cells that cover the ovary). The most common type - nine out of ten ovarian cancers are epithelial.

Germ Cell and Sex-Cord Stromal Cell

Germ cell and sex cord-stromal tumours are rare, comprising less than 15% of ovarian cancers combined. Germ cell tumours typically affect those who are younger, present in early stage disease and respond well to treatment.

Of the different types of sex cord stromal cell, granulosa cell tumours are the most common. Typically they affect those aged 50-55 years. They often present early and surgery is the mainstay of treatment. Fertility sparing surgery can be considered for both germ cell and sex-cord stromal cell tumours.

Borderline Tumours

A group of epithelial tumours which have a lower risk of spreading than other types of tumours. These are tumours that are neither completely benign nor full-blown cancer. The cells are slowly dividing and are not likely to be invasive. The treatment usually consists of surgery only.

For information regarding rare ovarian cancers visit:
https://ocrahope.org/ocrahope.org.

For information regarding low-grade serious ovarian cancer contact:
Cure Our Ovarian Cancer: *https://cureourovariancancer.org/nz*

Risk factors

In most cases there is no clear reason why you have ovarian cancer. However, some risk factors can include:

Family history

Ovarian cancer can occur within families. Your chances of getting ovarian cancer are increased if other family members have previously been diagnosed with the disease. Please note that Increased risk for ovarian cancer can come from your mother or father's side. Personal or family histories of other cancers including those of the breast, uterus, colon or rectum, may also increase the likelihood of ovarian cancer.

Having a family cancer syndrome

Hereditary breast and ovarian cancer syndrome is caused by inherited mutations in the genes BRCA1 and BRCA2 - these are the most common, but more is being learnt about other genes that may be involved.

This syndrome is linked to a high risk of breast cancer as well as ovarian, fallopian tube, and primary peritoneal cancers (peritoneal cancer is a rare cancer, It develops in a thin layer of tissue that lines the abdomen. It also covers the uterus, bladder, and rectum).

The lifetime ovarian cancer risk for those with a BRCA1 mutation is estimated to be between 35% and 70%. This means that if 100 people had a BRCA1 mutation, between 35 and 70 of them would get ovarian cancer.

For those with BRCA2 mutations the risk has been estimated to be between 10% and 30% by age 70. In comparison, the ovarian cancer lifetime risk for those in the general population is less than 2%.

Age

The risk of developing ovarian cancer gets higher with age. Please note that ovarian cancer can affect people of ALL ages, it does not discriminate, it is the risk that increases with age only.

Having children later in life or never having a full-term pregnancy

People who have their first full-term pregnancy after the age of 35 or who have never carried a pregnancy to full term have a higher risk of ovarian cancer.

Being overweight

Obesity has been linked to a higher risk of developing many cancers.

Taking hormone therapy after menopause

Some research suggests that using estrogens after menopause can slightly increase the risk of developing ovarian cancer. For some, the benefits of taking HRT may outweigh the risks, so talk to your GP about your options

You have previously been diagnosed with breast cancer

If you have had breast cancer, you might also have an increased risk of developing ovarian cancer. Why? Some of the reproductive risk factors for ovarian cancer can also increase breast cancer risk. The risk of ovarian cancer after breast cancer is highest in those people with a family history of breast cancer. A strong family history of breast cancer can be caused by an inherited mutation in the BRCA1 or BRCA2 genes.

PART TWO:
Treatment

Planning your treatment

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 ovarian cancer you have, the stage (the size of the tumour and how far it has spread) and grade (how abnormal the cell is) of your ovarian cancer, your age, and your general health.

Almost all those diagnosed with ovarian cancer require surgery. For many, treatment will require a combination of surgery and chemotherapy:

Surgery

During surgery, doctors attempt to remove all visible tumours (tumour debulking). 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 - for earlier stages surgery may be the only treatment needed, but chemotherapy can still be an important component. For more advanced stages chemotherapy is generally offered along with surgery. Chemotherapy can take place on its own when surgery isn't recommended, before surgery in order to shrink the tumour, afterwards to help prevent the cancer returning, or before and after surgery - again this will depend on the type and stage.

Chemotherapy

Chemotherapy uses drugs to kill or slow the growth of cancer cells. The pros and cons of chemotherapy will be discussed with you by your doctor. Medical oncologists are doctors who specialise in chemotherapy treatment.

Chemotherapy may be given before or after surgery. It can be used when the cancer is first diagnosed or if the cancer has come back. Occasionally it can be used with radiation. Chemotherapy for ovarian cancer is typically given as an injection into a vein (intravenously). You will usually have a number of treatment sessions, followed by a break. There may be some tablet types of treatment for some situations but this is less common.

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.

Treatment by stage

Staging

If ovarian cancer is diagnosed, the next step is to identify its stage and grade. All cancers are given a ‘stage’. The stage indicates the extent of the cancers spread throughout the body.

Stage	What this means
1 (early)	Cancer cells affect only the ovary or ovaries and have not spread to another area.
1a	The cancer is contained inside one ovary.
1b	The cancer is contained inside both ovaries.
1c	The cancer is in one or both ovaries as well as some on the surface of an ovary, or in abdomen fluid during surgery or the ovary ruptures before/during surgery.
2	The cancer has affected one or both ovaries and also other organs within the pelvis, such as the uterus, fallopian tubes, bladder, or rectum.
2a	The cancer has spread to the uterus or fallopian tubes, or both.
2b	The cancer has spread to other nearby organs which may include the surface of the bladder, uterus, fallopian tubes, bladder, sigmoid colon or rectum.

Stage	What this means
3 (advanced)	The cancer affects one or both ovaries and either the lining of the abdomen or lymph nodes in the back of the abdomen.
3a	Very small (only visible through microscope) cancer cells in abdomen lining/lymph tissue
3b	Visible tumours (up to 2cm) across abdomen lining.
3c	Tumours larger than 2cm across abdomen lining. They may have also spread to lymph nodes.
4 (advanced)	The cancer has spread to other parts of the body, outside the peritoneal cavity. This cavity includes the abdomen and the pelvis. Areas that may now be affected include the liver, spleen, and the fluid around the lungs.

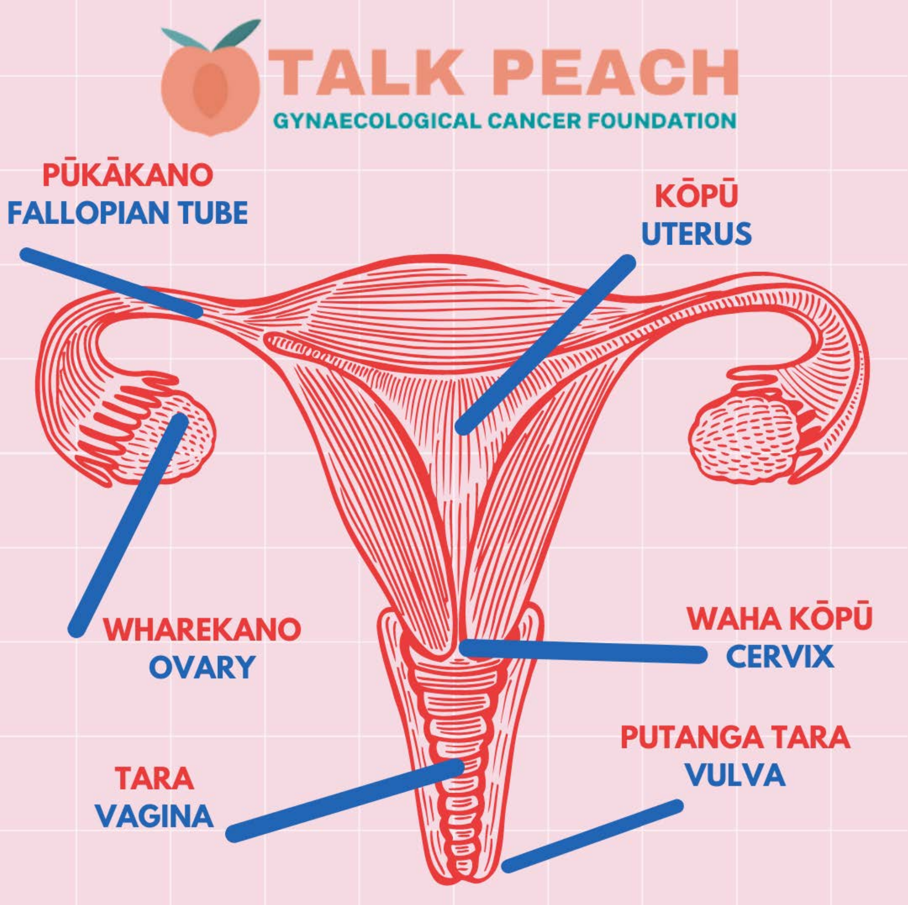
* **85% of those with ovarian cancer are diagnosed in it’s advanced stages (3 and 4)**

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.

You may have an operation to remove:

- The ovaries and fallopian tubes (a bilateral salpingo-oophorectomy)
- The uterus (a total abdominal hysterectomy)
- As much of the cancer as possible (debulking)



During your operation, the gynaecological oncologist will examine the abdomen for signs of cancer. They might then perform what is called ‘debulking’ where they remove as much of the cancer as possible if it has spread to other areas in your pelvis or abdomen. This makes chemotherapy more effective because there are fewer cancer cells to target.

In some cases they may remove part of the omentum (a fold of protective tissue which connects the abdominal organs. This fatty lining contains lymph nodes, lymph vessels, nerves and blood vessels) and any other affected tissues. This could involve removing part(s) of the bowel.

This may - but very rarely - result in temporary colostomy or stoma. There may be some cases where the colostomy is permanent. In these cases you are given support and guidance from a stomal therapy nurse. There is also a New Zealand based stoma support group called Ostomy New Zealand: *https://ostomy.org.nz/*.

Your pelvic area (and sometimes para-aortic) lymph nodes are also checked for cancerous cells and can be used to determine the stage of cancer. It will then also be determined whether it is necessary to remove them.

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 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 your surgeon or anaesthetist 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 a 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

Ovarian cancer surgery will leave a wound, as most operations do. This will likely run from your pubic hairline to your belly button, and sometimes just above it. This is where you may have the abdomen tubes mentioned earlier. The surgery can also be done laparoscopically, which reduces scarring, as it is done with two small incisions. The method will be confirmed by your surgeon.

This wound will 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).

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

In most cases, your healthcare team will advise you of a few activities to avoid while you recover. This can include heavy lifting, housework and driving, as well as sex.

There can also be complications that arise from your operation - as with any surgery. This may include:

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, or smells and is a green or yellow 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. Again, 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, and 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 build up 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.

Chemotherapy

Chemotherapy uses anti-cancer drugs (usually carboplatin and paclitaxel for epithelial ovarian cancer) which circulate throughout the body in the bloodstream to kill the cancer cells, or to slow down or stop their growth. The choice of cancer drug depends on the type of ovarian cancer and stage of the cancer.

Your oncologist will explain what happens during chemotherapy and at what point it will be administered - on it's own, before or after treatment, or both. 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.

You may require chemotherapy if your cancer is:

- Stage 1c or above.
- At an earlier stage (1a or 1b), but is high grade.
- Has come back after you were first treated (recurrence).

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 felt to be 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 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
- Hot and cold episodes
- A lowered resistance to infections
- Bleeding and bruising easily
- Diarrhoea or constipation
- Hair loss
- Rash/skin changes

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 I know if it's working?

Your doctor will monitor how well your chemotherapy has worked using CA125 blood tests and scans.

How do the doctors decide what treatment to give?

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

TIP - Keep a record of your treatment schedule, the side effects you experienced at different stages and what helped you manage them.

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, fatigue and 'chemo brain' - see our **'managing symptoms and side effects'** section for more information .

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.

Research

Your doctor may talk to you about research that is going on in ovarian cancer. Sometimes this may offer different treatments that would otherwise not be available or it may help us understand the disease better or how to improve the quality of your experience. Talk through the options with your doctor, your whānau and friends.

PART THREE:

Managing symptoms and side effects of treatment

Chemotherapy destroys, stops or slows the growth of cancer cells and makes them less likely to grow back. However, chemotherapy also affects healthy cells and this is what causes its side effects. The side effects will vary - person to person, day to day, week by 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 chemotherapy side effects 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 - avoid adding salt before you taste it.

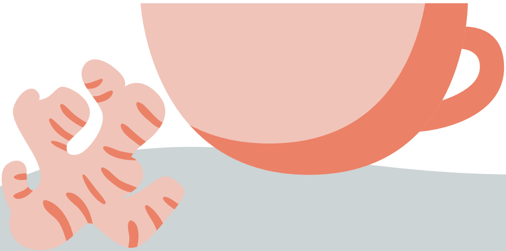
Mouth care and swallowing difficulties

Sometimes chemotherapy can affect the salivary glands causing dry mouth, or it can cause thick saliva or mucus that can make eating difficult.

- 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.
- 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 dietician 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 to experience a loss or lack 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 will 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 dietician (or ask your caregiver to). 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 those sections above.
- Determine which times of day you are hungry and eat at those times. This may vary though- 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 dietician 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 ie. 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 controlled.
- 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.

- 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 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:

- **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"

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

It remains unclear if this is specifically due to the chemotherapy or includes stress-related factors or hormonal changes, but it can be incredibly frustrating as you recover - many who have undergone chemotherapy 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. Contact your doctor if your hearing changes, you feel dizziness, or you experience ringing in your ears.

Skin problems

Chemotherapy can have side effects for your skin, including dryness, itching, redness or breakouts. Similarly, radiotherapy can result in dry or red skin where the treatment occurs.

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 - make sure to use SPF30+ sunscreen.

Lowered resistance to infections

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 nose bleed or bleeding gums
- You are bruising very easily
- You have 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. Similarly, ensure you continue practicing good COVID-19 pandemic behaviours - always wash your hands thoroughly and minimise close contact with others, particularly in public areas.

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 with 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.

Infertility after treatment

When ovarian 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 **menopause, fertility and sex** section for more information, advice and support.

Hair loss

Chemotherapy for ovarian 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.

PART FOUR:

Wigs and hair loss

The Talk Peach guide to all things hair

Why does chemotherapy cause your hair to fall out? How can I prepare for this?

Are there any special tips for taking care of my hair during chemotherapy treatment? How long until it grows back?

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 regimens use different combinations of drugs depending on what 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, if it's short you will only have to deal with shorter hair strands falling and this can be helpful when it comes to the shower, 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 also 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.

TIP: Look on YouTube for wig reviews - you can check out ones you like on real people and they are often reviewed by people who have alopecia and wear wigs a lot - so they know what they’re talking about!

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.

TIP: Hats. Get plenty! They’re great to put on over a wig if you have one that’s having a ‘no, I’m not behaving’ day.

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/hair piece 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.

www.health.govt.nz/system/files/documents/pages/wigs-section-88-notice.doc

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 (eg, 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 inc- at the time of writing this document) over a 1-year period. You can claim all of or part of your $408.88 entitlement at any time over the 1-year period.

PART FIVE:
Support

Support for those with ovarian cancer

Dealing with ovarian 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 ovarian 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-to-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.

Cancer Society

Cancer Society offers a wide range of services. They can help with practical problems - like getting to medical appointments. Their cancer helpline can help you understand your treatment options or lend an ear when you just need to chat, they also offer one-to-one support, psychology or counselling, and can connect you to support groups in your local area.

Visit their website: *https://www.cancer.org.nz/*

Call their cancer Information Helpline: 0800 226 237

Send them an email: *info@cancersoc.org.nz*

Chat with people who've had similar cancer experiences:
https://www.cancerchatnz.org.nz/

> *"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*

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*.

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).

Ripple App

A 24/7 cancer support app that connects you with someone who has had the same cancer for advice and support. You can download the Ripple App for free from: Android Google Play, or iOS App Store.

Ovarian Cancer New Zealand Support Group

A Facebook support group which was founded specifically to support those who are going through, or have gone through ovarian cancer.
https://www.facebook.com/groups/OvarianCancerNZSupport

Look Good Feel Better Charity

Offers support to people with any type of cancer at any stage. They 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*

Dove Hospice

Offer a variety of services - offered to anyone with cancer, at any stage - including; art therapy, massage, reiki and skin care.
https://www.dovehospice.org.nz/is-dove-hospice-for-you

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 that is available for 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. For more information 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 that WINZ provides.
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 the ones 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-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 ovarian 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.

Sharing the load

If you are the main support person for someone with ovarian 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 ovarian 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, 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 a 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 that's quick and easy to prepare when they ask for food - 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 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 striked" - Kevin*

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

- 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.

> *"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*

- 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'.

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:

Cancer Society

Cancer Society offers free counselling for people with cancer and their whānau. They can help you deal with the effects of cancer on your relationships and guide you through different ways of providing support.

To see what counselling services are available in your area:

Visit their website: *https://www.cancer.org.nz/*

Call their cancer Information Helpline: 0800 226 237

Send them an email: *info@cancersoc.org.nz*

Talk Peach

As ovarian 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 at *info@talkpeach.org.nz*

Cancer connect

Cancer connect offers a free over the phone support service for people with cancer - but 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 emotional and physical wellbeing to help you feel better during this difficult time.

> *"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*

Many people with ovarian 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.

* **Important:** Complementary treatments are used with conventional treatment - they are not an alternative. Always run any complementary treatments, exercise ideas or special diets past your healthcare team. They will tell you whether it's safe, if there is a better time during or post treatment to try it out, or suggest something else.

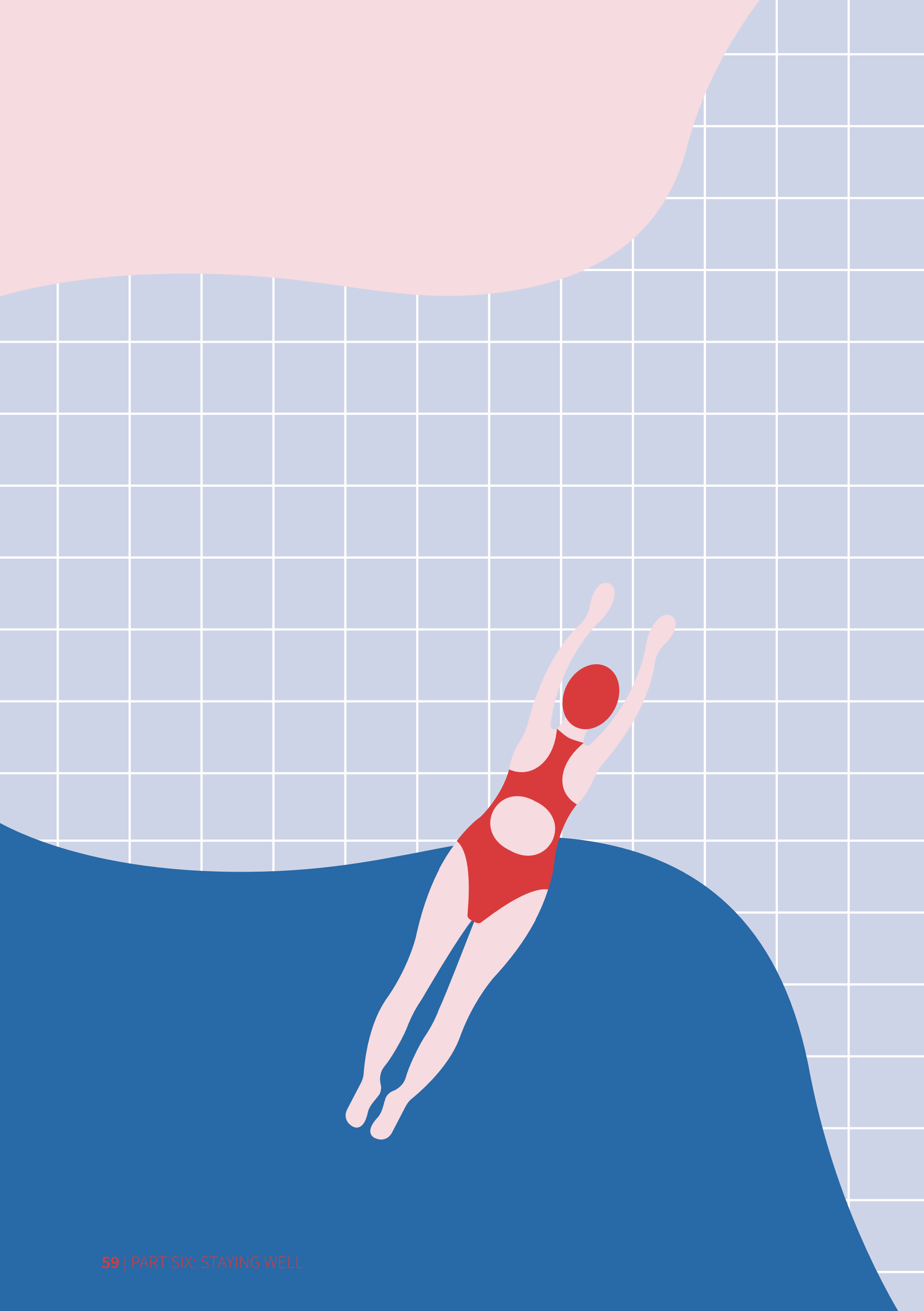
Eating well

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 well being by improving energy levels, your emotional state, and your body's ability to fight infection and to recover from surgery.

Everyones' 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 dietician can be very useful, 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 well being. 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://www.nzac.org.nz/search-for-a-counsellor/

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 treatment

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 visualization. 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 - maybe go for mindfulness meditation, to help with chemo brain - try focussed mediation.
- Mindfulness aside from meditation, mindfulness practices can include being aware of and controlling your breathing, writing out your feelings, focussing on the present to help with worries about the unknown, and self compassion - all of which can reduce stress and improve outlook.

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

When ovarian cancer is diagnosed at childbearing age it can impair your ability to have children and in some cases cause infertility.

Available options for preserving your fertility will depend on your age, the type and stage of your ovarian 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 ovarian cancer only affects one ovary - because it is caught early or you have a germ cell or stromal cell tumour - the uterus can sometimes be preserved and the other ovary may retain its fertility. In vitro fertilisation (IVF) will increase the likelihood of successful pregnancy under these circumstances. However, it is also possible that chemotherapy treatment damages the remaining ovary, 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*

If your treatment involves the removal of both ovaries, fallopian tubes, and the uterus, you will not be able to carry your own baby. However, you may still be able to freeze or bank your eggs, embryos or ovarian tissue. Here, surrogacy can be a viable option, but it will not be possible for everyone.

> *“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. It wasn’t until after treatment that it really hit me. It will always hurt a little, but counselling has definitely helped” - 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 ovarian 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 ovarian 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

Ovarian 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 damage your self esteem. We understand these can be difficult conversations to have with those close to you - let alone a medical professional - and 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.

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 kind is the best for your situation.

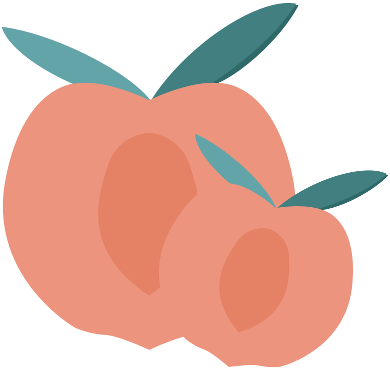
If your lowered sex drive is due to other changes to your body such as scarring, hair loss, weight gain or loss, or just not feeling like yourself, see our '**self image and intimacy**' section for advice.

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, changes to your body, or your feelings. 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 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.

Acknowledgements

This guide is in honour of all those whose lives have been affected by ovarian cancer.

Thank you to our incredibly strong ovarian cancer community and their families who contributed to this guide - *we see you, we appreciate you, we fight for you.*

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talk peach
GYNAECOLOGICAL AWARENESS

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Notes

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https://www.talkpeach.org.nz
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