

TE TAUWHIROTANGA WHAI MURI I TE MATE PUKUPUKU

CANCER FOLLOW UP CARE WHEN TREATMENT ENDS



Cancer Follow Up Care

'I feel like the team are still very supportive of me as a young person who has to face late effects of treatment.'

Young person

Now that you have finished treatment, you might have questions about what your healthcare looks like moving forward.

The type of follow-up you receive and how often your appointments are, depends on a few things including where you were treated, the type of cancer treatment you had, when you completed treatment and whether you are experiencing any late or on-going effects.

There are three main reasons for follow-up:

1. To check there are no signs of the cancer coming back.
2. To monitor your health for any health problems or 'late effects' related to the cancer treatments you received.
3. To ensure you are staying healthy as you move into survivorship.

You may have questions for your medical team about follow up care. These might include:

- Why do I need check-ups?
- How often will I need to come in for check-ups?
- What tests and scans do I need?
- Who will be responsible for my follow-up care?
- What should I do if I feel ill?
- Who can I contact if I'm worried about something?
- What should I look out for?
- Am I at risk of getting any late or long-term complications?



Life and Health Insurance

If you already have cancer, it can be difficult to apply for a new health, life or disability insurance policy. Normally when you sign up you will be asked to complete a full medical statement for the insurer and you must disclose everything about your health. In New Zealand, all companies must genuinely attempt to offer you insurance because of the Human Rights Act, but there will likely be restrictions on what you can access with a pre-existing medical condition like cancer. To help you work out what insurance company or policy is best for you and your needs, it might be a good idea to approach an insurance broker. Most insurance brokers do not charge for this service but liaise with insurers on your behalf to find the best deal. Check out www.nzbrokers.co.nz for more information.



Notes

What to expect in the first few months after treatment

Most young people will have follow-up appointments every 2 to 4 weeks at first. As time goes by, your appointments will be more spaced out.

When can I stop worrying about infection?

When you finish treatment, you may still have a central line in place and have low blood counts. It may also take several months for your immune system to recover. If you develop a fever or become unwell, contact your health-care team immediately as you may need to come to the hospital for antibiotic therapy.



If you are still on antiviral medication to help boost your immunity, it is important to keep taking this medication until you are told to stop. You may also be more susceptible to infections during this time so if you're exposed to illnesses such as shingles, chicken pox or measles, and your immune system is still compromised, contact your health-care team immediately for guidance.

When can my central-line be removed?

Some young people may have had a central-line or port-a-cath inserted before beginning treatment. Most of the time this will be removed shortly after completing treatment. Ports are usually removed in the operating theatre and PICC (Peripherally Inserted Central Catheter) and central lines are removed in the procedure room at clinic or in the radiology department. These are minor surgical procedures and generally you will have minimal discomfort that may last one or two days.



It is important to stay away from baths, spas and swimming after your port has been removed, until you are healed.

Will I still have to take medicine?

Following intensive treatment, you may have to continue to take some medications. It is important you take these medications, as they will help aid your recovery.



If you have questions about the medications you are taking, talk to your healthcare team.

What about immunisations?

Chemotherapy delivered during treatment can affect the immunity you had from childhood immunisations, so you may need to repeat some immunisations. You may need to complete a blood test to see if any boosters are required. These are often repeated 6 - 12 months after treatment.



Ask your healthcare team if you require your childhood immunisations again. Keep track of when you need to have them and put them in your diary.





What to expect with Long Term Follow-Up care

With long-term follow-up, the goal is to help you stay as healthy as possible and to monitor you for any late-effects or signs of recurrence. It is important to remember that cancer returning is not common in young people, but if you are worried about any symptoms, ask your healthcare team for guidance.

Everyone keeps talking about late-effects but what are they?

Late-effects refer to health impacts from the cancer treatment you received. These may not appear until months or years after treatment. The effects can range from mild to serious and depend on many different factors including what kind of cancer you had, where it was in the body, how it was treated (i.e. surgery, radiation therapy, chemotherapy or bone marrow transplantation) and how old you were at the time. Late effects can present themselves in any part of the body and can include:

- Lung, heart, kidney and liver problems
- Fertility and sexual health issues
- Bowel problems
- Thyroid issues (e.g. changes to your metabolism/energy/hormone levels)

- Tooth decay
- Osteoporosis (changes in bone density, bones becoming softer or weaker)
- Memory and concentration problems
- Cataracts (clouding of lens in the eye)
- Changes to the body from surgery/amputation
- Developing another type of cancer

Not everyone will go on to have long-term or late-effects. Even if you had the same type of treatment as someone else, this does not mean you will experience the same long term, or late effects.



Ask your healthcare team about potential late-effects. They can help detect these and support you to manage any challenges you might have.

What happens when I come to clinic?

Prior to attending clinic, you may have had blood tests, an x-ray, an MRI or a CT scan. At your appointment you will be weighed, measured and have your blood pressure checked. The doctor will ask how you are feeling and will give you a physical examination. Depending on the treatment you had, you may also need other tests such as a heart scan.

Tip Write down your follow-up appointments and/or save them into your phone so you don't forget. Make sure you have any tests that are required **before** coming to clinic so your health care team has all the information they need for your appointment.

What role does my GP (General Practitioner) have in my cancer follow-up?

Your GP (local doctor) is your first point of contact for your everyday health issues. It's important you have a good relationship with your GP, so you feel comfortable talking to them and are confident they will take care of you. If you don't, let someone know so you can change to a different GP.

Tip We advise that you make an appointment to meet with your GP soon after finishing treatment. Talk about how you're feeling, your cancer treatment and current health. You may be entitled to a Community Services Card which will reduce the cost of GP appointments. Speak to WINZ for more information about this.

What do I talk about during a follow-up visit?

It's important to talk to your healthcare team about any emotional or physical challenges you're having. This is your opportunity to talk about any symptoms or concerns. Physical problems might include fatigue (tiredness), bowel problems, sexual function, memory changes, trouble sleeping, weight gain or loss, or fertility issues.

Tip It's common for young people to struggle in the first year or two after completing treatment. Remember your psychological wellbeing is just as important as your physical wellbeing, so make sure you discuss any feelings such as anxiety or low mood so you can access support.

Check out the wellbeing checklist on the next page.



Late-effects refer to health impacts from the cancer treatment you received

Use this wellbeing checklist to keep track of the things that are impacting on your current health. If you write in pencil you can reuse the form, or take a photo and bring to your appointment.

Wellbeing Checklist	
Physical / Taha Tinana	Emotional / Taha Hinengaro
<input type="radio"/> Fatigue (low energy) <input type="radio"/> Pain <input type="radio"/> Trouble sleeping <input type="radio"/> Constipation/Diarrhea <input type="radio"/> Sleep challenges <input type="radio"/> Body Image/Physical appearance <input type="radio"/> Adjusting to new disability - support services <input type="radio"/> Weight Loss/Gain <input type="radio"/> Side effects from treatment <input type="radio"/> Dental issues <input type="radio"/> Physical exercise tools and resources <input type="radio"/> Nutrition and Healthy Eating	<input type="radio"/> Worry/Anxiety <input type="radio"/> Low Mood/ Depression <input type="radio"/> Anger/Frustration <input type="radio"/> Losing people I care about <input type="radio"/> Feeling helpless/hopeless <input type="radio"/> Feeling alone/isolated <input type="radio"/> Feeling like 'it's all too hard' <input type="radio"/> Fear/worry about the future <input type="radio"/> Low self esteem <input type="radio"/> Access to Psychological/Counselling support <input type="radio"/> Flashbacks/nightmares from cancer treatment <input type="radio"/> Need info on self-care tools and resources
Sexual Health & Fertility/Hauora Tōkai me te Taupiri	Concentration / Te Hihiwatanga
<input type="radio"/> Fertility status unknown <input type="radio"/> Unsure of fertility options <input type="radio"/> Unsure where to seek fertility support <input type="radio"/> Contraception and Sexual Health Services <input type="radio"/> Intimacy and changes to Sexual Health	<input type="radio"/> Short attention span <input type="radio"/> Memory loss - trouble remembering things <input type="radio"/> Taking longer to finish things than before <input type="radio"/> Brain Fog <input type="radio"/> Trouble concentrating
Social / Taha Whānau	Family / Taha Whānau
<input type="radio"/> Feeling different to friends/others <input type="radio"/> Finding it hard to socialise <input type="radio"/> Feeling left behind <input type="radio"/> Romantic relationships <input type="radio"/> Challenges talking to others about cancer <input type="radio"/> Access to social supports & peer support <input type="radio"/> Friendships	<input type="radio"/> Finding it hard to talk to loved ones <input type="radio"/> Feeling responsible for family members <input type="radio"/> Worry about impact cancer has on others <input type="radio"/> Feel the need to 'protect' everyone <input type="radio"/> Struggling with place in whānau <input type="radio"/> Supports and resources for whānau <input type="radio"/> Cultural Support
Education and Employment / Kura & Mahi	Survivorship / Te Mōrehutanga
<input type="radio"/> Challenges with school/education/study <input type="radio"/> Financial Support for study/work <input type="radio"/> Helpful info on returning to education/study <input type="radio"/> Managing Energy levels at work/study <input type="radio"/> Employment rights and support services <input type="radio"/> Info on Goal setting /Career planning	<input type="radio"/> Fear about cancer coming back <input type="radio"/> Long term effects <input type="radio"/> Feeling different to who I was before <input type="radio"/> Maintaining a healthy lifestyle <input type="radio"/> Alcohol and Drug use - what I need to know <input type="radio"/> Managing Immunity
Spirituality / Taha Wairua	Other Areas of support
<input type="radio"/> Maintaining Hope/Faith <input type="radio"/> Spiritual guidance /Support <input type="radio"/> Connection with nature/ Outdoors	<input type="radio"/> <input type="radio"/> <input type="radio"/>

Can I sunbathe or use sunbeds now?

Cancer treatment along with medications can affect your skin's sensitivity to the sun. If you have had radiotherapy, or have any scars on your body, skin protection is even more important. Avoid sunbeds as these expose you to higher levels of UV radiation and increase your risk of skin cancer.



Tip Limit your UV exposure and wear protective clothing that covers your body (especially where there are scars). Stay in the shade, wear a hat and sunglasses and use a broad-spectrum, water-resistant sunscreen of at least **SPF 30**. Talk to your healthcare provider if you are concerned. Check out www.sunsmart.org.nz for more info.

Will the cancer come back?

It's natural to worry that cancer may come back but it's important to remember that:

- Most cancers that young people experience do not recur.
- The chance of relapse decreases the further out from treatment you get.
- For many young people, treatment may still be successful if the disease does return.

Knowing the signs of recurrence or secondary cancers can help you keep track of your health. Maintaining a healthy lifestyle can also reduce secondary cancers and other health conditions.

Tip If you find yourself feeling especially anxious - check out our 'Emotional Health and Wellbeing' booklet at www.ayacancernetwork.org.nz

Notes

Blank area for taking notes.



My Treatment Summary

‘The dentist noted my allergy to a chemo drug and asked if I’d had cancer. I didn’t think I needed to put that info down, but he told me it’s good for him to know, as it’s part of my medical history.’

Young person

When you finish treatment, you should receive a Treatment Summary. This is a good record to have on file and can be helpful for any future medical care.



If you do not have this, ask your healthcare team to download and complete it online by scanning the QR code here.

What kind of information is in my treatment summary?

- The type of cancer you had
- The type of cancer treatment you received including details of any surgeries, the sites and amount of radiotherapy, and the names and doses of chemotherapy or other drugs you received

- List of possible long-term or late-effects
- Any problems that occurred during treatment
- Follow-up care recommendations
- Contact information for the healthcare team involved in your cancer treatment.

NOTE:

If you move house or town make sure you update your details with your healthcare team so they can refer you to a consultant at your closest treatment centre.

Tip

Take a pikitia (photo) on your phone of your Treatment Summary and Follow-Up Care Plan so you always have a copy with you.

Who should I share my Treatment Summary with?

Share a copy of your Treatment Summary with your GP and any other health professional who may need a copy of your medical history. For example, if you received anthracycline chemotherapy, there may be an increased risk to your heart during pregnancy, which is important for medical professionals and health-care providers to know.

Information on late-effects and follow-up can be confusing and it can be difficult to figure out how it relates to you. **Below is a checklist to help you keep track of all the info you need.**



Notes

Follow-up Checklist	Yes / No
I have received a copy of my Treatment Summary and follow-up care plan	
I am aware of my follow-up appointments and plan for the next year	
I have the contact details for my healthcare team if I become worried about my health and I know when to contact them	
I have completed the wellbeing checklist before my follow up appointment to ensure I can make the most out of my appointment	
I have found a GP and met with them to review my Treatment Summary and Follow-Up Care Plan.	
I have spoken to my healthcare team about my immunisation status and if and when any boosters are required.	

Questions I have for my Healthcare Team:



Notes

