

HE RĀ KI TUA LIFE AFTER CANCER

16+

A guide to moving forward after cancer treatment



*He rā ki tua
Better times are coming.
The sun will shine tomorrow.*

The AYA Cancer Network is hugely grateful for the support of the various people who have come together to create this resource. Thank you to the rangatahi on our Consumer Advisory Group, key health professionals and passionate supporters of AYA who made themselves available to help.

*Ko te pae tawhiti whāia kia tata,
ko te pae tata whakamaua kia tina.
Seek out those distant horizons,
and remember how far you have come.*



Introduction

Young people have told us that life after cancer can feel a little daunting, so we created this resource to help. In this booklet, you will find tips and information on a range of topics related to your hauora -wellbeing after treatment ends.

If you're worried about how much info there is to read, don't be. The booklet, is designed for you to turn to a page and read what you need, when you need it. There is no need to start from the first section, or even read it all in one go! It's written to be shared, so feel free to show your friends, whānau, partner, education provider or even workplace, and be sure to tear out the helpful pull out sections, and try some of the services, apps and resources that young people have recommended.

We hope this resource will help fill your kete with tools to help you step into your future.

VOICES OF YOUNG PEOPLE

Kia Ora, Talofa Lava, Hello,

What I found challenging with my own survivorship, was the unknown and uncertainty of what the future was going to bring.

The sense of understanding that has come through connecting with other survivors, and information from resources like this one developed by the AYA Cancer Network, has been incredibly helpful. I hope that through this booklet, you feel more prepared for the road ahead, and that you become aware that your experiences are understood by others, and that you are not alone.



You have done it, you have made it through treatment, you are a survivor. Life may have not played out as you expected, but it is time to start building your 'new normal'. You can do this!

Samsara Guillemot-Mene

Kia ora,

This booklet was written with the help of young people just like you.

Surviving cancer isn't easy. For me, there were many things I didn't know or understand, and it was challenging to find answers to the myriad of questions I had. At the time, resources like this weren't available, and it was hard to know what the 'new normal' was supposed to look like.

Returning to life when I felt physically, mentally and emotionally depleted felt confronting, confusing and overwhelming and it took a while to build back strength. There were days with my hauora [wellbeing] when I felt like the walls were caving in, but going at my own pace, and setting realistic goals helped me feel more capable and confident. Now I look back and hardly recognise myself.



There are some things that only cancer survivors understand and connecting with peers through organisations like CanTeen and the AYA Cancer Network really helped me accept my own journey.

I am grateful for the support I received and hope the resources contained in this booklet, help you navigate your life after cancer, in a way that works for you.

Alex Hunt

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TE TAUWHIROTANGA WHAI MURI I TE MATE PUKUPUKU CANCER FOLLOW UP CARE

Section
1



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 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 it 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.

Tip 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.

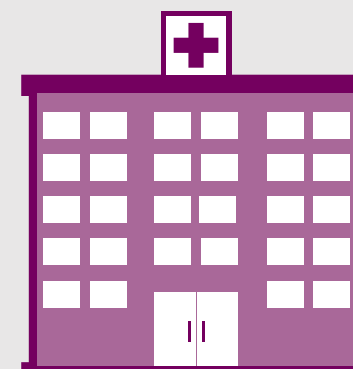
Tip We advise that you make an appointment to meet with your GP soon after finishing treatment. Talk about how you're feeling, your cancer treatment and current health. You may be entitled to a **Community Services Card** which will reduce the cost of GP appointments. Speak to WINZ for more information 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
<div><input type="radio"/> Fatigue (low energy)</div> <div><input type="radio"/> Pain</div> <div><input type="radio"/> Trouble sleeping</div> <div><input type="radio"/> Constipation/Diarrhea</div> <div><input type="radio"/> Sleep Challenges</div> <div><input type="radio"/> Body Image/Physical appearance</div> <div><input type="radio"/> Adjusting to new disability - support services</div> <div><input type="radio"/> Weight Loss/Gain</div> <div><input type="radio"/> Side Effects from treatment</div> <div><input type="radio"/> Dental Issues</div> <div><input type="radio"/> Physical exercise tools and resources</div> <div><input type="radio"/> Nutrition and Healthy Eating</div>	<div><input type="radio"/> Worry/Anxiety</div> <div><input type="radio"/> Low Mood/ Depression</div> <div><input type="radio"/> Anger/Frustration</div> <div><input type="radio"/> Losing people I care about</div> <div><input type="radio"/> Feeling helpless/hopeless</div> <div><input type="radio"/> Feeling alone/isolated</div> <div><input type="radio"/> Feeling like 'it's all too hard'</div> <div><input type="radio"/> Fear/worry about the future</div> <div><input type="radio"/> Low self esteem</div> <div><input type="radio"/> Access to Psychological/Counselling support</div> <div><input type="radio"/> Flashbacks/nightmares from cancer treatment</div> <div><input type="radio"/> Info on self-care tools and resources</div>
Sexual Health & Fertility/Hauora Tōkai me te Taupiri	Concentration / Te Hihiwatanga
<div><input type="radio"/> Fertility status unknown</div> <div><input type="radio"/> Fertility options</div> <div><input type="radio"/> Where to seek fertility support</div> <div><input type="radio"/> Contraception and Sexual Health Services</div> <div><input type="radio"/> Intimacy and changes to Sexual Health</div>	<div><input type="radio"/> Short attention span</div> <div><input type="radio"/> Memory loss - trouble remembering things</div> <div><input type="radio"/> Taking longer to finish things than before</div> <div><input type="radio"/> Brain Fog</div> <div><input type="radio"/> Trouble concentrating</div>
Social / Taha Whānau	Family / Taha Whānau
<div><input type="radio"/> Feeling different to friends/others</div> <div><input type="radio"/> Finding it hard to socialise</div> <div><input type="radio"/> Feeling left behind</div> <div><input type="radio"/> Romantic relationships</div> <div><input type="radio"/> Challenges talking to others about cancer</div> <div><input type="radio"/> Access to social supports & peer support</div> <div><input type="radio"/> Romantic Relationship</div>	<div><input type="radio"/> Finding it hard to talk to loved ones</div> <div><input type="radio"/> Feeling responsible for family members</div> <div><input type="radio"/> Worry about impact cancer has on others</div> <div><input type="radio"/> Feel the need to 'protect' everyone</div> <div><input type="radio"/> Struggling with place in whānau</div> <div><input type="radio"/> Supports and resources for whānau</div> <div><input type="radio"/> Cultural Support</div>
Education and Employment / Kura & Mahi	Survivorship / Te Mōrehutanga
<div><input type="radio"/> Challenges with school/education/study</div> <div><input type="radio"/> Financial Support for study/work</div> <div><input type="radio"/> Helpful info on returning to education/study</div> <div><input type="radio"/> Managing Energy levels at work/study</div> <div><input type="radio"/> Employment rights and support services</div> <div><input type="radio"/> Info on Goal setting /Career planning</div>	<div><input type="radio"/> Fear about cancer coming back</div> <div><input type="radio"/> Long term effects</div> <div><input type="radio"/> Feeling different to who I was before</div> <div><input type="radio"/> Maintaining a healthy lifestyle</div> <div><input type="radio"/> Alcohol and Drug use - what I need to know</div> <div><input type="radio"/> Managing Immunity</div>
Spirituality / Taha Wairua	Other Areas of support
<div><input type="radio"/> Maintaining Hope/Faith</div> <div><input type="radio"/> Spiritual guidance /Support</div> <div><input type="radio"/> Connection with nature/ Outdoors</div>	<div><input type="radio"/></div> <div><input type="radio"/></div> <div><input type="radio"/></div>

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 especially anxious, turn to page 17 for more advice on managing any fears or worries. Check out the **Getting Active and Kai after Cancer** sections, for more information about how to maintain a healthy lifestyle.

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.

- 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.

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

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 end-of-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:

TE HAUORA Ā-ROTO

CARING FOR YOUR HAUORA Ā-ROTO - EMOTIONAL HEALTH AND WELLBEING

Section 2

Caring for your Hauora Ā-Roto - Emotional Health and Wellbeing

'Going through an experience like this isn't easy. You need to have a massive support system around you to be able to get through it. However, the memories will always be there, and while it may feel like it haunts you, understanding helps make it a little better.'

Young person

Surviving cancer can bring up a range of emotions, and finishing treatment might be the first opportunity you have had to explore them.

There is no right or wrong way to process what you have been through, but having some self-care tools, talking things through with people who care, and having a good relationship with your healthcare team can make a big difference to how you feel.

How do I explain to others how I am feeling?

'Talking about your experience with loved ones and letting them know how you feel is a great way of dealing with your feelings.'

Young person

Some people in your whānau and community might expect you to be happy, grateful or relieved when you finish treatment, not realising you might have other emotions going on too. If you are not telling people how you feel, sometimes things can build up and leave you feeling isolated or overwhelmed. Kia pono - Be honest. Talk with your whānau or friends, a counsellor or youth-worker. If you are stuck on what to say when people ask you how you are, just be honest, or try some of the phrases below:

- Actually - I'm still just coming to terms with things - it might take me a while to work out what it all means.

- Yep, I'm pleased to finish treatment, but I'm still pretty nervous about the future and what it might hold for me.
- I feel like I'm only just catching up with myself.
- I have a lot to think about now; life is different to how it was before.
- I'm still just processing it all.
- I have to be monitored for some time, which makes me feel nervous.
- I'm excited to finish treatment but I still struggle with my energy levels.



Young people have told us that feeling heard and accepted helps. Hang out with the people who you can be real with and access more support if you need to.

**Kia pono -
Be honest.**
Talk with your
whānau or friends,
a counsellor or
youth-worker.



Stress and emotions

'Sometimes I get quite stressed when I have health-related issues. I worry that my cancer is reoccurring and it's constantly on my mind.'

Young person

I definitely feel more emotional when stressed. Any tips?

Pay attention to your stress levels. Are you rushing back into life and trying to do everything you did before cancer? Try a gradual approach so you are not loading yourself up with too many commitments straight away. Energy levels can have a big impact on emotions too, so if you wear yourself out physically by doing too much, it is likely you will feel the impact emotionally too.

Whakangā - Relax. Relaxation can help your central nervous system unwind. Try yoga or basic stretches, mindfulness, meditation or prayer. Listen to relaxing music or take a hot bath or shower. All of these activities have been proven to help relax the central nervous system and reduce tension in your body, which can also reduce anxiety. Focusing on breathing can also help reduce feelings of panic or stress. Try some of the following exercises, listed on the right, and see if you feel any different.

WEBSITES

Hikitia te hā

A simple breathing exercise you can do by yourself or with others. Hikitia te Hā breathing exercises take you on a journey using sacred phrases you can follow to direct and move with your breath. <https://www.allright.org.nz/tools/hikitia-te-ha>



See our Useful Websites and Apps section on page 25 for more info.

RELAXATION EXERCISES

If you find yourself feeling overwhelmed, try some breathing exercises on your phone through apps or YouTube. Regulating your breathing can help overcome stress and reduce panic. Try these clips on YouTube. Just enter the headings into the search:

4-7-8 Calm Breathing Exercise

Relaxing Breath Technique. Following the guided instructions in this breathing exercise can help calm your breath and relax you. There are a few versions and most go for 5 minutes. See how you feel afterwards.

5-4-3-2-1 Grounding Exercise

This is a great activity to help you refocus your senses. It is the same as the Five Senses Activity on page 19.

Box Breathing

This type of breathing encourages you to breathe in for 4 counts, hold for 4 counts, breathe out for 4 counts and hold for 4 counts. Draw a square box in the air with your finger. Each side of the box will be 4 counts. Learn about it by watching the clip.

Relax and Breathe

Do nothing for 10 minutes. This is a good visual one for if you're feeling panicky or overwhelmed. Just watch and breath with the lotus flower on screen as it opens and closes.

Mānawa Maiea te Atawhai | Mindfulness Tools for Rangatahi

A short episode series of mindfulness tools taught by young people through a Māori worldview. Includes mauri tau (mindfulness), yoga, taonga puoro (instrument sound healing) mindful hiko (walking) and connection to nature. Put Manawa Maiea te Atawhai into the search engine in YouTube.

FIVE SENSES ACTIVITY

To ground yourself quickly into the present moment, try this exercise to help you refocus. Pay attention to:

- 5 things you notice in the room
- 4 things you can feel (such as your shirt on your skin, the chair you are sitting on, the breeze from a fan, your feet on the floor, etc.)
- 3 things you can hear
- 2 things you like the smell of
- 1 thing you like the taste of OR 1 good feeling you have about yourself.

Ngā mahi ka taea me mahi, ngā mahi tē taea me tuku.

Focus on what you can control and let go of what you can't.

A great way to reduce stress is to focus on what you **can** control. This can stop you from feeling powerless and help you focus your energy on improving your wellbeing. Check out the circle of control:

THE CIRCLE OF CONTROL



ACTIVITY

THE CIRCLE OF CONTROL

Fill in the model with the things that are relevant in your life. What **CAN** you control? What are the things that you can't control?



Tear or cut out to pop on the fridge ✂

What can I do when worry takes over?

'There was a period of time where it was like I'd panic over anything that would possibly link to cancer.'

Young person

UNDERSTANDING ANXIETY - WHEN TO SEEK HELP

You might find yourself overwhelmed by fear or anxiety even after your best efforts to cope with it. The following feelings may indicate serious anxiety or depression (tick any that you feel relate to you).

- ☐ Worry or anxiety that gets in the way of your relationships and daily activities or prevents you from going to your follow-up care appointments
- ☐ Feeling hopeless about the future
- ☐ Having trouble sleeping or eating well
- ☐ Not participating in activities you used to enjoy
- ☐ Having trouble concentrating or making decisions
- ☐ Feeling that you have nothing to look forward to
- ☐ Being unusually forgetful

A good place to start is to talk to your health care team or GP if you notice or experience any of the above. They can refer you to counselling services for help.

I'm having flashbacks and nightmares. What does this mean?

It is normal to have occasional feelings of anxiety such as worry, fear or dread. But if these feelings don't go away over time, continue to get worse, or affect your daily life, they could be a sign of Post-Traumatic Stress Disorder. Other symptoms include:

- Nightmares and flashbacks
- Avoiding places, events, people, or things that bring back hard memories
- Strong feelings of guilt, hopelessness, or shame
- Continuous feelings of fear or anger
- Self-destructive behaviour such as drug or alcohol abuse
- Frightening or unwanted thoughts
- Difficulty feeling emotions
- Being on alert all the time or easily startled.

PTSD symptoms are different for everyone and can come and go. They normally develop within 3 months of a traumatic event, but they can also occur several months or even years later. PTSD does require a medical diagnosis, so make sure you speak to your healthcare team if you have symptoms, especially if they last more than a month.

Tip Post-Traumatic Stress Disorder is nothing to feel whakama (ashamed) of. Accessing support can help you learn to cope so you carry on with your follow-up care with as little distress as possible.

*E kore koe e tū
mokemoke ahakoa
te whakaaro.
You are not alone,
even if you may
feel that way.*



Counselling and psychological support

'I think all cancer patients should have therapy or counselling when completing treatment. I didn't think I needed it, but I actually really did.'

Young person

What is counselling and what does it involve?

Counselling is a confidential, safe and non-judgmental space where you can talk with a trained professional about any challenges you may be experiencing from your cancer diagnosis. It can also help with:

- Adjusting to life after cancer treatment
- Fear, anxiety and depression
- Whānau or relationship issues
- Communication strategies for talking about your diagnosis
- Worry or fears about the future
- Returning to school, work or study
- Setting personal goals.

Counsellors begin by establishing an open and trusting relationship so you can share your thoughts and feelings and discuss any difficult emotions you may be grappling with. Through the counselling sessions, you and the counsellor will explore ideas and tools you can apply to help you cope. The counsellor will also help you with strategies to address

any fears or worries you might be having. Finding the right counsellor can take time. If you don't click with the first one you see, don't let this put you off. Ask around for a recommendation or utilise youth-friendly counselling services. It's important you feel comfortable with the person you are seeing.

*Kia maumahara, he rawe kia kōrero.
Remember, it's cool to talk about things.*

How can I access counselling?

There is free support available across Aotearoa through psychologists employed with the cancer services or through non-governments organisations like CanTeen and the Cancer Society. Check out the resources box at the end of this section or ask your AYA Key Worker.

CanTeen provide free counselling via phone or online and is available to any young person with cancer or their sibling aged 13 to 24. Speak to a staff member from CanTeen for info on how to access this or go on their website www.canteen.org.nz

Cancer and taha wairua (spirituality)

'Throughout my experience of cancer, I had many different enlightening and transformational breakthrough experiences that changed the way I see, experience and care for my te whare tapa wha (wellbeing).'

Young person

After having cancer, many young people have gone on to feel a sense of purpose, deepening of faith or a strengthening in their whanaungatanga (relationships) with others. Wairua means different things to different people. For some, it encompasses faith or religious

beliefs and for others it could be belief in a higher power or feeling an internal connection to their ancestors, the universe, or the sacred. Connecting with your spirituality through practices such as prayer, meditation, or spending time in nature have been proven to help people feel more calm and grounded and can form an important part of your hauora (wellbeing).

How do I care for my spiritual and emotional wellbeing?

The key is to integrate wellbeing strategies into your daily life. Try some of the following and when you find ones that work, make them a regular thing.

TIPS FOR SELF CARE

Distraction. If you find yourself overthinking things, watch a movie, read a book, or get creative.

Connect with nature. Appreciate Papatūānuku (mother earth, the land) and spend time in beautiful surroundings such as the beach or bush. Pay attention to your surroundings and share them with others.

Use relaxation techniques. Try yoga or stretching, or try some mindfulness or meditation. See the recommended apps and websites on page 25 to help you get started.

Pay attention to your body. What are your energy levels telling you? Are you working with your body or against it? Are you getting enough sleep or battling with fatigue? Are you managing to stay active. For more tips check out page 39.

Make healthy choices. Cut down on sugary foods and reduce any excessive alcohol intake as this will only make you feel worse. For more tips on nutrition check out page 52.

Spend time doing things that bring you joy. See mates you can be yourself with and/or take part in activities or hobbies that you enjoy. Seek out opportunities to laugh with others.

Set goals. Goals can help you focus on moving forward and achieving them can help bring a positive mindset. Start with short-term goals. Plan an outing, visit a place you haven't been before, make a plan for a holiday, or update your CV.

For more tips, check out page 87.

Focus on the positive. Think about the things you are proud of, challenges you have overcome, people who are important to you, or keep a gratitude journal and write down things you're grateful for. If you are feeling low, pull it out and remind yourself.

Stay connected. Access the support available to you. This could be friends or whānau, church, team sports, hobby groups or support from some of the organisations mentioned in this resource.

Access spiritual support. Attend a place of worship or connect to a spiritual healer or leader. If you're unsure where to go, ask friends or family for recommendations. Read spiritual writings or have them read to you, listen to podcasts, or read stories of hope.

Listen to uplifting music. Listen to music that makes you feel good/fills your soul, sing waiata (songs) or dance, share your playlists with others.

Reflect. Write down your reflections by recording your thoughts in a journal or electronically. If you enjoy social media, consider a blog or share your journey with others online.

Give service/support to others. Young people have told us that helping others gives them a sense of purpose. Consider some ways you can support other people who are having a difficult time such as volunteer for a charity you are passionate about.

Peer support - Te tautoko a-hoa

I lost good friends through treatment and coming out of it, I felt like I didn't have anyone to talk to. Coming to CanTeen, going back to school, meeting new people and reconnecting with friends again was a bizarre experience - but also really good. You realise there are people out there who will stick by you.'

Young person

Peer support can help provide a sense of belonging as well as a safe space to share your worries or get help from people in the same situation as you. Organisations such as the ones below have peer support and survivorship programmes available either in person or online.



WHERE CAN I GO FOR SUPPORT?

Talk to your GP or healthcare team. You may be able to access counselling services in your local community. The following organisations also offer support:

CanTeen. A youth led organisation offering a range of support services for young people aged 13 - 24. CanTeen Connect has free online counselling available 24/7 and peer support activities you can attend locally and regionally. www.canteen.org.nz or phone 0800 2268 336.

Leukaemia & Blood Cancer New Zealand. Provides emotional and practical support, survivorship programmes and education forums for people with leukaemia and blood cancers. www.leukaemia.org.nz or phone 0800 151 015.

Shocking Pink. A peer support organisation for women with breast cancer. You can join the Facebook page from anywhere in NZ or attend regional peer support catch-ups. www.shockingpink.org.nz.

Breast Cancer Foundation. Offer a range of emotional support services including MYBC - an online peer support community. They also provide free counselling for up to a year. Phone 0800 902 732 or www.breastcancerfoundation.org.nz.

Cancer Society. Provide a range of emotional well-being resources nationally to anyone aged over 18. Resources include free one-on-one psychology sessions, free webinars and online talks, and online support groups. www.cancer.org.nz or phone 0800 226 237.

Youthline. Support youth aged 12-24 years. Free Helpline service (text, phone, webchat & email), face-to-face counselling, mentoring, and programmes in schools and communities. www.youthline.co.nz or 0800 376 633 or text 234 for 24/7 counselling support.

RESOURCES

The following resources have been reviewed and recommended by rangatahi (young people). You don't have to love them all, but having a couple of meditation/relaxation tools on your phone can be super handy.

WELLBEING APPS

Smiling Minds. An Australian mindfulness app with guided exercises for young people.

Headspace. A UK mindfulness app with a range of guided relaxation exercises you can try

Melon Health. Free meditation, sleep and mindfulness activities

Mylife Meditation. An American app designed for under 25s which has a range of breathing activities, meditations and mood check in tools.

Declutter Your Mind. Short, simple, guided meditations for sleep, anxious thoughts, or overwhelming feelings. Aimed at adults.

WEBSITES

www.mentalweath.nz Designed for young people in Aotearoa by Le Va. Provides online resources to help young people look after their mental health and includes free online counselling.

www.thelowdown.org.nz A website providing videos and articles about anxiety and depression. Also includes support through a free 24/7 helpline, text and webchat.

www.sparx.org.nz A computerised kiwi self-help tool for 12 to 19 year-olds who might be feeling low.

www.melonhealth.com Provides online tools and resources to help people manage stressful times. Has an app available for download

www.auntydee.co.nz Aimed at Māori and Pacific youth, the website has a library of tips and tricks for some common problems such as trouble sleeping or problems with relationships, friends, health, and school.

www.smallsteps.org.nz A website to help you take small steps to manage stress, calm your mind and lift your mood. Has breathing activities you can try along with short clips to watch.

*Hongihongi te wheiwheia.
Face with courage those
unseen things that can create
worry, anxiety and fear.*

Emotional Wellbeing Checklist

	Yes / No
I have the details for local counselling support services that I can access	
I talk to others regularly about how I am feeling	
I have downloaded some relaxation apps and given them a go	
I have read the section on when to seek help and know where to go if I am worried about myself	
3 organisations I can go to for support are: • • •	

Notes

TE HONO Ā-WHĀNAU Ā-HOA

CONNECTING WITH FRIENDS AND WHĀNAU

Section 3

Whakahoahoa - friendships

Spending time on whakawhanaunga (relationships) can help you feel less isolated and contribute to your identity and sense of belonging. While you might have formed new connections through cancer, keeping positive relationships with your whānau (family), mates and community is super important.

I lost some friends because I spent less time with them and missed out on a lot when I was sick. People didn't know how to talk about stuff, and some people avoided the topic and avoided me. I also felt uncomfortable when people kept saying things like "I told you everything will be alright" or "but that's a while ago; you're fine now."

Young person

I was pretty upset and angry when I had cancer. How do I let my friends know this wasn't about them?

It's normal to go through some tough emotions when you're diagnosed with cancer. If you felt angry or questioned why you had cancer, and not someone else, you're not alone. If you couldn't share how you were feeling with your mates at the time, it doesn't mean you can't share it now. They might be more understanding than you think.

My friendships have changed. Is this normal?

Perhaps you have discovered new interests, found a new purpose, or developed different beliefs since you have had cancer. Consequently, your friendships may have changed too. You may have become closer to some mates, drifted apart from others or formed new friendships. If you have discovered you don't have as much in common with some of the people you were close to before, that's okay.



Remember to focus on the friendships that matter and don't sweat the ones that don't.

I get more nervous in social situations than before. Why is this?

If you have been isolated for a while, it's normal to feel a little out of practice socialising or to feel nervous about seeing people. However, spending time with your mates has HUGE benefits. It can improve your mood, provide you with something to look forward to, and give you a chance to receive some comfort and support from others. Try a gradual approach to socialising to help you get started.



If the social plans your mates invite you to feel overwhelming, suggest alternatives: for example; if you're not up to going out, ask your mates to come to your place, or if you're struggling with fatigue, suggest alternatives like watching a movie. Plan activities at the times you have the most energy so you are up for it. For tips on managing fatigue, check out page 35.

I've lost connection with some of my mates. What can I do?

'Reply when they message you, even if it's just to say "Hey I'm not up to it right now. I'll message you later."

Young person

If your mates are not in touch as much as you would like, it may be because they think you're still sick, or maybe they've been reaching out and not getting a reply. Remember, good communication is two sided so reply to messages and say yes to invites to hang out when you can.



If you get tired easily, tell people, and ease back into things at a pace that works for you. Be open to making new friends as your social confidence increases.

How do I talk about cancer with my friends?

I think you just need to tell your friends how you feel as they are not going to know unless you tell them. If you're feeling down and are over life at the moment, they can help you. They're there because they want to be.'

Young person

Many young people find talking about cancer challenging. Setting boundaries for how much information you share, and with who, can help. For example, you might tell your best friends every detail, but just tell casual friends that you had cancer and are better now. People's responses may also bring up strong feelings for you. For example, you might get annoyed when people say things like "at least you got through it" or "you're lucky you didn't lose your hair," or you may get frustrated if someone starts to give you advice or compare you to other people they know who have had cancer.

Questions you might get asked:

- What was it like having cancer?
- Are you cured now?
- Will the cancer come back?
- Will your hair grow back?
- Can you have children?
- What was it like?
- Were you scared of dying?



Preparing some responses ahead of time to questions that people might ask, may help you feel more in control.

TOP TIPS FOR CANCER KŌRERO/TALK

It's not just about cancer. Remind friends and whānau that there may be times when you want to talk about what you have been through and times when you don't.

Find some key phrases. If you don't feel like talking about your experience - Try phrases like: "Thanks but I'd rather not talk about it" or "Actually, I'm sick of talking about cancer. Can we talk about something else?" You are not being rude; you are just setting a boundary.

The elephant in the room. Friends may be avoiding bringing things up because they are afraid of saying the wrong thing. Tell your mates **how you feel** and if you are up for it, answer their questions and let them know where you are at.

Pick a good time. When you are ready to kōrero, choose a time when you are free from distractions. It is not a good time to pour your heart out just before you enter a party or before you rush off somewhere.

Have a laugh. Don't be afraid to laugh and joke. Humour is a great way to start a conversation about a difficult topic.

Share what you're comfortable with. Jot down notes on topics you are happy to chat about or send an email, letter or message if talking kanohi ke te kanohi (face to face) feels too much. Maybe the person just needs to know what your cancer was and where you are with things now.

Share your feelings. Be honest. Anger, frustration, fear and resentment are normal reactions to cancer. Hiding these feelings will only make them grow and make you feel isolated. If people care, you do not have to be upbeat for them if you're not feeling it.

Share info. There are some good resources on The AYA Cancer Network Aotearoa website under the Young People and Whānau section that your friends can read. Canteen Australia have also produced the resource 'Supporting Your Friend When They Have Cancer' which you can find on their website.

When your mates have cancer too

Mates with cancer are more likely to understand what you are going through and this can provide a lot of comfort. Unfortunately, some of the friends you have built strong connections with may not survive cancer, and this can be tough. Losing a mate is not something many people your age experience, and it can be upsetting and hard to cope with.

'When my friend died I didn't know who to turn to, I felt so lost. I also couldn't stop thinking about the fact that it could have been me.'

Young person

As grief affects everyone differently, you might feel a range of emotions like sadness, anger or loneliness. Some people also experience 'Survivor's Guilt', which is when you feel guilty that you are here when your mate is not, and it is quite common. While it might be hard to talk about your friend after they have died, keeping their memory alive is important and acknowledges what they mean to you. Don't be afraid to share stories or talk about your time together. Remember you do not have to carry the loss on your own; there are people who can support you.



Talk with someone close to you, your healthcare team, counsellor, support worker, or psychologist. Check out the helpful grief resources produced by Aotearoa youth charity Kenzie's Gift www.kenziesgift.com or refer to page 22 for how to access counselling support.



The healthcare team became part of my whānau and I was sad to say goodbye. Is this normal?

If you developed close bonds with members of your healthcare team, saying goodbye can be hard. Remember that transitioning from the team that cared for you is a good thing, as it means you are getting better.



Celebrate moving on creatively, for example make a scrapbook of your time in hospital and include photos of the staff, or invite them to include a message. Alternatively, you could bring in morning tea when returning for follow-up appointments or arrange to pop in and say hi.

NOTE:

It can be tempting to try to reach out to your healthcare team through social media, or by inviting some of your favourite health professionals for a catch up. Unfortunately, as part of their Professional Code of Conduct, they will not, be allowed to engage with you outside the healthcare environment.

Whānau

'My parents and I have become much closer since my diagnosis as they've been supporting me with every step. They've become more understanding of me.'

Young person

Cancer affects whānau too

Having a family member with cancer brings up emotions for whānau too. Fear, worry, concern or grief are just a few. You have had a life-threatening illness and that can be scary for the people who feel aroha (love) for you.

Many young people, say they do not know how they would have got through treatment without their whānau, and in many cases, that cancer has brought them closer together. But, that doesn't mean it hasn't been hard for whānau too.

Things at home have been hard since I had cancer. Is it my fault?

When a household is under stress, people can argue or disagree with each other more than normal. If this has been happening in your household, remember that some of the stress might have already been there before you had cancer. Every whānau manages stress in different ways. It's important to not blame yourself for any disagreements that go on in your household.

Tip Check out the Circle of Control model on page 19. Remember you can't always control the behaviour of the people around you, but blaming yourself won't make things any better.

Family roles shift when treatment ends

Before cancer, you may have been attending school, living away from home, studying or working, then WHAM cancer hit and everything changed. During this time, you may have become dependent on your whānau or partner for practical, emotional or financial support. Perhaps they took time off work to care for you, stayed with you in hospital overnight or attended appointments with you.

Now that you have finished treatment, you and your whānau might go through a period of transition before establishing a new normal. During this period, some young people find being "fussed over" frustrating and want more independence, while others report feeling abandoned and find it hard to take on household roles or manage their healthcare when they don't feel ready.

Tip Gaining **some** independence is great for learning to manage things on your own, but take it at a pace that works for you. If your whānau have been caring for you, mahi tahi (work together) to manage the transition and keep communication open and honest.

Partners

Many partners become the primary caregiver during cancer treatment and it's common to take on a different role in the relationship, household or family unit. Now treatment is finished, it might be a good time to re-establish your roles in your relationship.

Tip Cancer treatment is tough for partners too. Your partner may like to access support through organisations like The Cancer Society. For more information on intimacy after cancer check out page 77 in this resource.

Tuakana Teina - Brothers and Sisters

During treatment, the roles in your whānau may have changed. Perhaps your siblings were cared for by other members of your whānau, or missed activities they enjoyed.

Younger siblings may have been scared or worried about you and this may have come out in other ways like attention seeking behaviour (behaving badly or being argumentative), jealousy of a special opportunity that you've had, or being upset about the attention you've been receiving.

Older siblings may have become protective or over-involved in your life, bossed you round more, or been controlling around your mates. Remember this is only because they care about you, and they may not know how to show you in other ways.

Tip Encourage your sibs to access support too. They may like to chat to a counsellor at school or access sibling activities or counselling through CanTeen or the Child Cancer Foundation.

'It put a lot of stress on my family and looking back, I should have recommended my mum went to support meetings to help her deal with it all emotionally.'

Young person

Your caregivers, siblings, cousins, partner or koro may be holding things together not wanting to show you how upset or worried they have been. Let them know where they can go for help.



If you are a parent yourself

When you had cancer, your tamariki may have been scared something bad had happened to you, or worried about whether they would see you again. If they visited you in hospital, they may have noticed changes to your appearance, or been worried about medical equipment and what it was for.

Try to make space for your tamariki to share their feelings or find some helpful resources to help them talk things through. Kenzie's Gift are a charity that support children and young people with a parent with a life threatening illness. They have a range of recommended resources online, as well as free counselling services for children www.kenziesgift.com.

WHĀNAU TAUTOKO SUPPORT FOR WHĀNAU

The Child Cancer Foundation. CCF provide support support to caregivers of children up to the age of 20 and siblings under 13. This includes peer support through parent groups and sibling activities and includes practical support through the Family Support Team. Phone 0800 424 453.

The Cancer Society. Provide support to partners and caregivers of young people over the age of 18. They have a range of online booklets and resources for family members along with online and in person groups for whānau and caregivers. www.cancer.org.nz or 0800 424 453.

CanTeen. Provide online counselling for parents, partners and siblings of young people with cancer and activities for siblings age 13-24. www.canteen.org.nz or 0800 2268 336.

Leukaemia & Blood Cancer New Zealand. Information for patients and family members. www.leukaemia.org.nz or phone 0800 15 1015.

Whānau Ora. Culturally-based, whānau-centred support with a focus on whānau wellbeing. Check out the website to see which services are available in your area. www.whanauora.nz.

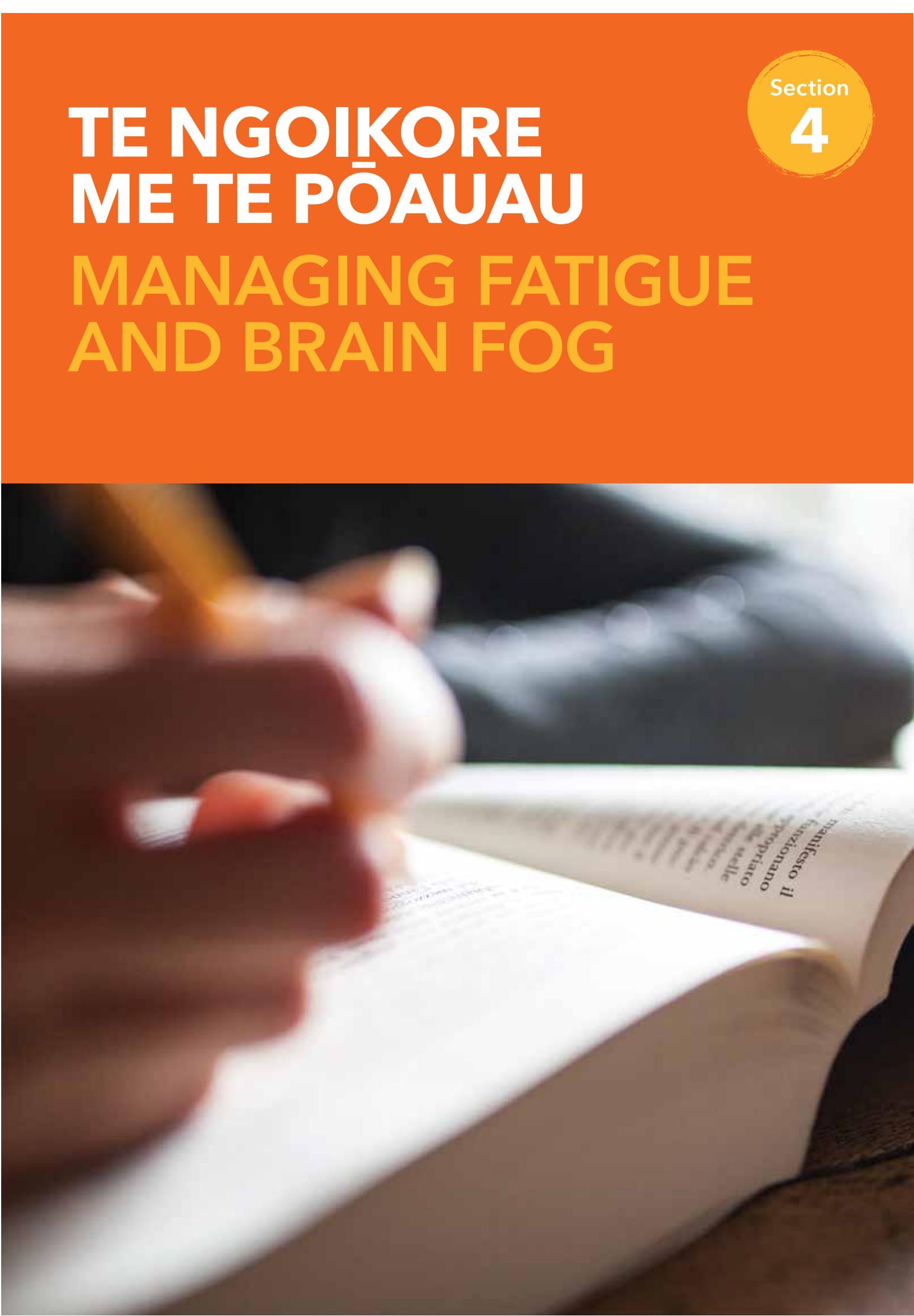
National Family Services Directory. Information about whānau support services in your area. www.familyservices.govt.nz.

Engage New Zealand. An online directory with services across Aotearoa for the refugee and migrant community. www.engagenz.co.nz.

The AYA Cancer Network Aotearoa. Check out the Young Person and Whānau sections for online booklets and resources. www.ayacancernetwork.org.nz.

Self Check In	Yes / No
I am able to talk to my whānau and friends about my feelings	
I feel able to share with my whānau what I need from them	
I know where whānau can go for support	
I have some sentence starters to talk about cancer with others	

Notes



Managing Fatigue

'Because I've finished cancer treatment, people expect that I should just be able to get on with work and activities. They don't understand how hard this is for me and how tired I am all the time.'

Young person

It can take a while for your tinana (body) to rebuild strength and stamina and find its new rhythm after treatment. Cancer fatigue is common and can feel like 'an overwhelming sense of tiredness along with lack of energy which doesn't improve after rest or sleep'. You may experience some of the following:

- Difficulty doing simple things, such as brushing your hair or getting dressed
- Feeling you have no energy or strength
- Difficulty concentrating and remembering things
- Difficulty thinking, speaking or making decisions
- Feeling breathless after light activity
- Feeling dizzy or lightheaded
- Difficulty sleeping (insomnia)
- Losing interest in intimacy
- Feeling low in mood and more emotional than usual.

With time, things usually start to improve. However, as everyone is different, some young people will notice improvements in a few months, while others may find the fatigue continues for longer, possibly even a few years. The exact cause of cancer fatigue is unknown, but it's thought to be caused by a combination of the cancer itself and cancer treatment.

How can I manage fatigue?

Fatigue can affect your work, education and relationships, but there are things you can do to help manage it:

Get moving. The next time you feel a wave of tiredness coming, take a short hikoi (walk) outside. Fresh air and gentle movement will help stimulate blood flow and help you feel more alert.

Tip Regular exercise can boost your appetite, give you more energy and improve your sleep. For more tips on getting active check out page 40.

Eat well and drink plenty of wai (water). Reduce your sugar intake and eating a well-balanced diet high in nutrient-rich foods, will help you regain strength and give you more energy. Drinking plenty of water also reduces headaches and tiredness.

Tip For more tips on healthy eating check out page 54.

Rest. Don't push yourself too hard. Rest when you begin to feel tired and schedule regular rest periods each day, especially after long periods of work.

Tip Rest can be lying down or sitting quietly - not just sleeping.

Try complementary therapies. Some people find a massage, yoga or aromatherapy to have great benefits. Not only can they help unwind the central nervous system, but they can be enjoyable too.

Get help with daily chores. Keeping up with daily chores when you have fatigue is tough. You don't have to do it all by yourself.

Tip Let others know you need help and accept any support offered. Having someone else do the cleaning or cooking can make all the difference.

TRY A FATIGUE DIARY

Find balance. As fatigue affects everyone differently, it can be hard to keep track of the impact it has on your daily life. A good way to do this is to keep a fatigue diary.

You can use a fatigue diary to:

- See what times of day you have the most energy
- Note down things that might be affecting your fatigue
- Plan important activities for when you have the most energy
- Look at the last week and decide if you planned too much or not enough activity
- Work out what makes your fatigue better or worse.

Give Yourself an Energy Rating

In your diary note down things that might be affecting your fatigue. If you don't have a diary, you can do this in your calendar on phone. When you feel your energy levels change, just add an entry to the time of the day and give yourself an energy rating.

Use a scale from 1 to 5:

- 1 No fatigue** - able to do all normal activities.
- 2 Mild fatigue** - able to do most normal activities.
- 3 Moderate fatigue** - able to do some activities but need rest.
- 4 Severe fatigue** - difficulty walking or doing activities such as cooking or shopping.
- 5 Extreme fatigue** - feeling like you need to sleep or rest all day.

After keeping track of your activities for a week, look back and adapt your timetable for the next week. You can use something like the example here or download and print free copies of a fatigue diary from the following website. www.macmillan.org.uk/fatigue Macmillan is a UK charity that has resources to support cancer recovery.

Tip Try to do only one thing at a time. Avoid overloading yourself and try to plan your week to ensure an even balance of education or work, physical exercise, home and social activities.

Example of a fatigue diary:

Fatigue Diary	Mon	Tues	Wed	Thurs	Fri	Sat	Sun
Morning							
Afternoon							
Evening							
Sleep hours							

Things that helped improve my fatigue:

Keep track of any things that you have done which have helped you improve your fatigue. For example: having a rest in the middle of the day or going to bed earlier, taking a hikoi (walk) in the morning, or saying no to activities when tired.

Sleep

Sleep is what gives your body and mind the opportunity to rest and recover and lack of sleep can have a huge impact on your wellbeing. Most adults need between seven to nine hours of sleep a night.



WHEN SHOULD I TALK TO A HEALTH PROFESSIONAL?

If pain is keeping you awake, or if your fatigue is interfering with your ability to go about your daily life, tell your healthcare team.

Some medications can cause side-effects such as sleeplessness or nausea, or make you need the toilet more, which can interrupt your sleep patterns. Your healthcare team may be able to help you with different medications or interventions to help you sleep better and reduce fatigue.

Tip It is important you talk to your doctor before taking medication or herbal/alternative treatments for sleep trouble.

TOP TIPS FOR IMPROVING SLEEP

Sleep when you are sleepy. If you have not fallen asleep after 20 minutes, get up and do something boring or calming with dim lights until you're sleepy.

Try only to sleep in bed. This will help your brain and body to associate your bed as a place for sleep.

Turn off the screen. Bright lights tell your brain that it is time to be awake whilst dark/dim lights tell your brain it's time to sleep. Make sure you are not using screens in bed, especially games and social media which keep your brain active.

Stay away from alcohol and caffeine. Avoid coffee, tea, and energy drinks for at least 4 hours before bed as it can keep you awake and affect the quality of your sleep.

Avoid naps. To make sure you are tired at bedtime choose rest over naps. If you are exhausted and need a nap, try to ensure it's shorter than an hour and before 3pm in the afternoon.

Do not look at the time. Checking the time when you are trying to get to sleep can make you feel more stressed about how much sleep has been lost.

Create a great sleep space. A quiet, cool and dark space is ideal. If it's noisy use ear plugs, or wear an eye mask if it's too bright. A comfy pillow or blanket may help you feel more cosy.

Check your tummy. Being too hungry or too full can affect your sleep. Have a light snack before bed or a glass of warm milk, milo or herbal tea.

Create your own sleep ritual. Calming activities like stretching, yoga or reading can help prepare your body for sleep. A hot shower or bath before bed can also help drop your body temperature afterwards, which can help induce sleep.

Try sleep aids. Sleep apps or calming music, lavender oil on your pillow, or a cooling sleep mask. Ask friends for recommendations, you will be amazed at how many people struggle with sleep.

Brain fog - what is it?

'My memory is extremely frustrating, my mind feels disorganised all the time and I find it difficult to think as quickly as I used to.'

Young person

Many young people talk about the 'brain fog' or 'chemo brain' after treatment. These symptoms include feeling tired, disoriented or distracted; forgetting about a task, taking longer than usual to complete a task; or experiencing headaches, memory problems, or lack of mental clarity.

If you are experiencing this, you may:

- Find it hard to learn new things
- Feel 'spaced out'
- Find it hard to get organised
- Struggle to find the right words when you speak
- Struggle to keep track of names, dates, or your schedule.

Why does cancer treatment cause brain fog?

Although cancer treatment is partly to blame for how you feel, there may be other reasons, such as:

- Stress about your illness
- Other health conditions (like diabetes)
- Not eating a healthy diet or getting enough nutrients
- Other medicines you're taking
- Trouble sleeping
- Feeling very tired
- Hormone changes in your body.

Tip If you are struggling with your memory, write 'to do' lists. Keep notes from appointments or meetings or bring someone along to your appointments to take notes for you.



Managing brain fog

If you are starting a job or returning to work, share your medical history and any challenges you are having with your employer, so they can offer assistance. They may be able to help by ensuring you have regular breaks to help with fatigue, or by being flexible around tasks that require longer periods of concentration.

Tip For more information on returning to work and education, check out pages 90. Most learning institutions also have student support services that you can access for support.

TIPS TO IMPROVE MEMORY AND BRAIN FUNCTION

- Meditate.** This involves focusing attention in a calm, controlled way and can help you declutter your mind. Turn to page 25 for more info.

Visualisation. The key to visualisation is to imagine the scene vividly and in as much detail as possible. For example: before going shopping, visualise how you will get to and from the shops and imagine what you will buy when you get there.

Play games (i.e. cards, chess, or other board games), or complete a jigsaw. Play with friends or whānau over a morning cuppa or after a meal.

Video games. In particular problem solving games that involve attention and cognitive flexibility (i.e. get your brain working). Remember not to do these too late at night so it doesn't interrupt your sleep

Learn new skills. Try sewing, arts and crafts, painting, photography, or learning a new language.

Read. Learn new words and increase your vocabulary.
- Listen to music.** Try playlists on platforms like Spotify, YouTube Music or iTunes. Relaxation music, classical music or chill out music are just some of the playlists available.

Socialise. Have discussions with mates, play games together, engage in sports or physical activity.

Brainteasers. Grab a magazine and do the word finds, crosswords or sudoku in them.

APPS

- Lumosity** Daily brain-training exercises. Has both free and paid activities.

Elevate Maths, word and memory puzzles. Free and subscription options available.

Peak Brain training games to sharpen your memory, stay focused and problem solve. Free and paid options available.

Brain Plus. Classic riddles and puzzle collections.

Sudoku/Solitaire/Crossword Apps. Download one and use it when you are on the bus or listening to music.

Self Check In

I have spoken with a healthcare professional about fatigue/brain fog and asked for assistance	Yes / No
I am aware of some of the apps and supports available to help me with memory and concentration	
I have looked up the recommended websites and resources for more info	

Notes

KIA KORIKORI
WHAIMURI I TE
MATE PUKUPUKU
GETTING ACTIVE
AFTER CANCER



Getting Active

'I was a very active person and it has taken some time to build back up the strength that I used to have.'

Young person

Why do I need to get moving?

There are many reasons to exercise and many of them have long lasting benefits.

Less Pain. Doing the right type of exercise for your body can improve range of motion and decrease stiffness and joint pain caused by treatment side effects.

Increased Energy. If you remain active and make an effort to do some exercise (even if it is the last thing you feel like doing), this can increase your stamina and energy levels.

Weight Maintenance. Exercise can help you return to a healthy weight, which in turn can help lower the risk of other health conditions like diabetes, high blood pressure and heart issues.

Positive emotional wellbeing. Getting regular exercise can decrease stress and improve your confidence. Exercise helps you sleep, gives you more energy and releases endorphins (happy hormones) which help to make you feel good. It's a win win!

Is it safe for me to return to exercise after cancer?

A big question many cancer survivors ask with exercise is **where do I start?** There is a lot you can do, however if you're worried talk to your health care team for advice in case there are limitations or restrictions you need to consider.

I was really active and playing high-level sport. Will I be able to return to that level of fitness.

As everyone's cancer recovery is different, it's best to check in with your healthcare team or get an assessment from a physio or personal trainer. This will help you set a realistic pace for your current abilities. Once you have built up strength, you can reset your goals to your optimum fitness level.

Practical things to consider when you return to exercise:

Low blood counts. If your haemoglobin (Hb) counts are low, there may not be enough oxygen flow in your body, and exercise may cause you to faint or feel breathless. Avoid over-exerting yourself until your counts return to normal.

Low platelet counts. These increase the risk of bruising and bleeding. Avoid contact sports and high-risk sports like skateboarding or mountain biking if your platelets are low.

Surgery and/or physical limitations. If you have had surgery or have body modifications, your surgeon will have given you some guidance on the type of exercise that is appropriate for example: if you have metal-ware in your legs, they may suggest avoiding contact sports or high-risk activities that can cause injury or affect the bones or joints. Make sure you ask about alternative options.

Pain. If you have had a period of inactivity, returning to exercise will stretch your muscles in places that you will definitely notice. Rest, or reduce the intensity or time you exercise. If you're getting constant pain that doesn't go away or **unusual pain at rest**, contact your healthcare team, physio or specialist.

Where can I go for support?

Before beginning any kind of exercise programme, seek advice and support from your medical team, your AYA Key Worker or physiotherapist.

PINC & STEEL are a charity providing Cancer rehabilitation physiotherapy across Aotearoa. Physiotherapists assess each person individually and treatment may include:

- Individualised exercise programs
- Online or in person group classes
- Education on the prevention and early detection of common treatment-related issues
- Support with positive healthy lifestyle behaviours.

PINC & STEEL:
To access PINC & STEEL you can refer yourself via their website www.pincandsteel.com or ask your AYA Key Worker or healthcare team to refer you. PINC & STEEL also have funding available to help with the cost of your appointments.

'Nothing is impossible. If you want something hard enough then go get it, you just have to put in a lot of work to get there.'

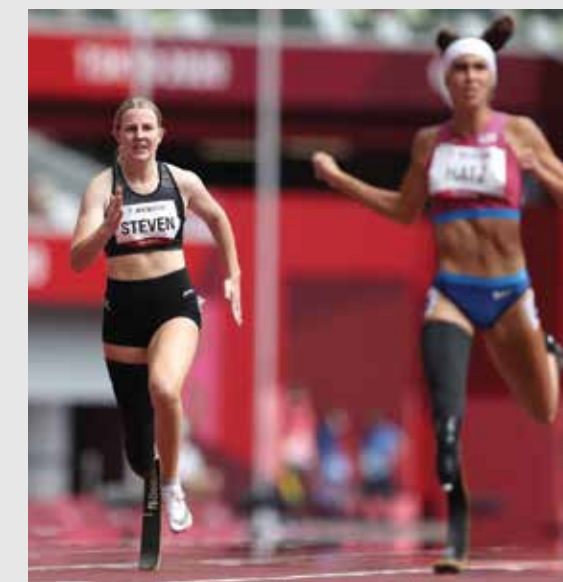
Anna Steven

PARALYMPIC RUNNER ANNA STEVEN

'I had two choices – either have an operation which would leave me unable to walk without constant pain, or have amputation surgery.'

At age 13 Anna Steven endured six months of chemotherapy and major surgery that led to the amputation of her leg but she didn't let that stop her. In 2021 Anna represented New Zealand at the Paralympics.

It was 2013, and I had been diagnosed with osteosarcoma, a form of bone cancer and because I wanted to lead as normal a life as possible, I elected to have an amputation. It still wasn't easy. The chemotherapy knocked me around and then, after the swelling had eased, I had to get used to walking with a prosthetic leg. But, it also meant I learned how to overcome challenges, to focus on a goal, and to make the most out of every day. I kept telling myself that my life was what it was and I couldn't really change it.



Top tips to get moving

Warm up before you start. 2 to 3 minutes of gentle movement before exercise can help your muscles relax and prevent injury. Try shoulder shrugs, lifting your arms overhead, touching your toes, marching, and knee lifts. For the maximum benefit, hold your stretch for 15 to 30 seconds and then relax.

Tip Check out www.TrekStock.com under the EXERCISE section for online exercise videos including stretching and core muscle building. The exercises are free, easy to follow and have been developed specifically for young people with cancer.

Start with light exercise. Try a hikoi plan. As you get used to walking each day, you can build up to longer walks. You can also alternate the intensity of your walk: for example, walk briskly for a few minutes, slow down, then walk briskly again, until you have done 30-minutes of brisk activity or divide the activity into three 10-minute sessions a day or set an exercise goal like the 5k challenge. Check out the plan below for how to increase exercise gradually to build up your fitness.

Tip Monitoring the number of steps you take each day is an easy way to increase your physical activity. Experts recommend 10,000 steps a day – start at a level that suits you and work up.

Use a fitness tracker. Fitness wearables like watches and pedometers can motivate you and places like Kmart and \$2 Discount Stores sell basic versions.

Exercise when you have energy. If you lack energy in the evening, consider exercising in the morning. Doing a little bit of exercise can actually give you more energy (for more information on managing fatigue check out page 35).

Try exercise that increases your flexibility and range of motion in your joints. Yoga, dance or fitness classes are great, as is swimming, cycling or any sport like tennis, basketball, or volleyball, which can help to build strength.



Try resistance or light weights to help build strength. This reverses weakness and keep your muscles and bones strong, so you can go about your daily activities easily.

Tip Get advice about strength training and what's required or join gym classes and access trainers who can help you increase your intensity. Check out Trekstock for more online exercise clips.

But, I just don't have time to exercise!

Stop thinking of exercise as something you have to do, and incorporate it into your daily activities. **Sitting less** helps make your muscles, bones and joints strong.

Take regular breaks - if you're at work or studying, for every 30 mins of screen time take a 5-minute break and do some

stretches. Set a timer on your phone to remind you.
Exercise to your favourite tv show - got enough floor space in front of the telly? Do some stretching while you are enjoying your favourite show.

WEEK 1

10 MINUTES EVERYDAY

WEEK 2

10 MINUTES EVERYDAY

WEEK 3

10 MINUTES EVERYDAY + ONE 20 MINUTE WALK

WEEK 4

10 MINUTES EVERYDAY + ONE EASY WALK - 0.5 KMS

WEEK 5

10 MINUTES EVERYDAY + ONE EASY WALK - 0.5 KMS

WEEK 6

10 MINUTES EVERYDAY + ONE EASY WALK - 1.5 KMS

WEEK 7

10 MINUTES EVERYDAY + ONE EASY WALK - 3 KMS

WEEK 8

15 MINUTES EVERYDAY + ONE EASY WALK - 3.5 KMS

WEEK 9

15 MINUTES EVERYDAY + ONE EASY WALK - 4.5 KMS

WEEK 10

15 MINUTES EVERYDAY + ONE EASY WALK - 5 KMS

CELEBRATE

Well done. Now Plan your next walk.

Walking

COUCH TO 5KMS

in 10 weeks!



Make exercise fun

Let’s face it, if you can’t find a type of exercise you enjoy, then you’re probably not going to do it! Try making it fun:

Get creative. Try something new like hip-hop or hula dancing, tai chi, surfing, yoga, or an outdoor boot camp.

Get your whānau, colleagues and mates involved. Head down to the local courts and shoot some hoops, throw a frisbee or play backyard cricket. Find an exercise buddy who is keen to get fit and improve their exercise regime with you. Set daily step goals, tautoko (support) each other or start some healthy competition.

Use your phone. Make an exercise playlist or check out a podcast while you are moving. Use the free health or fitness apps to keep track of your steps. One phone chat with a mate whilst doing moderate exercise and you have done your exercise for the day!

Set personal goals. Get motivated by using charts or apps to record movement and track your progress. Treat yourself to something special once you have achieved your goals.

Try a weekly exercise/Movement Plan. Put some time aside in the calendar for exercise each week. See the sample plan or fill in the 6-week movement plan on page 48 to help you get started.

RECOMMENDED WEEKLY EXERCISE

It is recommended that you do at least **2 ½ hours of moderate** or **1 ½ hours of vigorous physical activity** spread throughout the week. This is equivalent to doing:

- 30 minutes of brisk walking on 5 days per week.
- OR
- Going for a 45 minute run twice per week.













Moderate intensity activity causes a slight, but noticeable, increase in breathing and heart rate. With this type of exercise, you can still carry on a conversation. **Some examples of moderate intensity activities** are walking, cycling, swimming, stretching, doing pilates, and completing household tasks such as vacuuming.

Vigorous intensity activity makes you out of breath - you cannot do these activities and chat at the same time. **Running, playing sport** such as basketball, volleyball, touch, going up stairs, doing high energy classes like dance or box-fit or doing a workout at the gym.

Strength Training. It’s recommended that people who’ve had cancer do resistance exercises (strength training) twice a week. This is 2 x sets of 12-15 repetitions weekly which is equivalent to bicep curling 2 litre water bottles 15 times a week (30 bicep curls in total). Carrying heavy shopping bags and doing yoga also count.

How much exercise should I be building up to?

Check out the chart below for guidance.

	Be Active Keep your heart and mind healthy		Build Strength Strengthen muscles, bones and joints	Improve Balance Also builds strength
How often?	150 minutes of moderate activity a week	OR 75 minutes of vigorous activity a week	2 days a week	2 days a week
	WALK 	RUN 	GYM 	DANCE 
	CYCLE 	SPORT 	DANCE 	YOGA/PILATES 
	SWIM 	STAIRS 	WEIGHT 	SURFING 

Sign up to events. Do a walk or fun run, put a team for triathlon or waka ama together, sign up to cycling or swimming events.

Incorporate exercise into your daily life. Mow the lawn, wash the car, or walk the dog. These activities use several muscle groups and with some music can be an enjoyable way to get stuff done and exercise at the same time.

Swap in exercise. Park your car in the farthest parking space and walk to the building, use the stairs instead of the lift or escalator, or get off the bus several stops early and walk. Allow time in your day for exercise in between work and home.

Create or find a good exercise space. This could be at home or in the backyard. Make sure you have everything you need. Yoga mats are great for stretching and are affordable. Some public parks also have strength-training equipment you can use free. Home gym equipment can be hired or bought from K-mart, The Warehouse, or sports shops.

Tip

YouTube has a variety of free, at home workout videos such as yoga, dance and cardio. See the resources section for more info.

Do what you are comfortable with. Choose exercise that doesn't make you feel self-conscious - for some it's the gym, for others the pool. Choose people who are up for the same exercise as you, and who you feel comfortable exercising with.

Incorporate exercise into your holidays. Aotearoa has many great bike tracks, bush walks, trail rides, lakes and beaches. Exploring some of these in your next holiday or break. Check out www.greatwalksofnewzealand.co.nz and www.freewalks.nz for some great walks. If you enjoy orienteering check out www.orienteering.org.nz for recommendations.



INTERNATIONAL SURFER AND COACH MATT SCORRINGE

At age 14 Matt represented New Zealand at the International Surfing Association World Junior Titles in Bali, but everything changed in 2009 when - at the age of 24 - he was diagnosed with leukaemia.

"I got home from a tour in Hawaii and eight days later I was having chemotherapy," recalls Matt. "There was really no time to process it or make decisions. I've always been very competitive, so once I was at the hospital, I thought,

'Well, this is another challenge and I'm going to smash this thing and win it'

I set a goal of being back and competing in the New Zealand nationals the next year - and, though I still looked like a cancer patient when I got there, it was a stepping stone for my journey back."

After recovering from his illness, Matt decided to follow his passion and use his experience to coach. In 2013 he developed The Art of Surfing and has coached some of NZ's top Olympic surfers along with locals who are keen.

'I came home with all the knowledge I'd picked up and, after recovering, I sincerely wanted to use that to help our surfers do better'



Try a weekly movement plan

Put some time aside in the calendar for exercise each week. See the sample plan below or fill in the 6-week movement plan to help you get started.

SAMPLE MODERATE WEEKLY MOVEMENT PLAN

	Mon	Tues	Wed	Thurs	Fri	Sat	Sun
AM	30 min walk Moderate exercise		Yoga or Trekstock class Strength activity		Yoga or Trekstock class Strength activity		
PM		30 min walk or swim Moderate exercise		30 min walk or swim Moderate exercise			30 min walk or swim Moderate exercise
Time	30 min	30 min	15-30 min	30 min	15-30 min		30 min

This plan has a total time of 2 ½ to 3 hours moderate activity which is the recommendation. If you prefer more high intensity exercise, you can swap this out for 1 ½ hours of high intensity exercise instead.

WEEKLY MOVEMENT PLAN

My physical activity goals are:

I would like to achieve these by:

My barriers to being active are:

My solutions to overcome these barriers are:

Supporters who will help keep me on track are:

Now it's time for you to set some exercise goals.

ACTIVITY

Fill in your own Movement Plan

MOVEMENT PLAN:

Use the template to put some activity into your week. While the first week might be hard, don't give up. Keep going for the next 4 - 6 weeks so you can see the change unfold. Remember to make it fun too!

WEEKLY MOVEMENT PLAN							
	Mon	Tues	Wed	Thurs	Fri	Sat	Sun
Week 1	Time	Time	Time	Time	Time	Time	Time
AM							
PM							
Week 2	Time	Time	Time	Time	Time	Time	Time
AM							
PM							
Week 3	Time	Time	Time	Time	Time	Time	Time
AM							
PM							
Week 4	Time	Time	Time	Time	Time	Time	Time
AM							
PM							
Week 5	Time	Time	Time	Time	Time	Time	Time
AM							
PM							
Week 6	Time	Time	Time	Time	Time	Time	Time
AM							
PM							

Tear or cut out to pop on the fridge ✂

APPS AND ONLINE RESOURCES

There are a range of apps and online resources to support you to get active. Try them and see how you find them.

YOUTUBE CLASSES:

Just Dance. Follow the dancers on screen and learn steps to your favourite tunes. Get your heart rate up and have fun at the same time.

Yoga with Adrienne. If you want to build up your core strength slowly, doing yoga is a great place to start. There are a range of different programmes and intensities to choose from and sessions go from 12 - 30 minutes.

WEBSITES

www.trekstock.org.nz - enter exercise videos into the search button. These are specifically for young people with cancer and cover a range of different levels and abilities.

APPS

Healthmate. A free Fitness, Activity and Health Tracker app. You can track your progress, and get tips to help you improve over time. Can connect to activity trackers or you can enter manually to help you achieve your goals.

Apple Health (for iPhone). A free app that can keep track of your activity, sleep and health data. Can track steps if wearing whilst exercising.

Samsung Health (for Samsung phones). A free app to help you with exercise, fitness tracking and wellbeing. Comes with free fitness videos. Track steps whilst exercising and set personal goals.

Fit on - a free app giving you access to a range of different exercise programmes that you can watch on your phone, computer or stream to your TV.

ORGANISATIONS

PINC & STEEL are qualified cancer rehab physiotherapists who provide support with exercise programmes and physio treatment for young people and adults who have had any form of cancer. If cost is a barrier, you can apply for funding for treatment through their website to receive support for free. www.pincandsteel.com

www.breastcancerfoundation.org.nz Breast Cancer Foundation fund recovery physiotherapy through PINC & STEEL also.

Green Prescriptions. You can get a referral through your GP for a green prescription for physical activity classes or gym memberships. There are affiliated providers across Aotearoa. Check out the Manatu Hauora - Ministry of Health website for more info.

Council Leisure Centres. Offer discounts for people with community services cards or students and are a cheap way to access the full range of exercise options including pools, gyms and classes.

www.halberg.co.nz. The Halberg Foundation provide activity fund grants to help physically disabled young people, aged 5-21 years, to participate in sport and recreation. They fund equipment - the adaptation of equipment or the purchase of disability specific equipment, lessons and/or coaching and fund support costs for young people to attend a camp including a support person or adapted accommodation.

*Kaua e hoki i te waewae tūtuki, ā, āpā,
anō hei te upoko pakaru.
Do not turn back because of the obstacles
but press ahead to the desired goal.*

Self Check In	Yes / No
I have spoken to my healthcare team about any worries or concerns I have about returning to exercise or staying active	
I am aware of available support and organisations to help me reintegrate back into exercise	
I am aware of my physical abilities and any limitations I have along with the type of exercise to best support my body	
I have set some short-term goals and have asked for support and encouragement from friends and whānau to help me get started	
Some of the questions I have for my healthcare team about returning to exercise are:	

Notes



Notes

Section 5 | AYA Cancer Network Aotearoa

TAIORANGA ME TE KAI WHAIMURI I TE MATE PUKUPUKU KAI AFTER CANCER – HEALTHY EATING AND NUTRITION

Section 6

Kai after Cancer

‘Wading through the advice around food and figuring out what worked for me took time. It’s not one-size-fits-all, but lots of people feel the need to tell you how you should be eating.’

Young person

Nutrition is giving your body the nutrients it needs to function well. When combined with exercise and healthy weight, it is an important way of helping your body stay strong and reducing the risk of developing other health conditions in the future.

MYTHS

There is a lot of advice out there about what and how you should eat, and it is common to feel overwhelmed by it all. Let’s start by busting open the myths about kai and cancer, based on the most up to date information and evidence.

MYTH: Organic Kai is better. There is no evidence that organic kai is higher in nutrients that help to prevent cancer than non-organic food farmed in traditional ways. As long as you are eating food from the four key food groups, it shouldn’t matter whether it’s organic or not. If you choose to eat organic food that’s absolutely fine. The key is to make sure, organic or not, that you are eating from the four key food groups.

MYTH: Red meat causes cancer. Red meat is a source of protein, iron, zinc and vitamin B12 and there is no research to suggest you should stop eating it entirely. However, the World Cancer Research Fund recommends limiting processed meat (such as ham, salami, bacon, and sausages) and only having red meat a few days a week to support a balanced diet.

MYTH: Sugar feeds cancer and makes it grow. There is no evidence that consuming sugar makes cancer cells grow faster or causes cancer. However, over-consumption of sugar, particularly added sugars in soft drinks and processed foods, can contribute to obesity, which is a risk factor for other health conditions.

MYTH: I need herbal supplements. Most people who eat a well-balanced diet don’t need to take herbal supplements. However, if you do, with so many on the market, how do you know which one to take, or whether the ingredients are appropriate for you? Some ingredients in herbal supplements impact on the effects of medication, so getting advice before purchasing or taking them is important.

MYTH: Anti-cancer diets help prevent cancer returning. There are no studies that prove that any special diet can slow, cure, or keep cancer from coming back. This includes; macrobiotic, low acid/alkaline, intermittent fasting, ketogenic diets (low carbs, high fats) and diets centred on vitamins, minerals, or supplements. The challenge is that if a diet, is not specifically tailored to your body, it might not give your body the nutritional goodness that it needs. Fortunately, healthy eating, keeping active and maintaining a healthy body weight has been shown to reduce the risk of developing some cancers.

He aha hei kai? What to eat?


So what does a well-balanced diet look like and what should I be eating?

According to the Ministry of Health 2020 Eating and Activity Guidelines, eating a variety of foods in suitable amounts from all food groups, will go a long way towards meeting your daily nutritional needs. The four food groups are:

- 1. Fruit and Vegetables
- 2. Grains Foods (Fibre)
- 3. Milk and Milk Products (Dairy)
- 4. Lean Meat and Alternatives (Protein).

What kai to eat and how much you need in your diet explained below.

A healthy balanced diet will give you all the vitamins and nutrients your body needs to provide you with energy, strong bones, an effective immune system, help with digestion, and reduce the risk of obesity and related diseases.

What and why	How much and how often
<p>FRUIT AND VEGGIES</p> <p>Eat as many colours as you can, Red: tomatoes or strawberries; Green: broccoli or kiwifruit; Orange: carrot or mandarin; Purple: eggplant or plum; White; potato or pear.</p> 	<p>At least 2 serves of fruit and 5 servings of vegetables every day.</p> <p>A serve is the amount that fits into the palm of your hand.</p> <ul style="list-style-type: none">- ½ cup of cooked veggies e.g. broccoli, peas, corn, spinach, puha- A medium potato or kumara (it's good to keep starchy veg like this to a minimum)- 1 cup of salad- 1 cup fruit salad – apple, pear, banana or orange or tinned fruit- 2 small apricots or plums <p>Replacing your higher-calorie foods with fruits and vegetables (which tend to be lower in calories) can lead to a lower calorie intake.</p>

What and why	How much and how often
<p>GRAIN FOODS (FIBRE)</p> <p>Breads, cereals, rice, and pasta.</p> 	<p>At least 6 servings each day.</p> <p>A serving is approximately:</p> <ul style="list-style-type: none">- 1 roll,- 1 medium slice of rēwana/bread- 1 cup of cornflakes or rice bubbles or 2 weetbix- ½ cup of cooked porridge- ½ cup of muesli- 1 cup of cooked pasta, noodles or rice.
<p>MILK AND MILK PRODUCTS (DAIRY)</p> <p>Milk, cheese and yoghurt</p> 	<p>2-3 servings every day.</p> <p>A serving is:</p> <ul style="list-style-type: none">- 1 cup of milk,- 1 pottle of yoghurt- 2 slices of cheese or ½ cup of grated cheese. <p>Reduced or low-fat options are lower in fat but have higher calcium and protein, so make good choices all round.</p>
<p>LEAN MEAT AND ALTERNATIVES (PROTEIN)</p> <p>Lean meats, chicken, seafood, eggs, legumes* nuts and seeds.</p> 	<p>2.5 or more servings each day.</p> <p>A serving is:</p> <ul style="list-style-type: none">- 2 slices of cooked lean meat e.g. roast lamb, chicken, beef or pork- ¾ cup of cooked mince- 1 medium fillet of cooked fish- 2 chicken drumsticks or 1 chicken leg- ¾ cup of cooked beans (e.g. kidney beans, baked beans or lentils)- 1 medium pāua or kina- 1 egg- ¾ cup of tofu. <p>Try lean meat such as beef or pork with the fat trimmed, skinless chicken or seafood. Limit red meat to only 2-3 times a week.</p>
<p>Remember to choose foods, drinks and snacks that are lower in fat, salt and added sugar. Use cooking methods such as grilling, baking or microwaving instead of frying. See the plate guide to help you work out how much of each food group you should have on your plate.</p>	

What Does a Healthy Diet Look Like?

A good tip to remember is that you should have more veggies and grains than meat on your plate.



What if I am vegetarian?

If you are vegetarian, it is important to get the vitamins and minerals you need without meat. Choose kai with lots of iron such as wholegrain cereals, dried fruits and dark green leafy vegetables and ensure you get enough vitamin C through fresh fruit or veggies to help your body absorb the iron.

If you are **dairy free** and do not eat cheese, milk or eggs, you'll need to get protein from foods such as tofu (**soy bean extract**) or vegetarian substitutes. If you drink dairy free milk such as soy, almond or oat, choose one that has added calcium and vitamin B12.

Tip

For more info on how to get a healthy and balanced veggie diet, check out the pamphlet Eating for Healthy Vegetarians at www.health.govt.nz

Tips for common food challenges after treatment

Cancer treatment and its side effects can result in challenges with eating and weight and you may need help as you transition.

NOTE:
Tips and advice provided below do not replace advice from a registered dietitian.

When I had cancer, I had to eat differently. What can I do to start eating better?

If you struggled with poor appetite or weight loss during treatment you may have been encouraged to eat more high energy and high fat foods to maintain your weight. When treatment is over, many young people struggle to make the switch to a healthier, more balanced diet. Remember - The purpose of making positive changes to your diet is to help you avoid excessive weight gain and to support you to develop and maintain positive eating habits for the future. Educating yourself on a healthy diet can help you get started.

What can I do if I am underweight?

Side effects such as mouth sores, nausea, constipation, diarrhoea or changes to your taste buds are all factors that may have contributed to you losing your appetite or struggling to eat, and this may have contributed to weight loss. If you are currently underweight, your body may not be getting the nutrition it needs and you may need to try healthier ways to gain weight. Some tips to help:

Take your time. Introducing new foods to your diet and enjoying kai again can take a while.

If you still have nausea (feel sick) talk to your healthcare team about continuing to take anti-nausea medications as prescribed.

Avoid eating high sugar snacks. Good nutrition is just as important as calories.

Speak to your healthcare team about which nutritional supplements would be best for you.

If you are struggling with your appetite try eating smaller, regular meals and snacks throughout the day rather than big meals less often.

Last, but not least, eat when you're hungry and don't wait for a mealtime.

TIPS FOR HEALTHY WEIGHT GAIN

If you are underweight, remember once you have reached your optimal weight, you will need to switch to a more balanced diet so you do not continue to gain weight.

HIGH PROTEIN FOODS

Meat, fish, chicken, eggs, tofu, legumes, lentils, and hummus. Nuts and nut butters. Milk and soy milk (oat, nut, rice and coconut milks are lower in protein). Cheese and yoghurt.

Nutritious Drinks include: milkshakes, smoothies or supplement drinks (like Complan, Fortisip, Ensure, and Sustagen).

HIGH ENERGY FOODS

Oils, margarine, butter, avocado, mayonnaise, cream, sour cream and cream cheese. Baking such as cake, muffins, scones/pikelets, jam and cream. Desserts such as rice and custard puddings, ice cream and jelly, instant pudding, and yoghurt.

Choose fruit juice.

HOW MUCH AND HOW OFTEN

- Use high fat milks, blue or silver top. Add extra margarine, avocado, oil, sour cream or grated cheese to bread, rice, pasta, vegetables, savoury dishes and soup.
- Cook food in oil or a little butter and add extra on the top.
- Add a little cream to cereals, stewed fruits, desserts, baking, soups or drinks.
- Snack on yoghurt, custard, ice-cream, milk puddings, stewed fruit, baking, dried fruit and nuts.
- Eat bread or toast, pita bread, crumpets or crackers with margarine, cheese, hummus, peanut butter, avocado, jam and honey.

Choose nutritious fluids like milk milo, milkshakes, fruit smoothies, juice and supplement drinks.

TIPS FOR HEALTHY WEIGHT LOSS

Switching to a balanced diet will help you develop healthier eating habits and in turn reduce weight gain. Here are some tips:

Swap out certain foods for healthier options. For example, swap potato chips for popcorn. Check out the 'Swap this for that' table on page 58 for guidance.

Take your time. Try to lose weight slowly and steadily. Make a couple of changes at a time, like swapping fizzy drink for water, then make other changes gradually.

Eat smaller meals. Use a smaller plate and avoid going back for seconds.

Steam or BBQ your food instead of frying and limit the amount of takeaways you have.

Get your friends and whānau on board. They can tautoko (support) you. Share the resources in this booklet and mahi tahi (work together) to create healthy kai options.

Pack a healthy lunch and snacks.

This will help stop you buying from the shop or café. You will have more success with switching to healthy kai if you have it on hand.

Complete a weekly meal plan.

Prepare your meals each day so you have healthy snacks available. Do a good weekly shop to stop you 'popping in' to the supermarket where you might be tempted to buy snacks.

Keep active. Losing weight is not just about your eating habits. Check out page 42 for tips to help you get moving.

Easy Healthy Changes

Swap this

Fizzy drinks

Fruit juice

Full-fat milk

White bread

Muesli bars

Chippies with creamy dip

Dried fruit

High-fat cheese

Butter

Coconut cream

Coconut oil

Lard or Dripping

Chilled water with a slice of lemon

Chilled water and a piece of fruit

Reduced-fat milk

Higher fibre, whole grain bread

Fresh fruit or a small handful of unsalted nuts

Raw vegetable sticks with hummus, or homemade popcorn

Fresh fruit

Reduced-fat cheese such as edam

Margarine

'Lite' coconut cream or milk, or half water and half coconut cream

Small amount of canola, olive, sunflower or rice bran oils

Small amount of canola, olive, sunflower or rice bran oils

healthykids

healthykids.org.nz

Te Whatu Ora

Health New Zealand

NPA156 | JULY 2022

HEALTHY SNACKS AND LUNCH IDEAS

Choose healthy snacks and lunches lower in saturated fat, salt and sugar such as:

Bread/Sandwiches. Use different types of wholegrain bread such as rolls, rewena, wraps or pita bread. Add your favourite fillings or spread such as marmite, hummus or avocado.

Fruit buns, scones, fruit bread or homemade pancakes are healthier than sugary muffins or cakes.

Breakfast cereal with low fat milk/yoghurt for example weet-bix or muesli is good for digestion after muesli.

Popcorn is a quick, cheap snack. Add only small amounts of butter, salt or sugar, and if buying ready-made popcorn, choose the plain varieties.

Crackers with cheese or dips. Choose low fat crackers, rice or wholegrain options.

Nuts and seeds are good, just make sure you choose unsalted or low fat options.

Fresh fruit with yoghurt in a bowl or blended into a smoothie. Bananas, watermelon, oranges, kiwifruit and apples are delicious options.

Use low fat yoghurt or plain or flavoured low fat milk.

Veggie sticks with dip or spread. Try hummus, salt-reduced peanut butter, cottage cheese or other dips).

Pasta and rice or reheated leftovers. Anything with veggies such as stews, homemade stir fries, and soups.

Salad. Include protein like kumara, taro, rice or eggs to keep you full. You can also include lean meat like chicken, or a veggie option like falafel. Include vitamins and minerals from lettuce, spinach, carrot, cucumber or tomatoes and increase flavour with low fat dressing.



What should I drink?

Drink mostly wai (water). Stay hydrated by aiming for 6 - 8 glasses a day. This reduces the risk of constipation and is good for your skin, hair and gut too.

Tip Choose tap or sparkling water, sugar free soft drinks, unsweetened tea, and coffee. Limit drinks with a high sugar content like fizzy, sports or energy drinks, sweetened coffee, and sweet tea.

Eating when you're out and about

We all love a good takeaway, but if you are out and need a snack or meal, try healthier options such as:



Keep some fruit and a bottle of tap water in your bag in case you get hungry thirsty.

MAKE KAI FUN AGAIN

Try some of these tips to help you enjoy it again:

When I had cancer, there was so much focus on what to eat, that I'm struggling to find food enjoyable. What can I do?

If you had a bad experience with kai when you were on treatment, find new ways to bring enjoyment back to your meal experience, rather than just focusing on what you put in your mouth. Cooking and healthy eating is more than the food you eat.

Try and keep your relationship with kai and your body - positive

Proper nutritional advice does not come from social media or magazines. It comes from speaking with a health provider, such as a dietitian. With the huge emphasis in society on looking good and diet culture, it can be easy to develop unhealthy eating habits or thought patterns without even realising it. Sometimes our mood can also affect our food intake. Pay attention to how you're feeling before you eat so you can be mindful of your food choices.

If you are bingeing or denying yourself food, reach out for support from your AYA Key Worker or healthcare team.



If weight gain is affecting how you feel about your body, check out the Body Image section page 69 for some tips to help.

Healthy eating
has so many health benefits. Once you start eating the right kai, you will have more energy, you will feel better and your body will love you for it. For ideas on healthy snacks to make at home, tear out the following posters and put them up in your kitchen.

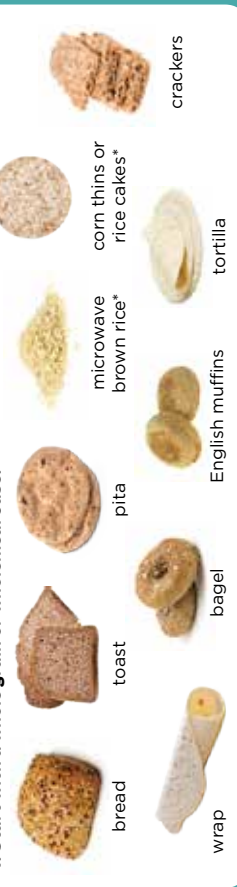


MIX AND MATCH:

These simple ideas can be made by using everyday kitchen appliances (eg. toaster, fridge or microwave).

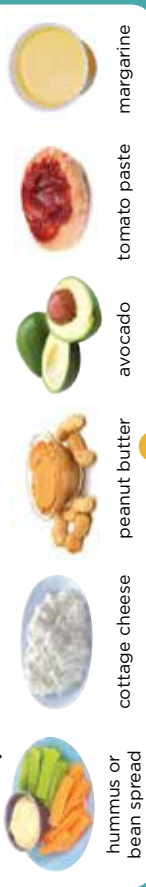
Using the steps below, mix and match foods to create exciting and affordable meals and snacks.

1. Start with a whole grain or wholemeal base:

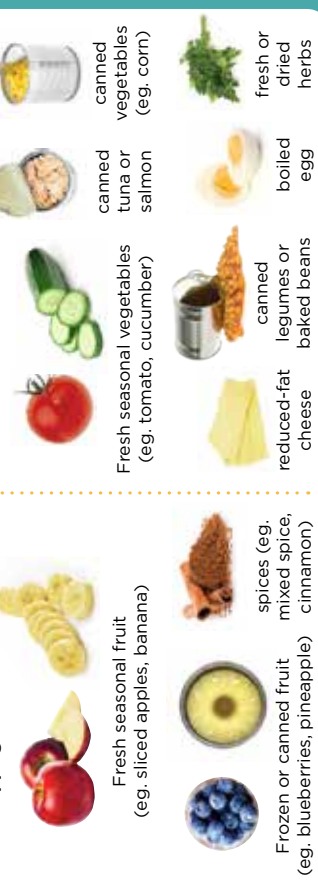


Gluten or wheat free

2. Choose a spread:



3. Add toppings: SWEET



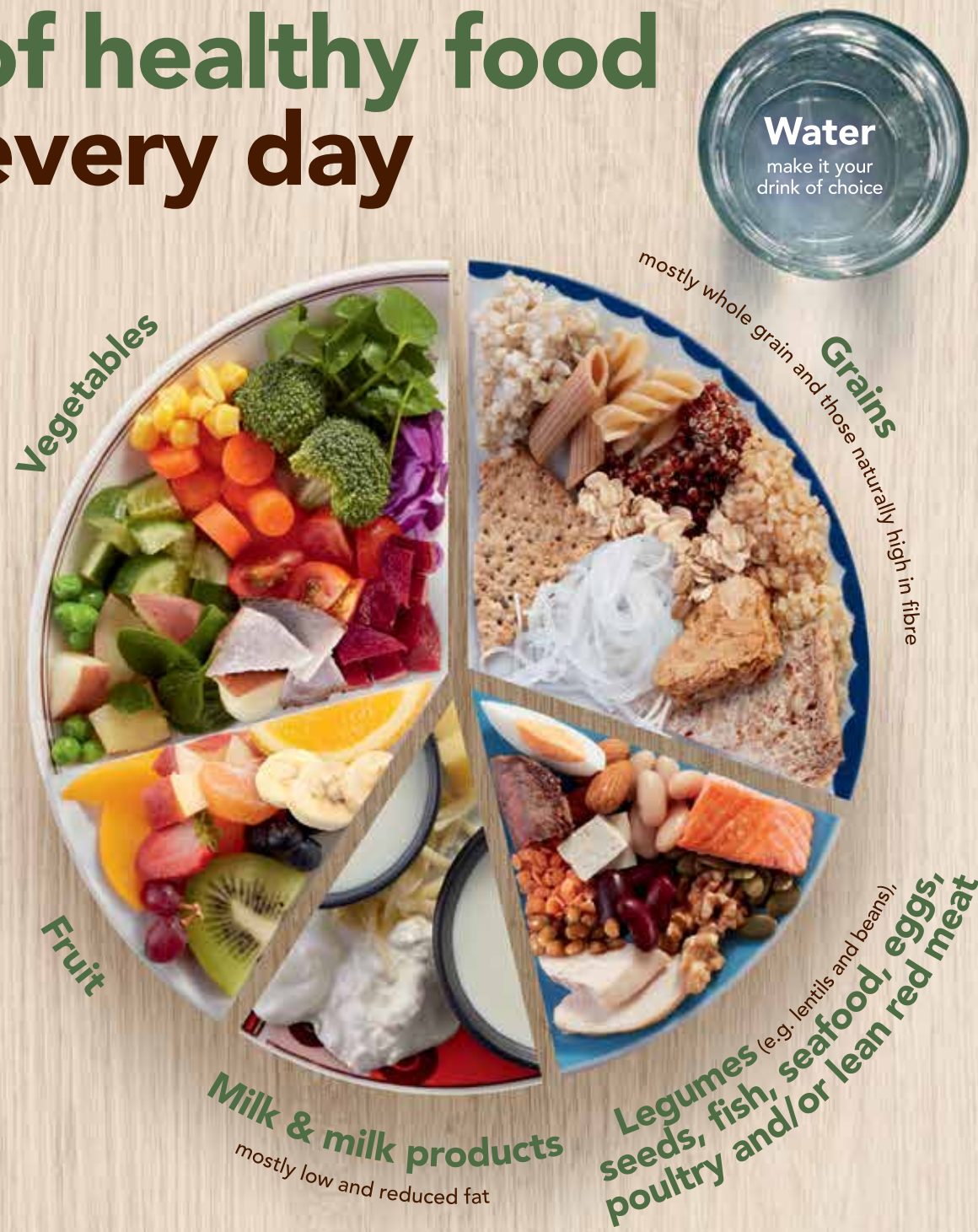
Egg, lettuce, hummus wrap

Brown rice, boiled egg.

Pita with hummus & salad

Subject matter

Choose a balance of healthy food every day



Eating a wide variety of nutritious food each day is important for good health.

www.health.govt.nz



Tear or cut out to pop on the fridge ✂

RESOURCES

WEBSITES

- www.nutritionfoundation.org.nz - recommendations for healthy eating.
- www.healthyfood.com - has free recipes with images and guidance on healthy food choices.
- www.health.govt.nz - see the healthy eating section.
- www.heartfoundation.org.nz - for recipes, downloadable posters and tips for healthy eating.
- www.toitangata.co.nz - kaupapa Māori based approaches to food. Includes recipes.

APPS

- Easy Diet Diary NZ.** A free app featuring a calorie counter, diet tracker, and barcode scanner which tells you what ingredients are in the product. The app aims to monitor energy, protein, fat, carbohydrates and a limited number of micronutrients. Additional features of the app allow weight and exercise monitoring.
- Foodswitch NZ.** This app helps search and compare nutritional information on food products. By scanning the barcode of a food label, you get easy-to-interpret nutritional information presented using colour-coded, traffic light labels of red, amber and green along with suggestions for healthier alternative foods or products.
- Foodeye.** Allows you to access food information such as ingredients, nutritional information, nutrition claims and allergen warnings. You can add or delete foods from your comparison list in your online profile for future use. You can also search for the product by scanning the barcode or search by name, brand or category.

Self Check In	Yes / No
I am aware of what foods I need to eat to stay healthy	
I know where to find recipes and tips to help me with a balanced diet	
I know where to go for support with healthy eating	
My healthy eating goals are to:	
People who can support me with these goals are:	

Notes

NGĀ TARUKINO ME TE WAIPIRO

DRUG AND ALCOHOL USE - WHAT YOU NEED TO KNOW

Section
7

18+

Alcohol - Waipiro

If you find it hard to tell your mates you are not into alcohol, check out our top tips below.

'I definitely noticed my tolerance for alcohol wasn't the same after treatment. I had to pace myself and watch how much I was drinking.'

Young person

If you are over 18, it's likely many of your friends will enjoy drinking alcohol. While drinking in moderation can be an enjoyable part of socialising, there are a few things to consider after you finish treatment:

- Your tolerance to alcohol might not be what it was before cancer. If you are planning to drink alcohol, alternate drinking water between drinks, or just start with a couple before having more as you may feel the effects of alcohol more than you used to.
- Medication and alcohol don't always go well together. Check with a healthcare professional about whether alcohol interferes with your medication.
- If you've been warned about drinking alcohol, or you have any issues with your liver function, follow the guidelines.
- If you have mobility challenges, or are a little unsteady on your feet, make sure you are in a safe environment or that you have a friend handy to help you.

Friendly reminder the age for drinking alcohol in Aotearoa is 18.



If you do choose to drink alcohol, check in with AYA Key Worker or healthcare team about how it can affect your health after cancer.

*Pai ana te kī atu e kāo.
It's okay to say no!*

TIPS TO STAY SOBER

Clue in a friend or two. If you tell your best mates before the party that you plan on being sober, you'll be more likely to stick to your word than if you keep it to yourself.

Plan to be the designated driver (only if you have a license, of course). That way, you will have an easy, non-negotiable excuse for not drinking, and your mates will owe you one.

If someone tries to hand you a drink, say you have to be somewhere later. To them, it will sound like you're saying, "This party might be cool enough for you, but I've got bigger and better places to go."

Carry around a glass filled with soda or water. People will assume you're drinking booze, and there's no reason why you have to set the record straight for them.

If people keep bothering you to take a drink, say you are having enough fun without it. It will probably make them wonder why they're not secure enough to have fun without being wasted.

Just say no. It's your body and your choice. If other people have a problem with it - that's their issue.

If you are still not comfortable, leave the party. People who don't know how to party without drinking - and without forcing others to drink - aren't worth partying with.

Smoking and Vaping

Most of us know that smoking is a bad idea. If you were a smoker before treatment or are thinking of taking it up, remember it is super hard to stop once you have started. Being a smoker affects your health, and is linked to secondary cancers like lung, mouth and throat cancer, **so why risk it?** The risk is especially high for cancer survivors who have had radiotherapy to their chest and lungs.

WARNING

Nicotine - the chemical in tobacco and tobacco smoke is super addictive. Some people can get addicted to nicotine after smoking just a few cigarettes. According to the Smokefree Aotearoa website, nicotine is as addictive as drugs like heroin or cocaine. That is why it can be so hard to stop smoking!



Vaping - is it safe?

Vaping is a relatively new product, and there is very little research confirming whether it is safe or not. We don't know what the long-term effects of vaping are, but there is increasing evidence linking lung and respiratory disease to vaping, so while vaping is less harmful than smoking, it is unlikely to be totally harm free. We recommend that you **do not vape or smoke**. For more information about how to quit smoking talk to your health care professional or contact Quitline.



Recreation drugs - Tarukino

I was definitely self-medicating with weed. It helped block out what happened. But after a while it made me feel worse.'

Young person

Marijuana or cannabis is one of the most common recreational drugs used by young people in Aotearoa and due to the fact that it is easily grown, one of the most easily accessible. Smoking marijuana increases the risk of secondary cancers like lung cancer later in life. If you are already struggling with post treatment fatigue or cognitive challenges like poor concentration or memory loss, marijuana is definitely going to make this worse.

Medicinal Cannabis

In 2000 The Medicinal Cannabis Scheme allowed access to medicinal cannabis for health reasons but there's strict criteria around this. Medicinal cannabis is only available on prescription and is only used to treat certain conditions. If you want more information about medicinal cannabis, please consult with your healthcare team for advice. **We do not recommend self-medicating with marijuana and encourage you to speak to a health professional.**

What are illicit drugs?

Illicit drugs include: stimulants, hallucinogens, ecstasy, sedatives, opiates, inhalants, and un-prescribed steroids. These drugs are not recommended as they are illegal, unpredictable and can increase your likelihood of engaging in risky behaviour. For honest information about drugs, check out the following NZ website aimed specifically at young people: www.thelevel.org.nz.

When to seek help

It's common for young people to experiment with drugs and alcohol for some of the reasons below:

- **Your mates do it** - it's pretty common to socialise with drugs or alcohol.
- **It's normalised in the media** - TV, movies and social media often portray drug use.
- **Escapism** - a chance to get away from your current situation.
- **Self-medication** - for pain or feeling low.
- **Boredom** - something to do.
- **Instant gratification** - it makes you feel better straight away.
- **Lack of confidence** - to help social anxiety or to help you fit in.
- **Relaxation** - some drugs help you feel more relaxed.
- **Misinformation** - mates told you it wasn't harmful.

If you find yourself turning to drugs and alcohol to help with any pain or stress you are experiencing since finishing treatment, or for any of the reasons listed, check in with yourself. It can be easy to turn to substances to help you cope, but ultimately, the

feelings aren't going to go away. Seeking support is a much better way to support your wellbeing. If you are in any physical pain, let someone in your healthcare team know. There may be other pain management options to help you. Remember to check out the wellbeing tips in this resource. Being active, or reaching personal goals are great ways to help improve your mood, and enjoy time with others without the use of substances.



Ask for support

If you think you need support to minimise or stop using drugs or alcohol, speak to your healthcare team. You can also find more information or support on the following websites:

- **www.alcoholdrughelp.org.nz**. If you are concerned about your drug or alcohol use call the free, 24 hour helpline on: **0800 787 797** or text **8681**.
- **www.quit.org.nz**. Quit advisors work with people to make a plan to stop smoking. They offer 24/7 support by phone, text, or online. Call Quitline free on **0800 778 778**, text **4006** or visit www.quit.org.nz to register for free help. They also provide good info about how to quit vaping.
- **www.thelevel.org.nz** Run by the NZ Drug Foundation, this website is a space for people who use alcohol and other drugs, their friends and whānau. The website offers practical ways to begin to make changes.

Self Check In

I have been made aware of any risks of taking drugs or drinking alcohol alongside my medication/medical history	Yes / No
I would like support with alternative strategies to drug and alcohol use	
I would like support with quitting smoking/vaping	
I have looked up the recommended websites for more information	

Notes

TŌ TINANA BODY IMAGE

Section 8

How you look and feel about your body

'I think my hardest thing was not feeling physically like my pre-cancer self. With all the hair loss and weight gain and weight loss, I felt as though I lost my identity. It is slowly coming back now after one and a half years.'

Young person

Cancer treatment can change the way your body looks, functions and feels – and that can change the way you feel about yourself. These changes may be temporary or permanent. The most common changes are:

- Scars (if you have had surgery).
- Hair loss (if you had chemotherapy or radiation).
- Loss or change in shape, size or swelling to a body part.
- Weight gain or weight loss including stretch marks.
- Losing part of your body like a breast or a limb.
- Skin changes such as redness, itching, sensitivity, or pain in the area you had treatment on or where your body has altered.
- Problems with balance, movement or physical activity.
- Muscle weakness or fatigue that does not go away.

You may feel more self-conscious or worry about meeting new people more than you did prior to having cancer. Remember that who you are is not just how you look. Having a healthy body or feeling strong or fit is important too. There are many things you can try to grow your confidence and increase your body positivity.

Hair loss

'I was afraid to go out in public not having any hair. I thought people would look at me differently to other people.'

Young person

Most young people will grow a full head of hair 3-6 months after completing treatment but do not be surprised if it grows back differently to how it was before. When it grows back, it could be curlier or finer or even be a slightly different colour. Some exceptions include if you have had radiotherapy or have any scars from brain surgery. In this case, your hair may take longer to grow back or could grow back thinner or patchy.

In rare cases, some young people may experience permanent hair loss after radiotherapy or high dose chemotherapy. While this can be tough, talk to your healthcare team about any support available to you.

'Once I learnt to embrace the changes to my body, I felt a lot better.'

Young person





Get creative

'Don't be scared of haircuts in the regrowth stage when hair grows back uneven or patchy.'

Young person

Growing your hair back can be a great opportunity to experiment with changing your hair colour, style or shape. Find a hairdresser or barber you feel comfortable with to ensure you get a style that works for you. If you have sensitive skin or have scars on your head, get advice about the best products, to ensure you do not react to the ingredients like bleach or colour products.

'I had the same barber for years, as he knew how to cut my hair around the scar on my head and I didn't have to say the same thing over and over again.'

Young person

Head coverings. There are a range of wigs, hairpieces, hats, turbans, scarves, headbands or bandanas that you can explore. Hair extensions may also be an option. Any money left over from your Wig and Hair Piece Service Payment can be used towards purchasing hair extensions. You will require a separate medical certificate for this, so be sure to ask for one from your healthcare team.



Ask your AYA Key Worker for a Hair Loss Package, which has everything you need to know about hair loss and financial entitlements. You can also download the Hair Loss Brochure from the AYA Cancer Network website www.ayacancernetwork.org.nz.

Eyebrows and eyelashes

'Learn how to draw/stamp/colour your eyebrows. As long as you're aware of where they were sitting, then you can get an idea of how to stick them on.'

Young person

The appearance of eyebrows and eyelashes can change the way you look, and how your expressions appear to others.

Use Eye Makeup. If you have minimal or thin eyelashes, or pale lashes, use mascara to help darken and thicken them. Eyeliner or eye shadow can also help enhance your eyes. A simple tip is to draw on eyebrows using an eyebrow pencil or soft-powder and brush.



If you are worried about having a steady hand or unsure about what shape or style you want, you can purchase eyebrow stencils from most chemists.

Get 'falsies'. You can purchase false eyelashes from most chemists. Wear them daily, or for special occasions. Make sure you do not re-use disposable ones and test the glue on something first in case you react to it (this can be common).

Semi permanent Eye Make up Solutions you can explore include:

Micro-blading. Is semi-permanent eyebrow tattooing which can make your eyebrows look thicker. It can be pricey, so it pays to shop around.

Eyebrow tinting. Done by a beauty therapist, this is when the eyebrows are darkened with semi-permanent colour.

Lash Tint or Lift. Getting your eyelashes tinted to a darker colour can help them look thicker and a lash lift can make them appear more voluminous.

Eyelash extensions. If your lashes are thin these can be applied and last up to 6 weeks - note sometimes removing the lashes might pull more lashes out which might slow your progress of growing them out.



Ask your friends and family for a trustworthy beauty therapist and always test the products on your skin first.

WHERE TO GO FOR HELP

Look Good Feel Better are a charity that provide free workshops for young adults to help with the side affects you may have experienced as a result of cancer. The workshops cover skin care, skin changes and makeup application to help you get the best out of your new appearance. Workshops are free, hands on, and you get to take home the products as a gift. You can also attend online classes. The workshops are for anyone with cancer, and are free. www.lgfb.co.nz.

YouTube - search for makeup tutorials on eyebrows and eyes to help you try different looks.

Talk to a beautician or make up artist at a beauty or department store, or book in for a makeup tutorial at a beauty clinic.

Ask a friend - If you know someone good at makeup, ask them to help.



Take a picture after you have had your makeup done, so you can try the same look yourself.

Skin - managing scars and stretchmarks

'I have an obvious scar when I wear tops that show a little bit of cleavage. If I was single and out dating or getting intimate with people, I would feel quite self-conscious.'

Young person

Protect your scars from the sun. Some young people have scars from a portacath or from surgery or skin grafts. These areas of skin can appear a different colour, have raised edges or look different to surrounding tissue. New scars tend to darken and discolour when exposed to ultraviolet (UV) light so it is recommended to keep scars protected by applying sunscreen or covering them up.

Tanning. Some people feel they look healthier with a tan. If you are keen to darken your skin, stay away from sunbeds and sunbathing which can expose you to harmful UV rays.

Instead seek alternative options that are safer for your skin, such as a fake or spray tan.



Beware as some tanning product contains 'melatonin', which will speed up your burn time and increase your risk of sun exposure and skin cancer. Try fake tan without any nasties in it.



Skin - managing scars and stretchmarks

Explore covering scars with makeup.

Makeup artists recommend using a primer first, then concealer and/or makeup and powder (to stop the scar going shiny). Ask a makeup artist/beautician at your nearest beauty store to help you colour match the right shade of makeup for your skin tone.

Tip

Try some samples to see if they work before you buy. If everyday makeup is not sufficient for cover up, you may want to explore cosmetic camouflage for a better concealment. For more info speak to a beauty therapist or makeup artist.

You may feel more self-conscious or worry about meeting new people more than you did prior to having cancer. Remember that who you are is not just how you look.

Medical Tattooing. There is also the more permanent option of medical tattooing for breast reconstruction, discolorations, permanent hair loss and scar camouflage. If you want more information about this, please discuss it with your health provider who may be able to recommend a clinic.

Stretchmarks. In addition to daily moisturising, there are products such as Bio Oil and Vitamin E oil that can help reduce the visibility of scars and stretch marks. Ask your healthcare team for a recommendation.

Be Proud.

For some cancer survivors, scars can be a badge of honour, for others, they are a reminder of a tough time of life.

Whichever way you view things, there are choices for managing scars. Try not to feel shame around your body. Scars are part of your survivorship - and surviving cancer is a good thing!



Body changes and clothing

'The weight gain was hard. Trying out different styles and sizes of clothing to help adjust to my body shape, helped'

Young person

If your body has changed size or shape, you have scars from surgery, or use a prosthetic limb, you may find it challenging to find clothes that fit or cover the sensitive parts of your body comfortably.

Dress in a way that works for you. If you are worried about showing parts of your body, find clothing that covers them. For example, if you have a port scar, you could wear tops with a high neckline or wear a rash shirt in summer.

Customise your clothes. It might be possible for someone to create an opening and insert velcro, buttons or zippers to help you get clothes on and off easily so you can still wear your favourite wardrobe. You may like to wear skirts with an elasticated waist or ties that you can loosen or tighten to suit your needs.

Accessorise. Get creative with accessories that suit your style such as necklaces, earrings, scarves, and headgear. Dressing up can help you feel good and accessorising can add to your current wardrobe and give it a different look.

Embrace your new body shape. If you are trying to fit into old clothes that no longer fit, treat yourself to something new. Finding clothing that fits your current body shape can help make you feel more comfortable and confident.

Tip

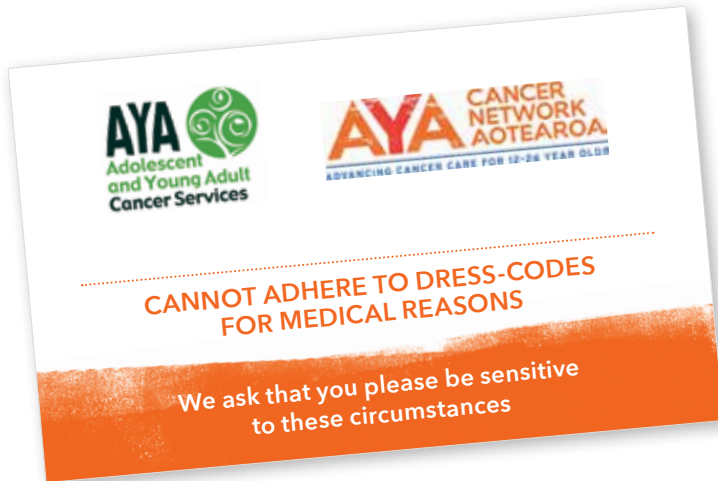
YouTube can be a great source for videos to help you style your current body shape or put clothing pieces together that work for you.



Complying with uniform requirements or dress codes

If you are returning to school or have a job that requires a uniform, speak to your school or employer about modifying this so you can cover any parts of your body that you feel self-conscious about. Maybe you would prefer to wear longer sleeves or trousers, or continue to wear a hat or head covering while your hair grows back.

Tip Turn to page 103 to tear out these wallet cards and start using them.



Tip Exercise at home until you gain strength, or go to the gym with a friend who understands what you've been through, and won't judge you. Adapt your exercise to your current fitness level and try and give yourself some positive self-talk, rather than beating yourself up.

When hitting the gym is harder than you think

'Connect with others who intrinsically understand the journey and can normalise the issues you might be having with your body image.'

Young person

Sometimes returning to the gym can be nerve-wracking, especially if your body doesn't look or behave the way it used to. Many people who undergo cancer treatment, experience changes to their muscle tone and physical strength, and this can make them feel self-conscious when they return to exercise.

Sometimes I hear negative messages in my head about how I look

'I realised I'd gone through so much and I wasn't actually taking care of myself. From there I had to rebuild a relationship with my body and myself'

Young person

The kindest thing you can do is treat your body with the aroha and respect it deserves.

Try to offer yourself the same compassion you would give to a friend going through a similar experience. The messages you say to yourself do make a difference, so affirm your body when you can.

- I am perfect, whole and complete just the way I am.
- I love and respect my body.
- My body is amazing just the way it is.

Me mihi tōku tinana ka tika, ahakoa te piki me te heke ka tiaki tonu i ahau.

I am grateful for my body; it has been through so much and continues to take care of me.

TOP TIPS FOR COPING WITH BODY CHANGES

Peer support. Talk to other cancer survivors about how they coped with their body changes. Join a support group through organisations like CanTeen.

Take care of your body. Eat well and get enough sleep. Exercise can help improve your mood, reduce fatigue and give you strength. Using nice products on your skin can make it look and feel good as well as keep it hydrated. For more information about nutrition, see section 6. For info on exercise, check out section 5.

Talk about your feelings. People will only realise you're worried about your appearance if you let them know. Be ready for conversations.

For more tips about talking to friends and whanāu check out page 29. You may also find talking to a counsellor beneficial.

Take your time. Give yourself time to grieve over any changes to your body, adjust to your new body, and heal from treatment. Remember, you are still yourself.

Seek support to manage any body image concerns or physical limitations. Write down your questions and concerns before going to any appointments with your healthcare team.

Self Check In		Yes / No
I have concerns about my body and know where I can go for help		
I have some strategies to help with my self-confidence /body image		
I have talked to other young people with cancer about what helped them		
I have cut out the wallet card and have it with me if I feel the need to use it		

Notes

HAUORA TŌKAI ME TE TAUPIRI

SEXUAL HEALTH AND INTIMACY AFTER CANCER

Section

9

'After treatment I felt I was physically less attractive than previously, which affected my confidence and my sexual health. This has come right over time.'

Young person

This section was developed based on feedback from young people who found there was little or no information available to them on the topic of sex and sexual health after cancer. If you are in a sexual relationship and are experiencing challenges with sex and intimacy, or you have questions about your sexual health or fertility, this section is for you. For young people who are not in a sexual relationship, you are welcome to skip this section or just take the information you feel is relevant to you at this time.

Cancer and cancer treatment can affect your sexuality (which includes how you feel about yourself, your body image and sexual feelings towards others) and your sexual function (your ability to have and enjoy sex). These changes may be temporary or ongoing and can be difficult to manage and talk about. The good news is, with time many sexually active young adults who have undergone cancer treatment can expect to have a normal sex life and engage in healthy intimate relationships again.

Physical challenges with sexual activity

While physical challenges for some can be embarrassing to talk about, it is common after cancer treatment to have difficulties such as painful sex or finding it hard to get an erection. The important thing to remember is that there is support available and we encourage you to speak up.

Firstly, keep track of your symptoms.

If you are sexually active, use the checklist below to help identify any challenges you are experiencing, and talk with someone in your healthcare team.

Symptom Checklist

Loss of libido (desire to have sex)

Anxiety relating to sexual intimacy or body image

Reduction in natural lubrication (vaginal dryness that makes sex painful)

Loss of sensation (reduced feeling during sexual intimacy)

Pelvic pain (pain in your private parts or lower abdomen)

Difficulty getting or maintaining an erection

Difficulty ejaculating (releasing semen or sexual fluid)

A rash or itching to your genitals (vagina, anus or penis)

Incontinence (leaking urine)

Irregular periods or lack of periods

Difficulty reaching orgasm

Other:

Yes / No



Premature Menopause

'I have no sex drive but my hormonal medication helps'

For some young people, the symptoms such as painful/uncomfortable sex, vaginal dryness, irregular or no periods or fatigue may be related to temporary ovarian failure or premature menopause caused by cancer treatment. For more information, please refer to the AYA Cancer Network's Cancer and Fertility brochure which is available at www.ayacancernetwork.org.nz. If you are experiencing any of these symptoms, please discuss with your healthcare team – there are effective ways to manage your symptoms and reduce discomfort.



I identify as LGBTQIA+ and don't feel comfortable talking about sexual health or intimacy with a health professional.

'Everyone just assumed I was straight. I didn't feel like I could be myself'

Young person

One of the keys to receiving support is to be accepted for who you are. Challenges with sex and intimacy can be much harder if you cannot be open with your healthcare provider. Share your name, gender identification, correct pronouns, sexual orientation and partner status with your healthcare team. This will hopefully lead to an increased level of comfort, honesty and trust and mean that you get support for your sexual health when you need it.

If you feel uncomfortable or experience any type of discrimination discussing your sexual health with your cancer treatment team, please speak with your AYA Key Worker or access services like Rainbow YOUTH, OutLine or Gender Minorities Aotearoa who can support you to address this.

All young people with cancer have the right to good sexual health information and to feel respected for who they are.

Who can I talk to about my concerns?

Talk with your AYA Key Worker or someone in your healthcare team first so they can refer you to the right service.

For example, if radiation therapy has narrowed or shortened the vagina and is causing discomfort, a physiotherapist who specializes in pelvic therapy may be the best person to help you learn to manage this. Alternatively, erectile problems can be supported by sexual health services.

Many young people comment that the biggest barrier to seeking support is embarrassment. But please don't be embarrassed. Your healthcare team are trained professionals who are here to listen and help you. If you would prefer to seek help outside cancer services, sexual health services such as Family Planning and school or university health centres are easily accessible. See the resources box at the end of this section for more information.



Many people talk to health providers about their sexual health. Remember everything will be kept confidential, so you don't have to worry about other people knowing.

Sexual Health – Common Challenges

I have pain inserting tampons and during sexual intercourse. What can I do about it?

It can be common after treatment to experience dryness in the genital region such as your vagina, which may lead to pain during intercourse or when inserting tampons during your period.

The cause of this can be treatment related, or be a result of anxiety or loss of libido (sex drive) during intercourse. Here are some practical strategies that may help:

Lubricant. If loss of natural lubrication or dryness is a challenge, use a water-based lubricant before inserting anything into your vagina and avoid any products with perfumes or colouring to reduce irritation.

Use Pain Relief. If you experience pain, take painkillers before you insert a tampon or before sexual intercourse or try relaxation exercises to reduce anxiety, which can in turn reduce any pain.

Try at the best time of day. Be intimate at the best time for you for example when your pain is low or energy levels high.

Pay attention to your body. Changes in the acidity of the vagina can lead to a common condition called thrush. The symptoms of thrush are a creamy white discharge or itchiness in the vagina. Thrush can also occur under the foreskin of the penis. Thrush is easily treated and is not cause for concern. Talk to your GP or nurse who can give advice about creams or tablets you can take to help.

Take it slow. If you are sexually active it might be helpful to spend more time on foreplay exploring different ways to be become aroused and intimate. Intercourse doesn't have to be the main goal unless you're comfortable with it. Take things at a pace that works for you.

I am having trouble getting an erection.

Struggling with an erection after treatment is more common than you might think. It's known as erectile dysfunction (ED) and both physical and emotional factors can be the cause.

In many cases, ED is temporary and can relate to fatigue or stress. However, it can be common with erectile dysfunction to experience performance anxiety, low self-esteem, or a loss of sexual arousal. Try these practical tips:

Arousal. Suss out what turns you on. What kind of things help you feel excited sexually? If you feel comfortable, share these with your partner.

Masturbation. Try masturbating or self-pleasuring on your own using lubricant. Once you know what works for you, show your partner how you would like them to stimulate you. Make sure you have some private time and space available, so you are not interrupted.

Take the heat off. Find other ways to be intimate that don't involve getting an erection. Try touching or kissing, or doing other things together you enjoy.

Talk about it. Speak to your partner or access counselling. CBT (Cognitive Behavioural Therapy) can help you understand what triggers the ED and can help you with strategies to manage it. Talk to your health care provider or contact Family Planning for more advice about how to access this.

NOTE:

In some situations, young people who have undergone surgery or radiation to the pelvic region, can experience permanent erectile dysfunction and it's important that you talk with a healthcare provider.



When whitiwhiti – communication is hard

'I lost a lot of confidence in having sex with my new partner. Also, I didn't have the same desire to have sex and felt pretty damn ugly at times.'

Young person

I feel like I have lost the sexual connection with my partner and I'm not sure what to do.

Firstly, be gentle on yourself and take your time. Focusing only on sexual performance can result in added anxiety and challenges with sex. Sexual connection is more than arousal, intercourse and orgasms; it also involves feelings of intimacy and acceptance. Try these tips:

Communicate. Be honest and share your feelings including any fears about sex. Your partner may be feeling confused or uncertain about how to react and may be waiting to take the lead from you.

Pick the best moment to talk. Start a conversation when you are feeling calm, not when you are in the middle of having sex or rushing somewhere.

Write stuff down. Think about what your needs are and what you want to say beforehand and write it down so you are prepared.

Set some ground rules. Let the person know if you find sex hard to talk about, and need them to listen and really hear you.

Offer up some suggestions. Help equip your partner with ideas. Don't tell them what they're doing wrong, encourage them to try things that **do** work for you.

If you are struggling to know where to start, try some of the following conversation starters:

IF IT'S A NEW PARTNER:

'Before anything happens – I just want to be up front and let you know that I've recently been through cancer and am still coming to terms with it all. I'm way more nervous about sex/intimacy after what I've been through. I'm keen to take it slow.'

'I really like hanging out, but I've just finished cancer treatment and my body's changed a lot. I feel way more self-conscious than I did before. I might need to take things slow.'

'So, I have super low energy since I finished cancer treatment and sometimes find it hard to get going. I'll be honest with you about where I'm at as we go along, but I'm going to need you to be patient with me.'

IF YOU ARE CURRENTLY IN A RELATIONSHIP:

'You've been amazing looking after me through treatment, but now I'm keen for us to go back to being partners. Can we connect in ways that aren't about you looking after me?'

'What are you most worried about with us being intimate again? Tell me and I'll tell you where I'm at too.'

'I feel way more self-conscious about how I look now, and I find it hard to feel sexy. I just need you to be patient while I work through it.'

'Some things have really changed for me physically in terms of how I feel and what I enjoy. How can I let you know if something feels different or I want to stop without upsetting you?'



If you are in a long term relationship and are finding it tough – you might want to consider seeing a couples' counsellor or a sex therapist for tips and advice to help you re-engage or reconnect sexually and intimately with your partner. While talking about your sexual wellbeing might be challenging, if you and your partner are honest about your wants and needs, you can go on to enjoy an intimate relationship together again.

Firstly,
be gentle
on yourself
and take
your time.

Strategies to help with intimacy - taupiringa

I feel like we are both stuck and not sure about how to be intimate again. Where do I start?

Keeping a good connection with your partner can reduce anxiety and pressure around sexual performance and allow you to rebuild an intimate and sexual relationship.

Try these tips:

Take things at a pace that works for you. Show affection through touching, hugging, massaging, talking and holding hands. If you do not want to go any further than that, don't. A date night or doing activities you enjoy can strengthen your connection and make it easier to talk about your feelings.

Practice some self-love. If you feel comfortable, stimulate yourself for sexual pleasure. This will make it easier to navigate what gives you pleasure with your partner.

Explore what makes you feel sexy. Some people find getting dressed up or spending time on their appearance makes them feel more attractive. Try reading romance books or watching romantic shows.

Explore your sensuality as well as your sexuality. Light candles, listen to relaxing music, take a bath together or give each other a massage.

Create a positive, safe environment for intimacy to occur. Set a peaceful scene to help you relax. Make sure it's private and free from interruptions.

Explore different sexual activities. Some of the sexual practices you used to enjoy may not be comfortable now. If intercourse is difficult, try oral sex, mutual masturbation, or using sex toys.

Rest. Low libido is common and can be a result of fatigue or low mood. Make sure you are getting enough rest to keep your energy levels up. Refer to the sections on mood and fatigue for more advice.



Your body - your choice - Nōu tō tinana

'I don't always feel like sex, but my partner is just not getting it.'

Young person

If you and your partner are not on the same page, you may want to access support to help you work through this.

However, if you feel pressured or your views and needs are **not being heard, respected or valued - this is not okay**. Remember, sex and intimacy is not just about making your partner happy, it is also about your pleasure and happiness too. Your sexual boundaries and views on intimacy are important, but if your partner is not respecting this, it's okay to decide to end the relationship. There is no reason to feel guilty and there is no reason why you cannot go on to find pleasure and happiness elsewhere if that is what you want.

We're keen to stay together but would like some support. Where can I go for this?

'Counselling really helped. I didn't realise how much I was holding on to, until we started to talk about it.'

Young person

Navigating intimacy after treatment can bring things up in your relationship and many couples turn to relationship counselling or sex therapy for support. Counsellors can offer suggestions for how to reignite your relationship as well as providing a safe and open space to talk things through.

A supportive and understanding partner can help your recovery and working through things together shows a commitment from each of you. Check out the resources on page 84.

Contraception

I am pretty sure I'm infertile. Do I need to worry about contraception?

'One day I went to the doctors not feeling well and found out I was pregnant. Even the doctor was shocked because of the way they put that I was not going to have kids again. Contraception - I didn't think I needed it!'

It is hard to predict who will experience fertility issues, so unless you want to become pregnant and start a family, it is better to assume that you could be fertile and use contraception when having sex. There are many contraceptive methods available such as condoms, the pill, the injection and implant. With your medical history, it's important to discuss the method most suitable for you with either your GP or specialist.

Remember that regardless of the contraceptive method you choose, you will still need protection from sexually transmitted infections. Using a condom or dental dam correctly when you have sex can reduce the risk.



Your AYA Key Worker is a great person to approach if you feel uncomfortable having conversations about contraception with your medical team. All conversations with your health provider related to contraception are confidential.

Fertility - Matahua

I would like to start a family, but I am not sure about my fertility status.

Cancer and cancer treatment (chemotherapy, radiotherapy and surgery) can affect your ability to have biological children. The risk of infertility (not being able to have children) is different for everybody and depends on the type of cancer and treatment you have had. For most young people, conversations around treatment-related fertility risks will have taken place at diagnosis and any potential fertility preservation options explored then. However, many young people say that these discussions become a blur when so much was going on at the time. Now that you have finished cancer treatment, you might find yourself thinking about having a family, and wondering about your fertility status and options.

These are the common questions young people have about their fertility:

- How do I know if my treatment has affected my fertility?
- Who can I speak to about my fertility and when should I do this?
- Should I use contraceptives?
- What happens when I'm ready to be a parent?
- Is there anything that I need to know about the frozen biological tissue i.e. sperm or eggs/embryos I have stored?
- If I am infertile, or have reduced fertility is there anything I can do about it?

All this information is in the **AYA Cancer Network - Cancer and Fertility booklets**. You can access these through the website or your AYA Cancer Key Worker.



If you are keen to try for a baby, the recommendation is to wait 12 months following treatment before you start trying. Make sure to discuss your plans with your specialist first.

For Partners

You might find it helpful to read the information in this chapter to give you an understanding of what your partner is going through. Supporting someone after cancer treatment is not easy and there are many resources in this booklet that can help.

Some charities also offer support groups for partners and caregivers.

Ask your partner to find out more about these through their AYA Key Worker or support worker. Information can give you more understanding, which can help strengthen your relationship.

RESOURCES AND SUPPORT

- www.cancersociety.org.nz** Enter sex and cancer into search for articles and information specifically relating to cancer. You can also access counselling or support from a nurse.
- www.breastcancer.org.nz** Enter body image and sexuality into the search. There is a section called 'Talking about Sex'. You can also access counselling or nursing support/advice.
- www.youngliveswithcancer.org.uk** Enter sex and fertility into 'search for more info'.
- www.ayacancernetwork.org.nz** Check out for the following booklets on our website or ask your AYA Key Worker for a copy: **Young People Cancer and Sex** and **Cancer and Fertility**.
- www.genderminorities.com** A NZ website offering online peer-to-peer info share forum for trans and intersex people, their families and supporters.
- www.outline.org.nz** National Rainbow friendly, free counselling support 0800 688 5463.
- www.nzshs.org/clinics** Find local sexual health services.
- www.familyplanning.org.nz** Confidential service covering contraception, STI testing and treatment, cervical screening, pregnancy, menopause and other advice for sexual and reproductive health. Free for under 22. Look online to find a family planning centre in your area.
- www.sextherapy.co.nz** Check out the network of sex therapists across NZ.
- www.villainesse.com/therealsextalk** Info on sexual health topics for young people.

Self Check In

I know about sexual health challenges caused by treatment, and where to go for help
I have strategies for talking to my partner about issues related to sex and intimacy
I have spoken to my health care provider about my fertility and know my fertility status
I understand what's involved with starting a family and know where to go for support with this if I need it
I pay attention to my sexual health and wellbeing and know where I can access contraception or sexual health advice or treatment

Yes / No

Notes

TE WHAKARITE WHĀINGA GOAL SETTING



*In the beginning I had the mind-set of not being **ABLE** enough to do all the things I told myself I would've been able to do if I hadn't gone through treatment. That mindset took away any possibility of me even trying. Since overcoming that **mindset barrier**, I've been able to level up in how interactive I can be socially, how much exercise my body can endure and now the possibilities of me being able to do whatever I put my mind to, is endless!*

Young person

Before you step back into school, work and life, pause and set some intentions for how you would like to move forward.

You do not have to rush into doing everything at once, but looking forward is a positive step for your wellbeing, and there are tools that can help.

I find it hard to imagine my future, especially as I have lost a lot of confidence. What can I do?

Me tīmata i te whakaaro pai.
Start with a positive mindset.

If you believe you **cannot** do something, it can be hard to get started. When you start to look to your future and set goals again, it's important to believe that you **can** achieve them. There's no point in focussing on things that are unrealistic, or which you think you can't achieve, as you'll only be setting yourself up to fail. Having a positive mindset will help you to explore the possibilities of what you **CAN** do and is a great place to start. Believing you **CAN**, is the first step.

Foster a Growth Mindset



*Ka mate kāinga tahi,
ka ora kāinga rua.
When one door closes
another will open.*

Are there any tools to help me start thinking about my future?

If you are struggling to find motivation for your next steps, representing your goals and dreams in images can be a powerful motivator to help. **Vision boards** are a creative way to help you focus on the future. You can create these digitally or on paper.

ACTIVITY

How to make a vision board

- Create a list of goals you'd like to achieve in the next year
- Find pictures or photos from old magazines that represent your goals and inspire you
- Make a collage out of your photos and images
- Add motivational quotes or "affirmation words" to inspire you
- Put the board somewhere you can see it.
- Take a few moments to contemplate your vision board every day
- Share it with others who can support you and motivate you on the way to achieving your goals.











Top tips for vision boards

Choose words and images that best represent your ideal future and which help inspire positive emotions in you. This activity is just to help you focus and you do not have to put specific time frames down if you're not ready to. Some of the areas you might want to focus on could be:

Health and fitness. Choose images that show people getting fit or eating good food.

Relationships. Use images or words showing positive friendships or relationships.

ACTIVITY Fill in some goals under the headings or use a whole page and add words and images to help you focus in the year ahead.

My goals for:	
HEALTH AND FITNESS 	CAREER PATH 
PERSONAL DEVELOPMENT 	ROMANCE AND RELATIONSHIPS 
FINANCES 	HOBBIES AND FUN 
FRIENDS AND WHĀNAU 	SPIRITUAL 

Happiness. Choose images of nature, people laughing, or cute animals. Anything that makes you feel good.

Spiritual Goals. If you want greater spiritual understanding, choose images representing your faith or culture.

Money. If you are keen for more money, include images of cash or the items you would like to buy with that money.

Study Goals. If you are keen to get work towards a qualification, include an image of someone studying or graduating or write down the title of the qualification

Travel. If you are keen on travel or adventure, include images of this.

Tip Now that you have your vision board up on the wall, make sure you look at it every day to help motivate you. You can even share it with friends or whānau or make one together.

Mauria te pono – believe in yourself!

Tips on travel insurance

If one of your goals is to travel, it is important to note that all travel insurance policies **exclude** pre-existing conditions. This means there may be restrictions on what you're covered for when you travel overseas. When you apply for travel insurance, be sure to answer all of the health questions carefully and fully disclose your pre-existing conditions. You may find that some companies offer full coverage at an additional cost. Others may decline full cover but offer partial cover with special acceptance terms. Phone the **Cancer Society 0800 226 237** help-line for support as they are known to give good advice and know of individual insurers who could help you.

RESOURCES

If you are interested in more tools to help you focus on your future, check out the following:

Goal setting - www.teenagecancertrust.org/information-about-cancer/setting-yourself-new-goals-after-cancer A helpful half hour clip from a young person with cancer on setting goals after cancer. The website also has some great tools and resources you can download and use.

Life coaches - www.lifecoaching.com and www.anzcal.org.nz online directory for coaches in NZ.

Journals - www.awesomeinc.co.nz produce some good journals for young people. Search online or in stores.

Careers advisors - If you're unsure what direction you want to focus on with your career, speak to the careers advisor at school, polytech or university. They may have goal-setting tools to help you understand your career pathway.

Mood or vision boards - check out Pinterest for ideas or google 'moodboard' or 'goal setting' for free templates.

TE AHU WHAKAMUA
- HOKI KI TE
MĀTAURANGA,
TE WHAKANGUNGU,
TE MAHI RĀNEI
MOVING FORWARD
- RETURNING
TO EDUCATION,
TRAINING, OR WORK

Self Check In	
I know where to go for support with goal setting and planning my future	
I have some things I would like to achieve in my future	

Notes



Returning to kura/school

‘Going back into high school, you just really have to be realistic about how much time at school you can handle and it’s probably less than you think.’

Young person

If returning to school or kura and you’re worried about seeing friends, catching up on school work or managing fatigue, let your education provider know as soon as you’re ready so they can start coordinating your return.

Create a plan for your return to school/kura.

Set up a meeting with your caregiver and key staff including any of the following: your dean, school nurse (if there is one), guidance counsellor, AYA Key Worker, Charity Support Worker and/or Regional Health School teacher. To guide the meeting, we recommend completing the **Health Summary** sheet and taking it with you. This will inform what you put in your **Return to School Plan**. Both forms are at the end of this section.

Tip Remember to specify who you want your information shared with so that it remains confidential. If you feel uncomfortable having too many people in any meetings, just choose a couple and ask for the information to be shared.

Arrange a key point of contact. Nominate one key person as your point of contact and catch up with them weekly or fortnightly to review your plan. This person can then be responsible (with your permission) for communicating and sharing information with other staff members. This will stop you having to share information multiple times.

Tip Choose a person that you have a good relationship with so you can be honest about how you are feeling and what your needs are.

Set realistic expectations. If it is taking a while to get your energy back, plan a gradual return. This could mean just going a few days a week or reducing how many subjects you take, and slowly increasing as you feel up to it.

Meet with friends. Arrange to meet your mates before you start, especially if you have not seen them in a while. This can help you feel more connected and excited about returning. Many of your friends might want to know how they can help so be prepared to ask for what you need.

Tip Having a buddy at school can be helpful. This person can go with you to class, carry your bags or just be by your side if you need them. It can be helpful to identify this person before you return so teachers know they will be helping you in class when you need it.

Choose the best spot in class. If you find it hard to concentrate, or your vision or hearing is impaired, request to sit closer to the front.

Tip Ask your teacher if a friend can reserve a seat for you so you don’t have to rush to class.

I find it hard to get around school, what can I do about it?

If your classrooms are difficult to access, highlight this **before** your return, so your school can consider things like ramps, or assigning classes on the ground floor to help you. If getting around takes you a little longer, ask if you can leave 5 minutes early to avoid the crowded areas to allow time to get to class.

I have a Regional Health School teacher. What support can they provide?

There may be an option for you to complete some subjects at school and others with your Health School Teacher, especially if there are subjects you struggle with.

Tip Speak to your Regional Health School teacher or ask to be referred to one so you can liaise with them about managing school work through a combination of learning from home and school.

Everyone keeps asking me about cancer – what should I say?

It can be hard to know what to say to classmates about cancer. Consider having your teacher or health provider talk to your class before you return or give a talk or presentation yourself if you feel comfortable doing that.

Tip If you want to keep your medical history private, that’s up to you. For tips on talking to your peers check out page 28.

I feel self-conscious about how I look.

You may still have visible signs of cancer and treatment like hair loss or scars. If you’re feeling whakama (ashamed) or self-conscious, ask for a uniform exemption such as permission to wear a hat or long pants to cover up a scar, in your Return to Education Plan. As time goes on you will start to feel more confident about your appearance. Just give it time.

Tip Check out the Body Image section on page 68. You can also print our uniform exemption cards) and keep these with you to show teachers without drawing attention to the situation.

I’m worried about keeping up and managing exams and assignments. What support can I access?

‘If you talk to your teachers they will most likely understand and give you an extension. In my last year of high school, they didn’t make me do all the assignments. I got to pick the ones that I wanted to do that would give me extra credits in all the subjects I needed to get university entrance. Just talk to your teachers about it.’

Young person

Your school may be able to provide alternative exam arrangements for you such as organising a reader/writer to help. For more information about this, see the resources box on page 97.

Tip Ask your teacher if you can access extra tutoring support at home or school. Some cancer charities may also be able to help cover the cost of this for you.

Haere ki to heke mai me to māhunga ki runga.

Step into your future with your head held high.




My Return To Education Plan



My return date is:
My graduated plan includes these days/classes:
My key support people/contacts are (include Support Workers, friends, nurse etc):
When I feel tired or unwell I can:
The agreed resources and support I need to attend my classes are: <i>(example: comfortable seating, extra tuition, permission to wear a hat, reader/writer for exams)</i>
Other important information:
This plan will be reviewed on:

Notes

 Tear or cut out to pop on the fridge



About Me - My Health Summary



The type of cancer and treatment I had was:

Some of the challenges that I currently face are:

- | | |
|---|---|
| <input type="radio"/> Fatigue/extreme tiredness | <input type="radio"/> Hearing loss |
| <input type="radio"/> Pain | <input type="radio"/> Visual challenges |
| <input type="radio"/> Hair loss, scars or visible signs of cancer treatment | <input type="radio"/> Brain fog such as issues with concentration and memory |
| <input type="radio"/> Cognitive challenges, for example trouble finding words quickly | <input type="radio"/> Mobility challenges, e.g. using a wheel chair or crutches, or finding it hard to walk long distances: |
| <input type="radio"/> Other: | |

Things that would help with my transition to education:

- | | |
|--|--|
| <input type="radio"/> Have a friend support me e.g carry my bag | <input type="radio"/> Skip Physical Education |
| <input type="radio"/> Leave class early to get to my next class | <input type="radio"/> Take a rest break during the day |
| <input type="radio"/> Return part-time | <input type="radio"/> Sit in a different chair |
| <input type="radio"/> Extra tuition and learning support | <input type="radio"/> Move around or stretch when I need to |
| <input type="radio"/> Be able to take medication when I need to | <input type="radio"/> Use special equipment to help me write or learn |
| <input type="radio"/> Access to a quiet space to sit or rest | <input type="radio"/> Seek extensions or help with exams |
| <input type="radio"/> Have a pass for toilet breaks | <input type="radio"/> Have a point of contact at school |
| <input type="radio"/> Sit up the front so it's easier for me to concentrate/ see the board | <input type="radio"/> Go to see the nurse or go to sick bay whenever I need to |
| <input type="radio"/> Other: | |

Things I'm worried about are:

Important Medical information

My doctor's name and contact details are:

My current medications are:

Allergies and how to manage them :



RESOURCES AND SUPPORT FOR KURA/HIGH SCHOOL

Some cancer charities may be able to help with the cost of tutoring or equipment costs like a laptop. Talk to your support worker or youth worker for more information.

Regional Health Schools

Regional Health School provides community and hospital-based teaching if you are unable to attend regular school. There are 3 regional health schools covering all parts of NZ: Northern Health Schools: www.nhs.school.nz Central Regional Health School www.crhs.school.nz and Southern Regional Health School www.srhs.school.nz.

Derived grades

If you are too sick to sit exams, or if treatment has had a major effect on your performance in an external assessment, you can apply to the New Zealand Qualifications Authority (NZQA) for a derived grade. A derived grade is based solely on your pre-existing results record, held by your school.

Special Assessment Considerations (SAC)

SAC provide extra help for approved students when assessed for their NCEA to give you a fair opportunity to achieve credits. The support is for internal standards and external standards (exams). Examples of SAC include being able to have a reader or writer, use a computer, have rest breaks or have enlarged papers to help with reading and vision.

Visit the NZQA website to find out more about Derived Grades and Special Assessment Considerations. www.nzqa.govt.nz

Ongoing Resourcing Schemes Funding (ORS)

ORS funding is available in schools for young people experiencing challenges in the following key areas: Learning, Hearing, Vision and Language and Communication. For more information about ORS, and about how to apply for funding, check out the ministry of Education website. www.education.govt.nz.

School High Health Needs Fund (SHHNF)

SHHNF provides teacher's aide support for 6 weeks or more if a young person has a serious medical condition and needs help to attend school or kura safely. The Ministry's learning support team will work with you to plan your support needs. You can access this service if you have a physical disability that prevents you from participating in learning, or if you have difficulties with mobility and/or hand movement. The fund can help you access specialised equipment to help you walk, write and perform tasks requiring fine-motor skills. To find out more speak to your school about accessing the fund.

The Physical Disability Service

The Ministry of Education Physical Disability Service can help your school adapt to the environment to better meet your needs. To access support, you will need to have challenges with:

- moving safely around the classroom and the school
- taking part in learning activities, particularly physical ones
- using pencils, pens and other tools (including technology) and materials, especially if your disability causes problems with your handwriting
- managing basic tasks, such as changing clothes when you go swimming.

Speak to your school about the supports available, and how to access them.

Returning to study or training

‘Everyone goes through things at a different pace. Don’t feel bad because someone else had treatment and returned to work 3 months later and you’re still stuck at home a year later.’

Young person

While some of the tips in the returning to high school section might be helpful (like meeting with your friends or arranging a key contact at your place of study), attending a training course, university or polytechnic is different.

I feel nervous about studying full time after being off. What are my options?

Consider studying part time or, if you are at uni, only take 1 or 2 papers in the first semester so you can see how you go. This will give you the opportunity to ease into things as well as allowing you time to see how your energy levels are.



Don’t load yourself up with too much, too soon. Check out your financial entitlements around part time vs. full time study to make sure you are accessing all the financial support you are entitled to.

What support services are available if I am attending university or polytechnic?

Most learning institutions have **Student Support Centres**, which offer free and confidential support to all students enrolled. Make contact early, as they can help you overcome any obstacles that you may experience when re-engaging with study.



If you do not feel like you require support while studying, check out the services anyway, in case your situation changes.

Student Support Centres will help you access the following:

Disability Services. You may not think of yourself as having a “disability”, but a chronic medical condition like cancer is actually considered a disability. If you do choose to tell your education provider, you may have the right to access special support services. Disability Liaison Officers are available at most learning institutions to discuss your needs confidentially.

Learning Support. These services often provide workshops or tutorials to help you with study skills. They should also be able to assist you with the following:

- Alternative formats of learning, like recorded lectures.
- Access to specialist equipment and assistive technology such as laptops, microphones and speakers for the lecturer to assist with voice projection.
- Communicating with lecturers on your behalf regarding your support needs.
- Guidance on applying for alternative test and exam arrangements – this could include special equipment, a writer, or extensions for assignments.

Student finance support. Guidance and help with paying fees and managing general living costs. Student Support Services can help you find out what financial support you can access while studying.



Many learning institutions offer scholarships in the form of hardship funds, or scholarships for Māori & Pasifika. Check out the scholarship section on the website of your provider to see if you meet the criteria. You may also be able to access funding from your local iwi.

Healthcare. Most universities have a health centre where you can access a GP or nurse who can provide healthcare at subsidized rates. They should also have free counselling services available to support your mental and emotional wellbeing while you study.

Childcare on campus. If you have children, check out if there is a day care or nursery on campus where students can drop their child/children off while they attend class. Some university-affiliated kōhanga (daycare centre) and nurseries offer special rates and discount prices for students.

I’m starting a course that doesn’t have a student support centre. What can I do?

Apply the same process as returning to school – complete the health summary and return it to a key contact at your education provider. Smaller courses often have the ability to provide a more tailored, personal approach to your transition. If you require help advocating for support, speak to your support worker, counsellor or AYA Key Worker to see if they can advocate for you.

‘Finding the right support was tough; there are so many barriers that existed for us low-income earners. It was hard to get what was actually there.’

Young person

I am currently on a benefit – will this be affected when I return to work or study?

If you are currently on a benefit and are thinking about study, you may be able to get help from **Work and Income** through **StudyLink** but do note that your entitlements may change when you go into employment or study. If you are returning to **full-time employment**, your benefit will likely stop, but depending on your income, you may be eligible for other entitlements like the disability allowance, or family support payments.

If you are returning to work or study **part-time**, you may still be able to access your **current benefit**. For example, at the time this was written, those on the Job Seeker Allowance could earn \$160 a week in part-time employment before it impacted on the amount they received. However, those on the Supported Living Allowance couldn’t work more than 15 hours a week or earn over a certain amount of money.



When your situation changes, so can your entitlements. We recommend you meet with a WINZ liaison officer to find out what you can access **before** returning to work. To find out more WINZ entitlements phone 0800 559 009 or check out their website www.workandincome.govt.nz. Contact www.studylink.govt.nz for more information about entitlements if you’re studying.

What other support can WINZ provide?

WINZ has a range of schemes to support your return to study or the workplace. These schemes can change often so it pays to check their website. Some of the current support plans available include:

Training Incentive Allowance. You can apply for the Training Incentive Allowance (TIA) if you are getting certain benefits. The TIA can help pay for things to help you study, like tuition fees, books, equipment and transport. It can also help cover the costs of childcare and any extra care expenses during your study. You do not need to pay this money back. You can apply for TIA while you are studying a course from levels 1 to 7 of the New Zealand Qualifications Framework.

Course Participation Assistance. You can access this through WINZ if you are doing a short course (less than 13 weeks) and have associated costs to pay. You do not have to pay this money back.

Mainstream Programmes. If you want to work, but have a disability or health condition, including a mental health condition or neurodiversity, you can access one of WINZ’s Mainstream Programmes. There are several programmes to choose from, including internships and paid work experience. You need to be a client of Belab (see the list of organisations) and meet the criteria.

These programmes can help you get into paid work and support you towards getting employment.

Guaranteed Childcare Assistance Payment. If you have children, are under 20, and are in full-time education, training or work-based learning, you may be able to get the Guaranteed Childcare Assistance Payment (GCAP) to assist with the cost of childcare.

Modification Grant. A Modification Grant is a payment which assists people with disabilities and can help pay for workplace changes or equipment that assists you to stay in, or get work.

Tip Again, as entitlements can change, be sure to check with WINZ to see what you can apply for.

What other help can I access while I am studying?

If you are keen to start a training scheme or get back to work, there are organisations that can help. Some even offer financial assistance to get you started or work with your employer to help you transition into employment.

Belab. Previously named Be Accessible, Belab offers various programmes and services to people who have challenges with accessibility (those who are differently abled), and who are keen to get into education or employment. Belab offer the following:

- Paid work experience and internships
- Career pathways
- Skills development
- Mentoring and guidance

Eligible candidates include those who:

- Are living with an access need or disability
- Are a New Zealand/Aotearoa citizen or resident
- Are not in receipt of ACC payments
- Are on, or are eligible for, a benefit.

For more information www.Belab.co.nz or phone 09 309 8966.

Workbridge. Workbridge is New Zealand's largest free employment service for disabled people or those with an injury or health condition. Workbridge supports people to find employment. They offer the following confidential services:

- Help finding the right job with the right employer
- CV development and interview skills training
- Preparing you and your future employer for your new job
- Tools and training to help with confidence building
- Help accessing tools and support to help you succeed at work
- Ongoing support for you and your employer.

Check out the website www.workbridge.org.nz to see if you meet the criteria. You can fill in the online form or phone 0508-858-858.

If you require help advocating for the support you need, speak to your support worker, counsellor or AYA Key Worker to see if they can advocate for you.

Returning to mahi/work

I was enormously privileged to be supported by my employer during and after my treatment financially, mentally and socially. My support network was everything for me, and maintained my positive state-of-mind that got me through treatment and helped me quickly bounce back. I immersed myself in work as a way of coping and it worked out alright.

Young person

Starting a new job or returning to a previous one is exciting and you may be looking forward to the opportunities that lie ahead. You may also worry about how you will manage, or be grappling with fatigue or feelings of low self-confidence or self-doubt. All of this is completely normal.

Returning to your previous mahi. If you are returning to the job you had prior to your diagnosis, talk with your employer about possible options for a gradual return. Flexi-time, job sharing, or working from home may help you ease back to mahi. Once you do return, set up regular meetings to check in about how the plan is going.

Tip You may require a note or letter from your healthcare team to advocate for a graduated return to work plan. You can also request a support person for any work meetings you might have. This could be a Youth Worker from CanTeen, friend or family member. See the links below for more advice about your rights in the workplace.

If your role changes. In some cases, the job you had before may no longer be possible. Make sure you and your employer are clear about what your current capabilities are and whether your current work environment is a good fit for you.

Tip If you are unable to do the job you did before, ask if there are other roles available or whether your employer can support you in finding a new position.

Employee Assistance (EAP). Many organisations have Employment Assistance Programmes and you might be able to access free counselling. Talk to your Human Resources Department (HR) or manager to find out how your workplace can support you. These sessions can help you manage any emotions returning to work brings up for you, and can help you develop goals for your return to work.

Tip EAP is confidential and most employers normally cover the cost of a few sessions.

Re-evaluating the future. Many young people report that cancer makes them re-evaluate the kind of job they want. If you think you might benefit from support and advice about different career options, a career advisor, counsellor or coach can help you figure out what your interests are and what skills you have.

Tip Speak to your AYA Key Worker or enquire about EAP at your workplace. There may also be services in the community you can access for career support.

Know your rights. It is good to think the best of your workplace before you return to your mahi, but knowing your rights where to go for support can be helpful should things change.

Fill in the Return to Work form, or take a photocopy and fill it out with your employer. You can also fill in the Health Summary at the beginning of this section and bring it with you if you choose to.

YOUR RIGHTS AT WORK

‘Employers can’t discriminate in hiring or firing, paying, training or promoting an employee because of their race, colour, national or ethnic origin, sex or sexual orientation, marital or family status, employment status, age, religious belief, political opinion, disability, or participation in certain union activities, or if they are affected by family violence. This also includes people who are applying for jobs’.

www.employment.govt.nz

Disability discrimination happens when you are treated unfairly or harassed because of your illness or its side effects. It is illegal to discriminate against anyone based on their medical condition or disability – this includes anyone with cancer. There are several ways you can be discriminated against:

- Not being offered a job or being fired from your job
- Being treated unfairly at work
- Not being able to enrol in higher education
- Not being offered the same opportunities as others
- Being unable to access public buildings such as libraries, hospitals or government offices.

Your Rights. Remember you have the same rights as everyone else in the workplace and should be given equal opportunities regardless of your health condition.

Do you need to tell your employer you had cancer? No, not necessarily but you must answer any questions honestly. Some jobs may ask for your medical history because they need to know you are fit and well to carry out the job. If your employer asks questions and you are unsure about the answers, talk to your healthcare team for more information.

Resources for legal advice and rights in the workplace

Employment NZ is a government website with useful information to help you work out your entitlements and rights in the workplace. It is a generic website with some online learning tools to help you navigate the processes and laws in relation to employment. www.employmentnewzealand.govt.nz

The Human Rights Commission can help you understand your rights. If you have faced discrimination, the commission can help you find out if the discrimination is unlawful and they can support you to resolve the issue with your employer. Phone 0800 496 877 for support. www.hrc.co.nz.

Youth Law is an organisation for young people. You can learn about your rights at work and access free legal support for any challenges you might be facing. Check out their website www.youthlaw.co.nz or call 0800UTHLAW (884529).



Uniform exemptions. If you wear a uniform or need to comply with a dress code and feel self-conscious, or are worried about being judged, or treated differently, fill in these exemption cards and keep them with you.

✂ – – Cut out the double sided card below, add your name and place it in your wallet, pocket or bag. This is a discrete way to communicate with a person (for example; employer, teacher, shop assistant) the reason you may be not complying with a dress code.

<p>CANNOT ADHERE TO DRESS-CODES FOR MEDICAL REASONS</p> <p>We ask that you please be sensitive to these circumstances</p>	<p>CANNOT ADHERE TO DRESS-CODES FOR MEDICAL REASONS</p> <p>We ask that you please be sensitive to these circumstances</p>
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Keep your uniform exemption cards somewhere handy like your wallet



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My Return-To-Work Plan



My return date is:	Days of work are:
My key contact at work is:	
I can liaise with them about the following:	
Other important contacts at work include (example: Human Resources, EAP Scheme, Health and Disability Support):	
Things I need assistance with at work include (example: comfortable chair, reasonable time frames for deadlines, regular breaks for stretching or to help manage fatigue):	
My support person/advocate is:	
My Return-to-Work Plan will be reviewed on:	
Current entitlements through WINZ or other financial entitlements I can access whilst working are:	

Notes

Tear or cut out to pop on the fridge



Practice good self care

Stepping into work, education or training is exciting. Remember to take care of yourself as you move forward and apply the self-care tools and wellbeing tools you’ve gained from this resource to help you.

Return To School/Work/Study Checklist	Yes / No
I have spoken to my healthcare team about my transition to work/study/training	
I have made contact with my employer/education provider and arranged to meet about my return	
I have completed a summary for my teachers/lecturers/employer around my health needs	
I have a transition plan that makes me feel comfortable about returning	
I have spoken with WINZ, and am aware of my financial entitlements	
I have reached out for additional support available through organisations such as Workbridge, Student Disability Services or Regional Health Schools	
I have all the information I need to feel comfortable returning to education/work	

Notes

TE AROWHAI HAUORA WELLBEING CHECK IN TOOL

Section
12

Wellbeing Check in Tool

In this booklet, you have found tools and resources to help support you with the challenges life after cancer brings. To help identify the areas you can strengthen, we have included a useful self-care check in tool. You can use this tool at any time to support your hauora - wellbeing and use the booklet for ideas to help you.

What is hauora?

Hauora - wellbeing is a Māori view of health unique to Aotearoa and covers the physical, mental, social and spiritual needs we have. Māori believe that each of these four concepts makes up our wellbeing. When all these things are in balance, we thrive. When one of these things is out of balance, our hauora is impacted. In the model Te Whare Tapa Whā, the areas are shown as a whare - house. All parts of the whare must work together to stay strong and hold it upright and this shows the interconnectedness of our health and wellbeing.

The key areas of hauora are:

Taha whānau - social wellbeing. Your whānau are the people you feel you belong with, who you care about you, and who you share your life with. Whānau includes extended relationships like friends, hoamahi - colleagues and your wider community and all form part of your identity.

Taha hinengaro - mental wellbeing. This is your mind, heart, conscience, thoughts, and feelings. It also includes how you communicate and think, as well as your mood and concentration.

Taha Wairua - spiritual wellbeing. Wairua is different for everyone and can mean faith, religion or belief in a higher power. It can also be your relationship with the environment and connection to whakapapa - genealogy/ lineage. Your sense of meaning and self-awareness, your essence or life force.

Taha Tinana - physical wellbeing. How your body grows, feels and moves, and how you care for it. Nourishing and strengthening your physical wellbeing can help you manage the 'ups and downs' of life. Feeling physically well can help you feel mentally well.

Kei a koe te oranga.

Your wellbeing is in your hands.



Try the following activity to help you identify where your wellbeing might be off-balance so you can explore tools provided in this resource to help. You can do this any time, as each time will be different.

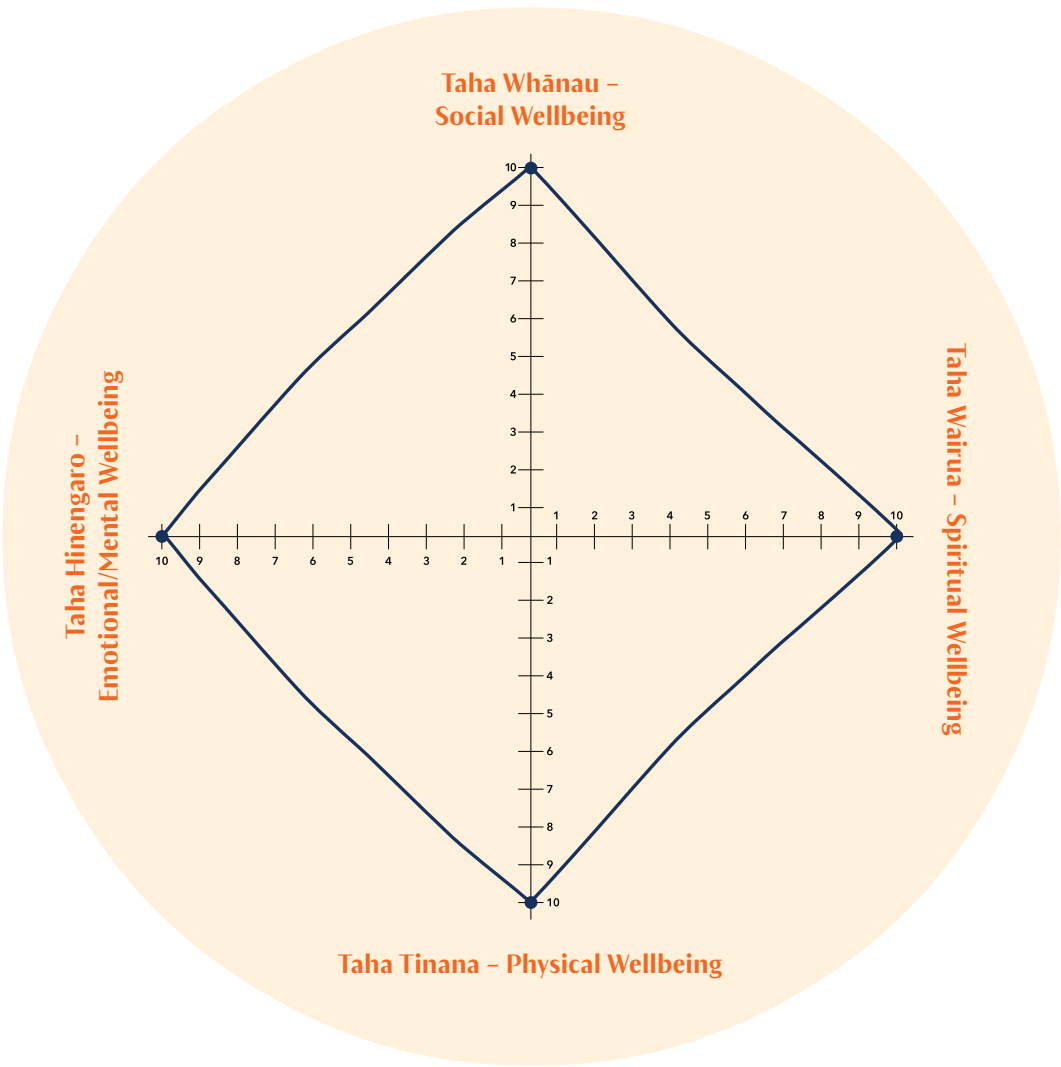
WELLBEING CHECK IN ACTIVITY

- 1. On the Hauora Check In Tool mark on each axis where you think you are in each area of your hauora out of 10. A rating of 10 means you’re doing amazing, and 1 means things aren’t going great.
- 2. Join the dots from each area to see your position. If you achieve 10 out of 10 in each section – you should have a perfect diamond. (Don’t worry if you don’t. This just means there are areas you can work on).
- 3. On the Hauora Plan list things you can do to improve your wellbeing. You can use suggestions in this resource to help. Do it with your mates or whānau and try to be specific.

Taha Whānau	Taha Tinana - My Physical Health Things I can work on
1. Make time for my family	1. Do daily stretches to build core strength
2. Say ‘yes’ to social invitations	2. Keep a fatigue diary to help manage energy
3. Attend an event	3. Keep healthier snacks to hand

- 4. Make a plan for how you can achieve these goals and put in a review time to do the exercise again to see if you can achieve a bigger diamond. Use different coloured pens to map your progress and enjoy watching the positive changes take place.

How a perfect diamond looks



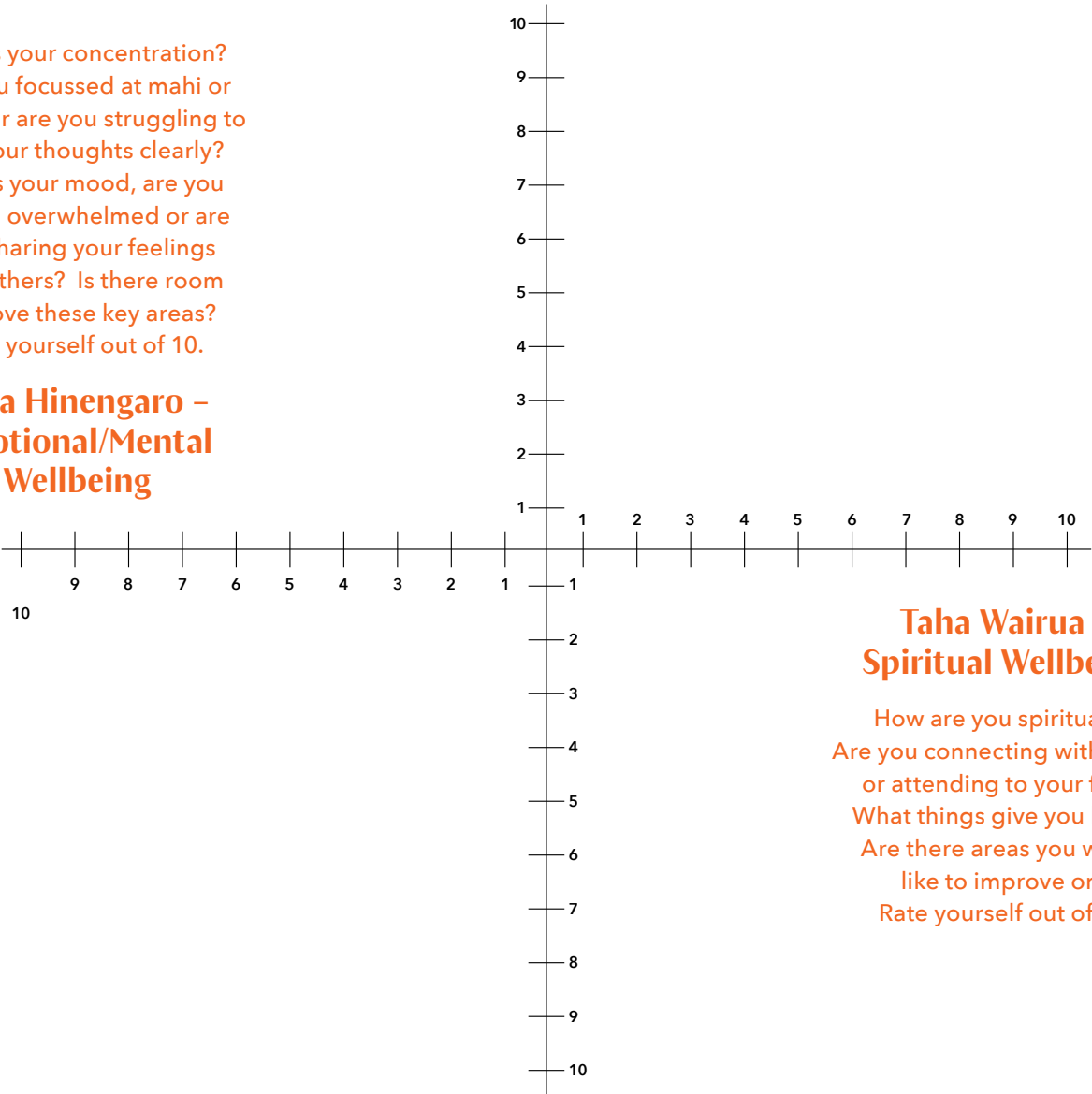
ACTIVITY - MY HAUORA CHECK IN
Give yourself a rating in the key areas.

How is your social wellbeing? Are you connecting with friends and whānau regularly? Do you have activities to look forward to or would you like to increase your social activities? Rate how well you feel this area of your life is going out of 10.

Taha Whānau –
Social Wellbeing

How is your concentration? Are you focussed at mahi or school or are you struggling to find your thoughts clearly? How is your mood, are you feeling overwhelmed or are you sharing your feelings with others? Is there room improve these key areas? Rate yourself out of 10.

Taha Hinengaro –
Emotional/Mental Wellbeing



Taha Wairua –
Spiritual Wellbeing

How are you spiritually? Are you connecting with nature or attending to your faith? What things give you hope? Are there areas you would like to improve on? Rate yourself out of 10.

Taha Tinana –
Physical Wellbeing

How are you feeling physically? Are you getting enough sleep or exercise and eating well or is there room for improvement in this area? How are your energy levels – are you leaping out of bed or is your body struggling to get going? Rate where you think you’re at out of 10.

✂ Tear or cut out to pop on the fridge

ACTIVITY - MY HAUORA PLAN

For each area that needs improvement put down 5 things that you can do to strengthen your hauora. You can check back through this booklet for ideas.

Taha Whānau – Social Wellbeing

Examples: say yes to more social activities, make a time to visit whānau, join a club, get out more, organise social events at my mahi-work.

1.

2.

3.

4.

5.

Taha Hinengaro – Emotional/Mental Wellbeing

Examples: read a good book, try brainteasers, look into a course, keep a diary about my feelings.

1.

2.

3.

4.

5.

Taha Wairua – Spiritual Wellbeing

Examples: listen to music, take a walk in nature, pray or meditate, try mindfulness apps.

1.

2.

3.

4.

5.

Taha Tinana – Physical Wellbeing

Examples: walk three times a week, try a healthy food box, play sport with friends, get 8 hours sleep a night, sign up for a sports event.

1.

2.

3.

4.

5.

Make a plan and get to it!

Now you have some strategies tell your friends and whānau. Fill the check in tool again in a month and see if any areas have improved. Remember, your wellbeing is ongoing, and integrating new things into your life can take time. Small changes can still make a big difference, now it's up to you.



Notes

At the AYA Cancer Network we are always looking at ways we can improve our resources.

If you or your whānau have suggestions or feedback for this resource, or any future resources you are keen to see developed, we would love to hear from you. Please drop us a line at AYACancer@adhb.govt.nz.

We hope you have come away with some wellbeing tools for your kete (bag).

If you forget, just pick up this resource and read it again, or go to the AYA Cancer Network Website for more tools and resources. www.ayacancernetwork.org.nz.

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KIA KAHA
Be strong

KIA MAIA
Be brave

KIA MANAWANUI
Be steadfast

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INFORMATION

AYA Key Worker contacts and further information go to: ayacancernetwork.org.nz



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