

PRACTICAL HELPFUL USEFUL

WHAI TAKE WHAI HUA WHAI KIKO

A guide to the practical supports available to
young people undergoing cancer treatment

He pae arataki ki ngā momo whai take mō te hunga taiohi
e whai ana i te maimoatanga mo te mate pukupuku



The AYA Cancer Network provides a wide range of resources to help guide young people through the many challenges cancer brings.

Below are other resources that you might find useful. You can find these resources through our website (ayacancernetwork.org.nz) or by asking your keyworker.

Cancer and
Fertility

Mate Pukupuku
me te Matahua

Young
People, Cancer
and Sex

Te hunga taiohi, te
mate pukupuku
me te ai

Cancer
Treatment
and Hair Loss
Maimoatanga mate
pukupuku me te
ngahoro noa o
ngā makawe

Alcohol,
Drugs and Cancer
Paekaka, ngā
pūroi me te mate
pukupuku

For updates please follow us on social media



Introduction

Kia ora,

We know from talking to young people who have or have had cancer that they often don't know who and what is available to support them and their whānau.

‘Having past experience with chemo I had a fair idea of what I had access to and therefore what questions to ask. But for those who are not so fortunate, who may be tired, and do not have the confidence to speak up or ask questions... I imagine that these... could be major barriers when going through chemo, which is hard enough on its own.’

Young person

This book has been created to help reduce some of this confusion by explaining what is available (from financial assistance to travel aid) and how to go about accessing it.

We don't expect you to read this whole thing at once which is why it is divided into sections that you can read when, and if you need to. We recommend keeping it handy so that you can get the most out of it during your treatment. There is space to write down notes and list numbers of people that can support you. There is a checklist for you to complete at the end of each section to help you make sure you have everything you need and are able to receive.

If this booklet feels too overwhelming to read we recommend asking your whānau (parent, partner, support person) to read it on your behalf.

If you have any worries or questions about anything that you read in this book, or if something isn't covered in here, please speak to your **AYA Keyworker or healthcare team.**

What is an AYA Keyworker and how do I contact them?

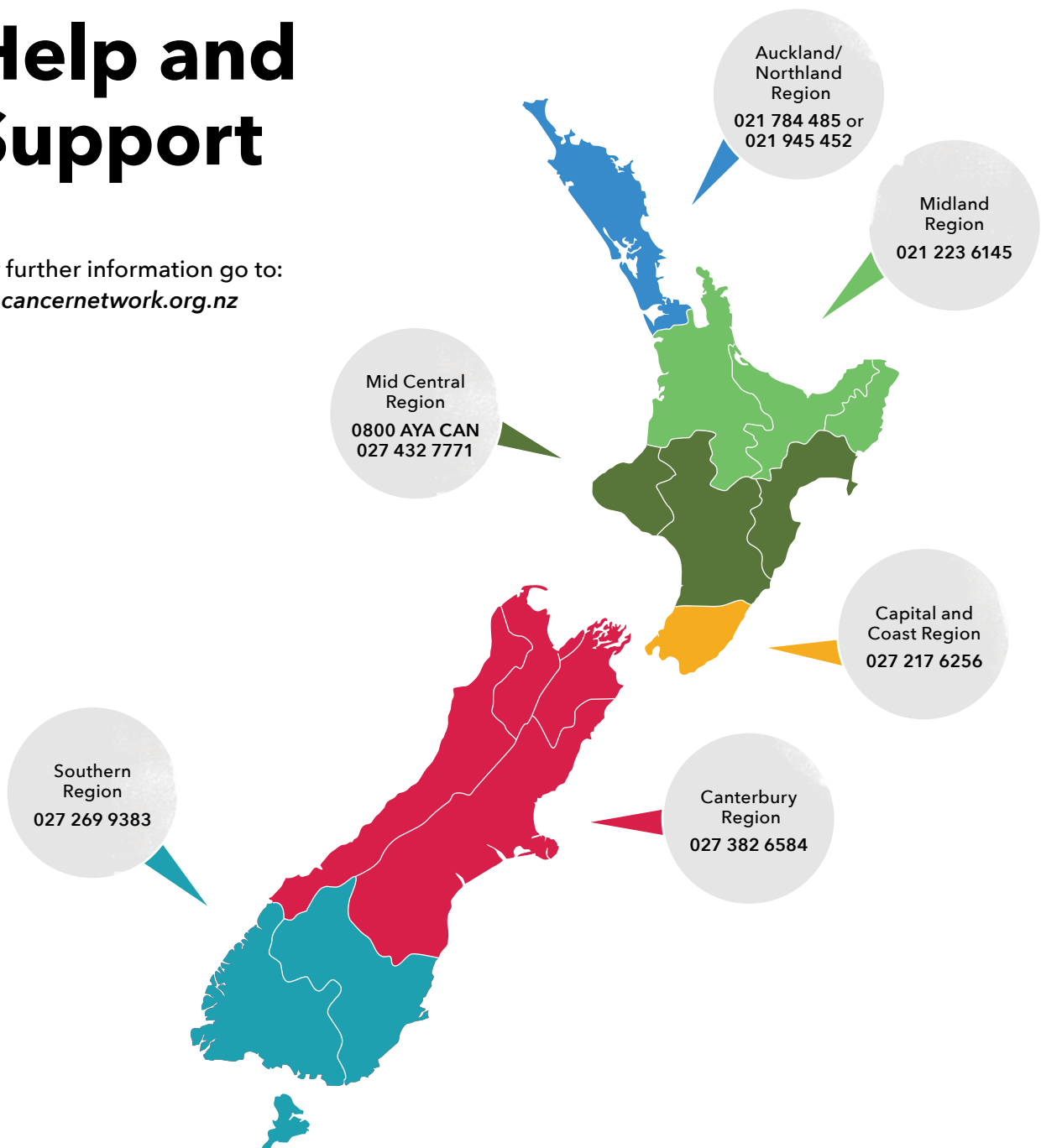
An Adolescent and Young Adult (AYA) Keyworker is a nurse specialist or social worker who is there to support you and your whānau through your cancer and to help coordinate the care you receive. Below is a map with the details of your local AYA Keyworker – if you have any questions, concerns, or would like support and information please contact your local AYA Keyworker.

'My AYA nurse... is probably the most helpful person for information about my treatment and alongside my treatment. She makes herself available around the clock for contact and has made my treatment many times easier.'

Young person

Help and Support

For further information go to:
ayacancernetwork.org.nz



Contents

Topic or issue	
SECTION 1 – BENEFITS AND ALLOWANCES	7
Benefits and allowances available to:	
School students	9
Tertiary (studying) students	9
Those in employment	9
Those in a relationship	9
Those with children	10
Your whānau/family	10
SECTION 2 – TRAVEL AND ACCOMMODATION SUPPORTS	15
SECTION 3 – FINANCIAL (MONEY) AND HOUSING WORRIES	20
SECTION 4 – CULTURAL SUPPORT SERVICES AVAILABLE	23
SECTION 5 – PSYCHOLOGICAL SUPPORTS (HELP WITH FEELINGS AND WORRIES)	27
SECTION 6 – EDUCATIONAL/VOCATIONAL (JOB RELATED TRAINING) AND EMPLOYMENT SUPPORTS	30
SECTION 7 – ORGANISATIONS AND CHARITIES AVAILABLE	33
SECTION 8 – AN A-Z OF WHO’S WHO AND WHAT’S WHAT	40
Useful contacts	44

Section

1

BENEFITS AND ALLOWANCES



Benefits and allowances

The process of understanding what you are eligible for, how to apply, and what documents are needed in order to be considered for benefits and allowances, can be confusing and often stressful for young people.

'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 unbeknown to me.'

Young person

The best source of information relating to benefits and allowances is from **Work and Income New Zealand** (WINZ) (www.workandincome.govt.nz). Here, you can seek out individual benefits and allowances or complete the online 'check what you might need' questionnaire for guidance. Your application is backdated to when you first began the process of applying, so the sooner you do this the better. You can also contact WINZ directly, or speak with a social worker.

We strongly recommend contacting your regional AYA Keyworker for support and guidance.

'I was lucky to have the care of an incredible AYA Keyworker who made it more than her personal mission to ensure that I was well looked after... she stepped in and took action with my day to day stableness and assisting me with my job, government support...'

Young person

Below are answers to some of the common questions AYAs have regarding benefits and allowances:

I am too tired and stressed to deal with all of this. Can anyone else do it on my behalf?

Yes, you can appoint someone such as a member of your whānau, to act on your behalf (called an agent) for things like completing and signing WINZ forms, contacting WINZ to find out information about your applications and changing information for you e.g. change of address. Having an agent is very helpful, particularly if you cannot leave hospital while on treatment.

You can still talk and act for yourself when you have an agent and they can be removed or changed at any time. To appoint an agent you can either fill out an **'Appointment of Agent'** form (<https://www.workandincome.govt.nz/documents/forms/appointment-of-an-agent.pdf>) or phone **0800 559 009**.

Appointing an agent is recommended especially if you are not always feeling up to managing everything



I can't work or study full time anymore - what financial help can I access?

There are two main benefits that you can access through WINZ. These are the job seeker allowance or supported living allowance. You might be asking yourself - what is the difference? Check them out below:

- The **job seeker allowance** is for anyone over 18 years with a cancer diagnosis that is unlikely to be able to work or study for at least 6 months as a result of their illness and treatment. We recognise that including "job seeker" in the title implies you are actively looking for a job but this is not the case - it recognises you are expected to be able to return or work within two years. A work capacity medical certificate will remove the need for you to be actively seeking a job during these times.
- The **supported living allowance** is for anyone 16 years or over with a cancer diagnosis that means they are unlikely to be able to return to work for at least 2 years or their condition cannot be cured.

Can I receive a benefit while I'm still attending school?

If you meet the criteria for the supported living allowance (see beside) then yes you can receive the benefit and still attend school.

Please note that an automated letter is often sent out to young people when turning 16 years if their parents are receiving the child disability allowance, stating you can swap over to your own supported living allowance. For many, this is not the case even if they receive the letter as their medical condition is expected to improve within the two year period. To avoid disappointment we encourage you to talk

with your AYA Keyworker or social worker about your situation before spending a lot of time on the application.

There are some exceptional circumstances for 16 and 17 year olds where a breakdown in your relationship with your guardians/parents may result in you being able to access financial support. These situations need to be discussed with WINZ.

What if I'm a tertiary student (studying) - do I still receive my student allowance/loan during this period?

If you are suspending or withdrawing from your course your student allowance will be stopped and you can transition across to one of the two WINZ benefits mentioned, depending on the medical criteria you meet. If studying part-time we recommend speaking with WINZ as allowances can be case dependent.

WINZ will often need proof you have withdrawn from the course and are no longer receiving Studylink.



If I reduce my hours at my job will I still get financial support from WINZ?

This is dependent on what other benefits you are applying for or are already on, the hours you will be working and your income.

For example, if on the Job Seeker allowance, you can earn up to \$80 a week in part-time employment before it impacts on the amount received. However if on the Supported Living Allowance, you can earn up to \$100 a week but can work no more than 15 hours a week. The reason for the 15 hour restriction is that the Supported Living Allowance is granted based on the unlikelihood that you can return to work for at least 2 years.

I am in a relationship - how might this impact what I am entitled to?

This is an area that often takes young people by surprise when applying for a benefit. Being in a relationship can affect your eligibility for benefits. A relationship is measured by WINZ on the degree of companionship two people have. Two key characteristics of a WINZ defined relationship are that two people are committed to each other for the foreseeable future and that they are financially interdependent (you rely on each other to contribute to bills including weekly shopping).

To give you a better idea of what they mean by this, think about whether your relationship includes some of these things:

- you live together at the same address most of the time
- you share responsibilities, e.g. bringing up children (if any)
- you socialise and holiday together
- you share money, bank accounts or credit cards
- you share household bills
- you have a sexual relationship
- people think of you as a couple
- you give each other emotional support and companionship/friendship.

'So even if I have my own job, and pay my own rent, I miss out on extra support because me and my boyfriend flat together?'

Young person

What if I have children?

Your benefit application will be assessed taking into consideration your dependent children. If your cancer/treatment has made it difficult for you to be able to care for them fulltime, and you have limited options for alternative childcare, you may be eligible for up to 50 hours a week childcare subsidy.

I worry about my parents/guardian/partner - what support is there for them?

If you are under 18 years and have a condition lasting longer than 12 months and need care and attention for this, your parents/guardian will likely be eligible for a **child disability allowance**. This is a fortnightly payment and is not income tested (currently this is \$98.52).

Your parents/guardians may also be able to receive the **disability allowance** on top of the child disability allowance. Whether they can receive this and the amount they can receive depends on any other income they receive.

If your parents or partner are required to give up work to care for you and you would otherwise need hospital level or residential care (or similar) they may be able to receive the **supported living payment**.

A tight criterion exists for this, but it is definitely worth exploring. A medical certificate will be required.

Carer support provides funding to help support people have some time out or receive financial reimbursement for the care they provide. It is available to 'full-time carers'. A full-time carer is someone who gives more than 4 hours unpaid care to a person with cancer per day that doesn't live at the same address as the person with cancer - this could be a family member or a friend for example. There are restrictions around who is able to receive this and it is assessed on a case by case basis. We therefore recommend speaking to your social worker about this.

What information and documents do I require to make an application to WINZ?

For many young people knowing what you need to provide can be the most frustrating part of the process so we have outlined the key documents that you will need to include in your application.

Even if you don't have the required documents now, you should still apply for your benefit as payments will be backdated from this first application date. You are then given 20 days to provide the requested documents.

1. If you were born in New Zealand, you will need to provide **one type of official identification** that has your full legal name and your date of birth (for example, your birth certificate, passport, driver licence).
2. If you were born overseas, you need to provide proof that you have a right to live in New Zealand (for example a citizenship certificate, a New Zealand passport, a passport from another country with a residence class visa or proof of permanent residence).
3. All people applying need to provide **two more documents** that help to prove who you are (for example, a marriage certificate, bank statement, phone or power account, driver licence).
4. You will also need a form or letter from Inland Revenue showing your **IRD/tax number**.

Contact
WINZ on
0800 559 009

5. A **medical certificate** filled out by your GP or specialist/cancer doctor to inform WINZ of how your health condition or disability affects your ability to work. On occasion, you may be sent through the mail details on seminars to attend for 'returning to work'. You just need to provide your medical certificate to show that you do not need to attend.

If you have any worries regarding this contact your Keyworker or social worker.

6. Proof of your last pay and all income you have received from any source in the last 52 weeks (1 year).

Tip

1. You will need to provide original copies of all government issued documents (passport, birth certificate, driver licence). This will need to be done in person by visiting your local WINZ office. You can provide copies of other non-government issued documents that have been assessed as a 'true copy' by a lawyer or a Justice of the Peace (JP). To find a JP to do this for you, go to <http://justiceofthepeace.org.nz/Find+a+JP.html>. Often the hospital will have someone who can do this for you. Your AYA Keyworker will likely know who this is.
2. Never leave these forms until the last minute, get them to your doctor early - your social worker and AYA Keyworker are there to support you with any difficulties you have in getting these filled out.
3. We recommend setting up an email address if you don't already have one, to help with online applications and getting any required documents.

I don't have these things - where can I access them?

Documentation or information needed	Where or how to get this?
IRD/Tax Number	<p>If you have one but don't know where to find it, go to https://www.ird.govt.nz/managing-my-tax/ird-numbers/find-my-ird-number</p> <p>If you do not have one, you can apply for this online by going to https://www.ird.govt.nz/managing-my-tax/ird-numbers/ird-numbers-for-individuals or completing a paper application and taking it to an AA driver-licensing agent or PostShop with any documents that need verification (signed off as authentic). Link to the paper form: https://www.ird.govt.nz/-/media/Project/IR/Documents/Forms-and-Guides/IR500---IR599/IR595/IR595-2017.PDF You will need to provide two forms of verified ID (e.g. NZ passport, driver licence).</p> <p>Following your application, your IRD number will be emailed or texted to you within 10 working days.</p>
Birth Certificate	<p>If you were born in NZ you can order a birth certificate online at a cost of \$33, through https://certificates.services.govt.nz/ or phone 0800 225 252.</p>
Proof of last pay and income (last 52 weeks)	<p>You can provide this in several ways:</p> <ul style="list-style-type: none"> • Payslips • A letter from your employer(s) • A print out of your earnings for the last 12 months from Inland Revenue • Bank statements
Work Capacity Medical Certificate	<p>This is a WINZ specific form provided by your GP or your cancer specialist and can be completed electronically or in paper form by your doctor.</p>

What other benefits or allowances might I be eligible for?

- ▶ A **disability allowance** is a weekly WINZ payment to cover any regular on-going costs because of your cancer diagnosis such as GP visits, prescription fees, counselling, medical alert bracelet, additional heating requirements, phone top ups so you can keep in contact with your health care team and travel not covered by national travel assistance/NTA (for more information on what the NTA scheme is see page 16).



WINZ needs to see proof of these things so keep all receipts or seek quotes to show them. If your travel is not covered by the NTA scheme make sure you take note of the trip including how far you travelled, how you travelled (e.g. in your own car) and any parking tickets/receipts.

- ▶ The **accommodation supplement** is an additional WINZ payment on top of your benefit that helps with rent, board or the cost of owning your home. Again, you will need to provide proof of these costs such as a rental/tenancy agreement.
- ▶ A **Community Services Card** can help you with the costs of healthcare. You will pay less for some health services just by showing your card, and it can entitle you to other services such as NTA. Most people who are on a benefit automatically get one of these cards. If you are on a low income, you can also apply for one. You can download a form from the Work and Income website, contact the Community Services Card National Centre on 0800 999 999 and get one sent, collect one from any Work and Income Service Centre or your family doctor or local pharmacy.
- ▶ The **Special Needs Grant** is there to support with additional unexpected one-off costs such as a hair-wig, ambulance fees, medical equipment and health travel costs not met by NTA.

- ▶ The **Wigs and Hairpieces Service Payment** (Ministry of Health) is a payment that any young person undergoing cancer treatment which causes hair loss can receive. The payment is available to cover the cost of a wig and/ or headwear (hats, beanies, etc.). For details on how much you are able to claim and how to go about this, please read the AYA Cancer Network Cancer Treatment and Hairloss booklet which can be found at <https://ayacancernetwork.org.nz/aya-cancer-treatment-side-effects> or please ask your AYA Keyworker for a copy.

I need support but I don't qualify for any of the benefits or allowances - what is available to me?

You can apply for the Emergency Benefit by contacting WINZ on **0800 559 009**. We also recommend contacting relevant non-governmental organisations for support (see page 34).

I'm struggling to get in touch with WINZ or I need more help with speaking to them - who can assist me?

Please let your AYA Keyworker know as they can support you and work with the WINZ hospital liaison officer.

For more information on some of the terms used you can visit <https://www.workandincome.govt.nz/about-this-site/words-we-use.html>



Benefits and allowances checklist

Yes / No / NA	Checklist Item	PAGE
<input checked="" type="radio"/> _____	I have received this practical support booklet	
<input type="radio"/> _____	I have visited the WINZ website and completed the online questionnaire to find out what benefits and allowances I may be eligible for	8
<input type="radio"/> _____	I have had the opportunity to speak with a social worker or my AYA Keyworker for guidance on the benefit process	5
<input type="radio"/> _____	I have applied for my benefit online early even if I do not have the required documents so that it can be backdated from the date I applied	8
<input type="radio"/> _____	I have collected/pulled together the documents needed to apply for a benefit and if I do not have these I have made arrangements to access them	10
<input type="radio"/> _____	I have made an appointment to visit my local WINZ office within the 20-day period after applying online and have prepared the required documentation	10
<input type="radio"/> _____	As a tertiary student with a student loan/student allowance I have let StudyLink know that I have withdrawn from my course or transferred to part-time study, and have provided WINZ with proof from my training institute that this has occurred	9
<input type="radio"/> _____	If I do not have an email address I have set one up to help with online applications and getting any required documents from WINZ	11
<input type="radio"/> _____	I have recorded the date that my medical certificate will expire. This will allow me to extend it if required, and avoid my benefit being stopped	11
<input type="radio"/> _____	I have applied for a community services card if I am eligible and do not already have one	12
<input type="radio"/> _____	I have identified a person who can act on my behalf (as an agent) to work with WINZ around my benefits (this is not required but recommended especially if you are not always feeling up to managing everything)	8
<input type="radio"/> _____	I am collecting receipts for any regular on-going costs because of my cancer diagnosis that can support my eligibility for a disability allowance	12
<input type="radio"/> _____	My whānau have spoken to my social worker or AYA keyworker about any benefits/allowances they may be eligible for as a result of my condition	5
	My WINZ Client number is:	



Notes

Section

2

TRAVEL AND ACCOMMODATION SUPPORTS



Travel and accommodation supports

What support can I get with treatment related travel and accommodation?

The National Travel Assistance (NTA) Scheme may be available to cover some of your travel and/or accommodation costs if you meet the criteria outlined below.

1. You travel more than:
 - 80 km one way per hospital/specialist visit (under 18 years of age)
 - 350 km one way per visit (over 18 years of age)
2. You visit the hospital/specialist 22 or more times in two months (note you will need to complete all 22 trips prior to being able to receive travel cost repayment)
3. You visit a specialist six or more times in six months, and travel more than:
 - 25 km one way per visit (under 18 years of age)
 - 50 km one way per visit (over 18 years of age)
4. You are a Community Services Card holder and travel more than:
 - 25 km one way per visit (under 18 years of age)
 - 80 km one way per visit (over 18 years of age).

'Appointments are generally out of town so I need to travel and take time off work. Can't afford to have husband also having time off work.'

Young person

If I meet the criteria for the NTA scheme, how do I apply for this?

You will need to complete the NTA registration form that your hospital social worker or travel coordinator can provide. Your cancer specialist will then need to complete and sign part of this form and send to NTA. For support with applications, contact your social worker, AYA Keyworker or ask your local treatment centre's reception.

Once NTA determines that you are eligible for support, a confirmation letter will be sent to you, along with bank claim forms.

Now that NTA has contacted me to say I can receive assistance, how do I make a claim?

To do this you will need to complete the NTA claim form sent to you on confirmation, or visit the Ministry of Health website (<https://www.health.govt.nz/>) and search 'how to claim travel assistance' to download a claim form.

If you are using your own or a whānau member's vehicle, you will be reimbursed/refunded for mileage (petrol and 'wear and tear' costs). The amount is calculated based on the distance from the address you live at to the hospital or treatment location. If you are likely to have treatment from more than one hospital make sure that you are registered to travel to both.

You will need to bring your claim form to each trip and have it signed by hospital staff as proof of attendance.



You can instead ask your nurse, AYA Keyworker or treatment centre's reception to print out previous appointment dates which they can then sign, stating that these are accurate for proof of attendance.

As mentioned when making your first claim you have to have completed at least 22 trips (see point two in previous column) within two months or you visit a specialist 6 or more times in 6 months (see point three in the previous column). After this first claim, you can claim as many times as you need. You must make all claims within a year of the date of travel.

Make sure you complete all of the payment details section on the form and attach either a printed deposit slip, a screen shot/copy of the top of your bank statement or you can visit your bank and ask them to provide an account verification. You only have to do this once and it is so that NTA knows where to deposit the claimed money.

**Let your
AYA Keyworker know
if transport is an issue
so that they can support
you in finding
support**

I meet the criteria for the NTA scheme but I do not have access to a vehicle (e.g. car) or the travel distance is too far to drive - what are my options?

We recommend speaking to your hospitals travel coordinator or social worker as they can explore alternative transport for you - this may be through buses, shuttles, taxis etc. Depending on where you live there are different options. All air travel must be approved and arranged by the travel coordinator or social worker.

I do not meet the criteria for the NTA scheme or cannot afford the cost of transport or petrol upfront - what are my options?

There are a range of other options to assist. These include non-government organisations (NGOs) such as the Cancer Society providing volunteer drivers or petrol vouchers. Some regions also have shuttle services. For more details on these NGOs go to page 34. It is really important you let your AYA Keyworker know if transport is an issue so that they can support you in finding support.

In a medical emergency how do I get to hospital if I don't have transport or I can't afford to pay for an ambulance?

We would recommend exploring the St John ambulance supporter scheme. With this you pay a yearly amount (\$55 for one person) to receive free emergency ambulance cover throughout the year. The cost of a single ambulance call-out without being part of the supporter scheme is \$98 (note that St John does not operate in the Wellington or Wairarapa as Wellington Free Ambulance (donation appreciated) covers these areas).

If the yearly payment is unaffordable please talk to your social worker or AYA Keyworker about other support options.

What accommodation options are available to me when I have to travel long distance for treatment?

If you require accommodation e.g. you live in Whangarei but need to travel to Auckland for treatment, you may be able to receive up to \$100 per night (you can also receive an allowance if staying with friends or whānau during treatment). If accommodation costs more than \$100 per night you will be required to cover the extra amount. We recommend contacting your social worker, travel coordinator or AYA Keyworker as they can inform you of the hospital approved accommodation options for you (note accommodation is not usually approved for travel less than 100km away).

If you are under the age of 18, are receiving treatment in Auckland, Wellington or Christchurch and have to travel more than 80km one way to the hospital then you and your whānau (primary caregivers, siblings) can stay at Ronald McDonald House. Your healthcare team will need to make a referral for you so please speak to them about this.

If I am over 18 years of age can I have a support person travel and stay with me if I live far away (over 100km) from the treatment centre?

Yes and it is likely that financial assistance can be provided to your support person if they are needed to support you for things such as clinical decision making or emotional/physical support. This will need sign off from your specialist/hospital.



I do not meet the NTA scheme criteria to be able to fly to treatment but it is too far for me or I can't use public transport (immunosuppressed) - what are my options?

Angel Flight is a charity service that provides free flights to those who need to travel long distances to their medical appointment and are unable to travel by car or where commercial flights are unavailable or unaffordable. A health professional such as an AYA Keyworker will need to make the referral for you. For more information you can go to <https://angelflightnz.co.nz/>

For more information on the NTA scheme go to <http://health.govt.nz> and search 'travel assistance'.



'Because nothing means more to me than family if they can't visit regularly I get really panicked.'

Young person

Travel and accommodation support checklist

Yes / No / NA	Checklist Item	PAGE
<input type="radio"/> _____	I have spoken with my AYA Keyworker, social worker or travel coordinator about whether I qualify for the NTA scheme and have completed the registration form to apply	16
<input type="radio"/> _____	If I have qualified for the NTA scheme, I am keeping a record of visits that have been signed off by the hospital and/or keeping receipts if using public transport	16
<input type="radio"/> _____	I have considered joining the St John Ambulance Supporter Scheme in case of an emergency	17
<input type="radio"/> _____	I have spoken with my team about the transport or accommodation barriers I experience when getting to treatment (for example financial difficulties or lack of a vehicle) so that they can support me with an alternative solution	17



Notes

FINANCIAL (MONEY) AND HOUSING WORRIES

Section

3



Financial (money) and housing worries

I am worried about how going through treatment will affect my finances – other than WINZ, what support is available?

KiwiSaver: If you are a KiwiSaver member and are experiencing significant financial hardship (e.g. unable to pay for rent, power, etc.) you may be able to withdraw some of your savings if required. To apply for this we suggest speaking to your KiwiSaver provider (e.g. ASB, ANZ, Westpac) or your social worker.

Prescription/Medication Subsidy: Once you have paid for 20 new prescription medicine items from 1 February every year, you may be eligible for a prescription subsidy (reduced costs) which will cover any future prescription costs until the following year (31 January). Please note not all medicines are funded so make sure you discuss any questions you have about prescription charges with your pharmacist.



If possible, we strongly recommend using the same pharmacy for your prescriptions as they can provide a print out all prescriptions, which you can use to apply for the subsidy.

I am on a finance/hire purchase plan – how will I keep paying this?

You may be paying off items over time for things such as phones, cars or TVs that become much harder to pay when you can no longer work the way you did before cancer. We recommend talking to your social worker/AYA Keyworker, as you may be able to apply for a payment break and/or longer time to pay it off.

I currently rent a home that is no longer suitable (e.g. not warm or dry enough) – what should I do?

This is a situation where your social worker will be the best person to support you and help advocate for your needs. You can check your entitlement for government (state) housing by contacting Kāinga Ora on **0800 801 601** (Freephone).

I have (or my support person has) legal issues to deal with – what should I do?

We recommend letting your social worker or AYA Keyworker know as soon as possible, particularly if you have court dates that you need to attend, so that

they can support you. Sometimes these dates will clash with your medical appointments and hospital admissions so it is important to make sure you work with your social worker or AYA Keyworker to manage these situations.

What about medical/health insurance?

If you are under 18 you may be under your parents'/caregivers' medical insurance policy or if over 18 years you may have your own medical insurance. We recommend finding this out as it may give you other options for treatment. Talk to your AYA Keyworker or doctor if you need help with this.

I'm struggling with getting food to eat – can anyone help me?

Several non-governmental organisations such as the Cancer Society and LBC (see page 34) can help with food delivery. This is often based on individual circumstances. Please also let your AYA Keyworker know if you are struggling with this.

'If it wasn't for the Cancer Society I would not have had any food over the whole treatment as they were giving me food vouchers and help me sometimes get my medication cause I was getting that little and apparently I was maxed out when it couldn't cover rent let alone power and fuel and medication and food.'

Young person



Financial (money) and housing worries checklist

Yes / No / NA	Checklist Item	PAGE
<input type="radio"/> _____	I have spoken with my AYA Keyworker or social worker about any financial, housing, legal or other worries and now have a support plan	5
<input type="radio"/> _____	I am filling my prescriptions from the same pharmacy as much as possible so they can support my eligibility for prescription subsidies	21
<input type="radio"/> _____	I have informed my AYA Keyworker or social worker of any current involvement with the legal/justice system so they can support me to meet my multiple commitments	21



Notes



Section

4

CULTURAL SUPPORT SERVICES AVAILABLE

Cultural support services

New Zealand is a community of different ethnicities, nationalities, sexualities, languages, religious and spiritual beliefs. In recognition of this, there are a number of supports and services available to young people and their whānau.

Interpreter and translation services: If you or your whānau require or would benefit from having a trained interpreter (this includes sign-language) at your clinic appointments or when in hospital, please tell your AYA Keyworker who can arrange this.

You can also ask for Ezispeak which is a free phone-based interpreting service available in many different languages, 24 hours, seven days a week.

Chaplains and spiritual advisors: Many hospitals have an interfaith chapel (not specific to one religion), or a quiet place for prayer and thinking. The chaplaincy team can offer support, prayer and a listening ear in times of need. If you are staying in hospital you can ask your nurse, doctor, AYA Keyworker or ward clerk to arrange a visit from a chaplain.

Karakia: Tāngata māuiui and whānau should be offered the option of having karakia and if you would like support in this, the hospital's chaplain or kaumātua should be made available. You can ask your AYA Keyworker, nurse, doctor or ward clerk to arrange this.

Māori support services: Most hospitals have a dedicated support team for Māori patients and their whānau. They can offer a range of support including advocacy (help with speaking up, sharing concerns), co-ordinating whānau accommodation (where available), cultural support, linking patients to community supports and access to kaumātua. You can ask your nurse, doctor, AYA Keyworker or ward clerk to make contact and arrange a visit from the Māori health team.

Māori tikanga or tikaka accommodation: There may be free or low-cost accommodation services for your whānau if you live outside the area in which your treatment is located.

Pacific support services: Most hospitals have a dedicated support team for Pacific patients and their families. They can offer a variety of holistic support including communication between Pacific patients and clinicians, advocacy, linking patients to community providers and cultural support.

Asian support services: For those receiving care from the Waitemata DHB (North Shore/Waitakere) there is an Asian Support service that provides a range of services such communication, emotional, cultural, inpatient and after discharge support (<http://www.asianhealthservices.co.nz/>). For Asian new migrants there is also the CNSST foundation (<http://cnsst.org.nz>) available to support you.

Refugee/asylum seeker support services:

We recommend letting your social worker know if you or your whānau have refugee status so they can support you in re-engaging with the services who helped with your settlement into New Zealand. Note that refugees and asylum seekers whose claim to seek asylum has been accepted by Immigration New Zealand are eligible for public health and disability services regardless of their residency status.

Non-resident/international student: We recognise that much of this booklet may not be relevant to you. We therefore strongly recommend getting in touch with your AYA Keyworker for support and direction.

LGBTQ+: Rainbow Youth (<http://ry.org.nz>) and Gender Minorities Aotearoa (<http://genderminorities.com>) are available nation-wide and can provide a variety of information and supports online and over the phone.

Complementary therapy: There are a range of complementary therapies (other types of treatment to add to hospital medical care) available that you may be interested in. Examples include - massage, acupuncture, hypnosis and traditional healing such as Rongoā. We recommend letting your AYA Keyworker or doctor know if you are trying any of these therapies and you can also ask them about what is available. For more information on complementary therapy you can also visit <https://ayacancernetwork.org.nz/resources>.

'My parents did some research about Māori medicine, they did some Chinese medicine, they did Indian medicine alongside of what I was doing in the hospital. They believe it went hand in hand... as well as the karakia and prayer.'

Young person

We strongly recommend asking the relevant national services listed above as well as your AYA Keyworker to let you know about what is available locally to you and your whānau.



Local cultural support services

Name of organisation	Support they can provide	Contact details

Cultural services available checklist

Yes / No / NA	Checklist Item	PAGE
<input type="radio"/> _____	If English is a second language for either my whānau or me, I have informed my medical team/AYA Keyworker so interpreters can be used for translating information.	24
<input type="radio"/> _____	My whānau or I have been offered the opportunity to receive support from hospital based pastoral or cultural based services.	25
<input type="radio"/> _____	I have asked about and identified the local cultural support services available to my whānau and I	25



Notes



Photo credit: Trefor Ward / treforward.com

Section

5

PSYCHOLOGICAL SUPPORTS

(HELP WITH FEELINGS AND WORRIES)

Psychological supports (help with feelings and worries)

There are a number of different psychological supports available to you depending on where you live.

We therefore recommend speaking to your AYA Keyworker who can let you know what you can access in your region. Some of the key supports available across the whole country include:

- Psychologists employed within the cancer services where you receive your treatment
- A variety of non-governmental organisations (e.g. CanTeen, Leukaemia and Blood Cancer NZ, Cancer Society) also employ psychologists that you can access, or will privately fund a counsellor/psychologist of your choice.

Again your social worker or AYA Keyworker is the best person to connect you to these supports – you can find details of the various NGOs on page 34.

CanTeen is one such NGO (available to any young person aged 13 to 24) and they provide free counselling via phone (0800 119 229) or online (<https://www.canteen.org.au/new-zealand-support/>).

We encourage all young people to consider accessing this support **early in your treatment**

‘This is not just about treatment, but about our lives. It was so important to have someone to talk to that I could relate to and was easy to talk to.’

AYA patient

Psychological supports checklist

Yes / No / NA	Checklist Item	PAGE
<input type="radio"/> _____	I have been informed of the range of psychological supports available (we encourage all young people to consider accessing this support early in your treatment)	28



Notes

EDUCATIONAL /

VOCATIONAL (JOB RELATED
TRAINING)

EMPLOYMENT SUPPORTS

Section

6



Educational, Vocational (job related training) and Employment Supports

What options are available to me if I usually attend school?

Firstly, if you need to put school on hold that's ok. If you are able/wish to continue during treatment there are a several supports available.

'I wish someone had told me that it's ok to take a break from school and that I didn't have to carry on like everything was normal because it wasn't.'

Young person

Regional Health Schools

If your cancer treatment means that you are absent from school for more than 10 days in a row or 40 in a whole year, and you will stay enrolled at your usual school, you can join one of the three **New Zealand Regional health schools**: Northern Health School, Central Regional Health School, Southern Health School.

They can support you to keep up with your learning while unwell and help you to return to full-time education when possible. They can provide community, in-home and hospital based teaching. To access the school relevant to where you are receiving treatment talk to your AYA Keyworker.

Patience Project

If you are receiving treatment at Starship and are of school age, you may be able to partake in the Patience Project. This involves using a VR headset that is connected to a 360-degree camera that can be set up in your classroom. This means you can attend classes virtually and engage with your friends and students as much or as little as you would like.

To find out more about it you can visit their website <https://www.patienceproject.org/>

What options are available to me if I usually attend University?

Most universities have **student disability services**. This service is available to anyone with a cancer diagnosis who is still enrolled at the university. It can provide a range of supports to enable your learning. This may include additional writing time for an exam, or note taking from lectures. You can either contact this university service directly or speak with your AYA Keyworker about how to get in touch.

Most universities also have a **student health centre**. They provide a variety of services including doctor and/or nurse appointments, sexual health advice and contraception and counselling services. To access this you may need to register with the university health centre as your primary health organisation (main community doctor/GP) or you may only need to register to save money on fees. Make sure to bring your community services ID (discussed on page 12) as this will also help you to save money on appointment fees and prescription costs.

If you are an international student, most universities have an **international student support service** with advisers who may be able to help you.

What options are available to me if I usually work?

Unfortunately there are limited options as to what is available. We recommend talking to your AYA Keyworker as they can support you with how to best communicate your treatment needs and cancer related effects to your employer if required.

If you are having any issues with your employment situation (e.g. feeling that you are not being treated fairly at work, not feeling well supported in balancing your treatment and work commitments) we recommend contacting the Citizens Advice Bureau for assistance (**0800 367 222**).



Educational/vocational (job related training) and employment supports checklist

Yes / No / NA	Checklist Item	PAGE
<input type="radio"/> _____	If still attending school I have been offered a referral to my local regional health school	31
<input type="radio"/> _____	If at University, I have considered linking in with student disability services to receive support, and assistance with continuing on my course.	31



Notes

Section

7

ORGANISATIONS AND CHARITIES AVAILABLE



Organisations and charities available

There are a number of organisations and charities available to support you and your whānau following a diagnosis of cancer.

This support can range from having someone outside your whānau to talk to, being able to speak with people your own age who are experiencing similar things, to more practical help like petrol vouchers and hospital transport.

What range of supports do these providers offer?

Below is a summary of the national organisations and the support they can offer. There are other support groups specific to certain parts of the country. We recommend speaking to your AYA Keyworker to find out about some of these groups and how to get in touch with them.

AYA SPECIFIC

► CanTeen New Zealand

CanTeen supports young people aged 13 to 24 years dealing with cancer, including patients, those who have finished treatment, those whose parents have cancer and siblings of those who have cancer.

For those in the bigger centres (Auckland, Wellington and Christchurch), CanTeen can provide face-to-face support from their youth and psychosocial workers. For those living outside of these areas you can contact these same supports through phone and/or Zoom, and CanTeen also visits the regions occasionally.

There is also a free online platform called CanTeen Connect where you can find peer support and counselling: <https://canteenconnect.org/> this is available for you to engage with other young people from Australia and New Zealand who may be undergoing a similar journey to you. This website is moderated to keep it safe and so that there is help available if you need it.

Also available online are events to connect you with other young people with cancer. These range from baking and trivia events to learning ways to cope and how to manage stress.

CONTACT DETAILS: If you would like support from CanTeen you can sign up yourself via the website: <https://www.canteen.org.nz/join-now/> or call **0800 CANTEEN** (0800 226 8336). The number to connect directly with a counsellor is **0800 119 229**. Your AYA Keyworker can also refer you to CanTeen.

'The social support received from both CanTeen and my AYA nurse was brilliant. It was incredibly useful having someone other than my family or partner to talk to about what I was going through.'

Young person

► Look Good Feel Better

'Look Good Feel Better' (LGFB) provides free workshops for young adults to help with some of the side-effects you may experience as a result of cancer treatment.

The two hour workshops cover skin care, skin changes and makeup application. This is a hands-on class where trained volunteers guide you through how to use different skin and make-up products. And best of all, you will be given some of the donated skin care and cosmetic products to take home as a gift.

There are also live online video classes that you can register for and attend (these are currently not AYA specific).

CONTACT DETAILS: For more information you can contact them through their website <https://lgfb.co.nz/contact/> or call them toll free on **0800 TO LGFB** (865 432). Your AYA Keyworker can also help you connect with the LGFB team.

BLOOD CANCER SPECIFIC

▶ **Leukaemia and Blood Cancer New Zealand (LBC)**

LBC is for those of any age who have a blood cancer or related blood condition. It aims to support people where and when it is needed most. They can provide a range of support to you including:

One to one support: The LBC support services team are there to help you and your whānau through answering questions you may have, listening to concerns, sourcing practical help, financial assistance and information relating to specific diseases and treatments.

Financial assistance: If you are experiencing financial difficulties, LBC can provide support through food and petrol vouchers or helping to pay basic living bills. Each case is assessed individually.

Education and support programmes: LBC run a number of education and support programmes throughout the country for people who are going through similar experiences. These programmes are open to those currently undergoing treatment and those who have finished treatment. There is also online computer/PlayStation gaming support to connect and meet others who may be going through similar things.

Educational materials: LBC has a number of patient information booklets related to blood cancers and conditions to help you and your whānau understand these diseases.

It's important to ask your local LBC team about what they are able to support and provide you with as this may be different depending on where you live.

CONTACT DETAILS: To get in touch with LBC you can call them toll free on **0800 15 10 15** or visit their website at leukaemia.org.nz for more information. Your AYA Keyworker can also help you with connecting with LBC.

FOR ANYONE WITH A CANCER DIAGNOSIS OF ANY AGE

▶ **Cancer Society**

The Cancer Society is available to people of any age who have a diagnosis of cancer. They have centres located across the country to help provide a variation of the following supports:

One-on-one support: The Cancer Society is available to provide emotional and practical support for you and your whānau. This may be in the form of information about cancer and treatment, listening to your questions and concerns, or connecting you with other support services or organisations.

Nursing support: There are experienced nurses available to give specialised support to those with cancer in the community.

Volunteer driving service: If you are finding it difficult to get to and from cancer-related appointments, the Cancer Society volunteer drivers or free shuttles may be able to help.

For some regions, you will need a health professional to make a referral on your behalf to access this service - we recommend getting in touch with your AYA Keyworker who can facilitate this for you.

Accommodation: Across the country there are options for accommodation located close to your treatment centre. This is assessed on an individual basis but your AYA Keyworker can help you find out if you are eligible.

Counselling: There are counsellors available if you would like to talk to someone outside of your whānau regarding issues related to your cancer diagnosis.

CONTACT DETAILS: To find out what is available in your area, visit the Cancer Society website at cancernz.org.nz (it will automatically load your location based on where you log on but you can change this in the drop down list). Your AYA Keyworker can also help you connect with the Cancer Society.

'The LBC service have been the best thing because they have helped me meet others going through the same thing of a similar age, helped me with petrol... supported me through work...'

Young person

FOR THOSE OVER THE AGE OF 20

▶ **Whole Lotta Life Foundation**

The Whole Lotta Life private Facebook group is for all young adults aged 20-45 years who have or have had cancer.

It is a safe place to share stories, triumphs and hardships, and a place to ask questions.

CONTACT DETAILS: <https://www.facebook.com/groups/687823174565607>

▶ **Shocking Pink**

Shocking Pink is a volunteer run organisation that is set up to specifically support young women (aged 20-45) diagnosed with breast cancer in New Zealand.

They run a really active online support group on Facebook and have yearly getaways.

CONTACT DETAILS: Visit their website at <http://shockingpink.org.nz> or check out their Facebook page @ShockingPinkNZ

Speak to your
AYA Keyworker to
find out more about
these groups
and how to get in touch
with them

FOR THOSE UNDER THE AGE OF 20

▶ **Child Cancer Foundation**

The Child Cancer Foundation (CCF) can provide support to young people up to the age of 13 years and once 13 years old they provide support to their families until the young person is 20 years old.

Family support coordinator: This is a dedicated member of the CCF team who can support you and your whānau during treatment.

Travel Assistance: CCF is able to provide financial support with hospital parking, petrol and other travel costs related to visiting the hospital.

Household Support: CCF offers help by assisting with groceries, heating and electricity costs as well as other basic living needs that families may struggle to meet during such a difficult time.

Personal Development Grants: CCF provides personal development grants to young people with cancer, their siblings or parents.

Support in the Community: CCF coordinates local parent support groups and provides camps for families and siblings of young people with cancer, allowing them to connect, communicate and find strength from shared experiences. The CCF branches across the country also host regular social activities, offering mutual support and shared experiences.

CONTACT DETAILS: To get in contact with your local family support team visit childcancer.org.nz; your AYA Keyworker can also help you to connect with CCF.

'The ladies at CCF gave us financial support. That was so invaluable as both my husband and I had to give up work and it was so financially tough for us.'

AYA Parent

FOR THOSE UNDER THE AGE OF 18

► Make-A-Wish

If you are under 18 years of age, you are eligible to receive a 'wish'.

This can range from receiving a new laptop to meeting a celebrity to riding in a helicopter. Your parent or legal guardian will need to make the application which can be found on their website at <https://www.makeawish.org.nz/wishes/apply-for-a-wish/> or your AYA Keyworker can provide a copy of this.

Tip

For many young people a car would be a popular wish however unfortunately this can't be granted for a number of reasons. Still, wish big as they can always tell you to tone it down!

Tip

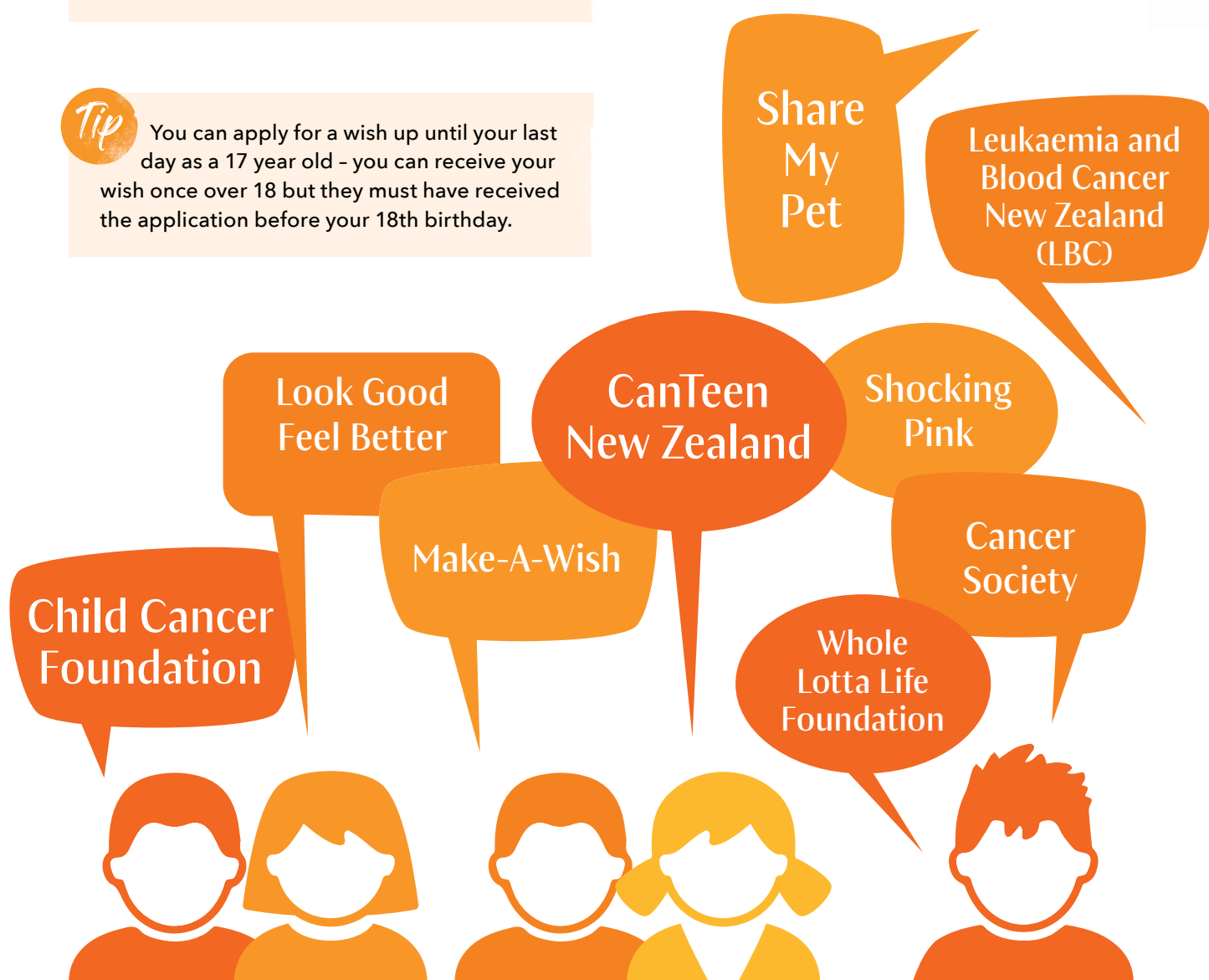
You can apply for a wish up until your last day as a 17 year old - you can receive your wish once over 18 but they must have received the application before your 18th birthday.

FOR PET OWNERS AND ANIMAL LOVERS

► Share My Pet

If you own a pet(s), 'Share My Pet' allow you to arrange care for them.

This may be helpful for when you have to go into hospital for treatment. As an animal lover who would like the companionship, you can become a meaningful part of a pet's life by becoming a 'carer'. Share my pet is free for anyone undergoing treatment or recovering from cancer. You can email help@sharemypet.co.nz or visit <https://www.sharemypet.co.nz/>



There are also additional support groups and organisations for specific cancer types such as Melanoma New Zealand and the Head and Neck Cancer Support Network. Please ask your AYA Keyworker if there are any additional organisations that may be relevant to you both nationally and locally.

Additional supports available to my whānau and I that have not been mentioned:

Name of organisation	Support they can provide	Contact details

Organisations and charities checklist

Yes / No / NA	Checklist Item	PAGE
<input type="radio"/> _____	<p>I have been told about and offered the opportunity to be referred (if appropriate) to the following NGOs:</p> <ul style="list-style-type: none"> <input type="radio"/> • Canteen <input type="radio"/> • Look Good Feel Better <input type="radio"/> • Leukaemia and Blood Cancer New Zealand <input type="radio"/> • Cancer Society <input type="radio"/> • Whole Lotta Life Foundation <input type="radio"/> • Shocking Pink <input type="radio"/> • Child Cancer Foundation <input type="radio"/> • Make-A-Wish <p>*If you don't want be involved with the above organisations right now but want to later just let your AYA Keyworker know or you can self-refer when ready</p>	34 to 37
<input type="radio"/> _____	<p>I have asked about and listed down other support organisations that are available to my whānau and me</p>	38



Notes

THE A-Z OF WHO'S WHO & WHAT'S WHAT

Section

8



The A-Z of who's who and what's what

You will come in to contact with many people during treatment. We have put together the list below to help you understand who some of them are and to identify those you would benefit from seeing.

For example if you are struggling with your appetite, you may read that a Dietitian can help you with this; we therefore recommend asking your AYA Keyworker or medical team about a referral to this service.

'I was surprised to hear from other members of our group that they were not offered the same supports as I was... honestly I'm not sure how they got through their treatment without the support I received.'

Adolescent and Young Adult advisory group member

AYA Keyworker: a health professional with expertise and experience in youth health and cancer who can help you navigate you through your journey. They can advocate for you, provide education, link all of the different services together and support you in every aspect of your care.

Clinical trials manager: this is someone who helps run clinical trials. Clinical trials are where young people test new treatments, or existing treatments given in new ways, to see if they work better. Clinical trials are important because they provide important information about how to improve treatment by achieving better results with fewer side effects. You can ask your AYA Keyworker about whether there are any clinical trials available to you.

Community/District Nurse: a nurse that comes to your home for help with medications, changing dressings etc.

Complementary Therapists: someone who provides therapies that complement or assist with recommended medical treatment e.g. yoga, acupuncture, massage, relaxation, meditation.

Cultural Support: support that assists families and whānau to access services and ensures cultural needs are both recognised and met

Dietitian: someone that helps you with your nutrition and assist in planning a diet that meets your unique health needs.

Doctors: You may meet some of the following doctors

- House Officer/House Surgeon – a junior doctor who has not yet begun specialty training
- Registrar – a doctor who is more senior to a house officer and is beginning to specialise in an area
- Consultant – an expert/specialist doctor. They are in charge when you are given treatment in hospital. They have a team of doctors working with them (often house officers and registrars)
- Haematologist – a doctor who specialises in blood problems and blood cancers
- Oncologist – a doctor who is an expert in all non-blood cancers
- Pathologist – a doctor who studies cells and looks at biopsies
- Radiologist – a doctor who is trained to look at x-rays and scans

- **Surgeon** – a doctor who does operations
- **Palliative Care Doctor** – a doctor who specialises in helping people cope with the symptoms of cancer
- **General Practitioner/GP** – a community doctor. You may know this person already. They can help when you are out of hospital. You should continue to see them for non-cancer related health issues.
- **Medical Student** – someone who is training to become a doctor. They may visit you with the qualified doctors who are treating you, so they can learn about what happens.

Fertility Specialist: is a doctor that specialises in fertility (defined as the ability to have your own biological children or further biological children in the future) likely working at one of the following clinics – Fertility Associates, Fertility Plus, Repromed, Genea Oxford Fertility.

Regional Hospital School Teacher: a teacher that helps coordinate your schooling and provides extra help to keep up with studies when unwell – either at home or in hospital.

National Travel Assistance (NTA): financial support from the government for those who meet the criteria in regards to treatment related travel and accommodation.

Non-Governmental Organisations (NGOs): e.g. CanTeen, LBC, Cancer Society: support groups that provide opportunities to meet other people with cancer and opportunities to take part in activities and social events.

Occupational Therapist: someone that provides you with ways to make life and work more manageable with a focus on meaningful activity and function. They can also help with assessing your home/work place to see what equipment you may need to make it safer and easier for you.

Pain Management Team: a team that provides knowledge in pain control methods, pain management strategies and programmes.

Palliative Care/Hospice Team: a team that focuses on relieving/helping your symptoms such as pain and/or can provide you with care and support if there is uncertainty around your survival from your cancer.

Pharmacist: someone who gives out medicines that doctors have prescribed and gives advice about medicines.

Phlebotomist/Venipuncturist: someone who takes blood samples (except from central lines).

Physiotherapist: someone that helps you with your physical mobility and keeping your body fit and strong.

Psychologist/Counsellor: someone that helps you with your feelings and worries. They can help you to come to terms with your situation and help you work out new coping strategies. Some of the common issues they can help with are anxiety/worry and trouble sleeping.

Radiographer: someone who takes x-rays and scans.

Radiation Technician: they give radiotherapy treatment, which is planned by an oncologist.

Social Worker: someone that supports you with financial, work or social issues and can link you in with the right services and supports.

Spiritual/Religious Counsellor: someone who supports your taha wairua (spiritual health) such as a Chaplain, minister, priest, spiritual therapist.

Ward Clerk: someone who works alongside the hospital team and does administration duties within the hospital. This includes greeting patients, answering phones, requesting patient notes etc.

Ward Nurse: a nurse who makes sure you are looked after in hospital. They will give you any regular treatments you need.

Whānau/Family: any of the people who are part of your support team – family, whānau, partners and loved ones.

WINZ: Work and Income New Zealand. They are the government organisation that can help financially.

Youth Worker/Activity Coordinator: someone that offers you activities in the hospital and provides opportunities to keep you linked in with your friends and other social activities.

Ask your
AYA Keyworker or
medical team
for a referral
to these services

The A-Z of who's who and what's what checklist

Yes / No / NA	Checklist Item	PAGE
<input type="radio"/> _____	I have been told about and offered the opportunity to be seen by the support providers I believe could help me – where this hasn't happened, I have discussed a referral with my AYA Keyworker	41-42



Notes

Useful contacts

Contact name	Contact details
AYA Cancer Network Aotearoa	P: 021 337 129 E: AYACancer@adhb.govt.nz http://ayacancernetwork.org.nz
Cancer Society	P: 0800 CANCER 0800 226 237 http://cancernz.org.nz
CanTeen	P: 0800 226 8336 or for a counsellor 0800 119 229 E: info@canteen.org.nz www.canteen.org.nz or for online counsellors https://www.canteen.org.au/new-zealand-support/
Child Cancer Foundation	P: 0800 424 453 E: info@childcancer.org.nz https://www.childcancer.org.nz/
Citizens Advice Bureau	P: 0800 367 222 https://www.cab.org.nz/
Kāinga Ora - Homes and Communities	P: 0800 801 601 E: enquiries1@kaingaora.govt.nz https://kaingaora.govt.nz/
Leukaemia & Blood Cancer New Zealand	P: 0800 151 015 E: info@leukaemia.org.nz https://www.leukaemia.org.nz/
Look Good Feel Better	P: 0800 TO LGFB 0800 865 432 E: info@lgfb.co.nz http://lgfb.co.nz
Make-A-Wish	P: 0800 80 70 80 E: info@makeawish.org.nz http://makeawish.org.nz
National Travel Assistance (NTA)	P: 0800 855 066 - option 2 - claims https://www.health.govt.nz/new-zealand-health-system/claims-provider-payments-and-entitlements/national-travel-assistance
Whole Lotta Life Foundation	Fb: https://www.facebook.com/groups/687823174565607
Work and Income New Zealand (WINZ)	P: 0800 559 009 Website: https://www.workandincome.govt.nz/
Youthline	P: 0800 376 633 or free text 234 E: info@youthline.co.nz http://youthline.co.nz



Notes

A large, light gray rectangular area with a torn paper edge effect, intended for handwritten notes.

Acknowledgements

The AYA Cancer Network Aotearoa would like to especially thank the AYA Cancer Consumer Advisory Group who both identified the need for this booklet and helped to develop it in the hope that it will make your experience that little bit better.

Thank you also to the AYAs and their whānau who have shared their voices, some of which are included in this booklet.

Please note:

To make our resources as easy to understand as possible and to avoid overwhelming you and your whānau, we aim to provide enough detail to help in the majority of situations but may not cover all possible scenarios.

The information within this booklet is current at the time of publication but please be aware that some of this information may change over time. The Network will work to keep the publication updated.

While the AYA Cancer Network Aotearoa has taken all reasonable steps to ensure that all information is from trustworthy sources and is accurate, it accepts no responsibility for any errors or mistakes. The quality, views and helpfulness of services listed within the booklet are the responsibility of individual organisations and not the Network. Listing should not be taken as a recommendation of the service or organisation.

The AYA Cancer Network Aotearoa also accepts no responsibility for the manner in which this information is utilised.

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THE VOICE OF THE YOUNG PERSON



Kia ora,

I hope that the information in this booklet answers some of your questions and helps you to navigate through all the information and support available. We know that this may not have answered all your questions and concerns so please remember your AYA Keyworker is there to help.

I can recall being quite overwhelmed when I was diagnosed but knowing that there were people like my AYA Keyworker just a call or text away to answer any questions, was incredibly comforting.

My AYA Keyworker and all the support services made the early stages of my diagnosis right through all my treatments and post-care for cancer so much easier and helped me to focus on getting better and maintaining my sense of 'normal'.

Just remember that you are not alone, and that there are so many people that all care about you and have your best interests at heart. If you ever feel like you're having a bad day and it's all a bit much, speak to someone about it.

We will aim to keep updating this every year as needed so if you think we have missed anything, get in touch and let us know.

Sophie Perham

Co-chair of the AYA Cancer Consumer Advisory Group

INFORMATION

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



AYA Cancer Network Aotearoa



@NZayacancer



ayacancernetwork

