

CARE CONNECT



The notebook belongs to:

Unit Record (UR) number:

This is the number on your ID bracelet





About the Illustrator

"Hi, I'm Liana.

I was diagnosed with stage 4 nasopharyngeal carcinoma when I was 22, and it completely changed my life. Going through cancer as a young person was one of the scariest things I had ever faced, especially in a stage of life where you're still figuring out who you are and what your world is meant to look like.

One of the hardest parts for me was not seeing anyone who looked or felt like me in the treatment spaces around me. I didn't know anyone my age going through something similar, and it made navigating appointments, specialists, and all the unfamiliar medical language feel even more overwhelming. That's why this notebook means so much to me.

I hope it helps give you some power in your voice, confidence in trusting your body, and the reminder that it's always okay to ask questions, speak up, and expect good care.

The illustrations throughout these pages were created to reflect people like us - people in that forming stage of life. Maybe a little alternative, creative, curious, or still figuring things out. I wanted to capture little moments, some emotions, some of the medical equipment and spaces you may come across, and help create something that makes you feel seen, understood, and less alone.

Most of all, I hope this notebook reminds you that even in the hardest moments, your voice matters. If you're reading this, I'm proud of you. You've got this."



Acknowledgements

This resource has been developed through the shared efforts, insights, and experiences of many individuals and organisations.

Youth Cancer Services are funded by the **Australian Government and State and Territory health departments**, whose support enables resources like this to reach adolescents and young adults with cancer across Australia.

The content in this resource was developed by people with a lived experience of cancer, in partnership with **CALHN clinical staff**, and **co-designed with Youth Cancer Services Youth Advisory Group (YAG) members** from across the country. Their voices, ideas, and experiences are at the heart of this resource.

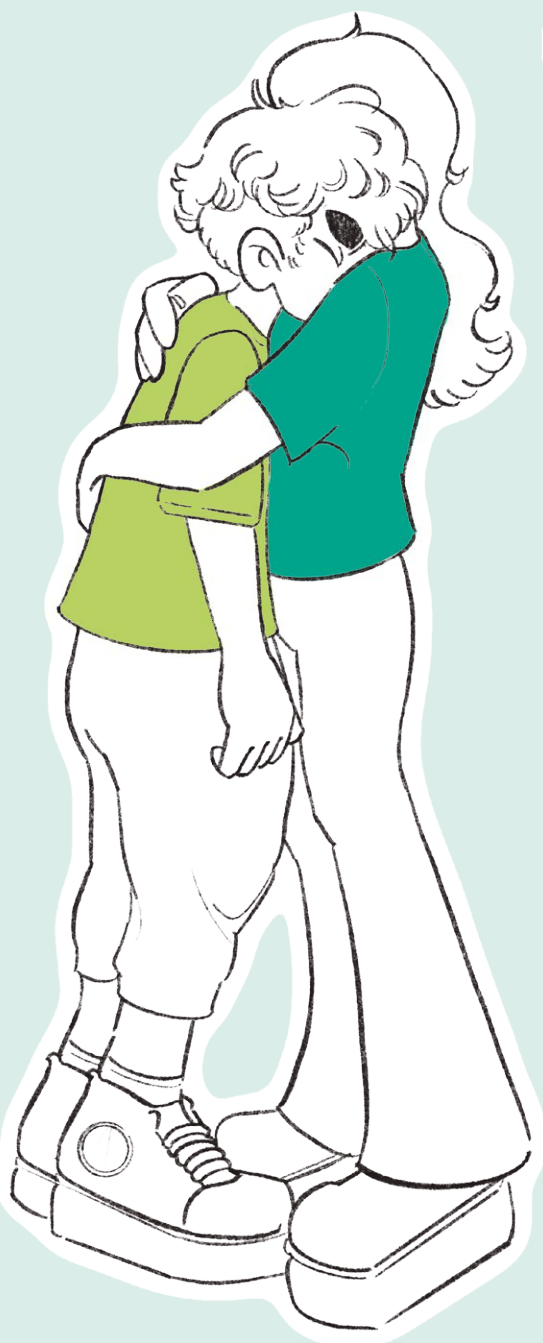
We also acknowledge **Thomas Binns** and **Tereena Cocks** for their contributions to the development of this resource.

Special thanks and acknowledgement to **Liana Galic** for the beautiful illustrations throughout this resource, which bring meaning, lived experience, relatability and warmth to the content.

We recognise the **Youth Advisory Group members** from across Australia whose input and perspectives helped shape this resource in meaningful ways.

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What matters to you?

- People often have questions and concerns when they come to their appointment.
- Your care team is keen to answer your questions.
- Thinking of your questions and concerns before your visit will help with your appointments.
- This notebook will help you work out the most important questions and concerns you have right now.
- Common questions and concerns for appointments are listed throughout this notebook, these may or may not be important to you.

Spend some time to get ready for your visit

- Some people find it helpful to talk with family and friends about their appointments.
- Write down all your questions and think about which ones are the most important.
- Bring this notebook with you and show it to your care team.
- This notebook is designed to be reusable across all of your appointments.



Scan to learn more about your health care rights.



Many people have questions during their visit

Here are some common things people have questions about. Feel free to tick what is relevant to you.



My Diagnosis

- ☐ What caused my cancer?
- ☐ How serious is it?
- ☐ How common is it?
- ☐ Should I or my family consider genetic testing?
- ☐ Can it be cured?
- ☐ What do you mean by 'grade', 'stage', 'prognosis', etc.?
- ☐ I've noticed changes in my body or how I'm feeling after my diagnosis and/or treatment.

Ideas

- ☐ I have questions about what caused my cancer.
- ☐ Other treatments I would like to discuss.
- ☐ Things in life important to me that will affect what treatment I might choose.
- ☐ Other treatments or medicines I am trying or thinking about.

My tests

- ☐ When do I get results?
- ☐ What are the results of the tests I have had?
- ☐ What other tests are possible?
- ☐ What are the reasons for and against each test?
- ☐ When is my next test?
- ☐ Help me understand my test results.

Feelings

- ☐ How I'm feeling about my diagnosis.
- ☐ What can I do if I am feeling down or anxious?
- ☐ What do I expect might happen in the future?
- ☐ What is important to me?

Many people have thoughts and ideas they would like to discuss

Here are some common thoughts and ideas people like to discuss:
Feel free to tick what is relevant to you.

My Treatment

- ☐ What treatments are available (including clinical trials)?
- ☐ What are the most common side-effects?
- ☐ Will treatment affect my fertility?
- ☐ What could happen if I decide to not have any treatment?
- ☐ Could this treatment cause changes to my body or appearance?
- ☐ What are the long-term effects of my cancer and/or treatment?
- ☐ How can I better manage my pain?

My Care

- ☐ When should I come back to see you or my GP?
- ☐ Can you supply me with a list of other services and supports to help me?
- ☐ Where can I find more info about my treatment and support?
- ☐ How can I look after myself?
- ☐ Who can I talk to for support?
- ☐ Who can my family and/or friends talk to for support?



Concerns

- ☐ If you cannot answer these questions, who do I go to?
- ☐ How will cancer affect me?
- ☐ Can I still do [activity]?
- ☐ What this means for my work and/or studies.
- ☐ How the condition might affect my relationship or sex life.
- ☐ How can I explain my condition and/or appearance to others?
- ☐ How to tell my family about my condition.
- ☐ Are there any costs involved with treatment e.g. medication, tests, longer stays or parking?
- ☐ Can I have food brought in to me?



Family

- ☐ Can I bring my parent/s or support person/people?
- ☐ Can I speak to the doctor without my parents?

Other Considerations

- ☐ What are my options for accommodation?
- ☐ What services are available if I need assistance with transport?
- ☐ Preferences for follow up appointments.
- ☐ Can I record my appointments?
- ☐ Can I apply for National Disability Insurance Scheme (NDIS)?
- ☐ I need help with advanced care directives, enduring power of attorney, and wills.
- ☐ Where can I find a wig service and/or scalp cooling?
- ☐ Do I need any modifications for when I return home?



My Healthcare Team



Clinicians Name	Role	Contact Details

How to get to my Hospital/Clinic

My Appointment Tracker



What	Date and Time	Where

11

12

An illustration of a medical thermometer and an IV drip bag. The thermometer is white with a green top and a digital display showing '36.6'. The IV bag is green with a blue label that says '1000ml' and is connected to a white tube. The background is a teal circle.

Reminder, you can ask your healthcare professional for consent to record your appointment.

Could my next appointment be via phone or video?

Notes about my appointments

A stylized illustration on a teal circular background. On the left is a white digital thermometer with a green top and a small blue button. The screen shows '36.6'. On the right is a green IV drip chamber with a blue label that says 'Drip Chamber'. A white tube is connected to the bottom of the chamber and loops downwards.

Reminder, you can ask your healthcare professional for consent to record your appointment.

Could my next appointment be via phone or video?

A stylized illustration of medical equipment. On the left is a white syringe with a green plunger and a small blue dot near the needle. On the right is a green drip chamber with a blue label that reads 'Drip Chamber' and a white tube connected to it. The background is a solid teal color.

Reminder, you can ask your healthcare professional for consent to record your appointment.

Could my next appointment be via phone or video?

My Medication Tracker



Medication name	What it's for	Dose and frequency	Allergies	Notes

My Medication Tracker



Medication name	What it's for	Dose and frequency	Allergies	Notes

My Medication Tracker



Medication name	What it's for	Dose and frequency	Allergies	Notes



Here are some free support services that can help

Remember your healthcare team is here to help. You can ask your doctor, nurse or social worker questions, at anytime.

In an emergency call 000.

Cancer Supports:



Canteen Australia:

A not-for-profit organisation that provides free, tailored support to young people aged 12–25 who are impacted by cancer, offering counselling, resources, and programs.



Cancer Hub:

Canteen, Camp Quality and Redkite working together to help families with children and young people aged 0–25 impacted by cancer to easily access the practical and emotional support they need.



National Cancer Council: Helpline **13 11 20.**

A cancer charity providing support for people with cancer from the point of diagnosis through to treatment and survivorship.



The Leukaemia Foundation:

A national charity dedicated to assisting people with blood cancer such as leukaemia, lymphoma, myeloma, MDS, MPN.



The McGrath Foundation:

A charity aiming to provide education, support and awareness for people diagnosed with breast cancer.

Mental Health Support:



Headspace:

Provides mental health and wellbeing support for young people aged 12–25 across Australia.



Suicide Call Back:

Provides free, 24/7 professional phone counselling for people at risk of suicide, worried about someone, bereaved by suicide, or experiencing emotional distress.
1300 659 467



Lifeline:

Provides free, 24/7 crisis support for anyone in Australia experiencing emotional distress. **13 11 14**

Gender and Sexuality:



LGBTIQ+ Health Australia:

Supporting healthy lesbian, gay, bisexual, trans/transgender, intersex, queer and other sexuality, gender, and bodily diverse people and communities throughout Australia and the world, free from stigma and discrimination.



QLife:

Offers free, anonymous phone and webchat support for LGBTIQ+ people across Australia.



Disability Supports:



Australian National Disability Services:

Provides services and assistance for everything from daily tasks, transport and travel to long-term health and wellbeing support.

Cultural Supports:



NACCHO:

National peak body for Aboriginal Community Controlled Health Organisations, supporting culturally informed, community-led primary healthcare for Aboriginal and Torres Strait Islander peoples across Australia.



ReachOut:

A safe, anonymous online space offering accessible support for young people from culturally and linguistically diverse backgrounds.

An illustration of a spiral-bound notebook with a teal cover and a teal pen with a silver clip, both set against a light green background. The notebook is open, showing several lines of teal handwriting. The pen is positioned vertically next to the notebook.

These may help you form your questions and concerns:





