

AYA Cancer Network Aotearoa Patient Information Sheet



Every year around 200 Adolescent and Young Adults (AYAs) will hear the words 'you have cancer'. There is never a good time to be diagnosed with cancer but it can be particularly challenging for young people. That's why there are dedicated supports in place especially for AYAs aged 12-24 and their whānau.

The AYA Cancer Network Aotearoa was established in 2014 to make sure that young people across the country have the very best cancer care available. The Network employs a small team of professionals to drive improvements in cancer services for AYAs. The Network is funded by Te Aho o Te Kahu - Cancer Control Agency and sits within Health New Zealand - Te Whatu Ora.



Here are some of the things that we do



HE TAUTOKO ADVOCACY

We make sure that young people have a say in how cancer services are designed and delivered



HE RAUEMI RESOURCES

We make practical resources to help guide and support young people through the many challenges that cancer may bring



HE MĀTAURANGA EDUCATION

We help health providers learn more about AYA cancers and how to work effectively with young people



HE RANGAHAU RESEARCH

We lead and support research to improve AYA cancer treatment and care



HE WHAKAARO RANGATIRA SPECIAL PROJECTS

We work closely with AYA Cancer Keyworkers, health professionals, and young people to turn their great ideas into action



HE AROTURUKI MONITORING

We monitor AYAs with cancer to help ensure that young people across the country receive a consistent, high standard of care



You can find out more about us on our website. It includes an ever-increasing number of practical resources for young people and those who support them. You can also follow and connect with our social media for ongoing updates and information.



Website
ayacancernetwork.org.nz



Instagram
[instagram.com/ayacancernetwork](https://www.instagram.com/ayacancernetwork)



Facebook
[facebook.com/ayacancernetwork](https://www.facebook.com/ayacancernetwork)

The AYA Cancer Network's monitoring role

Part of the Network's role is to monitor the delivery of cancer and supportive care services for young people across the country. We do this by accessing information about you and your cancer diagnosis through the New Zealand Cancer Registry and your hospital electronic records.

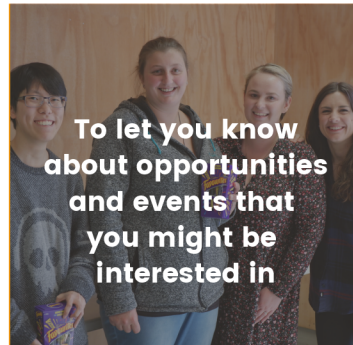
The Network uses this information to monitor your cancer care – making sure that you are referred to the right health care team to receive the right care at the right time. Monitoring also gives us a greater understanding of the care and treatments received by AYAs as a group. This helps us to make improvements for young people in the future.

We are telling you this because you have the right to know who has access to your health information. Just like your treating hospital or medical practice, we follow strict rules around who can access your information, how it is stored, and what it can be used for. If you or your whānau have any questions about this, please contact us at AYACancer@adhb.govt.nz

Contact from the Network

Most of what we do is behind the scenes. It's your healthcare team who you will have the most contact with during your cancer treatment. But we would like to be able to contact you occasionally by text or email if you are happy for us to do so. If you are under 16 we'll contact you via your parent or caregiver.

Some reasons why we might get in touch



If you don't want to hear from us then simply email us at AYACancer@adhb.govt.nz, or text/ phone us on **021 819 486**. We will remove your contact details from our distribution list. You can do this at any time and your decision will not affect your healthcare in any way.

A final message from us:

A cancer diagnosis can trigger big feelings and worries. It's important to remember that most young people with cancer are treated successfully and get better. There are many supports available for young people who are undergoing cancer treatment. Please talk to your healthcare team, an AYA Cancer Keyworker, or visit ayacancernetwork.org.nz to find out more about what help is available for you and your whānau.

Kia kaha