



April 2023 Newsletter

Kia ora and welcome to our AYA Cancer Network Aotearoa update. We hope that you saw our social media posts last week to mark AYA Cancer Awareness Week. We thank you all for your continued efforts in your respective roles to raise awareness of the unique needs of young people with cancer.

2023 marks the halfway point in the delivery timeline for our first ever AYA Cancer Action Plan. Our focus remains on progressing each of our 18 priorities to achieve equitable and world class AYA cancer care in Aotearoa. This newsletter covers just some of our current projects but be sure to also follow us on social media for regular updates of our mahi and the exciting things that are happening in the AYA cancer space.

Over the coming months, the AYA Cancer Network will be hosting live webinars from AYA and oncology experts specific to health care professionals. We are excited to announce that our next webinar will be on AYA palliative care. Keep an eye on our social media pages for the upcoming dates or register for updates [here](#).

We are continuing to develop our website as a 'one-stop-shop' for AYA cancer information and have an ever increasing number of resources developed specifically for the needs of AYAs in Aotearoa. These can be downloaded from [our website](#) or contact us at AYACancer@adhb.govt.nz if you would like us to send physical copies to you.

We hope that you enjoy the updates below from our small but incredibly committed team.

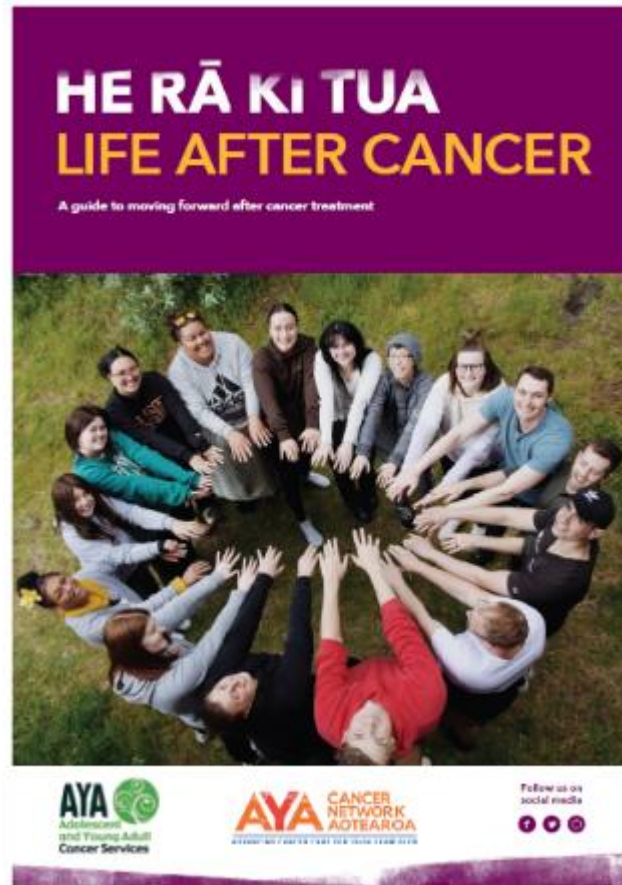
He Rā Ki Tua: Life After Cancer Resource

We are pleased to share that work on our new resource '*He Rā Ki Tua: Life after Cancer*' is nearly complete. We have developed this 100+ page survivorship resource for young people who have completed cancer treatment.

It has been extensively researched and covers a range of topics including:

- emotional wellbeing;
- returning to work and education;
- managing body image;
- returning to exercise;
- healthy eating and more.

The resource will be heading to the printers shortly and we look forward to sharing it with you very soon.

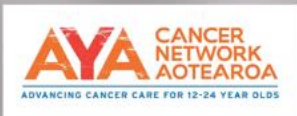


Fertility Guidelines

Over the last two years, a speciality working group of healthcare professionals and consumers have updated the Fertility Preservation for People with Cancer in Aotearoa Guidelines. The guidelines are aimed at healthcare professionals caring for people with cancer under 40 years of age, providing an overview of recommended best practice and a description of fertility preservation options. Excitingly at the end of last year, this crucial piece of work was endorsed by Te Aho o Te Kahu, The Cancer Control Agency. These updated guidelines are one part of a wider project supported by the AYA Cancer Network.

The second phase focuses on implementation, with exploration into fertility preservation barriers and inequities within New Zealand. Reestablishment of

the working group along with involvement from cultural experts, consumers, whānau and the use of specific equity tools will be used to guide the implementation plan. We are looking forward to progressing this next pivotal chapter and will keep our wider healthcare colleagues and consumers updated along the way.



Fertility Preservation for People with Cancer in Aotearoa

Clinical Practice Guideline
March 2023



Consumer Advisory Group



Our consumer advisory group members stand as experienced consumers co-creating with us to create change and to show us the way forward with our kaupapa and mahi. In October 2022, we held our annual AYA Consumer Advisory Group weekend workshop at Muriwai beach, Tamakī Makaurau. It was awesome to come together in-person after nearly three years. We have such a cool group on board. The weekend was filled with some great mahi, advocacy, whakawhanaunga, fun, laughter, kai, awhi, tautoko and aroha.

At the most recent monthly Zoom meeting the consumer group elected two new chairs, Esther and Mackenzie. We also extended our gratitude to the previous chairs – Sophie, Paul, and Justin – who did such an amazing job of representing rangatahi with cancer. We have no doubt Esther and Mackenzie will continue to do the same.



AYA Radiation Working Group

With help from the Network, a number of passionate radiation therapists from around the country have formed an AYA Radiation Therapy Working Group. The working group establishes vital links between departments to aid in collaborating AYA care delivery. The number of AYA patients who receive radiation nationally varies across departments, and some may only see one or two per year. The working group aims to ensure that services deliver equitable services nationally and helps to share knowledge and resources to strengthen the care that each rangatahi and their whānau receives.

One of the main goals has been to collaborate to create resources for young people that explains the entire radiation pathway. With the help of our amazing AYA consumer group and experts around the country we were able to release two wonderful resources specific to radiation; '*Radiation Treatment: A Guide for*

Young People and *Recovering After Pelvic Radiation*'. These are available in printed form and can also be downloaded [from our website](#). We are hoping that this is just the start for what our AYA radiation working group will achieve.

AYA Cancer Keyworkers

The AYA Cancer Keyworkers continue to do amazing work for rangatahi in each of the six cancer regions across the motu. In September 2022, we held our annual Key Worker face-to-face workshop that brought the team together after nearly 3-years apart due to Covid-19. We managed to get some great mahi done over the two days and it was awesome to re-establish that whakawhanaunga kanohi ki te kanohi.

Ellyn Proffit - the AYA Cancer Keyworker for the Midland region - recently had the opportunity through Canteen Australia and the Network to take part in the Youth Cancer Services Leadership Development Programme. Here's what she wrote about her experience;

The programme was awesome, not just from a professional development perspective but also in providing me with the ability to network with Australasian colleagues. This proved to be invaluable when I had a 'boss' (AKA patient) become ill while holidaying in Australia and, after a few phone calls to my colleagues, my 'boss' had health and support services wrapped around them and their whānau. It was heartening to experience the comradery between the Australasian AYA cancer community.

During the programme it was great to share and learn what similarities and differences our various roles and services had, as we came from various health fields – doctors, nurses, music therapists, physiotherapists – all supporting young people navigating a cancer diagnosis. From a mahi perspective our thinking was challenged, and we got to add numerous learnings and leadership

skills to our professional tool belts. I encourage other colleagues to do this course.



The AYA key workers and AYA Cancer Network team at our face-to-face workshop

AYA & Palliative Care

The AYA Cancer Palliative Care Working Group was established in March 2022 to support the development of resources for young people in Aotearoa, where cancer is incurable or life-limiting. The working group members from across the country meet quarterly with a focus on driving the development of youth friendly end of life resources for AYA and their whanau, and best practice guidelines and resources for health professionals working in palliative care with AYA with cancer. The network is hoping to complete and release these resources in the next three months.

A Final Small Request

There are so many great things happening in the AYA Cancer space. Rather than us sending out an occasional newsletter we prefer to regularly post on social media. So if you aren't already following us on social media, please take a moment to do so now by clicking on your preferred platform(s) below. Ngā Mihi.

