ADOLESCENT+YOUNG ADULT [AYA] CANCER SERVICE IN NEW ZEALAND




THIS SERVICE WAS DEVELOPED OUT OF THE NEW ZEALAND CANCER CONTROL ACTION PLAN, 2005.

AIMS:

- To coordinate care directed at the specific needs of AYA cancer patients aged 12 to 24 years old.
- To ensure Paediatric Oncology, Adult Oncology, Radiation Oncology and Haematology tertiary services work in partnership along with Palliative Care and Non-Government Services.

AYA Adolescent and Young Adult Cancer Services

OBJECTIVES:

- To provide improved outcomes for AYA patients and in particular focus on maximising the cure rate for AYA with cancer.
- To ensure entry onto age appropriate clinical trials.
- To provide psychosocial care for AYA with cancer and a youth development approach to care.

AUCKLAND AND NORTHLAND REGION:

KEY WORKER – HEIDI WATSON [021 784 485]

- Auckland DHB has over 468,000 people with a projected growth of 19% or 86,000 more people by 2026
- Over the next 20 years the total population in the Northern Region will grow by around 500,000 - which exceeds the current population of any DHB.
- Starship's Haematology/Oncology service provides assessment, diagnosis, treatment and long term follow-up for children and adolescents with cancer and non-malignant haematological conditions.
- The service also provides a comprehensive Haemopoietic Stem Cell (Bone Marrow Transplant and CORD) Transplant service for the North and South Islands.
- The Haematology/Oncology Service accepts referrals for children with cancer from Auckland, Northland, Waikato, Bay of Plenty, and Taranaki. Also for some children from the Pacific Islands.
- 5 Hospitals in the Auckland area catering to the various treatment needs of an AYA with cancer – Auckland Hospital, Starship, Middlemore, Waitakere, and North Shore.
- Whangarei Hospital (Northland DHB) Oncology Services is a satellite unit of Auckland DHB Oncology Services – which offers medical consultation with visiting Auckland specialists (Medical Oncology, Radiation Oncology and Haematology) for treatment plan/options including outpatient chemotherapy programmes.

MIDCENTRAL REGION:

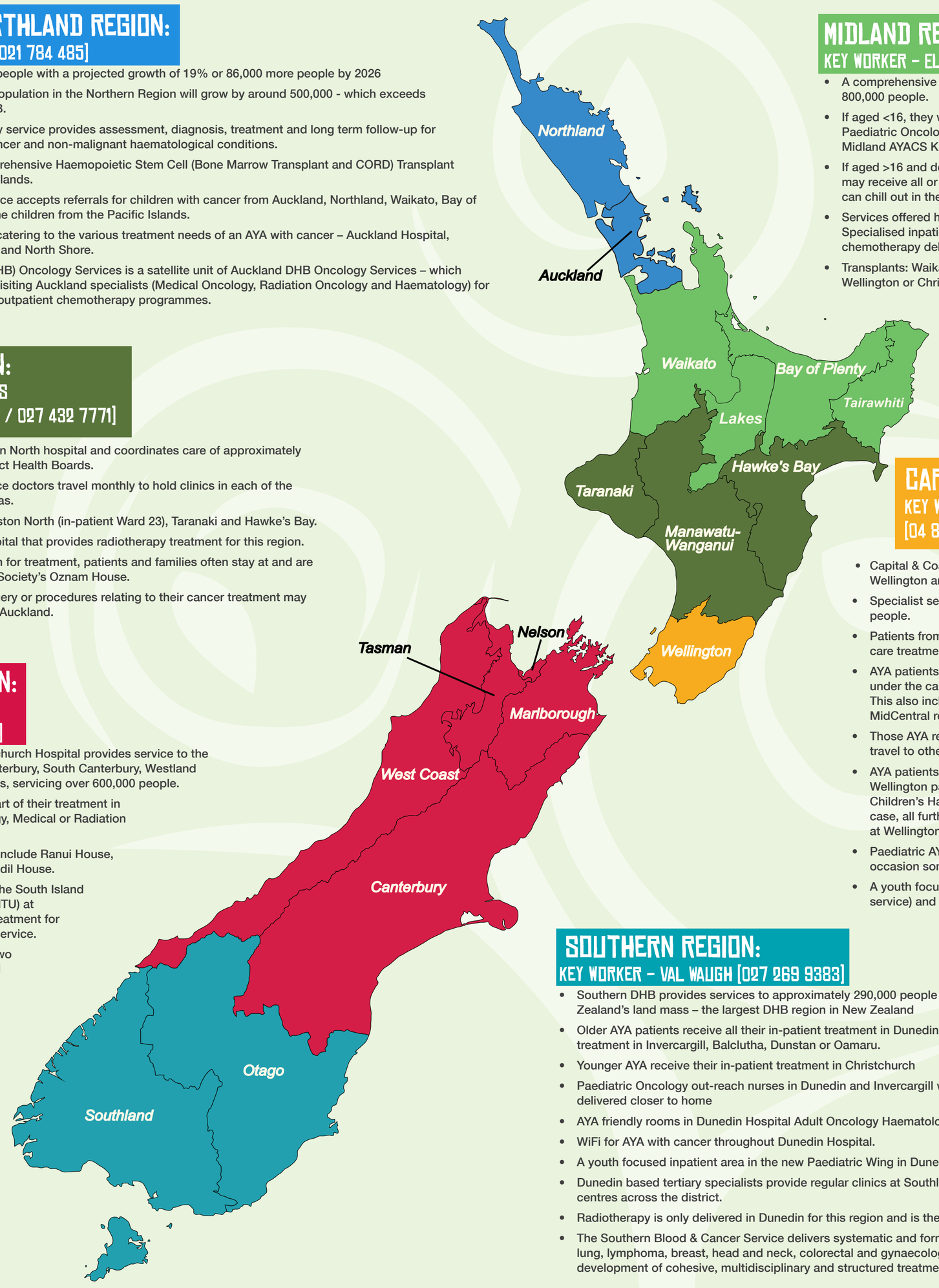
KEY WORKER BLANCHE COLLINS [06 350 8384 / 0800 AYACAN / 027 432 7771]

- The service is run from Palmerston North hospital and coordinates care of approximately 565,000 patients across the District Health Boards.
- Regional Cancer Treatment Service doctors travel monthly to hold clinics in each of the regional District Health Board areas.
- Chemotherapy is given in Palmerston North (in-patient Ward 23), Taranaki and Hawke's Bay.
- Palmerston North is the only hospital that provides radiotherapy treatment for this region.
- When staying in Palmerston North for treatment, patients and families often stay at and are supported by staff at the Cancer Society's Oznam House.
- Patients needing specialised surgery or procedures relating to their cancer treatment may go to Wellington or to Starship in Auckland.

CANTERBURY REGION:

KEY WORKER – JOHN CARSON [03 364 1541 / 027 382 6584]

- The AYA cancer service at Christchurch Hospital provides service to the upper South Island including Canterbury, South Canterbury, Westland and Nelson / Marlborough districts, servicing over 600,000 people.
- AYA patients may receive all or part of their treatment in Christchurch in Adult Haematology, Medical or Radiation Oncology or Paediatric Oncology.
- Accommodation options for AYA include Ranui House, Ronald McDonald House or Daffodil House.
- For those requiring a transplant, the South Island Bone Marrow Transplant Unit (BMTU) at Christchurch Hospital provides treatment for all South Island AYA in the Adult service.
- Christchurch is also one of only two treatment centres in New Zealand for specialised high risk tertiary Paediatric Oncology (for age <16). The other is Starship in Auckland. Patients may be from any part of the South Island or lower North Island.
- AYA focussed inpatient and outpatient areas in the new Child Haematology Oncology Centre in Christchurch Hospital are due to open late 2013.
- A South Island wide MDT by video-conference held regularly provides an overview for AYA patient care. Regional hospitals attend to enable shared care of AYA from more remote locations.



MIDLAND REGION:

KEY WORKER – ELLYN PROFFIT [021 223 6145]

- A comprehensive service is provided to a geographically distributed population of nearly 800,000 people.
- If aged <16, they will liaise with their local Shared Care Centre and Starship - one of two Paediatric Oncology treatment centres in New Zealand. Close contact is maintained with the Midland AYACS Key Worker and various Shared Care Nurses of each region.
- If aged >16 and depending on their geographical location and diagnosis, the AYA patient may receive all or part of their treatment at the Waikato Regional Cancer Centre. Here AYA can chill out in the 'Youth Pad' – the Centre's youth friendly inpatient lounge.
- Services offered here: Adult Haematology, Medical Oncology, and Radiation Oncology. Specialised inpatient care is provided at Waikato Hospital, with outpatient clinics and chemotherapy delivered at Thames, Rotorua, Tauranga and Whakatane Hospitals.
- Transplants: Waikato Regional Cancer Service provides Autologous Transplants. Auckland, Wellington or Christchurch Cancer Services provides allogeneic transplants.

CAPITAL AND COAST REGION:

KEY WORKER – LIZ SOMMER [04 806 0924 / 027 217 6256]

- Capital & Coast DHB provides cover to the lower North Island region comprising Wellington and the Kapiti Coast, Hutt Valley and Wairarapa.
- Specialist services are provided by the DHB for a regional population of about 900,000 people.
- Patients from the upper South Island are also able to access specialist tertiary-level care treatment at Wellington Regional Hospital (WRH).
- AYA patients >16 years generally receive all or most of their treatment in Wellington under the care of Haematology, Medical Oncology and/or the Radiation Oncology team. This also includes a Bone Marrow Transplant Service which extends to AYA from the MidCentral region.
- Those AYA requiring specialist oncological surgery e.g. limb sparing surgery - have to travel to other larger centres (frequently Auckland) is generally required.
- AYA patients 12 -16 years receive care within the Paediatric Oncology Service. For Wellington patients this generally now involves receiving induction treatment at the Children's Haematology Oncology Centre at Christchurch Hospital. Unless a high risk case, all further chemotherapy is administered in the Paediatric Oncology Day stay Unit at Wellington Children's Hospital.
- Paediatric AYA patients requiring Radiotherapy are also able to receive this at WRH. On occasion some Wellington-based AYA may be treated at Starship Hospital in Auckland.
- A youth focused hang-out space on the inpatient ward for haematology/oncology (adult service) and an "AYA room" in our Blood and Cancer Centre day ward.

SOUTHERN REGION:

KEY WORKER – VAL WALIGH [027 269 9383]

- Southern DHB provides services to approximately 290,000 people or just over 7% of New Zealand's total population, living on 28% of New Zealand's land mass – the largest DHB region in New Zealand
- Older AYA patients receive all their in-patient treatment in Dunedin in Adult Haematology, Medical or Radiation Oncology and out-patient treatment in Invercargill, Balclutha, Dunstan or Oamaru.
- Younger AYA receive their in-patient treatment in Christchurch
- Paediatric Oncology out-reach nurses in Dunedin and Invercargill work closely with Christchurch when out-patient treatment can be delivered closer to home
- AYA friendly rooms in Dunedin Hospital Adult Oncology Haematology ward.
- WiFi for AYA with cancer throughout Dunedin Hospital.
- A youth focused inpatient area in the new Paediatric Wing in Dunedin Hospital is due to open late 2014.
- Dunedin based tertiary specialists provide regular clinics at Southland Hospital in conjunction with the Southland based team and in rural centres across the district.
- Radiotherapy is only delivered in Dunedin for this region and is the sole national centre for the provision of Stereotactic Radio-surgery.
- The Southern Blood & Cancer Service delivers systematic and formal clinical multidisciplinary team meetings for the tumour streams of lung, lymphoma, breast, head and neck, colorectal and gynaecological malignancies. This provides a gold standard of care in relation to the development of cohesive, multidisciplinary and structured treatment plans.

8 QUICK TIPS FOR WORKING WITH AYA CANCER PATIENTS

- Be aware of where AYA is in their development and how this affects their experience.
- Understand and interpret the AYA patient's behaviour from their perspective. It is important to try to "put yourself in their shoes". This can help you to understand unexplainable behaviours and responses.
- Set well-defined boundaries, but show flexibility when possible. This can promote trust and safety. Clearly articulate to the young person where any "grey areas" are in their treatment and care planning. Encourage them to participate in planning their care by providing options in these areas. This can enhance the patient's sense of autonomy during treatment, but also their respect for the "black and white" areas of treatment that are simply not open to negotiation.
- Follow through on commitments. Young people are often less forgiving if commitments are broken. Follow through on commitments to maintain a trusting relationship. If commitments need to change, it is important that the reasons behind the change are quickly addressed with the young person.
- Have a holistic approach to the young person. If treating teams understand the AYA patient's goals, resources, past experiences, current relationships and future expectations they are better able to understand what will interest and motivate them. This can help with treatment adherence and this holistic understanding can be used to encourage the young person to maintain interests and goals outside of their treatment.
- Set mutual goals with the patient. This promotes control and assists the development of autonomy. It is important to remember that lack of involvement in decision-making can have a negative effect on a young patient's sense of self and developmental tasks. It is best to negotiate, rather than dictate, when working with this age group.
- Nurture realistic expectations to reduce the risk of failure. Sometimes this means discussing information repeatedly until the young person understands.
- Help the young person to identify and strengthen their supports. This may involve providing opportunities for contact with peers while an inpatient e.g. encouraging phone calls, visits, internet access and privacy for peer interactions. Research has shown that with greater support available, the patient is less likely to suffer psychological distress (Neville, 1998).

onTrac@PeterMac Victorian Adolescent & Young Adult Cancer Service. A practice framework for working with 15–25 year-old cancer patients treated within the adult health sector. Dr Susan Palmer & Associate Professor David Thomas. Melbourne, Australia. 2008