

'The Ever Changing Challenges'

Ellyn Proffit – Clinical Nurse Specialist: Adolescent & Young Adult Cancer Service
41st Enrolled Nurse Conference – The ChalleNge of Change
23rd May 2019

Ko Hikurangi toku maunga



Ko Waiapu toku awa



Ko Horouta toku waka



Ko Rahui toku marae



Ko Ngati Porou toku iwi



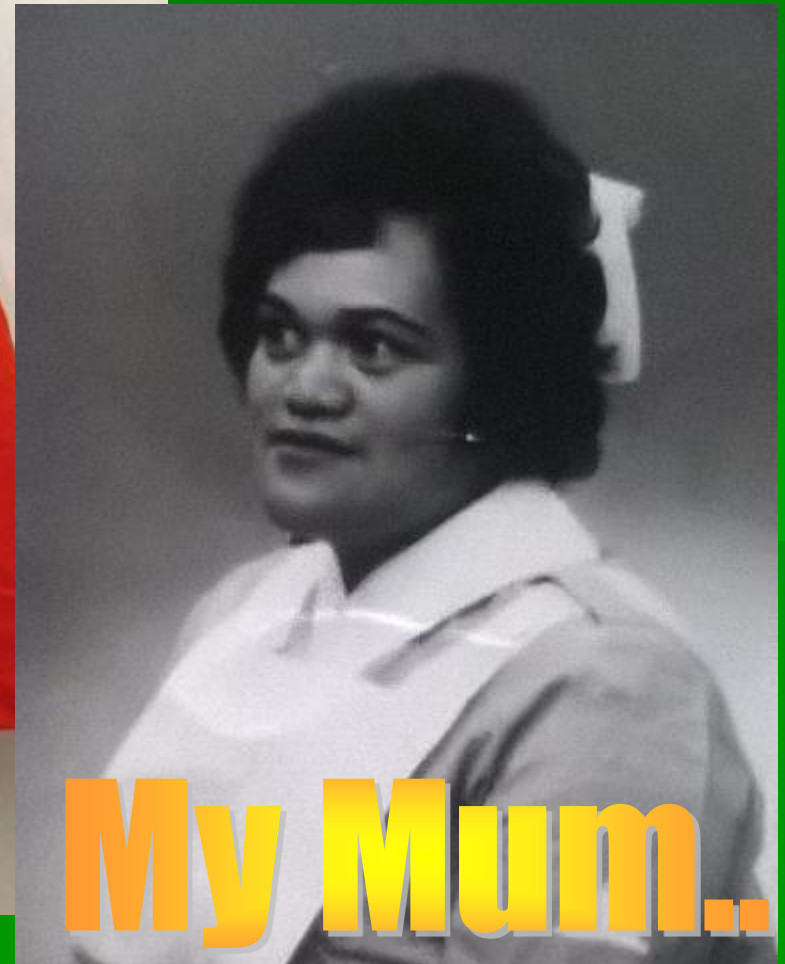
The Ever Changing Challenges...

- Personally
- Professionally
 - On the floor
 - CNS
 - Working with AYA
 - culture shock
 - Colleagues
 - Changes – Youth Pad, Key Support Person
- Volunteer

Nursing...



My role model...



My Mum...



Graduation!!!



Children's Nursing

- 10 years
- Surgery & Oncology
 - Various roles on the ward
 - Pre-op clinic
 - Bowel Training
 - Shared Care Nurse
 - Preceptor
- No two days the same
- Medical, ENT, Orthopaedic overflow etc.



Overseas Experience



Shared Care Nurse

- Support amazing children & whanau – at such a vulnerable and raw time
- Reality - Is it that bad?
- Collegiality –
Waikato & Starship
- Never stop learning:
Conferences – further education around
New Zealand and Australia





Clinical Nurse Specialist



The Adolescent and Young Adult Cancer Service

The Adolescent and Young Adult Cancer Service (AYACS) is a service that seeks to provide support for 12 to 24 year olds with cancer. This service is also extended to whanau/ family, nurses, doctors and organisations that are involved with youth cancer.

Its aims:

- To reduce the time it takes to find out the young person has cancer
- To improve their treatment experience and ultimately their ongoing quality of life
- To support young people with cancer, especially those who have poorer access to health care or are less familiar with the healthcare system
- To help them achieve the best possible treatment outcome.

Who works for the Adolescent and Young Adult Cancer Service?

A clinical nurse specialist who supports the young person and their family/ whanau while they are in hospital and when they return back to their community.

The nurse ensures that health services work together in the best interest of the young person, both in hospital and in their own community areas.

Where:

The service supports young people and their families who live in the Midland region (see map).

Young people under 15 years of age are referred to Starship, and when home, their care is shared between Starship and their local hospital.

Young people over 15 years of age remain under the care of the Regional Cancer Centre here at Waikato Hospital and their care is shared with their local hospital.

Midland Region

The Midland Region includes Lakes, Bay of Plenty, Tairāwhiti and Waikato District Health Boards.



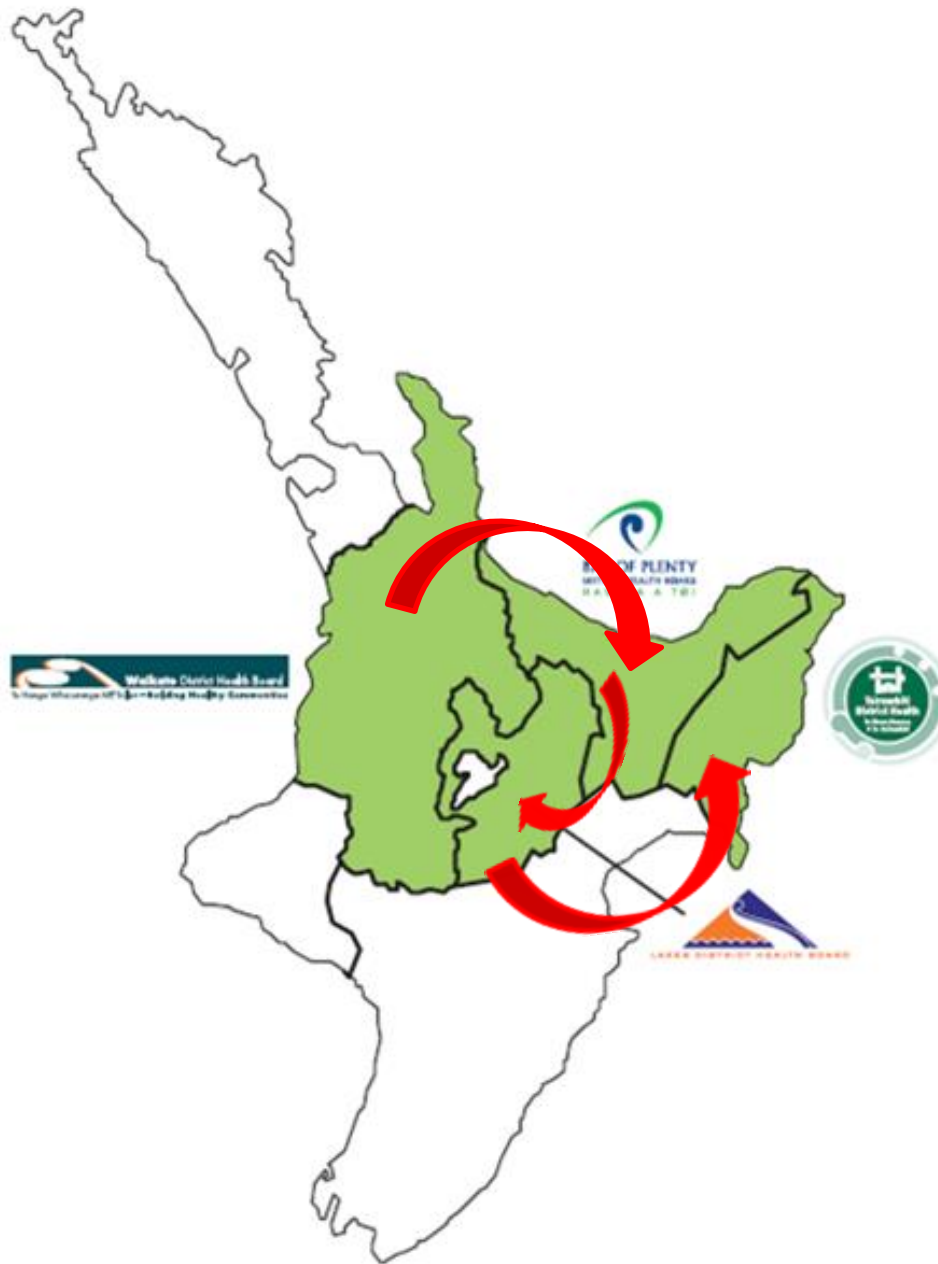
How do you access the service?

If you are in hospital or attending a clinic, ask staff member to make a referral.

Or you can self-refer by phoning:

Ellyn Proffit
Clinical nurse specialist
(07) 839 8899 ext 95643
or 021 223 6145
Monday – Friday, 8am – 4:30pm





Patient flow

12 – 16 year olds

- **Lakes**
- **Waikato**
- **BOP**
- **Tairāwhiti**

Starship



Patient flow

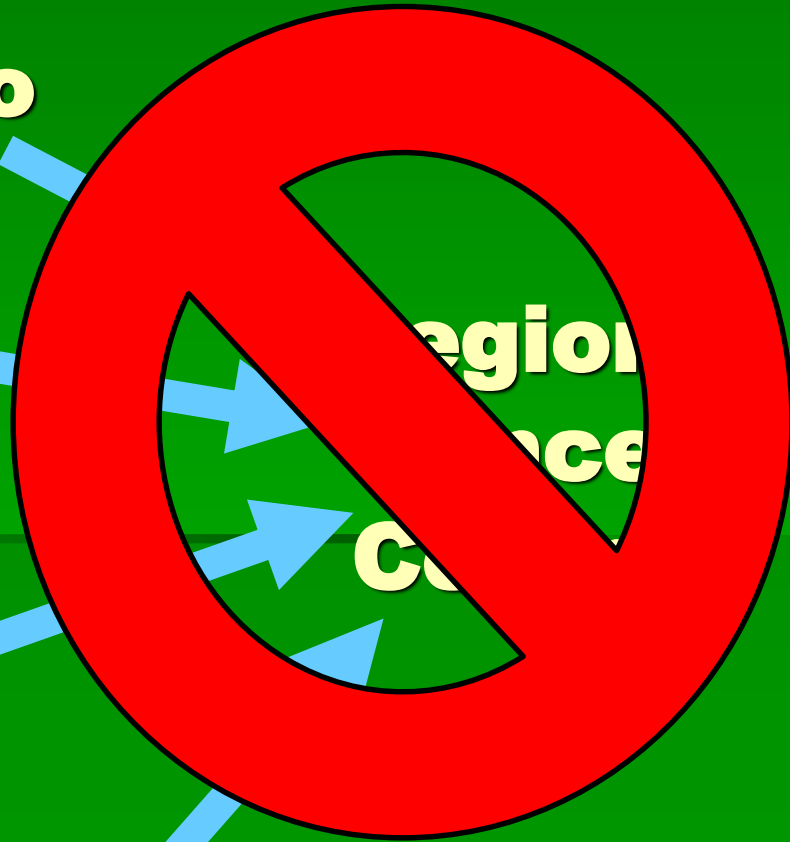
16 – 24 year olds

- **Waikato**

- **BOP**

- **Lakes**

- **Tairāwhiti**

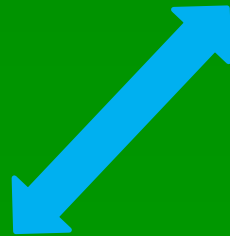
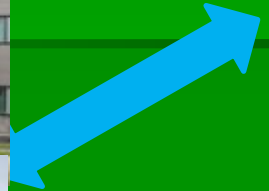
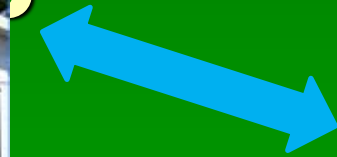


Patient flow

16 – 24 year olds -2019



**Regional
Cancer
Centre**



Whiti

My Bosses!

- Advocating
- Supporting
- Educating
- Walking the 'journey'
- Liaising with hospital staff – Waikato, Lakes, BOP, Tairāwhiti
- Liaising with community services: CCF, CanTeen, Cancer Society, LBC NZ



cul·ture shock

/ˈkəlCHər ˌSHäk/

noun

the feeling of disorientation experienced by someone who is suddenly subjected to an unfamiliar culture, way of life, or set of attitudes.

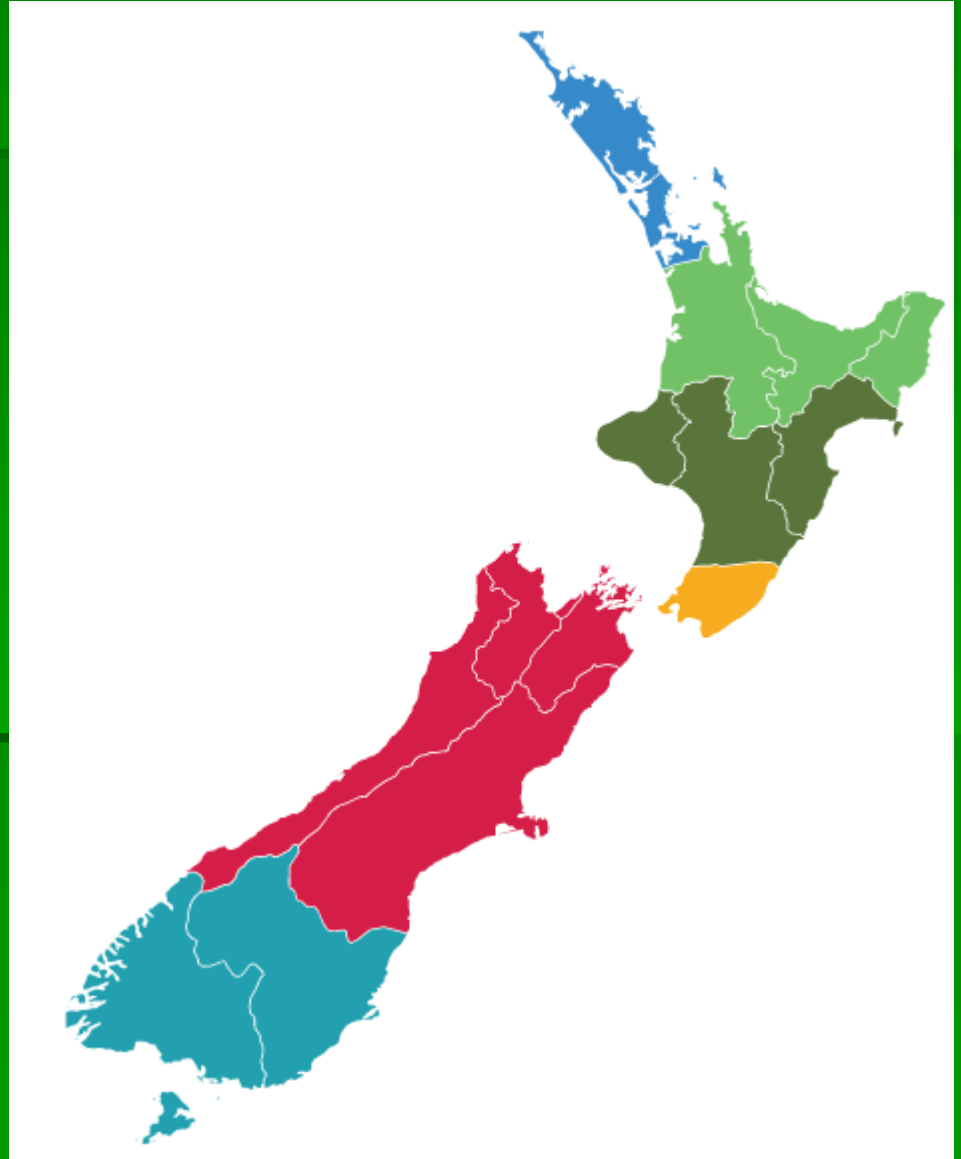




No Man's Land!!!



Is there anybody out there?





Heidi Watson

Clinical Leader

Richard Sullivan

Chair of the Governance Group

Tristan Pettit

Chair for AYA Standards of Care

Rochelle Moss

Programme Coordinator




PROVIDERS

- About Us
- Where Can I Find Help?
- Useful Links

- Standards of Care
- Self Review Tool
- Working Group Member Portal
- Clinical Guidance and Resources


BECOME A MEMBER


 Get the latest news and updates from the network.

SUBSCRIBE

GET IN TOUCH

If you have any questions, concerns or suggestions we'd love to hear from you

 021 337 129

 AYAcancer@adhb.govt.nz

Midland Team:



Meet the AYA Keyworker and Clinical Lead



Ellyn Proffit

Clinical Nurse Specialist

Mobile: 021 223 6145

Email: ellyn.proffit@waikatodhb.health.nz



Charles De Groot

AYA Clinical Lead

Phone: 07-839 8899 - Waikato Hospital

Email: charles.degroot@waikatodhb.health.nz

Adult Services - Day Stay Oncology & Haematology Nurses from around the Midland Region supporting AYAs:



Lakes DHB: Megan Mansfield



Waikato DHB: Anthony Roche



Tairāwhiti DHB: Kelly Norris



Bay of Plenty DHB: Jayde Kanawa

Paediatric Service - Shared Care Nurses from around the Midland Region supporting AYA:



Waikato Shared Care Nurse:
Danielle Polyblank-Finn



Lakes Shared Care Nurse:
Cath Mott



Bay of Plenty Shared Care
Nurse: Sarah Abbott



Whakatane Shared Care Nurse:
Sharon Powley



Tairāwhiti Shared Care Nurse:
Deb McKay

Waikato DHB Radiation technicians supporting AYAs:



Jessica Anderson



Megan Crowley



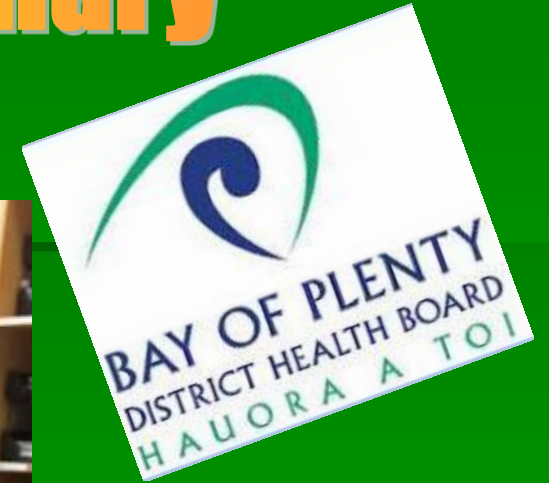
Cathy Zheng

BOP - KKC



Samantha Strongman

Paediatric Multi-disciplinary Teams



Further learning and opportunities – Australia, London & Hawaii!!!





Positive changes:



Key support person

Home > Patients and visitors > Support > Key support person

Patients and visitors

For patients

Feedback or complaints

For visitors, family and friends

Support

Key support person

Key support person

A patient or their family can nominate a key support person for emotional and practical support, and they will be able to stay with the patient for longer than the normal visiting hours. They are welcome to visit from 8am to 8pm.

A key support person is typically a loved one, for example, a spouse, partner, adult child, parent, sibling, close friend or whānau member.

If the patient is not capable of nominating someone, then whānau/family can do this.



Spreading



CANCER NET

of Care POSTS

YOUTH

teenteen

sibilities



- Conferences

and their...
different aspects of...
diagnosis - a non-frightening thing...
to talk about a frightening thing...
The conversations Ellyn can have...
with the young people using Te Awa...
- can range from coping with the...
impact of cancer, the positive and...
negative effects it can have on...
relationships with friends and family...
various treatment pathways along

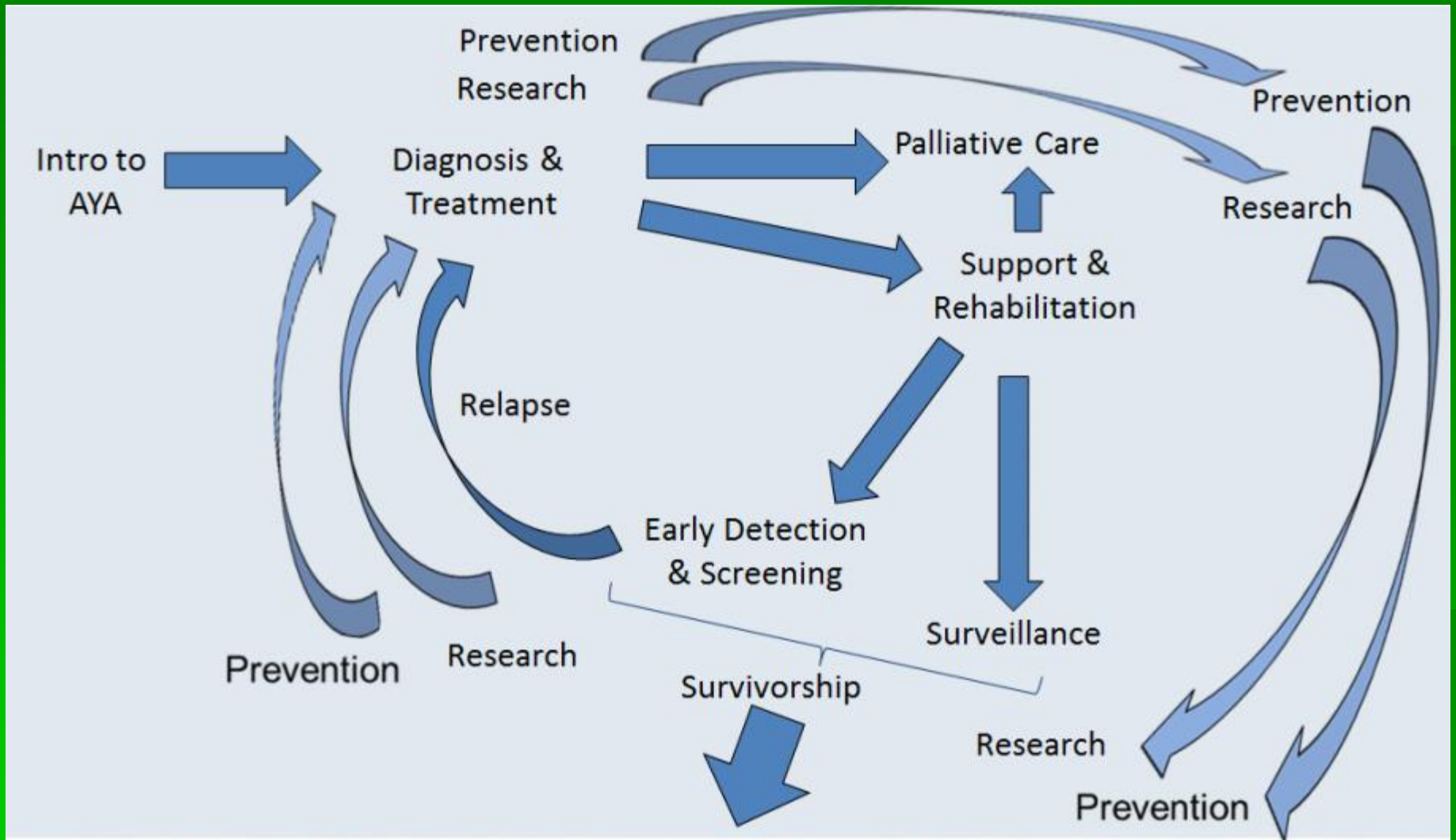
the...
adversity...
ability to understand...
the reactions they...
and/or experience.

"Ellyn, our waka is sailing on really rough water at the moment, and many of the fish are swimming out of range... we are hoping for smoother sailing soon."

MOTHER OF 15 YEAR OLD

What's Te Awa?





“Ellyn, Our waka is sailing on really rough water at the moment, and many of the fish are swimming out of range.... we are hoping for smoother sailing soon.”

Mother of 15 year old



“I’ve been telling other Starship parents your river analogy and they had found it comforting... just thought you might like to know.”

Mum of 13 year old



Anna* 23 yrs - “I used my river journey to explain to my Mum why we’ve had some of the reactions we’ve had from people we knew – and why they acted the way they did”



Tiria* 20 yrs - “I can’t wait to smell the salt sea air!!!”



Bosses made Changes



Te

es:

26 May 2010 - Ellyns River

Diagnosis

Unknown

Chemo

Family

♥ Friends Support ♥

Struggles

Recovery
VAJ

Surgery

Depression

Weight loss
Loneliness

Who
knows

OW

Bosses helped Te Awa:

- Patient centered metaphor
- Owning Te Awa
- Timing



~ Shortly after relapsing in July 2015 ~

When I first relapsed, in July 2015. I had a visit from Ellyn Proffitt while I was in hospital. She was telling me more about this river that I'm on.

The transplant and chemo was the waterfall and rapids. Then we hit the quiet spot, and now I'm about to join the rapids again. Ellyn asked me what I would like to use to help me navigate my way down the rapids this time around.

Last time, I had chosen a kayak. But this time I had the image of me being a frog, lazing in the sun, on a deck chair, on this upsidedown rainbow umbrella with a drink in my hand. Just letting the current / rapids take me.

This morning, I was thinking more on it, and decided that to me, the kayak meant control - to some degree.

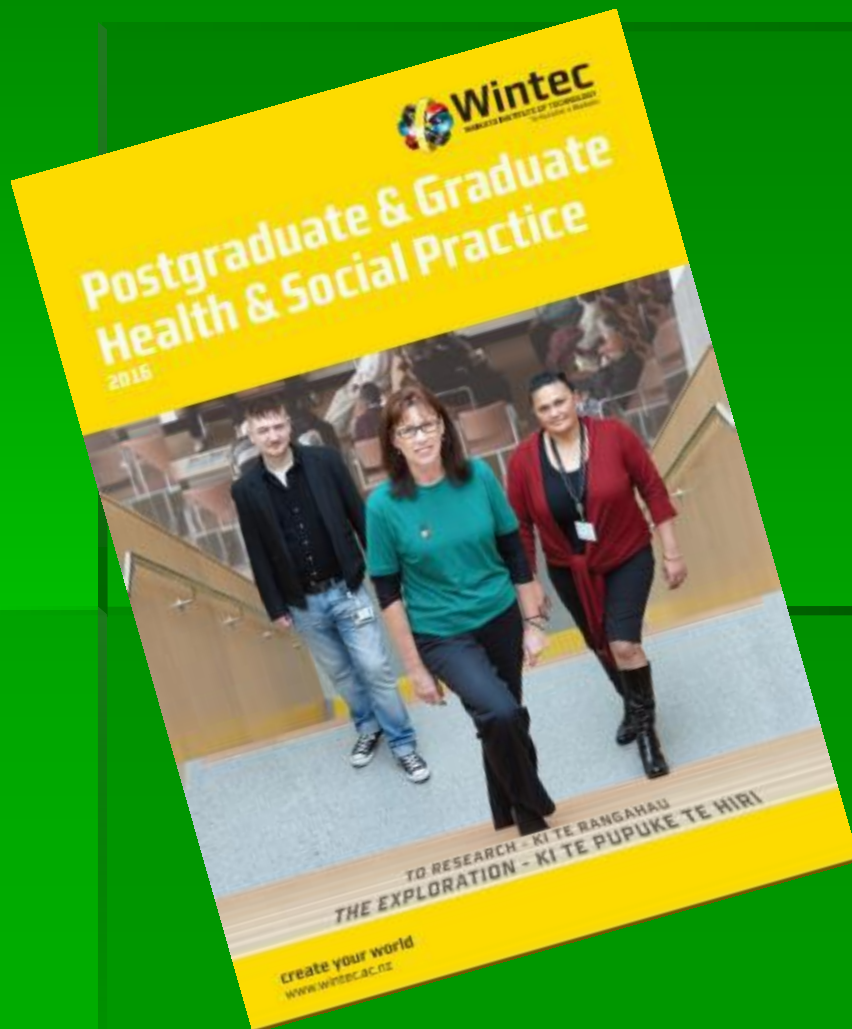
It was something I could use to sort of guide my way through the rapids.

But this time feels different. I am quite happy to completely let go and let God (the rapids) take me where I need to go, and I'll just enjoy the sun. Maybe put my foot in the water a little bit and give it a push if I get stuck somewhere. But I'm not worried about not having control.

I'm trusting that my rainbow umbrella will stay afloat. And it's such a freeing feeling. I thought having no control would drive me crazy. But it's not. I'm trusting God to keep my umbrella afloat and letting Him take me where He wants me to go. And I should just sit back, relax and enjoy the sun when it shines.



Promoting Nursing



Volunteer Nurse

- Camp Quality



For Children Living With Cancer

Become a friend of Camp Quality by [clicking here...](#)



Volunteer Nurse

- CanTeen



Volunteer Nurse

- Cancer Society

Tairāwhiti & Gisborne Support Team



Te Kāhui Matepukupuku
o Aotearoa

Cancer Society volunteers with connections to Tairāwhiti and Gisborne are available to provide support to those staying away from home at the Cancer Society's Lions Lodge.

How?

- We're available during the weekend - for outings, having a cuppa or going to the supermarket.
- We're available to have a friendly chat or phone call.
- We can touch base and see how you are going.

Contact volunteers:
Ellyn Proffit and Jolene Proffit
Ph: 027 282 7916



Cancer Society's
Lions Lodge

www.cancernz.org.nz | Phone: 0800 22 77 44 | www.facebook.com/CancerSocietyWaiBOP

Initiatives implemented and/or in progress, benefits and lessons learnt: from Ellyn Proffit's Clinical Nurse Specialist journey....2012

- Education
 - Be a change agent
 - Keep up – international best practises
- Grow together!!!
 - Stationed together
 - Get together
- Be guided by the 'Boss'

- You can't fix it all!
- Acknowledge the good work
 - Patient, service, regions, nationally!!
 - Good things take time!!!
- Over view of what's required
 - 'the bible' vs. 'just a guide'
- Find a mentor

Kia ora!!!