

A Cancer Journey

Peel Cluster



Donella Waters
Walk about



Health
Hunter New England
Local Health District



Tamworth Rural Referral Hospital

Dean St, North Tamworth NSW 2340 Phone: 02 6767 7700

WARNING: This booklet may contain images of, or have references to, deceased people. There may also be words or descriptions that could be culturally sensitive. This could upset some Aboriginal and Torres Strait Islander people; however HNELHD and Cancer Network wishes no disrespect or distress to Aboriginal and Torres Strait Islander people, families and community.

All images are displayed with consent.



Old entrance Tamworth Hospital



Main Entrance Tamworth Hospital

Gulbiyaay Ngindaayuu

Greeting Kamilaroi language - Welcome Everyone

Hunter New England Health District would like to acknowledge the original custodians of this land and pay our respects to the Elders both past, present and future for they hold the memories, the traditions, the culture and hopes of Aboriginal Australia.



Kamilaroi nhulay meaning this is Kamilaroi Country



Maaru nguwalay yanaylaya meaning go well here



Foreword

Tony Martin - Director of Aboriginal Health



This Cancer Journey Booklet has been produced to improve the effectiveness of Aboriginal peoples journey through the system for those that are

affected by cancer related illnesses who are located across the Hunter communities. Firstly I would like to acknowledge and thank our brothers and sisters and their families that have shared with us your individual insights from an Aboriginal perspective. Opening up these types of conversations with others assists in reinforcing the importance of health education and screening from an Aboriginal perspective. The Hunter New England (HNE) Cancer Network is committed to improving access to cancer prevention, screening and treatment

services for Aboriginal people, in an effort to “Close the Gap” in health and well-being between Aboriginal and non-Aboriginal people. The benefits of the collaboration will be relationship building and trust which will have a flow on effect improving cultural respect, awareness and sensitivity.

We want to empower Aboriginal people to collaborate with mainstream partners in the provision of advice, planning, service issues and identification of resources where appropriate in meeting the needs of the Aboriginal population relating to cancer illness.

We want to support Aboriginal people diagnosed with cancer as they progress through their cancer journey, linking them with cancer services in the acute sector and services available in the community more generally. Ongoing work will continue that

will enable us to:

- Reduce risks
- Identify culturally appropriate strategies that work in consultation with Aboriginal people and communities
- Improve cancer literacy through education and yarning
- Improve our data quality to effectively monitor progress and improve cancer care delivery for our people

I hope you find this resource useful and encourage you to share the contents with family and friends.

HNELHD Cancer Network encourages you to provide feedback about your cancer journey and how we can improve your experience through email HNECancerNetwork@hnehealth.nsw.gov.au

Foreword

Dr Tony Proietto - Director of Cancer Services and Cancer Network



This Cancer Journey Booklet has been produced to help Aboriginal people affected by cancer, their families, friends and communities throughout the Hunter New England region.

Cancer prevention, screening and treatment is the core responsibility of the Hunter New England (HNE) Cancer Network. It is well known that there is a significant discrepancy in cancer outcomes between Aboriginal and non-Aboriginal people.

The Cancer Network is committed to improving access to cancer prevention, screening and treatment services for Aboriginal people as part of the “Close the Gap” strategy. We need to work together to build a relationship based on trust, cultural awareness and sensitivity. It is essential that Aboriginal communities and health services collaborate to ensure mainstream services are able to meet the needs of the Aboriginal population who are affected by cancer.

We want to support Aboriginal people diagnosed with cancer through their journey, linking them with cancer services in the treatment centres and services available in the community more generally.

Ultimately we want to have a cancer service that works in consultation with Aboriginal people to develop culturally appropriate strategies that will improve cancer care for Aboriginal people and communities. In engaging with the cancer service you may be asked for some information about yourself. Any information you give will be used to improve the service to Aboriginal people and help provide a more positive experience.

I hope this booklet will help patients and families dealing with cancer and help to Close the Gap.

Your Cancer Journey

Kamilaroi Woman & Breast Cancer Survivor, Eunice Kennedy's Story



2002 I discovered a lump in my breast while in the shower I immediately broke down and cried thinking of my 4 young children and hubby. Not telling anyone I seen my GP who said it was most likely from having children but would send me for an ultrasound to ease my mind. It was as Dr said and eventually went away. I was so relieved. My family never knew.

10.09.2010 in the afternoon I developed a rash which worsened while travelling home from work and more overnight. I visited Emergency at Tamworth Hospital next morning and was told because I had some food allergies it was most likely something I

had eaten. While travelling back and forth for work I heard on the radio 1 in 10 people get cancer. I think of 2 groups of work colleagues I meet with and my family and yeah I am same 1 of 10. The weekend before my birthday I did a self-check and found a lump, this time I did not breakdown. I ring my GP first thing Monday morning to make an appointment he is not available for a week, they ask is it urgent, I explain and get an appointment with the other GP. Following an examination he doesn't think it's anything but will send me for a mammogram and ultrasound to put me at ease. It will be sometime for an appointment

in Tamworth, I get one much sooner in Armidale.

27.09.2010 I have the mammogram, they appear to be double checking, I have the ultrasound, they leave me alone to review the reports, I'm feeling a positive vibe, a doctor appears and informs me he is concerned and would like to perform a biopsy right now otherwise my GP will just send me back in 2 weeks for one. This confirms it for me. With the tears welling I have the biopsy. I am asked to make an appointment with my GP in 10 days' time to receive the results. I already have a regular one scheduled. I need to let the tears flow before returning to work.

07.10.2010 The GP with kindness says I'm sure you already know the diagnosis having had the biopsy, my tears agree. I was his 4th cancer patient. We discussed what happened now and I was referred to a surgeon.

09.10.2010 The house is full and buzzing with our 4 children, their partners and 3 grandchildren and now my husband rounds up the adults for us to share my pain. I begin to say I need to tell them when my youngest daughter starts to cry, which starts my tears, continuing to let them know my diagnosis, I have a lump that will be removed, My husband behind me tells them mum is strong she can fight it, do whatever treatment is required to make her better. I receive hugs and support.

My youngest son being the only family member not currently employed becomes my Carer driving me to and from Chemo and other appointments, he is on his learners, is good for increasing his hours, though sometimes I was concerned when it was during peak times and Country Music, he coped well particularly when he had to pull over quickly for me to be sick, I was so proud of him.

20.12.2010 Attended appointment with Oncologist to discuss results and confirm commencement of Chemo tomorrow. My eldest daughter calls from Sydney to send her thoughts and lets me know I will be a nanny again, this helps with my nerves and add to list of reasons to fight.

14.07.2011 Last day of Radiotherapy, my son asks if I would like to drive, to celebrate, I let him drive. He is still on his learners; I got a little less anxious with our little drives around Coffs when I was up to it. However it all came flooding back when I recalled that Bellingen was getting near as it is always overflowing with people. Being an 18 year old, caring for me, he did so well, I couldn't let my doubt spoil our trip home, we'll just take on Bellingen together, here it comes, and there is not one soul in sight.

I return to my family and work life. I am Aboriginal, I am woman and I am a Cancer Survivor. It is important to self-check and to visit a GP if you have any concerns. Earlier detection the better.



Your Cancer Journey

Kamilaroi Elder - Aunty Annie May Taylor's Story

You know your body and if you spot any little lumps or unusual pains get to the Doctor quickly. If you don't feel like your Doctor is listening to you get a second option. Family is very important you will need them to support you.

1990 October I was going to the Doctors for 12 months with blood in my urine he kept saying infection and giving me antibiotics. I ended up telling him it's more and I want tests. I was diagnosed with bladder cancer. I was sent to Prince Henry Hospital in Sydney had surgery had my bladder removed 8 weeks in hospital, they got it all I didn't need chemotherapy which was good I came home went back to work in one week.

2013 I was going to the Doctors complaining of pain unable to use my bowels eventually got diagnosis with bowel cancer. I was sent to Newcastle had my bowel removed they got the biggest part now I am back in Tamworth at North West Cancer Centre having Chemotherapy. They are so culturally respectful I feel welcome and safe there.

2014 Doctor at North West Cancer Centre diagnosed Liver cancer he is very happy with my progress, sending me to Sydney for surgery.

A Support circle is very important your family my daughter Kylie takes me every where I need to go. If not my grandson

Ryan, and Brandon helps me fix things around the home when I'm not feeling well all my grandkids they always ask if I'm OK. Family is very important.

Great support from many people Social Worker Lee helps me with money concerns, Kerry the Cancer Co-ordinator she helps me with any thing and will come in with me to the Doctor to support me. The chemotherapy nurses Cancer Council Shaen Frazer, Walhallow Co-operation, Walhallow Mob, local Aboriginal mobs, KADs, North Cott, Medicare Local, Blue Angel Foundation, Guurrama women's group, Tamworth ALO George.

Lost my sister just before Christmas to Breast

LOOK'N AFTER OUR MOB

'Now and into the Future' 

cancer never told anyone never got help.

My best friend and her son to Cancer they had to travel to Sydney leave their mob and community. We are lucky that North West Cancer Centre is here locally for our Mobs.

You have to face it, get to the women's check ups there are lots of programs in our communities.

You have to keep going for your family. Live your life get up and go don't sit around and feel sorry for your self it's the worst medicine going.

I attend many committee meetings, I am always here and give advice to any one who needs help if they worried about their health.

North West Cancer Centre very caring understanding they welcome Aboriginal people into their centre we are treated like everyone else.



Auntie Annie May Taylor's Family



Auntie Annie May Taylor's Grandchildren



Maarumaldandaay nalalay this is a place of healing

Your Cancer Journey

Wiradjuri Elder - Aunty Gloria Leigh's Story



If you feel different at all go to your Doctor torment them until you're satisfied, I did this and got it early.

Before I had Cancer I was very active 30 years working with Priest leadership training, weddings, funerals christenings. I had been involved in numerous roles over the years including Chairperson NSW Aboriginal and Torres Strait Islander Catholic Council NSWAIACC, Elected as representative NATSICC National Aboriginal and Torres Strait Islander Catholic Council NATSICC. Spent a lot of time in 30 years. I continue to be very active in the community, encouraged Elders and started the Elder's group in Tamworth. I started to get tired and weak kept going to the

AMS. I knew something was wrong. Didn't have energy to do my church duties I kept going back to the Doctor at the AMS.

I changed my Doctor and he sent me to a Haematologist, I had a bone marrow biopsy. My son came with me to the appointment but I made him stay in the car. I don't have Cancer stop the worry. The haematologist told me I had Cancer told me to make another appointment it seemed like 5 hours until I got back to the car and to my son.

I called a Family meeting we sat around at the back I told them I had Cancer and what I could expect, I didn't know how long I would be here and told family to just go along in your lives to love each other, and care for each other. When I go look after Graham

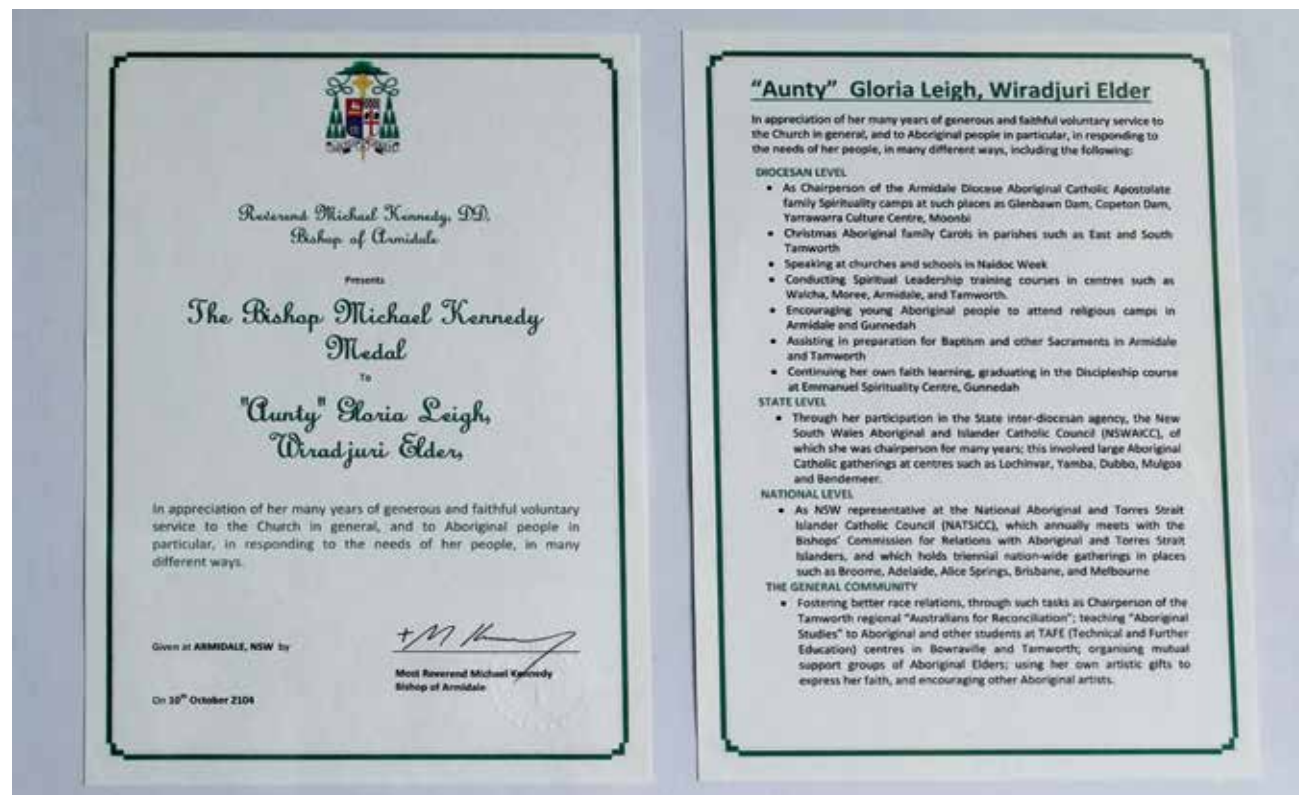
and Ralph as they don't have women to care for them. All the family don't know how I did this, but I did this for them. I love my family.

I was treated with Chemotherapy which knocked me around, it was terrible, Doctor had to stop treatment. If I get sick again I will try injections and tablets instead of Chemotherapy.

Gloria's message

Don't give up keep going on with your life if you can. Keep active I do knitting and attend Elder groups.

I am the first Aboriginal person to receive the Pope's Blessing.



Your Cancer Journey

Kamilaroi Man - Matthew Taylor's Story



My name is Matthew Taylor. I was diagnosed with cancer during my HSC year in early January 2013. I woke up in immense pain and went to my mother who took me directly to the hospital. Within in few hours I'd had an ultrasound, CAT scan & blood tests which confirmed I had stage 2 cancer.

The next few months were full on. I had urgent surgery to remove the cancer one week after diagnosis. I then proceeded to have a PET scan at The Calvary Hospital in Newcastle. The staff there were great. Being

17 I met the wonderful staff of the Youth Cancer Service who were there to help myself, my mum & sister. We had regular check-ups to see how we were coping and they put us in contact with Redkite who gave us assistance when needed.

All The staff at the North West Cancer Centre (NWCC) were all very friendly & supportive. I would come in the nurses would be very happy & cheerful. They would make you feel at ease as best they could. Most days I would just sleep while having my chemotherapy as tiredness was my biggest side effect.

As a young person with cancer I became a member of CanTeen Australia who are great support throughout my cancer journey. I got to meet other young people affected by cancer, others who really understood how I



was feeling. I am currently on the Leadership committee of CanTeen for the Hunter and Northern Division.

I am 12 months post treatment. I still have regular blood tests & scans to check the cancer hasn't returned. I have now completed my HSC & am currently studying a Bachelor of Science at the University of New South Wales. If I had not told my mother & kept this to myself my outcome could have been very different.

Matthew's message

Early detection don't be shamed to talk to someone. Cancer doesn't discriminate and it doesn't get only the old people. I'm young and I had Cancer.

Kamilaroi Nation

Tamworth Rural Referral Hospital is located on the traditional lands of the **Kamilaroi Nation**. You are welcome to bring your family or friends with you on your journey.

Yarning is very important when you find out you have Cancer – to listen – not only to your health care team but also your family.

For all of your cancer treatment you will be given dates and times for your appointments. You will be given access to people who can support you along the way including an Aboriginal Hospital Liaison

Aboriginal Hospital Liason Officer

Phone: 0437 727 076 or 02 6767 7066

Officer and a Social Worker. Don't be afraid to ask to see one of these people and ask any questions that you have.

You will be given an appointment card with the dates and times for your treatment and next clinic visit.



George Ferguson AHLO



Warramalay meaning standing strong/supporting each other

How to find NWCC - North West Cancer Centre

Tamworth Hospital Dean St Tamworth

Car Parking

When you arrive at the boom gate push the button let them know, that you're here to see the Doctor or have treatment. The reception staff will open the gate; there is a 30 space car park available for NWCC patients.

Map



Parking



Maarumaldandaay nalalay meaning this is a healing place

Oncology

Medical Oncology/Haematology Services

Phone: 02 6767 7760 Fax: 02 6766 9173

Clinics are conducted Monday to Friday

- Notify the reception staff of your arrival
- Very important to identify as Aboriginal or Torres Strait Islander
- You will see a Dr who specialises in Cancer
- There will be a specialist Cancer Nurse or Coordinator who will help you
- You can ask for the Aboriginal Hospital Liaison Officer who will support you and your family. **Phone 0437 727 076**



NWCC staff



Oncology Waiting Room



Amaroo meaning a beautiful place

Day Infusion Unit

Chemotherapy/Treatments. Phone: 02 6767 7760 Fax: 02 6766 9173

- Notify reception staff of your arrival
- Chemotherapy treatments are given by a specialist Cancer Nurse



Auntie Gloria Leigh having treatment



Auntie Annie May having Chemotherapy

Radiation Oncologists

Yarn to your Radiation Oncologists.

You will see a specialist Doctor for your Radiation treatment, this is a Radiation Oncologist.

Bring along your family for support and if you need an Aboriginal Health Worker phone: 0437 727 076

The Doctor will yarn to you about tests and treatments and advise you of the best way to treat your cancer.

You may need combination treatments of Chemotherapy and Radiation. **This may not be available in Tamworth and you may need to go to Newcastle or Sydney. If this is the case you will be provided with information about travel and accommodation.**

Chemotherapy is a medicine given to treat cancer. It is usually given with a needle into a vein, but some types of chemo can be given as tablets.

Ask questions and write the answers down, don't be afraid a family member can do this

- How long does the treatment last?
- How many times do I have to come back?
- Report back to the front desk just in case you need to see someone else



Ceiling in the Radiation Treatment Room

Radiation Planning & Education

Phone: 02 6767 8720 Fax: 02 6761 2780

Radiation planning and education will be provided by your Radiation Therapist.

Yarn to your Radiation Therapist (RT), they will give you advice on looking after your self during treatment and show you a video about the treatment process.

Notify reception staff of your arrival

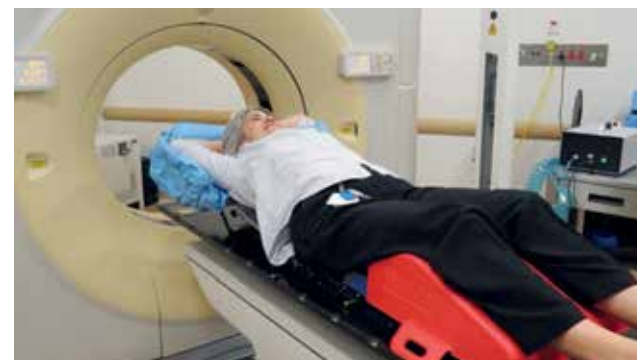
- Very important to identify as Aboriginal or Torres Strait Islander
- The whole visit can take up to 1-2 hours and is painless
- You will have a CT scan
- RT might give you a small dot tattoo on the part of the body that

needs treatment

- RT will give you your next appointment time and phone number should you have any questions
- Nurse will see you after this session before you leave

Next step is planning the process, which you don't need to attend

- All information, scans etc. gathered RT's will create your own specific treatment plan
- Treatment can not start until your plan is finalised by your Radiation Oncologist Doctor



Radiation Team

Radiation Treatment

Phone: 02 6767 8720 Fax: 02 6761 2780

The machine that delivers radiotherapy treatment is called a Linear Accelerator. The one in Tamworth is nick-named “TROY” after Troy Cassar-Daley. It makes powerful x-rays to treat cancer. It is not radioactive.

- Notify the reception staff of your arrival
- Most patients have treatment daily Monday to Friday
- To ensure every treatment is accurate, TROY needs regular maintenance, this means you might not have appointments on some days. The team will give you a list of your appointments depending on your Cancer treatments may take between 1 day to 9 weeks, your Doctor will tell you how many.
- You may need treatment 2 times a day, in the morning and the afternoon on some days
- The time on the treatment bed is only a few minutes
- TROY will make a buzzing noise, you won't feel a thing
- The treatment does not make you radioactive so its ok to be around other people, including kids
- You may need to change into a gown
- Very important that you stay very still, remember to talk to RT's and nursing staff
- The RT's will be outside but can talk to you through a video
- **REMEMBER** always see the receptionist when leaving just in case you need to see someone else.



Travel & Accommodation

Isolated Patients Travel and Accommodation Assistance Scheme - IPTAAS

If you need to travel more than 100kms in any week for treatment, you may be able to claim travel costs.

About the service Inala House is a 10 room accommodation facility located on the grounds of the Tamworth Rural Referral Hospital. Providing a home away from home for patients, who require treatment at the North West Cancer Centre, or in the Hospital, and their accompanying family member or carer.

If you need assistance contact:

Aboriginal Hospital Liaison Officer - 0437 727 076
or the NWCC Social Worker - 02 6767 7760 or 0428 249 149

Patient & Carer Accommodation:

02 6767 8880 or 0428 557676



Inala House Courtyard



Inala Cultural Garden



Inala is a Kamilaroi word meaning peaceful place in English

Outreach clinics

Chemotherapy treatments

Gomerio Country - Moree Health

Oncology Chemotherapy Treatment Unit

Oncology Nurse 02 6757 0261 - Monday to Friday

Chemotherapy Room 02 6757 0273 - Tuesday and Thursday

Aboriginal Hospital Liaison Officer 02 6757 0268 - Monday to Friday

- Notify reception staff of your arrival
- Very important to identify as Aboriginal or Torres Strait Islander
- Chemotherapy/treatments are given by a specialist Oncology Nurse



Moree District Health Service

Outreach clinics

Chemotherapy treatments

Wonnarua Country - Muswellbrook Health Service

Brentwood Street Muswellbrook NSW 2333 Phone: 02 6542 2000

Oncology Day Treatment Unit

Phone: 02 6542 2746

Fax: 02 6542 2765

- Notify reception staff of your arrival
- Very important to identify as Aboriginal or Torres Strait Islander
- Chemotherapy/treatments are given by a specialist Oncology Nurse



Muswellbrook Health Service

Outreach clinics

Chemotherapy treatments

Anaiwan Country - Armidale Oncology/Infusion Day Unit

Medical Oncology is provided as a consultative service by medical oncologists from Sydney. The chemotherapy is provided by Armidale Hospital staff.

Radiation Oncology consultations are provided as an outreach service from the NWCC in Tamworth. Radiotherapy is not available in Armidale but is provided at the NWCC in Tamworth, Port Macquarie, Coffs Harbour, Newcastle and Sydney.

Medical Oncology, Radiation Oncology, Chemotherapy/Day Infusion appointments

Phone: 02 6776 9761 or 02 6776 9944 **Social Worker:** 02 6776 9694

Aboriginal Hospital Liaison Officer: 0434 604 475

- Cancer Care Coordinator
- McGrath Breast Nurse
- Specialist Oncology Nurses



Your Support Circle

Your Treatment Team Health Professional

General Practitioner (GP) Name:	Phone:	Your local doctor who provides ongoing care. They will be able to help other doctors understand your cancer journey.
Social Worker Name:	Phone:	Provides support, Counselling, Referral, Financial support (Centre link), Travel assistance and accommodation
Aboriginal Hospital Liaison Officer Name:	Phone:	Is Aboriginal. Can offer support to you and your family. Talk with other members of your treatment team.

Your Support Circle

Some other Health professionals you may meet:

- Physiotherapist
- Occupational therapist
- Pharmacist
- Dietitian
- Radiologist
- Pathologists
- Administration (Front Line Clerical)



Your Treatment Team Health Professional

Cancer Coordinator Name:	Phone:	A specialist Nurse, knowledge of cancer, supports you and your family through your cancer journey
Surgeon Name:	Phone:	Doctor who performs operations.
Radiation Oncologist Name:	Phone:	Specialist in Radiotherapy treatments.
Medical Oncologist Name:	Phone:	Specialists in Chemotherapy and treatments.

Your Support Circle

If you are at home and require emergency treatment ring 000 and ask for an Ambulance



Speak Up



Asking questions is a good way to learn about your Cancer - **Have a Yarn**
You may not always understand what is going on or what is said.
You can get help from your - **Support Circle**

Here is some example of questions that might help you:

- You can ask any doctor, nurse or worker to write down what you have been told. So that you can read it later or don't forget
- Can I have a copy of my pathology (Blood results, test results) and can you explain it to me?
- Can you explain my treatment?
- What type of cancer it is?
- Who can I speak to about my feelings?
- Can I get help with travel and accommodation?
- Who is my Social Worker?
- Who is the Aboriginal worker and can I meet them?

Write your own questions here:

My Follow Up

After Cancer Care - Get Checked Up

When you have finished your treatment, it is **important to have regular check-ups** with your local doctor or your oncologist.

- Your doctors will tell you how often they would like to see you.
- You can also ask for information on what type of treatment you had and your results.
- If you or your family have any questions, you can ask your local doctor or oncologist.



Clinic Numbers

Aboriginal Medical Service, Tamworth 02 6760 2500

Pius X Aboriginal Medical Service, Moree 02 6752 8432

Armajun Aboriginal Medical Service, Inverell 02 6721 9716

Walhallow Aboriginal Medical Service, Walhallow 02 6746 2001

Helpful Information

There are other support services outside of the hospital that can also assist:

The Cancer Council Help line

Free Legal Service.....13 11 20

Free Wills.....13 11 20

The Leukaemia Foundation

Helpline.....1800 620 420

Monday to Friday 9am - 5pm

North West Cancer Centre for Leukaemia patients

02 6768 3321 or 0481 007 446

The Foundation has free car with a volunteer who can pick you up

Hunter Prostate Cancer Alliance

Helpline.....1300 881 826

.....02 4968 9455

Medicare Local

Helpline.....1800 652 800

.....02 49 252 259

Salvation Army

Salvo Care Line.....1300 363 622

Department of Human Services

Centre Link and Medicare for
Aboriginal or Torres Strait Islander people

Helpline.....1800 136 380

Carers.....132 717

Financial Information.....132 300

Look Good Feel Better

Womens business

Phone.....(02) 9837 3434

Fax.....(02) 9837 3435

Email.....nsw_act@lgfb.org.au

Monday - Thursday



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Be aware the spelling for names of Aboriginal groups may differ. Unless otherwise referenced, the spelling of Aboriginal language names in this booklet are taken from the NSW Lands Council Map. This map is just one representation of other map sources that are available for describing Aboriginal Australia. The map indicates only the general location of larger groupings of people which may include smaller groups such as clans, dialects or individual languages in a group. The boundaries are not intended to be exact and the spelling of each language Nation is variable.



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Steering Committee Cancer Project

- Dr Anthony Proietto
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- Tony Martin
- Karen Dahdah
- Jill Lack
- Michelle Wilkes
- Brendon Cutmore
- Rose Wadwell

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Acknowledgement of Art Work

Donella Waters: Walk about

Depiction of Toomelah people and their journey of where they are from, where they have been, where the old people have gone and the going back of people who have left.

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