

A Cancer Journey

Lower Mid North Coast



Terry Johnstone
Past and Present Aboriginal People



Health
Hunter New England
Local Health District



Manning Rural Referral Hospital

26 York Street, Taree, NSW 2430. Phone: 02 6592 9111

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.



Guudji Yiigu Guriguba

Greeting Biripi language - Hello Aboriginal peoples

Hunter New England Local 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.



Gagil Marrung
meaning
become well



Michelle Wilkes Aboriginal Health Education Officer



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.

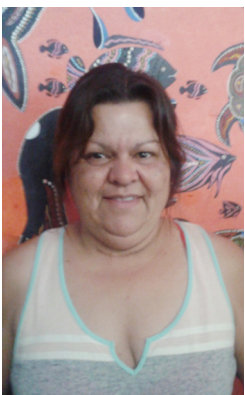
We want to support Aboriginal people diagnosed with cancer through their journey, linking them with cancer services in the treatment centres and services available in the community more generally.

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

Karyn Fletcher's Story



Found out by accident Doctor was checking my heart, machine found a small cold spot then I was sent off for Nuclear Medicine Scan and biopsy in Taree, I got this feeling it was Cancer.

Doctor at the AMS told me it's Cancer I didn't feel anything, I wasn't shocked and I didn't cry. Hardest thing was telling my family, I told my eldest daughter who came with me to the AMS. I thought "We can do this I got this" I broke down at night alone oh my god I have Cancer where

did it come from, didn't want to worry my family, my mind going around and around couldn't sleep. My mind couldn't take in any information. I was angry.

Karyn's message

You gotta stay strong inner strength, listen to your body if your body tells you something is wrong listen, get it CHECKED. Keep up your appointments, ask questions and write them down. I did it for my Family. Family first.



Your Cancer Journey

Anthony Avery Senior's Story

My big son Anno Avery, he is my first born son who I love and miss very much he was only 26 years old taken from us by cancer.

Anno did not drink or smoke and always was fit and he gets cancer. He left behind his one and only daughter Britney.

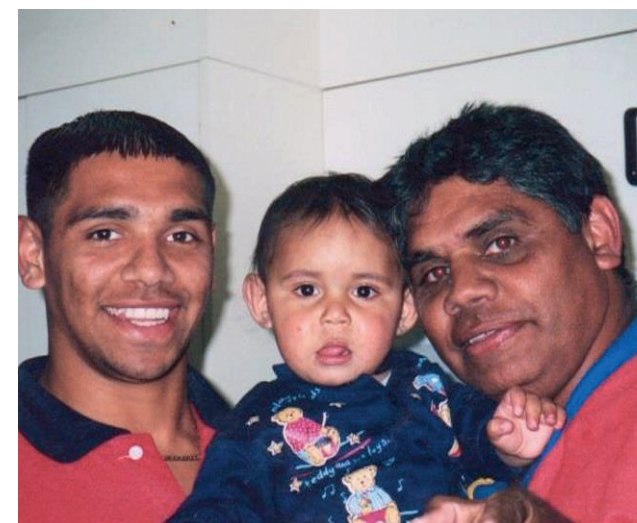
To all the younger and older fella's out there they say there is seven signs of cancer so if you have or notice anything wrong with your body GO GET IT CHECKED cause we all know our bodies and if you're not satisfied with your doctor get a second or third opinion in which I did not do cause the early the detection the better chance

of survival where we did not even know it was cancer that Anno had till it was too late cause they said it was irritable bowel syndrome, so please if you notice any changes in your body that's not right GO GET IT CHECKED. Please cause I don't want any family to go through what we going through still today.

I miss my big son, and love him in all the world.

Listen to your Patient

Anthony 'Anno' Avery Jr
18/05/1982 - 02/09/2008



Biripi Nation

Manning Rural Referral Hospital is part of Hunter New England Local Health District located on the traditional lands of the **Biripi Nation**. You are welcome to bring your family or friends with you on your journey.

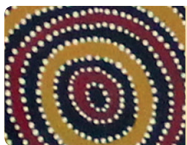
Yarning is very important when you find out you have Cancer – to listen – not only to your health care team but also your family.

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

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.

Aboriginal Hospital Liaison Officer Phone: 02 6592 9823 or 0417 412 011



Garuwa Guba meaning saltwater people

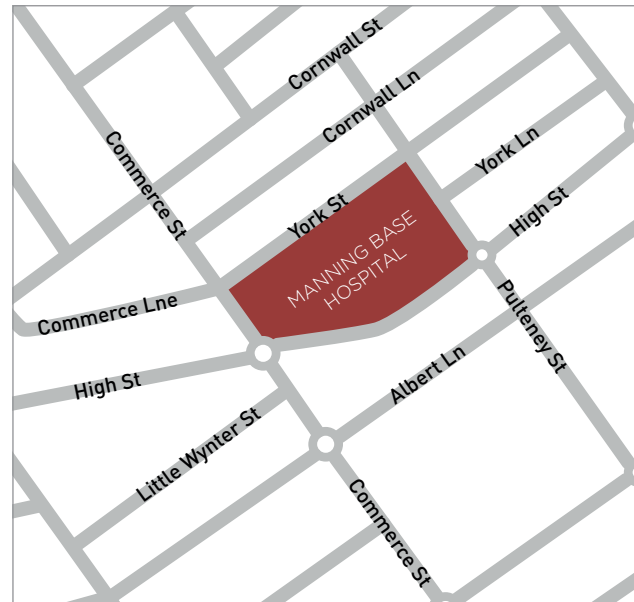


Colleen Devitt AHLO

How to find Oncology - Manning Hospital Taree

26 York Street, Taree, NSW 2430 Australia. Oncology Phone: 02 6592 9306

Walk through main door and Oncology is located on Level 1 of the Clinical Services Block, just through the main door to your left.

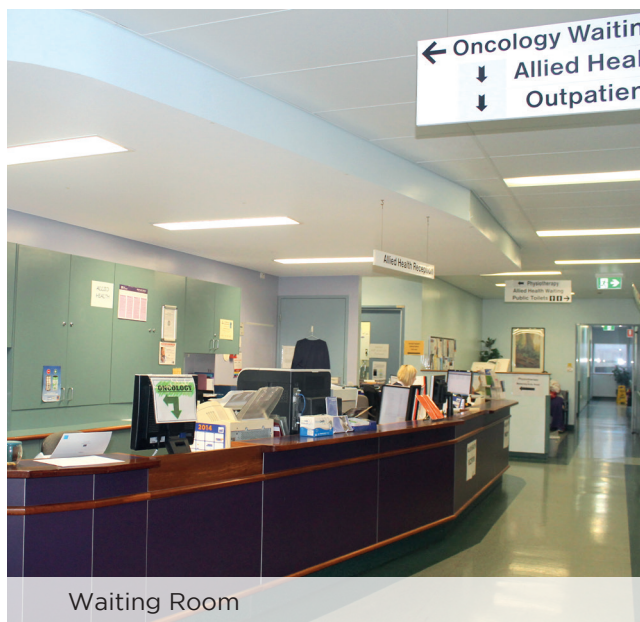


Oncology

Phone: 02 6592 9306 Fax: 02 6592 9120

Medical Clinics are open Monday to Friday

- Notify the reception staff of your arrival
- Very important to identify as Aboriginal or Torres Strait Islander
- You will see a Doctor 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 02 6592 9823**



Waiting Room



Oncology Reception

Oncology Unit

Chemotherapy/Treatments

Phone: 02 6592 9306 Fax: 02 6552 7458

- Notify reception when you arrive
- Chemotherapy is a medicine given to treat cancer



NCCI - Port Macquarie

Wrights Road Port Macquarie NSW 2444

Phone: 02 6580 1807

If you need Radiation Treatment you will be required to go to North Coast Cancer Institute NCCI – Port Macquarie.

Port Macquarie has an Aboriginal Hospital Liaison Officer who can assist you if you need help.

Phone: 0407 438 684



Radiation Oncologists

Yarn to your Radiation Oncologist.

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

Bring along your family for support, and if you need an Aboriginal Liaison Officer phone: 0407 438 684

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 it's called **combined therapy**.

This may not be available in Port Macquarie and you may have to travel 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 by infusion or needle or can be tablet form.

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

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



Warraliyn Dhanbarn Biripi meaning standing strong



Radiation Planning & Education

Yarn to your Radiation Therapist (RT), they will give you advice on looking after your self during treatment

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.

- Notify reception staff of your arrival
- Very important to identify as Aboriginal or Torres Strait Islander
- Can take up to 1-2 hours and is painless
- You will have a CT scan
- The Radiation Therapist will give you a small dot tattoo

- Radiation Therapist 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



CT Scan Machine

Radiation Treatment

The machine that delivers radiotherapy treatment is called a Linear Accelerator. 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, the Linear Accelerator 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
- The Linear Accelerator will make a buzzing noise, you won't feel a thing
- The treatment does not make you radioactive so it's 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 Radiation Therapists and nursing staff
- The Radiation Therapists 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

My Skin Care:

Daily showers with warm water not hot, use gentle soap e.g. Sunlight or baby soap. Use sorbolene cream morning and night



Travel & Accommodation

Isolated Patients Travel and Accommodation Assistance Scheme - IPTAAS

If you need to travel more than 100kms in any week for treatment, if you need assistance contact the **Social Worker or Aboriginal Hospital Liaison Officer**
Ph: 0407 438 684

You can get financial assistance with your travel and accommodation costs through IPTAAS scheme.

Rotary Lodge located in the grounds of Port Macquarie Hospital
Self-contained Unit – Communal lounge and kitchen

Phone: 02 6581 1076

Office Hours 8.30am – 3pm Mon-Fri

Weekends 9am to 12pm (noon)





Manning Lookout - Image courtesy of Judith Conning



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

Your Support Circle

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.

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

Biripi Aboriginal Medical Service	02 6552 2154
Town Clinic	02 6551 7444
Tobwabba Aboriginal Medical Service Forster	02 6555 6271
Forster Community Health	02 6539 6300
Taree Oncology Unit	02 6592 9306
Taree Community Health Centre	02 6592 9315



Helpful Information

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

The Cancer Council Help line

Free Legal Service13 11 20

Free Wills13 11 20

Medicare Local

Helpline1800 652 800

.....02 49 252 259

Salvation Army

Salvo Care Line1300 363 622

The Leukaemia Foundation

Helpline1800 620 420

Monday to Friday 9am - 5pm

Department of Human Services

Centre Link and Medicare for
Aboriginal or Torres Strait Islander people

Helpline1800 136 380

Carers132 717

Financial Information132 300

Look Good Feel Better

Womens business

Phone(02) 9837 3434

Fax(02) 9837 3435

Emailnsw_act@lgfb.org.au

Monday - Thursday

Hunter Prostate Cancer Alliance

Helpline1300 881 826

.....02 4968 9455



Acknowledgements

The Cancer Journey Booklet working party would like to acknowledge Aboriginal communities of the lower mid north coast for their time, contribution and support during the consultation process in 2014 – 2015, Dr Anthony Proietto, Jill Lack and Tony Martin for your initial concept for a culturally safe booklet for Aboriginal people diagnosed with cancer in HNE Health.

This initiative was partly funded by the Cancer Institute NSW, HNE Cancer Network and the Aboriginal Health Unit. The Cancer Journey Booklet Working Party is grateful for the help and assistance provided by the Manning Rural Referral Hospital Oncology staff.

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.





Acknowledgements continued

Would like to acknowledge the input from

- Artist Terry Johnstone – Past and Present Aboriginal People 2008
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- Mid North Coast Local Health District Cancer Journey booklet
- Manning Rural Referral Hospital Taree Oncology Team
- Dr Anthony Proietto – Director of Cancer Services HNELHD
- Michelle Wilkes – Aboriginal Health Unit HNELHD
- Tony Martin – Director of Aboriginal Health HNELHD
- Jill Lack – System Innovation Manager HNELHD Cancer Network
- Colleen Devitt – Aboriginal Hospital Liaison Officer
- Nursing Administration Manning Rural Referral Hospital
- Jeremy Saunders – Language Translator Biripi
- The Gathang language Group

Steering Committee Cancer Project

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

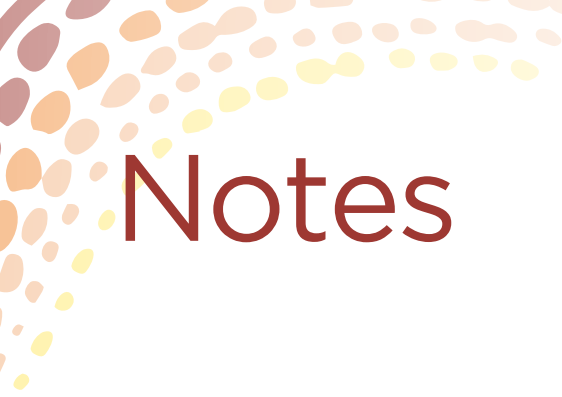


Notes



Handwriting practice lines consisting of 12 horizontal dashed lines.





Notes



[illegible]

The map illustrates the New South Wales Local Government Areas (LGA) network, categorized into 15 clusters. Each cluster is represented by a different shade of pink and contains a list of its constituent LGAs. The clusters and their members are:

- MEHI CLUSTER** (light pink): Boggabilla, Toomelah, Mungindi, Gomeroi, Moree, Warialda, Ashford, Inverell, Tingha, Bundarra, Guyra, Armidale, Uralla, Wee Waa, Pilliga, Narrabri, Gwabegar, Boggabri, Barraba, Manilla.
- TABLELANDS CLUSTER** (medium pink): Bundajalung, Tenterfield, Emmaville, Ngoorabul, Glen Innes, Anhuiwan, Anaiwan, Thungutthi, Walcha, Nundle, Murrurundi, Scone, Muswellbrook, Denman, Singleton, Clarence Town, Maitland, Kurri Kurri, Cessnock, Toronto, Belmont, Morisset, Bahtabah.
- ANAIWAN** (light pink): Bundarra, Guyra, Armidale, Uralla, Walcha, Nundle, Murrurundi, Scone, Muswellbrook, Denman, Singleton, Clarence Town, Maitland, Kurri Kurri, Cessnock, Toronto, Belmont, Morisset, Bahtabah.
- PEEL CLUSTER** (dark pink): Gunnedah, Tamworth, Gomilaroi, Werris Creek, Walhallow, Quirindi, Premier, Tambar Springs, Murrurundi, Scone, Muswellbrook, Denman, Singleton, Clarence Town, Maitland, Kurri Kurri, Cessnock, Toronto, Belmont, Morisset, Bahtabah.
- HUNTER VALLEY CLUSTER** (medium pink): Geawadal, Merriwa, Wonnarua, Denman, Singleton, Clarence Town, Maitland, Kurri Kurri, Cessnock, Toronto, Belmont, Morisset, Bahtabah.
- LOWER MID NORTH COAST CLUSTER** (light pink): Gloucester, Stroud, Bulahdelah, Hawks Nest, Nelson Bay, Werris Creek, Walhallow, Quirindi, Premier, Tambar Springs, Murrurundi, Scone, Muswellbrook, Denman, Singleton, Clarence Town, Maitland, Kurri Kurri, Cessnock, Toronto, Belmont, Morisset, Bahtabah.
- GREATER NEWCASTLE CLUSTER** (light pink): Biripi, Wingham, Taree, Harrington, Foster, Juncurry, Worimi, Bulahdelah, Hawks Nest, Nelson Bay, Werris Creek, Walhallow, Quirindi, Premier, Tambar Springs, Murrurundi, Scone, Muswellbrook, Denman, Singleton, Clarence Town, Maitland, Kurri Kurri, Cessnock, Toronto, Belmont, Morisset, Bahtabah.

The map also shows the state boundary and major cities like Sydney, Melbourne, and Brisbane.





Acknowledgement of Art Work

Artist Terry Johnstone 2008
Past and Present Aboriginal People

Main campsite showing early Aboriginal people moving out like arms and making life for themselves in different areas. This is showing the growth of Aboriginal people. The yellow red dots in the middle represent the sun and all the other colours represent the bush.

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