

Supportive Care

"Into the Dreaming"



ARTIST Carissa Paglino

Hunter New England Local Health District is alert to the cultural sensitivities of featuring images or names of people who have recently died. We offer our sincere apology for any offence to relatives and friends where this may occur in the "Into the Dreaming resources"

ACKNOWLEDGEMENT

HUNTER NEW ENGLAND LOCAL HEALTH DISTRICT, CALVARY MATER NEWCASTLE, AND MYNETCARE WOULD LIKE TO ACKNOWLEDGE THE ORIGINAL CUSTODIANS OF THIS LAND AND PAY OUR RESPECTS TO ELDERS PAST, PRESENT AND FUTURE FOR THEY HOLD THE MEMORIES, THE TRADITIONS, THE CULTURE AND HOPES OF ABORIGINAL AUSTRALIA.

**HUNTER NEW ENGLAND
LOCAL HEALTH DISTRICT**



HEAD OFFICE – NEWCASTLE
Lookout Road, New Lambton NSW 2305

REGIONAL OFFICE – TAMWORTH
7 Bligh Street, Tamworth NSW 2348

Our organisation's vision and goals are aligned to those of NSW Health.

At the same time, our strategic direction supports the principle of Excellence.

Every patient. Every time

**CALVARY MATER
NEWCASTLE**



Edith Street & Platt Street,
Waratah NSW 2298

Calvary Mater's mission is to provide quality, compassionate health care to the most vulnerable, including those reaching the end of their life.

MYNETCARE – A HUNTER ALLIANCE INITIATIVE



MyNetCare has been designed to improve communication between patients with serious advanced illness, their families and carers, and the clinicians and services providing them with care.

PALLIATIVE CARE, SORRY BUSINESS, SAD NEWS

The artwork aims to help create a welcoming, safe, comfortable environment for Aboriginal or Torres Strait Islander sick people and their families.

Each person's life is a rich tapestry with experiences, relationships and circumstances woven together to shape an individual. This artwork portrays that tapestry.

ARTWORK & STORY BY

CARISSA PAGLINO

My Aboriginal background: my grandfather was Walter Roy Smith, brother to Uncle Bill & Bob Smith who started Awabakal services.

I was born & raised in Newcastle & currently reside at Merewether. My aunty is Saretta Fielding nee Smith.

I have worked in local Aboriginal services from 2004 to 2015 including Miromaa Aboriginal Language Centre & Yarnteen Aboriginal and Torres Strait Islander Corporation.

The spirit or essence of all living things; people, animals and plants, that connects them to the past, present and future.

Life is a continuum, life-death-life cycle; everything is connected.

Layers of earth; time, age, ancestors, past, present & future



Mind (mental), **Body** (physical) & **Soul** (spiritual): holistic health care of a person.

Dying in 'place of choice' or 'on-country' is essential to the Aboriginal life cycle.

People; family, community, health care workers, friends, supporters.

Ancestors spirits returning back to earth, on-country, at the end of the life-death-life cycle; the time of sorry business.

Life journeys; peoples lives crossing paths.

ARTIST:

AUDREY TRINDALL

Kamilaroi/Gomeri (Goondiwindi)

Aunty Audrey was born at Goondiwindi and grew up on the mission at Toomelah until her family moved to Narrabri when she was a little girl. Aunty Audrey worked in Aboriginal health for 35 years until her retirement. She was very passionate about working in her community especially with mums, bubs and Elders.

Aunty Audrey loves to be with her family and focus on taking care of her health. Since her retirement Aunty Audrey has been very busy being involved in many projects in her local community including the Gomeri Gaaynggal Centre.

Aunty Audrey's father was an artist and he inspired her to sketch and draw as a young child. Aunty Audrey enjoys spending time at the Gomeri Gaaynggal Centre where she loves to paint, weave, make yarnng dolls .



AUDREY'S STORY

The figures in the image of my artwork represents the family, Aboriginal health staff, palliative care nursing staff and doctors.

The river flowing through the community

The footprints walking together across the land

The leaves and shrubbery represent bush tucker

The circles are the meeting and resting places

The animals and birds are a symbol of our connection to the sky and land

The sun is creator of life

The hands representing comforting and sharing the final moments with a loved one who has passed

Traditional practices vary between Aboriginal nations, HNELHD have 16 nations within our boundaries, each with their own traditions and cultural beliefs. This rich diversity means that Health's view of 'One size fits all' may not work in all situations and you can't treat everyone the same. Every person and their family should be asked what their cultural needs are.

Having recently experienced Sorry Business within the family my artwork depicts my vision of Palliative care and my own story.

It is a natural progression from birth to death; the families are there through this journey to support, nurture and provide guidance and comfort. It is the fundamental core value and strength as Aboriginal people. Spirituality is defined as the core of Aboriginal being and identity.

At a time of loss, we give comfort through sharing our grief, connecting, listening and sharing stories.

This links to the land, and belonging to the land.

Aboriginal Health Workers working in partnership with palliative nursing staff provide holistic care and continuum of care.

The resource has been developed in consultation with key communities within HNELHD district. We wish to thank the following communities who participated in a series of 'Cancer yarn ups' that were held throughout 2017/18 and contributed to the development of this resource:

- Biripi Community – Taree and Forster Community and Elders
- Gomeri/Kamilaroi – Moree Community and Elders
- Gomeri/Kamilaroi – Tamworth Community and Elders
- Gaba Binaal Elders Group – Church Street Tamworth
- Aniawan – Armidale Community and Elders
- Awabakal – Newcastle Community and Elders
- Wanaruah – Muswellbrook Community and Elders
- Armajun - Inverell Community and Elders
- Worimi Community - Gloucester Community Elders



FORWARD

TONY MARTIN

Director Aboriginal Health Unit

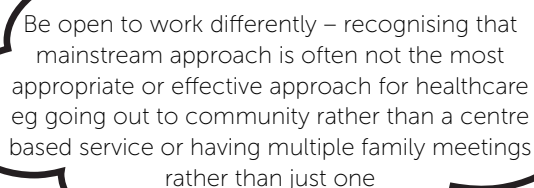
We are proud to release the Hunter New England Local Health District, Calvary Mater Newcastle and MyNetCare booklet - Supportive Care "Into the Dreaming". A Guide for Aboriginal and Torres Strait Islander people through "Sorry Business." This resource has been developed to provide culturally sensitive, respectful, responsive and appropriate methods of communication when dealing with health care and Sorry Business with Aboriginal & Torres Strait Islander people.

This booklet has been produced to improve the effectiveness of Aboriginal and Torres Strait Islander people's journey through the system for those that are affected by palliative illnesses – 'Sorry Business' who are located across local communities within the Hunter New England boundary.

I would like to acknowledge and thank our elders, aunties, uncles, brothers, 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 journeys from an Aboriginal viewpoint.

The Hunter New England Local Health District, Calvary Mater Newcastle and MyNetCare Network is committed to improving palliative care services for Aboriginal and Torres Strait Islander people in an effort to "Close the Gap" in health and well-being between Aboriginal and non-Aboriginal people. We want to empower Aboriginal and Torres Strait Islander people to collaborate with mainstream partners in the provision of supportive care.

I hope you find this resource useful and encourage you to share your insights and knowledge with family and friends.



Be open to work differently – recognising that mainstream approach is often not the most appropriate or effective approach for healthcare eg going out to community rather than a centre based service or having multiple family meetings rather than just one

DR RACHEL HUGHES
Director of Palliative Care
Calvary Mater Hospital

This Supportive Care "Into the Dreaming" booklet has been prepared to help enhance quality of life for Aboriginal and Torres Strait Islander people in the Hunter New England communities, as they and their families face the challenges of life limiting illness. It is hoped the booklet will inspire confidence that people can set and achieve goals, and receive support to live their lives as they wish.

The work of our Palliative Care Services around our district, and aided through this booklet, is to enable patients, families and community to maintain dignity, comfort and maximize the quality of life for all affected by life threatening illness.

We hope that this booklet can provide the information our community's people need and that it will also encourage people to consider what is important to them, have conversations and create goals and plans for their future care.

This booklet contains resources to link patients with our district's palliative care services, who provide assistance with communication, symptom management, rehabilitation, community social and emotional support, care planning and bereavement support.

In times of difficulty, I hope this booklet provides comfort and information to patients and their loved ones.

What is Supportive Care during
"Sorry Business"?



Supportive or Palliative care is a way of improving quality of life of patients and families facing life-threatening illness.

Palliative care brings together many different services including

- Aboriginal Hospital Liaison Officer
- Aboriginal Health Worker
- Family Doctor
- Aged and Community Care worker
- Spiritual healer
- Family and Community
- Palliative care doctor or nurse
- Allied Health workers can help with symptom management, activities of daily living, emotional support and rehabilitation services. Allied Health palliative care workers can be, Social Workers, Dietitians, Music therapists, Occupational therapists, Pharmacists, Physiotherapists, Podiatrists, and Psychologists.

Planning ahead:
Some people may find it difficult to make plans for future or complete an Advance Care Plan. Consider discussing with the family contacting an Aboriginal Hospital Liaison Officer to support you and the client. This may help the client to understand the important things when making a decision and understand what will happen next based on the decision.

Supportive and palliative care can help you access

- Assistance to Live Well – Symptom control, pain relief, diet and exercise, relaxation, goal setting, comfort care
- Rehabilitation services
- Equipment to make your home safer
- Physical, emotional, spiritual, financial and social support
- Care in your own home, acute hospital or palliative care unit
- Carer support and counselling
- Bereavement Support
- Patient and family education
- Dying with dignity in the location of your choice

Aboriginal and Torres Strait Islander people must have a genuine say in their own lives and matters that affect their people and community.

When do I have supportive/palliative care?

Palliative care is about being as comfortable and active as you can when you have a serious illness. You do not have to be “dying” to have palliative care. In fact, palliative care can help you at any time you have pain or symptoms with a serious illness. Palliative care can also support your family and community when you’re sick. Being looked after by palliative care does not make people die faster. In fact, palliative care can help people function better and have better moods.

Who organises palliative care?

Usually your doctor or nurse, but you and your family can ask for a referral if you’d like one.

Do I have to pay for it?

Palliative care services and equipment are usually free. You may sometimes have to help pay for special equipment or medications.

Where do I have palliative care?

You can have it at home, in a hospital or at a hospice (palliative care unit). Hospice is more home-like than hospital. Both hospice and hospital offer care by trained staff. You can move between these places if your needs change. You can stay for a short or long time. Often the person and their family and friends can choose where to have palliative care. It may depend on what is available in your area. If you are cared for at home, special services can help you and your family with medical support, nursing care and equipment hire.

MY JOURNEY: MELINDA CAIN



I was looking forward to the birth of my child when I was faced with heart wrenching news I had Acute Myeloid Leukemia and would need to start treatment immediately. At only 24 weeks pregnant I told my doctor I wanted to wait another five weeks until my unborn baby was stronger and more developed.

On 14 July 2011, at only 29 weeks, my third child (Tyler) entered the world and I immediately began my first round of chemotherapy.

I am a strong Aboriginal woman I don't want sympathy, but I would like people to understand the devastating effects of Cancer (leukemia).

Being diagnosed was the beginning of a roller coaster ride that caused emotional and physical heartache.

Over the period of three years I have undergone intensive chemotherapy and radiotherapy which required me to be close to the Royal Brisbane Women's Hospital. During that period my family spent 588 nights staying at one of the Leukemia Foundation's accommodation villages free of charge. We were so grateful; I don't know what we would have done without that help. The stress involved with my diagnosis of leukemia affected the whole family. The implications for my family were immediate and life – changing. Having to stop work and relocate to a different city to receive treatment while juggling the needs of three children was challenging to say the least.'

'Not only was I very ill, but I had a premature baby to look after as well as my other two children. My parents, Eileen Cain and Herbert Binge (dec), travelled from their home in Moree and took time off work to become full time carers of Tyler and myself.

My oldest son Kieran became full time carer of my two year old son Euraba, at home so he could continue to attend his day-care and keep up a normal routine.' 'My oldest son, Kieran; was completing year 12 at that time and drove to Brisbane after school with Euraba to visit me most days. I always look back and wonder how he coped with it all – I am very proud of him.

After my initial diagnosis, my sister and brother were tested as possible bone marrow donors. Unfortunately they were incompatible. My doctor told me that Aboriginal patients only have one percent chance of receiving a bone marrow transplant mainly due to low number of Aboriginal donors and the need for high level of compatibility'.

All my extended family was tested, but incompatible. I still recall my mum saying to the doctors, that I want to take my youngest daughter home so her children can have quality time with their mum and that Melinda, dad and I can have quality time together for the timeframe of 6 months at least. My mum said what is the next step? the doctors said Nations wide; mum said we are staying there and not giving up. The difficult search began and miraculously, after being on the waiting list for six months, a donor was found in America.

Going in and out of hospital twice a week for routine checkups for six months is very hard, and not knowing if you were going to live. I can remember that day clearly when the bone marrow support worker was looking for me in the treatment room, she was singing out Melinda are you here I said yes in room 14, she came in with the biggest smile and I knew straight away. I said have I got a donor,' she said yes shall we go and tell your family, I said my bloody oath. We came to the corner of the waiting room I said out loud Buddha in Kamilaroi language meaning (meeting where presents are exchanged) and when I started to cry my family came running to me and my mum saying to me what's wrong, dad holding my hand and my oldest son cuddling me I said Buddha and then my mum fell to the ground dad squeezed my hand that tight and I got down on my knees to look at my two youngest kids and said it's alright and to help mum back up and looked at my oldest son you are all going to have your mum around in your life.

The news spread to my family like the Murri grape vine everyone was happy.

I remember when I got a special visit from my grandmother a couple of months before my transplant. My extended family came to the village and had a BBQ and a big cultural healing with yarning. That night Nan healed my body and mind with cultural spiritual knowledge, her special oils and bush medicine (Eura). As Nan was departing the next day to travel back home to Moree, Nan said to me (ngarra-l gundirribiyaa yinarr guni) that means look at strong hard Aboriginal woman/ mother. I said (ngarra-l gundirribiyaa yinarr baagii balabalaa yuwi ngayaga-l) that means look at strong hard Aboriginal grandmother butterfly spirit kiss. That was the last time I saw Nan. Nan passed away one month before I had my bone marrow transplant.

On the 14th January 2013 I received my unrelated bone marrow transplant. Spending so much time in hospital ICU and Palliative care unit. I had to learn to walk, eat and shower myself again it was a hard road. My stay in hospital allowed me to do arts and craft for healing. I believe that my experience with leukemia has given me the strength and wisdom to help others. I am an Aboriginal support person for the Leukemia Foundation. My life has changed and now I focus my attention on caring for my immediate family and doing my art. I feel very lucky to have had such a strong support network of family, friends and community – not everyone has that.

The staff at the Leukemia Foundation village and the patients and friends I met there have also become a part of my family. We shared each other's journey, saw patients come and go, and saw some families lose a loved one.' I cannot express how grateful I am to receive a 21year old's bone marrow, a donor from America. I was able to write to her and tell her "thank you'. I wanted her to know that she gave me a second chance at life and gave my children back their mother. That is a priceless gift. It has now been 6 years in remission, I am still having bush medicine Eura and doing my art for healing to express my journey through my illness. My painting represents My Journey. The symbol represents' family and all the colours represents all the Cancers and the leaves are Eura bush medicine that is found on Kamilaroi country and the footprint is all the support people journeying with me.

Thank you for taking the time to read my journey.

ADVANCED CARE YARNING AND PLANNING AHEAD

WHAT IS PLANNING AHEAD?

Planning ahead means making plans for the future so you are looked after if circumstances change through your life. Your rights and wishes can be respected if they are properly documented. You can make decisions for yourself about your money, belongings and health care. You can also have your say about medical treatment near the end of life.

YOU CAN PLAN AHEAD BY MAKING 4 DOCUMENTS

1. **Will** – Who will get my stuff when I die?
2. **Power of Attorney** – Who will make decisions about money if I can't?
3. **Enduring Guardian** – Who will make decisions about my health and where I live if I can't?
4. **Advance Care Planning** – What medical treatment and care do I want in the future?

MAKING A WILL

A Will is a legal document that says who you want your stuff (money, belongings and property) to go to when you die. It is a way you can look after people you care about, or leave them something that reminds them of you. It also helps your friends and family know of any special funeral arrangements you want.

You don't need a lot of money or stuff to make a will. It takes away the stress when the family need to come together. It is important to make changes to your will when things change in your life.

Wills can be easy and doesn't have to be expensive, you can get a will kit from your local newsagency from around \$20-\$30. A solicitor may charge you a fee for preparing the Will. NSW Trustee & Guardian charge a fee for preparing a Will unless you are eligible for a Centrelink Age Pension, Dept. of Veterans Affairs pension then it is free. Some solicitors and NSW Trustee & Guardian also charge a fee to sort out the estate after you die. The fee comes out of your estate.

Your will, enduring power of attorney and enduring guardianship should be prepared with a legal professional like a solicitor or NSW Trustee and Guardian.

You can contact NSW Trustee & Guardian to find nearest service on 1300 364 103 or www.tag.nsw.gov.au

ARTIST:

KERRY PATTERSON

Descendant of Darkinjung, residing in the boundary of Hunter region and working at Glendore Public School (WALLSEND) as a teacher of Aboriginal descent.



The central represents palliative care and the individual approach palliative care takes in caring and supporting our people who have an incurable disease in providing our mob with quality of life through quality of care. The outer circles represent our people together supporting each other through a connection of love, spirituality and friendships. The small dots represent all our people, our journey, our diversity and coming together through the respectful approach of palliative care.

A large eagle flying over our country looking back at our community.

Palliative care team guiding nurturing and supporting the community to ensure we all are supportive and providing quality of life through quality of care.



Cultural resources play a critical role in creating a welcoming, safe, comfortable environment.

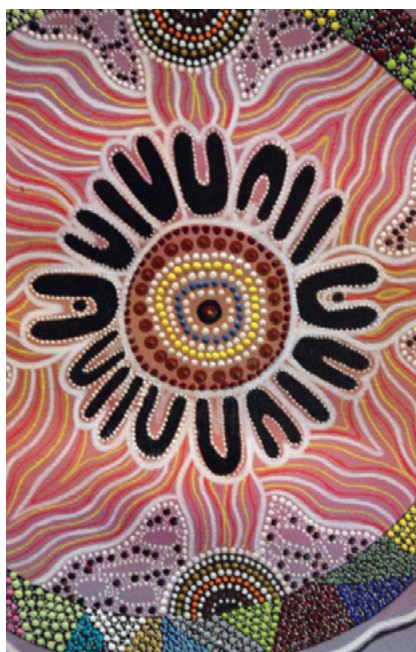


WILL PLANNING AHEAD CHECKLIST

1. **Details of your assets**
2. **Beneficiaries – who will receive your assets?**
3. **Name(s) of those you wish to appoint as guardian for your children.** This will make known who you want to look after your kids if they are under 18 years of age. You can add how you want them to be taken care of, for example schooling. If you don't have a Will set up the court might decide that your kids should be looked after by someone not related to your mob. It is important to ask the appointed guardian if they are happy to do this if something happens to you.
4. **Executor- name of organisation/ individual who will carry out the wishes in your Will.** The executor will have a lot of responsibility, so make sure when you choose a person who understands what they have to do. If you don't know anyone who can do this or don't want to burden family and friends, you can choose a professional executor like a solicitor.
5. **Details of your funeral arrangements.** You can say in your Will where and how you want to be buried.

POWER OF ATTORNEY CHECKLIST

1. **Attorney – name of the person or trustee organisation you want to make property and financial decisions for you.** This needs to be someone you trust, there can be times when we might need other people to help us to look after our money when we can't make those decisions due to illness or disability. You can choose one or more friends or family.



ARTIST Melinda Cain

ENDURING GUARDIANSHIP CHECKLIST

1. **Choose the person(s) you want to make health care, where you live or what services you need if you can't decide for yourself.** This lack of ability to make decisions might occur if someone loses capacity through for example dementia or stroke.
2. **Decide on the decision making areas your guardian will have authority over.** For example deciding where you live, decisions on prescribed treatments, services such as home care/meals on wheels.
3. **Consider any specific directions you would like to give your guardian.** Make sure the person you choose is willing to take it on and understands what you want.

// You may be able to use a Will as a way of passing on cultural information and secret knowledge after you die. //



ARTIST:

KALIELA THORNTON

I am a Gomeroi woman; I reside in the Tamworth area, married, mother of 6 daughters. I work in the health service.

I have a quote from a Gomeroi Aboriginal elder, Reginald (Uncle Roy, Mullion-Go) Knox who is my grandfather.

“Ngiyani ngima yilaadhu yalagiiray ngiyani gimiyandi gaalanha yilaalu-gi”

“We are here today as we were yesterday and will be forever”

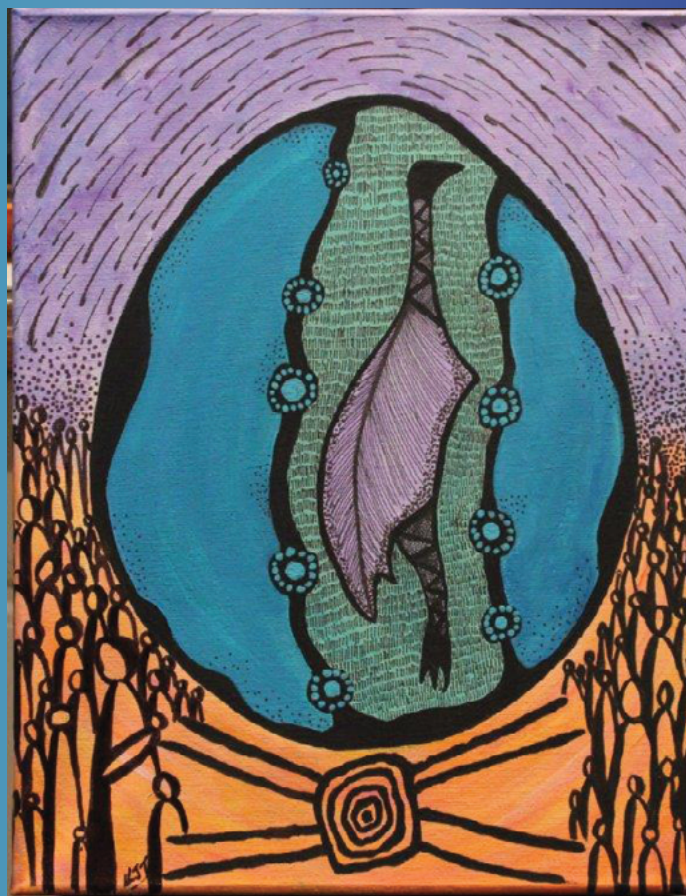
This quote also represents and introduces my artwork.

I drew my motivation from the emu egg, the emu in the sky- the milky way, and strong family connections.

The Dhinawan (emu) represents many things in my culture, spiritual achievement, being close to Biamie the All-Father Creator, the story of the emu in the sky (Milky Way) which leads us through our seasonal changes . . . everyday life, yearly cycle. Our spiritual connection to the dreaming and our ancestors spirits which have taken place beside the dhinawan in the sky after our spiritual journey through life (represented by the journey symbols either side of the dhinawan and the many strokes surrounding the dhinawan representing people) to spiritual achievement.

The Dhinawan egg - to me represents the fragility of the person in palliative care, to be handled with care and respect, with the carving of the journey and the dhinawan signifying our journey and experiences, culture and spirituality are carved into us identifying who we are in life - our layers of personality.

Surrounding the egg are colours representing land and sky, below is the gathering of family, kin and friends which is custom to my people, below the egg is the meeting place where we all gather for our loved one. Above the egg, I placed star trails (time lapse representation of stars in the sky) which also represents the spiritual release, spirits movement in the sky. Also the people are gathering on the earth, representing our connection with the land, where our bodies shall return and our spirits connection to the sky and stars.



“ The importance of family gathering, the meeting place which is palliative care/dying in place of choice, spiritual journey/achievement/significance and achievement, fragility of the egg, the shell of the body and the phases of life one goes through to reach this phase of end of life ”

ADVANCE CARE PLANNING AND DIRECTIVES CHECKLIST

DISCUSS YOUR HEALTH AND MEDICAL CARE WISHES WITH DOCTOR AND FAMILY

This involves while you have capacity, and understand your health issues, talking to key people, family, partner, friends and doctor about what is important to you. Involves thinking about your values, beliefs and your wishes in relation to medical and health care you would like to have if you cannot make your own decision if you become unwell, this is called advance care planning.

ASK YOUR DOCTOR TO DOCUMENT YOUR ADVANCE CARE PLAN IN YOUR MEDICAL RECORDS

WRITE DOWN ANY SPECIFIC HEALTH CARE DIRECTIVES YOU MAY HAVE THAT RELATE TO TREATMENT

If a treatment is important to you, or there is a treatment you do not want, you can write down your wishes in an advance care directive.

ARTIST:

MAREE BISBY

With the challenges of life comes the inevitable end to our journey. For us, as Aboriginal people we have traditions, an order, and respectful way of getting things done.

My painting therefore incorporates, Seeds of Hope which brings calling to the Spirit world to make our path as painless as possible, hoping that we are able to bare those things necessary to move forward, where the end of this life is inevitable. Hoping that this process is dignified and cradled with love, honour and respect.

The colouring in the hands represents the many people who form a part of our lives, and who may be there as we draw upon our last breath.

The markings and surrounds of the circle symbolise our return to the spirit form, where our ancestors will meet us on the astral plane and guide us."



"Where there is Love, there is Dignity"

ADVANCE CARE YARNING

Having your say about your future medical treatment is called advance care yarning. This process involves thinking about your values, beliefs, choices and what matters to you. This gives family, doctors nurses and Aboriginal Health Workers the opportunity to respect your choices.

It is best if Advance Care Yarning happens earlier in life, while you are still well.

WHY PLAN IN ADVANCE?

Putting your family in a position of having to make decisions for you, without knowing what you would want, can be difficult for them. If you discuss your choices it may bring you comfort now and into the future for your family. Make sure your decisions are heard.

ADVANCE CARE YARNING INCLUDES ONE OR MORE OF THE FOLLOWING ACTIONS:

YARNING ABOUT YOUR CHOICES

Yarning to your family, doctor or Aboriginal Health Worker about your values, beliefs, attitudes and what is important to you.

WRITING DOWN YOUR CHOICES ON AN ADVANCE CARE PLAN DOCUMENT

This can record your choice in health care and treatment options so people can communicate easily your wishes to doctors, nurses, and Aboriginal Health Workers who do not know you or know what you want.

APPOINTING ONE OF YOUR PEOPLE AS AN ENDURING GUARDIAN

An Enduring Guardian can legally make decisions on your behalf about medical and dental care, if you are unable to make decisions yourself.

MAKING AN ADVANCE CARE DIRECTIVE

This is a record of your specific choices. This includes treatments you would want or refuse if you had a life-threatening illness or injury. It will only be used if you cannot communicate your wishes yourself. This document needs to be signed by you and a witness. This is a valid and legally binding document if you had decision-making capacity when you made it and you were not influenced or pressured by anyone else to make it. This will only be used if you can no longer say what your wishes are. You can review it at any time. You cannot include any illegal activities such as euthanasia.



ARTIST Audrey Trindall



ADVANCE CARE PLAN



Name:

Address:

Date of Birth:

If I cannot speak for myself, I would like my doctor to talk about my health care and medical problems to the following person/s: (please write their name and contact number/s)

Name Contact number.....

Name Contact number.....

I have legally appointed the following:

Enduring Guardian (*Health decisions*) Yes No

Name of person appointed Contact number.....

Enduring Power of Attorney (*Money/Finance decisions*) Yes No

Name of person appointed Contact number.....

Who has copies of these legal documents? (Please include contact number of person/s)

.....
.....

If I am very sick or badly injured, and others need to make medical decisions for me, please consider my following statements when making substitute decisions (a person permitted under the law to make decisions on behalf of someone who does not have capacity):

The following things are important to me, and I want them to be considered in any decisions that are made on my behalf:.....

.....
.....

Cardio Pulmonary Resuscitation (CPR) (Initial the box that matches your choice)

If my heart or breathing stops due to old age or irreversible (not curable) health problems my choice, if CPR is a treatment option, would be:

Please try to restart my heart or breathing (Attempt CPR)

Please allow me to die a natural death. Do not try to restart my heart or breathing (NO CPR)

I cannot answer this question. Let my doctor decide.

Signature: Date:

PERSONAL VALUES

Please consider my personal values for the following statements if I am unable to make my own decisions in the future. (Put your initials in the box that is your response to each statement)

I would find life to be <i>acceptable</i> OR <i>difficult</i> but <i>bearable</i> OR <i>unbearable</i> if, for the rest of my life:	ACCEPTABLE	DIFFICULT BUT BEARABLE	UNBEARABLE
I do not recognise my family and loved ones			
I do not have control over my bladder and bowels			
I cannot feed myself, and cannot wash myself, and cannot do my own personal grooming and dressing			
I cannot move myself around in or out of bed and rely on other people to reposition (shift or move) me			
I can no longer eat or drink and need to have food given to me through a tube in my stomach			
I cannot talk, read and write			
I can never have a conversation with others because I do not understand what people are saying			
I do not get enjoyment from many of the things that I have always enjoyed			

Talking about end of life:

Please initial the statement which is closest to your personal belief

I am frightened of dying and do not want to think about it happening to me or my loved ones. I do not discuss death or dying with others	
Dying is a fact of life. You just have to deal with it when it happens. I hope that I can talk about it with loved ones and others before my time comes	
Dying is a natural part of life. I am comfortable discussing death and dying with my loved ones and others. I want to be prepared for when my time comes	

When my time for natural dying comes, if possible, I would like to be cared for

At home or in a home like environment	
In a hospital or hospital like environment	
I do not know. I am happy for my family / person responsible to decide	

Signature:..... Date:.....

Witness Signature:..... Date:.....

Additional optional page (not all people will want to include this page. Please staple to advance care plan if you wish this information to be included)

Name:

Date of Birth:

Specific requests with regard to medical care (Please initial the box if you wish to identify specific treatment limitations. If you DO NOT have specific requests, please cross out this section)

I DO NOT WANT to have the following life prolonging medical treatments:

.....

.....

.....

My personal, religious and spiritual care requests If I am unable to communicate my wishes, please consider that I would want to receive the following care:

.....

.....

.....

SPECIFIC REQUESTS FOR TISSUE, ORGAN AND / OR BODY DONATION PLEASE INITIAL THE SMALL BOX THAT IS NEXT TO THE STATEMENT YOU ARE COMPLETING. PLEASE CROSS OUT THIS SECTION IF YOU DO NOT WANT TO MAKE A REQUEST)

I have registered as an ORGAN AND TISSUE donor with the Australian Organ Donor register.

My organ donor registration number is

I have discussed my organ and tissue donation wishes with my family and friends and they are aware of my decision Yes No

I understand that my donation wishes may, in some situations, require the use of life sustaining treatment in an Intensive Care Unit. I understand and accept that I may receive this additional care so my donation wishes can be carried out.

BODY (CADAVER) AND OTHER DONATION

I have registered as a cadaver / other donor. Please contact the following number to arrange collection

I understand that there may be specific instructions that need to be followed shortly after my death for cadaver and / or other body part donation to occur. I have discussed what needs to happen with my family / friends Yes No

Your Signature: Date:

Witness Signature: Date:

PAIN AND PAIN MANAGEMENT

WHAT IS PAIN?

Pain is an unpleasant sensation, suffering or distress. Pain can make you irritable, it can cause restlessness, reduce appetite, and make it hard to be active and enjoy life. Pain can be relieved if you share information, choose right medications and use medications appropriately.



ARTIST Maree Bisby

PAIN FACTS

- **Not everyone with a terminal illness will experience pain**
- **Everyone experiences pain differently, so the way you experience pain will be unique to you**
- **Most pain can be relieved**
- **Pain is not always constant, it can change over the day**

SIDE EFFECTS

Not everyone experiences side effects from strong medications, and most of the side effects are temporary or manageable.

Possible side effects include:

- constipation — can be relieved by regularly taking laxatives
- nausea and vomiting — is often only temporary or can be alleviated with medicines
- drowsiness or confusion — may occur for only a short time after starting treatment or increasing the dose
- dry mouth — may improve with time
- itchy skin — may improve with time

Your doctor might prescribe some strong medication to help relieve your pain. Here are the names of some of the different types the doctor may give you.

- Codeine Phosphate
- Morphine
- Durogesic
- MS Contin
- Oxycodone
- Norspan
- Fentanyl
- Ordine
- Kapanol
- Panadeine Forte

These strong medications are for improving life — not used as a last resort. Relieving the pain changes your quality of life — not its length. The aim of these medications is that you should be as free from pain as possible.

Talk to your doctor about any side effects so they can try and alleviate them.

Leading up to the death of an Aboriginal or Torres Strait Islander person, it is common for family and community to gather and visit their loved one based on the belief that life is part of the greater journey. For many it is cultural practice to prepare for their loved one's journey to dreaming. This may mean large gatherings, especially if the loved one is a respected Elder.

ARTIST:

JODIE HERDEN

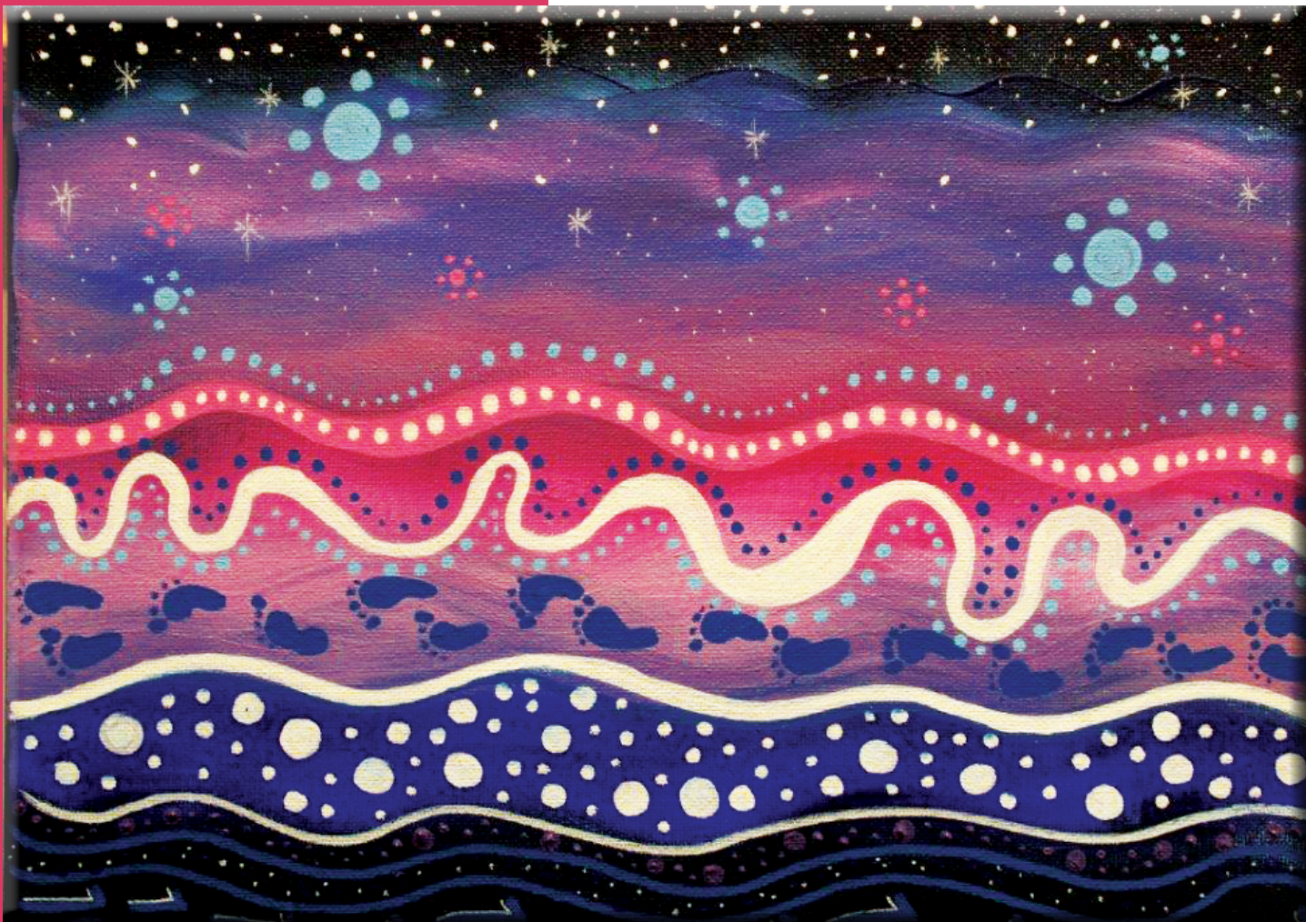
This artwork represents our Life Dreaming Path

Jodie's Story - We are born of Gunimaa, (Mother Earth) who created us from the soil in the form of Dhinawaan (emu) our protector totem. As we walk across country we also have taken the human form. Every stage we are nurtured, guided, comforted and supported, from birth to death.

We are born of the earth, the layers in life and the stages we travel through in being born, growing, living and the path to dying; all come from the support and guidance from the knowledge givers (Medical teams, Elders, family, friends and community).

They may take the form of an animal, or of the wind blowing on our face, of the rivers flowing, the salty ocean spray, or in the dirt beneath our toes. We will always feel their presence within us to be strong through the difficult times.

As we near the end of our life, we become strong and connected with our eternal spirit and make our way back in the stars, back to The Dreaming, for our final resting place!



BEREAVEMENT - SUPPORTING KEY PEOPLE

What to do after the "Into the Dreaming"

The time following the passing requires continuing support, sensitivity and respect for family and friends, and respect for cultural protocols and practices. These practices may be sacred in nature and therefore not discussed openly. Staff should not dismiss the need to perform these practices and ceremonies and should allow appropriate time and privacy.

THINGS FOR KEY PEOPLE TO CONSIDER:

- If it is part of your beliefs and customs a smoking ceremony can be arranged, this will help the spirit depart from this world and into the next. Smoking of the person's home, personal belongings and where they pass away is often involved in the smoking ceremony. Contact your local lands council to find out any local smoking ceremony providers.
- Aboriginal cultural protocols following death generally have two purposes, firstly sending the spirit onto the next world and secondly identifying the cause of death. Many Aboriginals believe that life is only part of a longer journey.
- Self-Care is so important for key person, family and friends. Sadness can make you sick, so talk about grief, allow yourself to cry. Remember to eat healthy food, your mind and your body needs nutrition. Share your stories. Ask your doctor to refer to professional help if sadness gets too much.
- Some key people will want to escort the family member back to their community, communicate with health workers if you want to do this.
- The Aboriginal Funeral Transport "Sorry Business" initiative provides assistance with transport for isolated and disadvantaged Aboriginal communities throughout New South Wales, including metropolitan Sydney, to attend funerals. To see if eligible please contact Managed Training Services on 1300361787 (Mon-Fri, 9am-5pm).

THINGS FOR STAFF TO CONSIDER:

- In some communities, it is advisable to avoid eye contact with the family members and friends as a mark of respect. If staff wishes to express their condolences, "We are sorry for your loss" and, a silent hand shake, without eye contact will suffice.
- Prepare for many people mourning, particularly if the deceased is a long way from their home or community or an Elder. Staff should consult with the Aboriginal Hospital Liaison Officer.
- In some cultural protocols the name of the deceased is not mentioned for a long period of time, from several months to years. This is to ensure that the spirit is not held back or recalled to this world.

CONTACT THE FOLLOWING PEOPLE AND ORGANISATIONS IF NEEDED:

- Funeral director to take care of burial or cremation arrangements
- If there is a funeral plan, contact the funeral fund to release funds, if you do not have this paperwork it may have been left in the hands of someone such as a solicitor (along with the will).
- If a will has been prepared and you are the executor contact with the appropriate service to organize the reading of the will.
- Insurance company
- Department of Human Services to update Centrelink 132300, Medicare 132011 and child support records 131272.
- Centrelink to see if eligible for bereavement allowance, bereavement payment, widow allowance, or pension bonus bereavement payments. Centrelink Bereavement Assistance number is 132300 (Mon-Fri 8am – 5pm).
- GP if a referral is required to social work services, for counselling, support and information through this difficult time.
- Superannuation fund to see if eligible for any payments to support.
- NSW Aboriginal Land Council Funeral Fund on 02 9689 4444 or funeralgrants@alc.org.au to see if eligible for a grant of up to \$1000 to help with funeral expenses.
- Other services to call could be, Australian Taxation Office 132865, banks, clubs, Australian Electoral Commission 132326, Employers, Health professionals (e.g. doctor, physiotherapist, dentist, podiatrist, optometrist), telecommunication (phone/ internet), utilities (e.g. Gas, electricity), and vehicle registration and licensing authorities.



PALLIATIVE CARE SUPPORT SERVICES

LOCATION	PALLIATIVE CARE SUPPORT SERVICE	ADDRESS	PHONE NUMBER	WEBSITE	TYPE OF SERVICE OFFERED
Armidale	Armidale Palliative Care Team	Clair House, Rusden & Butler Sts (Locked Bag 4) Armidale NSW 2350	02 6776 9600	http://www.hnehealth.nsw.gov.au/services_and_facilities/community_health_services/armidale_community_health_centre	Community support to patients in the home, Consultative service provided to the hospital, Equipment hire, Provide education and training, Social worker.
Bereavement Assistance Centrelink			132300 (Mon-Fri 8am to 5pm)		Payments, Counselling and other services to help people adjust after someone close to them has died. The type and amount of bereavement payment you get will depend on your individual circumstances and eligibility.
Cessnock	Cessnock Community Healthcare (Palliative Care)	19 Foster St (PO Box 154) Cessnock NSW 2325	02 4991 0438		Community support to patients in the home, Consultative service provided to the hospital, Equipment hire, Provide education and training, Social worker.
Maitland	Maitland Palliative Care Service	550-560 High St Maitland NSW 2320	02 4939 2170		Community support to patients in the home, Consultative service provided to the hospital, Equipment hire, Provide education and training, Social worker
Maitland	TLC Volunteers Maitland Inc (Your Care)	HSU Maitland Hospital, 550-560 High St Maitland NSW 2320	02 4932 2741	http://www.tlcmaitland.org.au/	
Moree	Moree Palliative Care	Moree Community Health PO Box 138 Moree NSW 2400	0267570294 0448 870 129		Advance care planning, Community support to patients in the home, Consultative service provided to the hospital, Consultative service to Residential Aged Care Facility, Education and Training, Equipment hire, Inpatient palliative care beds, Psychosocial support (counselling, pastoral care, bereavement), Social worker
Muswellbrook	Muswellbrook Carelink Inc	Brecht St Muswellbrook NSW 2333	02 6542 2041	mailto:muswell.carelink@bigpond.com	
Newcastle	Calvary Mater Newcastle (Department of Palliative Care)	Edith St Waratah NSW 2298	02 4921 1954	http://www.calvarymater.org.au/palliative-care/	Community support to patients in the home, Consultative service provided to the hospital, Day hospice, Equipment hire, Inpatient palliative care beds, Provide education and training, Social worker

LOCATION	PALLIATIVE CARE SUPPORT SERVICE	ADDRESS	PHONE NUMBER	WEBSITE	TYPE OF SERVICE OFFERED
Newcastle	John Hunter Hospital Paediatric Pain & Palliative Care Service	Lookout Road (Locked Bag 1, Hunter Region MC) New Lambton Heights NSW 2305	02 4921 3387	http://www.kaleidoscope.org.au/jhch-palliativecare.html	Community support to patients in the home, Inpatient palliative care beds, Paediatric palliative care service, Psychosocial support (counselling, pastoral care, bereavement), Social worker
Palliative Care after hours helpline			1800 548 225		NSW patients receiving palliative care, their carer's and families, have access to this help line for additional advice and support. A registered nurse with training in palliative care will provide advice and support. The call will be transferred to a specialist palliative care nurse if the issue is more complex. Some palliative care providers have an after-hours service for their patients, so should check with them or GP for locally provided services as well.
Tamworth	Tamworth Base Hospital (Palliative Care Service)	Dean St (Locked Bag 9783, NEMSC) Tamworth NSW 2348	02 6767 8100		Community support to patients in the home, Consultative service provided to the hospital, Equipment hire, Inpatient palliative care beds, Provide education and training, Social worker
Taree	Taree Community Health Service (Palliative Care)	64 Pulteney St (PO Box 35) Taree NSW 2430	02 6539 6316		Community support to patients in the home, Consultative service provided to the hospital, Equipment hire, Provide education and training

ARTIST:

JODIE FREEMAN

I am a proud Kamilaroi Aboriginal artist, originally from Narrabri. My artwork is a modern style, combining my Aboriginal heritage with my spiritual beliefs.

Jodie's Story - In the very centre, as it should be, is the person in care. It is a time of reflection and a time to be surrounded by those closest to us.

At the bottom we see the women and men, leading towards both the person in care as well as the groups above them, the elders. The elders lead the way for the men and women of the tribe, as much as they support the person in care.

Everyone comes together to surround and support the person as they transition from this world to the next, back to spirit, shown in the dots rising up towards the heavens and the person becoming a star just like their ancestors before them, watching over their tribe, using the lessons they've learnt from this lifetime to guide and mentor those who follow.

To bring together the different tribal nations, I've used more traditional earthy colours to represent the inland tribes for the time before transition, then I've used more modern colours for the coastal areas, to show the transition into spirit form.



GETTING MORE HELP AND INFORMATION

Aboriginal Legal Service (NSW/ACT)

The Aboriginal Legal Service can suggest Solicitors close to where you live who can do a will

Phone: 02 8303 6600

www.alsnswact.org.au

Aboriginal wills handbook – a practical guide to making culturally appropriate wills for Aboriginal people

This informative book contains Will preparation forms that can be filled out and taken to your Will making appointment.

Contact NSW Trustee & Guardian for a copy.

Ph: 1300 554 791

www.tag.nsw.gov.au/aboriginal-planning-ahead.html

NSW Ambulance Palliative Care Plan – Similar to the Advance Care plans through your GP, the NSW Ambulance service has an Ambulance Palliative Care Plan to direct Ambulance Officers when attending a call to treat you. For a copy go to the following link https://www.sldh.nsw.gov.au/btf/pdfs/Amb/Adult_Palliative_Care_Plan.pdf fill the form out with your Doctor and email to protocolp1@ambulance.nsw.gov.au

Department of Human Services (Centrelink)

This service can help with sickness/mobility, disability, and carer allowances.

Phone: 13 27 17 (Mon-Fri 8am-5pm)

www.humanservices.gov.au

NSW Trustee & Guardian

NSW Trustee & Guardian is a government agency.

It can make or update your planning ahead documents, and act as your executor or attorney.

Phone: 1300 554 791

www.tag.nsw.gov.au

NSW Aboriginal Land Council

Funeral Assistance Grants – For further details of eligibility under the scheme

1800 647 487

<http://alc.org.au/nswalc-in-the-community/funeral-fund.aspx>

Cancer Council

Information, Support, Legal Assistance,

Financial support & hardship assistance phone Service 13 11 20

<https://www.cancercouncil.com.au/aboriginalcancer/cancer-information-for-the-community/support-services/information-support-services/>

Lifeline

13 11 14

<https://www.lifeline.org.au/>

Can Assist – Financial and Accommodation Assistance for NSW Cancer patients

1300 226 277 <https://www.canassist.com.au/>

Medicare Services for Indigenous Australians

Aboriginal and Torres Strait Islander Access Line – 1800 556 955

To see if eligible for Medicare help with the cost of health care and medicine

<https://www.humanservices.gov.au/individuals/subjects/medicare-services-indigenous-australians>

Isolated patient travel and accommodation scheme (IPTAAS)

Subsidised travel and accommodation required for medical reasons

Ph: 1800 660 361

Fax: 02 6766 4576

<http://www.enable.health.nsw.gov.au/services/iptaas>

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ARTIST Carissa Paglino