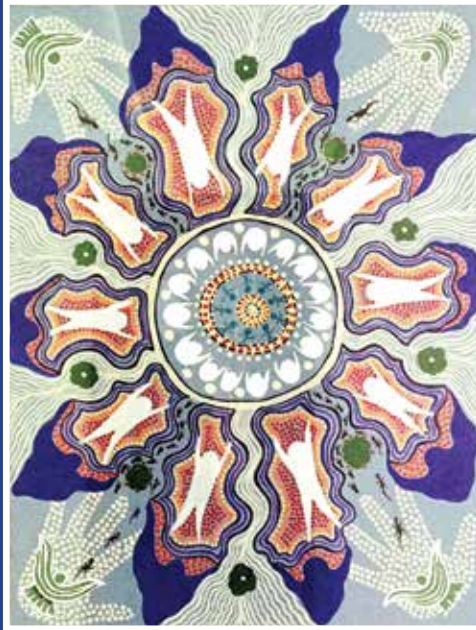


IN OUR CARE INTO YOUR HANDS: ABORIGINAL STORIES ABOUT APPROACHING THE END OF LIFE



About the painting used on the cover:



IN OUR CARE INTO YOUR HANDS

- By Loretta Parsley

This painting was a commissioned work for David Berry Hospital Palliative Care Unit. It was painted by Aboriginal woman Loretta Parsley. Loretta paints under the name DAWN, which stands for Doing Art With Nature. Loretta is a teacher, a spiritual artist and storyteller.

The painting is reflective of the Berry Palliative Care Unit, with each symbol having a different meaning.

The inner circle of 9 beings represents the 9 beds at the unit. The outer circle represents the 15 staff members who care for their patients. The large free spirits are guardian angels watching over everyone and the blue angels are the angels who take the patients into God's care. The doves represent peace and it gives meaning to the painting that all people can be at peace with themselves and others.

The footprints, trees, water and animals are all part of the cycle of life.

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ACKNOWLEDGEMENT

DISCLAIMER: This booklet contains stories of and/or paintings from deceased persons.

Storytelling has always been a vital part of Aboriginal culture since the Dreamtime. Our Elders knew the benefits of yarning about life. Some of those stories include losing people close to us. Aboriginal Elders also knew that sharing these stories whilst sometimes painful also helped people to understand about life and death and....healing.

This booklet is dedicated to all those people and families who have shared their palliative journey. They are not forgotten people but just the opposite, by telling their stories, we are remembering.

We, the Illawarra Shoalhaven Local Health District: Shoalhaven Palliative Care and Aboriginal Health Building Relationships Committee, would like to thank and acknowledge:

- All individuals, including Aboriginal Elders, and their families who shared their Palliative Journey. We are forever grateful to have been a part of telling and sharing your story;
- Auntie Gail Wallace for her gentle reminder that addressing Aboriginal people's cultural and spiritual needs is just as important as meeting their physical needs;
- The financial support of the Illawarra Shoalhaven Medicare Local, which made this project possible;
- All people and organisations who work to bridge the gap between Palliative Care and Aboriginal communities;
- All artists whose artwork appears in the booklet depicting patient health journeys and living in the Shoalhaven.

The various health care services and staff mentioned in this booklet have a shared goal to provide culturally safe and respectful care. We have recorded the stories as they were told to us. Slight editing has been done for privacy. We would encourage you to remember that every person has their own story to tell and no two stories are the same.

NO REGRETS

Angie McLeod, together with other family members, cared for her father Max McLeod, until his death in June 2014. Here is some of her story:

Dad was unwell most of my life, with arthritis, heart and gall bladder problems. We nearly lost him a few times. But as sick as he was, he was always there for other people first, especially Mum. Looking after Mum gave him something to keep him going.

He was a very private man and never really let on how much pain he was in. It was an everyday thing for him. He could be really stubborn too and wouldn't take enough of the pain killers that were prescribed for him. He often didn't say anything, but we knew that he was in constant pain.

Our family has experienced death before. Caring for someone at home before they pass has given us the help and support we needed to give them quality and dignity of life. I think I've learned a lot from those times and knew a bit about what to expect. I don't think I would of coped without the experience.

I think I came to accept death as a part of life. If we don't accept that people are going to die, then we can't deal with it and help them in their final stages.

Looking back I wouldn't have changed any of it – not at all. Knowing Dad wanted to pass at home surrounded by his loved ones made it easier for me to keep going.

One of the main things Dad wanted was to be at home with Mum. It was sometimes hard, and there were lots of dark times when I felt alone and I would just walk out of his room and cry.

But I wasn't really alone. I had strong support from my brother who played a big role in caring for our Dad. He did

things for Dad that he'd thought he'd never have to do. His wife would help with assisting with Mum and helped keeping the house and food in order. We had a lot of support from family, my kids and my brothers kids helped when they could.

One of the good things was having the support of Steve (Aged Care Clinical Nurse Consultant) and Annie (Palliative Care Clinical Nurse Consultant) and Bay and Basin Nursing Group (ie. the Primary Health Nurses from St Georges Basin). I could call them any time to talk about things. Sometimes this was several times a day.

We were grateful that Dr David Goldberg from Aboriginal Medical Service was able to be there to help and support us 24/7. Without him it wouldn't have been possible to have Dad at home until his final stages.

Violet (Aboriginal Liaison Officer) organised a couple of family conferences so that all the family could understand what was going to happen with Mum and Dad's care. It was really good for everyone to be involved.

Another important thing I learned was that Palliative Care isn't just about David Berry Hospital (Karinya). It's about the services that can be provided at home too. The OT spoke to us about organising equipment, and they spoke to Illaroo Aboriginal Corporation about getting a hospital bed for Dad at home.

They also helped with making sure Dad had the right medication, and offered a social worker for us to talk to.

There were lots of support services.

Sometimes it got confusing who was who. Sometimes they didn't turn up when they said they would and that was hard on Dad. Sometimes he felt overwhelmed and frustrated with it all.

Dad developed Bronchitis, we were pumping antibiotics into him, but then we asked ourselves who were we really doing this for, was it for Dad or were we being selfish and not letting him go. In the end he developed pneumonia which took his life.

Keeping him comfortable was the most important thing to us in the end. Both my brother and I were with Dad when he passed. It was so peaceful. I can't describe the feeling.

Angie went on to describe how her Dad had organised a funeral fund so that the family didn't have to worry about money to bury him. Angie said her Dad will be remembered as someone who always thought of other people before himself.



THE FIRST DOZEN - By Tom Avery

This painting tells of the journey of a 12 year old boy who lives in Milton. Some of his interests, including swimming, art and a love of beach culture are depicted in the painting. The artist Tom Avery has documented significant events in this young person's life, including the loss of a close friend.

JOHN'S STORY

"I am an Aboriginal man in my seventies. For 45 years I was an alcoholic. I drank metho too. For the last 15 years I have been dry. It wasn't easy: I had 11 attempts at detox up at Trevor Lodge, in Fairfield. It didn't help having the 'bottle-o' across the road from Trevor Lodge. I got dry at Oolong House. I ended up working there at Oolong House as a supervisor, helping other people, who were like I was once. It feels good to help people. When I am out shopping I see some of the young blokes I've helped and they shake my hand and say, "I'm dry today, Uncle." That is a good feeling.

I had lung cancer but they operated and it has gone now. I have x-rays to check that it isn't coming back. Before I had the operation I had to give up cigarettes because they wouldn't operate otherwise. That was really hard. I had to chew those nicotine lozenges to get rid of the cravings. I had key-hole surgery but they ended up taking out half my lung. That was a bit of a shock. I didn't know they were going to do that. Some advice I would like to give people is to make sure you know what they are going to do to you when they operate.

I had to see a specialist. The specialist sent me a letter telling me I had cancer. I took the letter to my local doctor who phoned the specialist. The specialist said I didn't have cancer, he said he just wanted to scare me into stopping smoking. That made me angry. It is disrespectful to try to trick people. My advice to people is to get a doctor who will listen to you. Get the right doctor.

Now the palliative care team visit me. I like them to visit because it is good to have someone to talk to. Sometimes I can go for days without having anyone to talk to. I still fall sometimes so I have a vital call. It is important to wear the vital call all the time, even in the shower. Once I fell and was on the floor for a whole day because the vital call was in another room. I was lucky someone came to visit that day. I have some good friends like Ivan Ardler who drives me to hospital when I have a nosebleed. I am back at Oolong too, as Chairman, and attend monthly board meetings with Ivan. It is good to be able to help people again.

Ivan's wife, Maureen, wrote this poem for me:

*"There are heroes who walk among us, never looking for glory or praise.
They don't seek recognition, for their thoughtful, caring ways.
Living lives of deep commitment, providing for those they hold dear,
Steadfast with a quiet strength, through times of laughter and tears.
You are a person like that to us, the most selfless man by far.
So John, we'd like to thank you for being the HERO that you are."*

It is good to have friends who know you, respects you and cares about you when you are sick.



A CLOSE ENCOUNTER - By Eileen Hampton

The painting depicts the story of a life threatening experience where the story teller had collapsed and stopped breathing for a number of minutes. The painting reflects the spiritual intensity of that few moments and also celebrates the positive impact on the story teller of this artworks' life changes.

GONE FISHING

Ray Smith told his story about being diagnosed with something they originally thought was a cold sore 15 years ago, which turned out to be a cancer. Despite four operations on his face, and cancers removed from his head and legs, the cancer continued to spread into an artery in his neck. Early 2014 his cancer specialist said they couldn't operate as it might end up giving him a stroke. Treatment after that focussed on helping him stay active and comfortable.

Here are a few things Ray, and his daughter Karyn Knopp, wanted other people to know about his journey with cancer:

"When they said they couldn't do nothing, it hit me like a ton of bricks.

They sent me to another doctor for radiation to try to help with the pain. The pain was shocking. The radiation helped a lot though. It reduced the size of the cancer in my neck from the size of an egg to something you could put a Band-Aid over. But it came back again within three weeks.

The next scan showed that that it had come back more vicious than it was before and had moved into my lungs. That was about a month ago.

They said they can't give me a time for anything. It's not like a light switch they can turn on and off, but I was told to get everything organised – things like my funeral, power of attorney, get a list of people who they have to let know once I do go.

I've had a lot of support from people who come around here. The outside help is much appreciated. I get help from the chemist – they have been great. And there was a dressmaker who offered to make me a special pillow to take pressure off my neck when I lay down. It's a good community. I've lived here all my life.

I worked at the Youth Centre down here for over 16 years, and it's only in the last fortnight that I gave that work away. I felt in myself I had to give it away, because

I'd get that cranky with the pain I was in, I was worried that if the kids did something I'd just break out and I didn't want to risk that.

It's been important for me to do what I can when I can, but the pain stops you. If someone asked me what my pain levels were out of 10, I'd say 15. That's not all the time. The medication stops it for four or five hours before I have to take another tablet. But there are also days when I can do things, like today. It's sore all the time, but you can work through the pain a bit.

They are getting better at sorting out the pain now. There was a time when I couldn't get off the floor for two days, and they gave me something that didn't agree with me at all. I was that sick. It was then that I thought 'I'm ready to go', and I got everyone to come down. That's how bad I was.

I now take a smaller tablet, and have a patch, and take some concentrated medicine instead. In the past two or three months I've only been sick one day. I can't swallow tablets very well now. I know there are a few other things they can try for the pain too. They'll tell me when it gets to that I'm sure.

People wonder why I get so cranky. It's mostly the pain, but one thing that gives me the horrors is that I have to be here all the time. I can't do nothing - like go

on a holiday to South Australia. I've got to be here every day to get things done here - dressings, tablets, flush the PICC line, chemo, to see a doctor, to see a nurse. I'm going to a wedding soon in Queensland and I'm trying to get services organised for the ten days I'm away. The Cancer Care Centre staff are trying to help get it organised.

They can do it for people on dialysis, why not cancer?

I'm still going fishing on the weekends. I haven't given anything like that away. Karyn helps me with the Fishing Comp write ups I do too. I think it's very important to keep doing things you love.

If you don't keep going you might as well not be here. In my opinion if I couldn't do what I'm doing, I'd be lucky to last a month.

I don't get too tired. I rest a bit and take the pressure off having to keep my head up all the time. When the tablets kick in I can feel a bit tired.

If I had to give advice to other people who might have to go through this sort of thing, it would be to talk to people to help you understand what's going on. To talk to people who can tell you about what's happened to other people and how they dealt with it, can help you pick up bits and pieces along the way.

And don't give up what you're doing for as long as you can. You might have pain, but when you're doing something you love you can tell yourself it's not too bad and get through it better. And if you can't do it today, you can have another go tomorrow.

And I love my music. I listen to music a lot. Some days that's all I'll do, listen to music all afternoon. You just need to keep yourself occupied. Sometimes family or friends come to visit, and we do bit of cleaning out of the shed. I don't stress about it, but these are the things I'm trying to clear up.

There are things like my superannuation that I have to sort out too. If you don't, you can lose it. The solicitor told me about writing out what I want (an Advance Care Directive) when I got my Enduring Power of Attorney done. I've got a simple letter here, and a bigger one too that he's got and one with the doctor. But basically it says I don't want to be resuscitated when my heart stops.

When I'm gone, I want them to scatter my ashes down at Tomerong Island, and maybe put up a sign up there to say that Ray's gone fishing."

Ray Smith died two months after he told this story. He will be missed by many.

Read Karyn's side of this story on the next page >>



GRASS ROOTS

By Ben Brown

Artist Ben Brown has depicted a Manyana resident who is actively involved in community life and is passionate about protecting nature and coastal environments. Ben has used symbols such as animals to reflect events in the story teller of this artwork's life.

GONE FISHING (KARYN'S STORY)

At the time of writing this story, Karyn served as her father's carer and describes the pain Ray was in from the ulcer on his neck. She said the ulcer came up after a number of needles he had to have before they put in the PICC line (a needle which stays inserted for long term IV treatments).

"The ulcer started like a pin hole and now it's huge. He used to dread getting up every day because the dressing had to be changed. It would really drill him.

I've been doing Dad's dressings ever since he had his mouth done. A lot of it's been trial and error. A lot I've picked up from my sister who cares for the elderly. But I've virtually taught myself. By the time the community nurses got involved, I already knew what to do. And whenever Dad had a cancer cut out on his legs or on his head, he'd tell them that I'd do the dressings. He just didn't trust anyone else, and he's still like that today.

If I had to give advice to the nurses, I'd say it's important to have someone with them who can write a script at the time (of their visits to Dad), but they aren't qualified (to write scripts). So we basically had to wait until he had to see the oncologist again to discuss a nerve pain drug with him, so HE could write the script. Dad could have been out of pain a lot earlier if the nurses had been able to do it*.

According to the Community Nurse (also known as the Primary Health Nurse) the next step is to get another referral for the Palliative Care doctor to see her again.

Lots of different pain medications were talked about for Dad. Patches, tablets, injections, lozenges. Some of them don't agree with him. It's a bit of a balancing act.

Ray: Karyn's been doing all the caring, but doesn't put in for any money to do it, and I think that's wrong. I'd like to see her get some money to compensate her for the money she's paying out for being here organising my medications and things, and spending on stuff for me.

Karyn: I don't really care about that stuff. I just want to see him comfortable. I give him a massage twice a day. It doesn't last long, but it feels good for him while I'm doing it. A bit of relief. I learned how to massage when my ex-husband's back was bad and someone showed me how to find the muscles that were hurting – you can feel them. And Dad can tell where he needs it most.

Yes, he gets cranky. And sometimes I think that he thinks I'm trying to hurt him but I'm not. Sometimes we have words, but once it's said we both get over it and it's forgotten.

I'll be worried when he stops going fishing."

* Primary Health Nurses work closely with GPs and the Palliative Care Specialists. Work is currently underway to make sure that scripts for emergency medications are written in advance of when they are needed, to make sure people can be out of pain as quickly as possible.

What Cancer Can't Do

Cancer is so limited
There's only so much it can do.
It cannot cripple love
If the love you have is true.

It cannot shatter hope
Or dissolve the faith you've got,
And it can't destroy the peace he has,
And by God he's earned a lot.

It cannot kill the friendship
Or the memories we have.
And it cannot silence courage,
Which in one word was our Dad.

It can't invade his soul,
And I know that this is true,
'Cause now you have him up there God,
His soul belongs to you.

Written by Karyn Knopp before her father's death and read at his funeral, at his request.



AN UNCOMMON PRACTICE - By Ben Brown

This painting is the story of a woman who overcame cancer and has strong spiritual beliefs in witchcraft. The Shoalhaven resident has a New Zealand heritage which is symbolised by the Silver Birch trees which are common in New Zealand. Artist Ben Brown has used the Butterfly to symbolise the story teller of this artwork's ability to overcome adversity.

MAKING HIS OWN DECISIONS

Marilyn Brown spoke on behalf of her family about her father's journey Uncle Benny (Brown). Uncle Ben died in 2009 at the age of 81 years from lung cancer. Here are some things Marilyn said might be useful for other people to know:

“Dad was diagnosed with lung cancer in 2008. He lasted about 12 months after he was diagnosed. He knew it was the end of his innings, and only really had a week or so of radiotherapy treatment to help prolong his life a little bit further.

Dad knew what he wanted. He didn't want to die at home and always planned to go David Berry Hospital for the final part of his journey. We said to him, “Dad, when you are ready to go, you go”. He made his own decisions, and was always an independent man.

He lived in his Elders unit on his own for about 12 months after he first got sick, apart from about six weeks at the start when his lung collapsed after some tests. He went to intensive care and we thought we were going to lose him then. All the family came to the hospital. They ended up giving him a private room to cope with the visitors. Hospital staff need to understand that it's customary for Aboriginal families to be with a loved one who is dying as a sign of respect; it's a part of our tradition; an expectation.

With ten kids in the family, and extended family, there were always a lot of people at the hospital, we made sure there was never any more than about six people in the room at any one time. If there was more than that, then people wouldn't have gotten their own quality time with him.

Months later, when he went to David Berry Hospital, the nursing staff would only allow two people to be with him at any one time, so we spent most of our time outside in the garden. I think things have changed a bit in the last five years in this regard and they are better about having family there now. The nurses wanted him to rest, but we knew he would have expected people to be there out of respect. That's important for nurses to know.

Another thing that is important to know about is discharge plans. When Dad first came out of hospital, there were a few things that had to be put in place before he could go home – like meals, showers and domestic care. This is part of the discharge plan. I think the doctor needs to be the one to make sure these plans are in place. The plan helps people know where they need to go next, who to see, who to call if there are problems – a proper holistic plan. If the discharge plans aren't talked about, families should request one to be done before they leave hospital. Otherwise people can slip through the cracks and not know where to turn for help.

The Aboriginal Liaison Officer at the hospital and the hospital Social Worker are good people to talk to too. It's their job to keep on top of what services are available, and to give you options.

My oldest brother and oldest sister were the ones from the family who spoke with the doctors and hospital staff about Dad's care. They would always talk to us about what was discussed, and we went with what they decided. We are a very close family and there were never any arguments. We respected that what was decided was what Dad wanted.

Even with the services that came to help Dad in those early days, the family still got a roster together to make sure he wasn't alone while he was recovering from the lung collapse. Everyone did their bit, including the older nephews and nieces. He couldn't get off the lounge on his own. He needed help to get to the toilet, and with things like his oxygen, for about six weeks. But as soon as he was well enough, he was off the oxygen and back to his usual routine – going to the club and the daily raffles.

He was very involved in the community too. He was on lots of advisory committees around town, like Council and the Hospital, and helped with flag raising ceremonies and Welcome to Country talks for NAIDOC Week at schools and other places.

He kept that involvement going for as long as he could. Even when he couldn't drive any longer, he'd get other people to drive him places. Once he had the services in place to be able to get around, he handed in his licence. He knew it wasn't safe.

He was always independent. He had to learn how to look after himself from an early age, as he was in care until he was nine years old. Giving up his independence was hard for him – especially his financial independence. I think that's why he wasn't really happy in an aged care facility, this absorbed most of his pension and he had to ask the family to buy the personal things he wanted.

He was only there a couple of weeks before he called me to take him to David Berry Hospital. I remember taking photos of him with my boys on his lounge and he said “You know I won't be coming

home from there”. He was right. He died three days later. But he felt comfortable there and it was the right thing for him.

Some people won't go to David Berry Hospital because of its history and that choice is respected, but it didn't worry Dad. He was really into reconciliation and we didn't know until he was there that he had even planted a memorial tree at David Berry Hospital. We think we worked out which one it was from a photo my Eldest sister has.

People have the right to decide where they want to die, and if they want to die at home, the Community Palliative Care team can help, and so can David Berry Hospital. They can get your medications sorted out and help you to be at home again if that's what you want.

Dad had everything organised. He even organised his own funeral. Just like Mum (who died in 2002). She refused treatment when her heart problem was diagnosed and she knew she could go anytime. She planned everything as well, right down to the flowers and the coffin.

We were lucky that Dad was able to do things and make his own decisions. That gave us a lot of peace.

Even after he died, there were little things that happened that reassured us that he was still around for us. He was very proud of the family and I see my eldest brother following in his footsteps, supporting and encouraging us. We are very fortunate and grateful to have had him as our Dad.”

JENNIFER'S MEMORIES

" I have a lot of sickness. I have cancer, diabetes, arthritis and anaemia. I also have Alzheimer's disease which leaves gaps in my memories, but I can remember my childhood really well. I was raised on a 200 acre property by my grandmother, who was white and my grandfather who was Aboriginal. My grandfather was a Light Horseman during the war. He loved animals and brought his horse back to Australia with him. He had a pet goanna called Francis and a pet pig called Daisy. Daisy used to sit on granDad's lap until she got too big. My twin sister and I used to sit on his lap too. He was the only one who could tell my twin sister and me apart. He was our protector and would hide us saying, "The gypsies are gonna come and take you." When I grew up I realised the gypsies were the government men.

One day my brother, sister and I went looking for rock orchids. We climbed up a cliff face and found a cave behind a waterfall. The walls of the cave were black with soot, which we got all over our clothes. There were worn bits of rock inside. It felt special in there. My sister and I took off our plastic bangles and left them there on the rock. When we got home we told our grandfather and he said we had found the ancient cook house and told us not to tell anyone where it was. Our grandfather taught us that you only need a few sticks and you have a house and if you can't afford a holiday just find a pine tree to play in. He died when I was nine. I saw him for a moment after he had died, standing under the clothes line, wearing his favourite vest.

Living with sickness is hard. I have also lost a lot of family members like my twin sister and my granddaughter. The sadness of that never leaves me. But, I can still knit and crochet. I go to Aunty Jean's programme and next week I am going to the Koori Olympics. I hope I win a medal. Every morning when I wake up I think, "I'm still breathin'."

A YOUTH WELL SPENT

- By Eileen Hampton

Artist Eileen Hampton has depicted the story teller of this artwork's fondest childhood memories in Sydney, including the Commonwealth Day Fire Cracker nights. The story teller of this artwork resides at Narrawallee and loves bush walking, the beach and technology.



