

PALLIATIVE CARE

*for Aboriginal and
Torres Strait Islander People*

Support
Teams

Training
Opportunities

Models of
Excellence

People's
Stories

Where
to Go

You're not
Alone



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Names and photographs This magazine does not contain any photographs of people who were ill or had passed away at the time of publication. Permission has been granted for the use of all photographs and images. Names of people who have passed away have been used only where that is the family’s wish and this accords with local custom.

Additional copies of this magazine are available from the Australian Government Department of Health and Ageing, by contacting the freecall inquiry line on 1800 020 787 or emailing palliativecare@health.gov.au. You can also download copies from the National Palliative Care Program website at www.palliativecare.gov.au.

Cover photos (left to right): Annie Milgan; Paul Munn; Pat Morris, Joel Chapman and the Kempsey Palliative Care Team; Robert Cole; and Kerry Wade.



ISBN: 0 642 82541 6
Publication Approval Number: 3532

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This magazine was produced by Kate Sullivan and Associates Pty Ltd on behalf of the Australian Government Department of Health and Ageing.

Artwork:
“Bush Tomato” by Patsy Kemarre, Dacou Aboriginal Gallery, South Australia (D9 00900).

Design and layout:
Jeffery Design & Associates Pty Limited

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Special thanks to everyone who took part in this project:

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Introduction

“There are many ways of caring for a sick person.

Everyone is different and special.

People might belong to different cultures or countries or they might speak different languages.

So it’s really important to look after them properly their way.”

Many Ways of Caring –
the Aboriginal Palliative Care
Paintings Project, central Australia

The time of caring for someone who has a life-limiting illness is a special time, and it can be tough and difficult. It can be a roller coaster ride of highs and lows for everyone concerned. There is often sadness and worry, emotional stress, and hard physical work. There can be laughter too, and treasured times that will always be remembered.

At times like these, people look to their families and communities for support and help – but other help is available too, from palliative care services all over Australia.

Palliative care offers many different kinds of medical, nursing and practical support to the person who is sick and to the family and friends who are caring for them.

What is palliative care?

Palliative care is care for a patient and their family when someone has a life-limiting illness and will not get better.

- It aims to provide the best care and quality of life possible, including physical and spiritual comfort.
- Palliative care can be given at home, or in a hospital, hospice or nursing home.
- The main aim of palliative care is to help the family look after the patient in the way the family and patient think is best.

Why this magazine?

A national study* on the palliative care needs of Aboriginal and Torres Strait Islander people in Australia was done in 2003. This study showed that Aboriginal and Torres Strait Islander people need much more information about palliative care, and much greater access to palliative care services.

This magazine is for Aboriginal and Torres Strait Islander families and for health care providers who work with Aboriginal and Torres Strait Islander people.

Thank you

This magazine includes many real life stories of people who have been helped by palliative care, as well as personal stories from Aboriginal health workers, hospital liaison officers, doctors, nurses, educators and others who work in palliative care services.

We sincerely thank everyone who took part, especially those who shared their personal stories, for so generously giving your time and experience to help others.

Claire Colyer and Kate Sullivan, Editors

* The National Indigenous Palliative Care Needs Study
(available from the Australian Government Department of Health and Ageing,
National Palliative Care Program website, <http://www.palliativecare.gov.au/publicat.htm>)

A model of excellence

A couple of years ago, Gordonvale hospital was a small rural hospital in a quiet country town, about half an hour's drive from Cairns.

Today it is a thriving 'Centre of Excellence' for palliative care and has a key role in an integrated palliative care service for the whole Cairns district.

As a hospital, it is still small, with 12 palliative care beds. Now, though, it has a community outreach service which provides equipment and nursing services for clients at home, a social worker who supports patients, and meals on wheels that provides 60 meals a day from the hospital's kitchen. Newly renovated live-in accommodation for family members is now available in the hospital grounds, and Gordonvale also offers clients a 24 hour, 7 days a week consultancy service, so clients can ring at any time and talk to someone they know for advice and support.

The integrated service links Gordonvale with other parts of the palliative care team at Cairns Base Hospital. It means that patients stay with one service throughout their illness. "We can follow the client from the community, to hospital, to home again and stay with that client all the way," says Bronwyn Luxon, the Director of Nursing at Gordonvale. "It's a unique model. There isn't another one like it, and the staff really love what they do. Everyone has the patient's best interest at heart."

Close to large Aboriginal populations in Cairns, Gordonvale and Yarrabah Aboriginal Community (which has a population of about 3,000 people), Gordonvale Hospital has many Aboriginal and Torres Strait Islander clients, even sometimes including people who live in the Torres Strait.

Gordonvale has also given palliative care training for Aboriginal health workers, both local and as far away as Thursday Island, and has joined the Program of Excellence in the Palliative Approach (PEPA), hosting the program's first placement of an Aboriginal health worker in 2004 (see story page 15).

Bronwyn believes there are several reasons why Indigenous people feel comfortable coming to Gordonvale. One is that the hospital itself is welcoming

and friendly, and employs Indigenous staff. "What makes it special is that it's not a big daunting brick hospital. It's got a very friendly feel about it. The staff are excellent nurses and put the patients at ease. We have some staff members who are Indigenous and that makes people feel even more comfortable. It makes a big difference," Bronwyn said.

Another reason is the long association between Yarrabah and Gordonvale. The hospital is well-known and well-regarded by Yarrabah residents. Bronwyn has worked with Indigenous peoples for most of her nursing career. Her ties to Yarrabah go back to 1977, and in 2000, she was acting Director of Nursing there. Bronwyn keeps a close working relationship with Aboriginal health workers there and in other local communities.

Paul Munn, the Aboriginal palliative care coordinator at Yarrabah, agrees that people in his community are happy to go to Gordonvale. "They love Gordonvale. I've heard wonderful reports that the staff are lovely and that it's a really nice place to be. Bronwyn is a wonderful, wonderful person. She's the right person for the job."

"I've heard wonderful reports that the staff are lovely and that it's a really nice place to be"

Bronwyn says that hospital staff also do their best to understand cultural sensitivities and totally support family members to come and stay at Sunbird Lodge, and patients having as many visitors as they wish. The staff also support families to grieve the death of a loved one in their own way, welcoming family and friends who come to say their farewells, and encouraging them to stay as long as they want.

"When you have an Indigenous client who has died, large numbers of people arrive and they like to spend time with the person and stay with them as long as they possibly can. We understand that – it's important that the relatives feel comfortable coming here, and the staff are really good. I hear wonderful feedback about my nurses. It's a very nice atmosphere."



Bronwyn Luxon outside the Palliative Care Unit, Gordonvale



Paul Munn is an Aboriginal Health Worker at the Yarrabah Community Health Service. Five years ago he began working in palliative care and now coordinates all palliative care for the community.

“There was a need there, and suddenly I was doing it. I was working in aged care and one of my clients needed palliative care. I coordinate the care of palliative care patients. The Medical Officer is in charge of the care and I just bring it all together.

“My work ties in with Gordonvale. It’s a resource place for me. The community nurses come and visit once a week if I need them. If the need is greater, I just give them a call and they come, and to support me as well.

“We get our patients respite at Gordonvale, or if they want to they can choose to pass away there, or at home, or at the service here. In this community, people like to die at the hospital, but just lately one of the recent deaths here was at home, and it was really quite beautiful.

“I think cross-cultural awareness training as a component of training in palliative care would make a huge impact. People are more comfortable if I’m there, whatever the service is – physiotherapy for example. The protocol here is for a health worker to assist them on the first visit. It makes the job a lot easier – it’s all about building rapport. I think the harmony between the Aboriginal and non-Aboriginal workers really helps. If they see that there’s a good working relationship there, and they can see that I trust them, then they’re going to trust them.

“It takes a special person to deliver palliative care. Sure, you have to be strong – but also you’ve got to have a heart. People are frightened, it’s really life-shattering to learn you only have a short time to live. My fulfilment is just being there for them.

“I’m passionate about what I do. It is an honour and privilege to serve my people and be able to help them.”

Getting in touch with palliative care - *sooner is better!*

If you are caring for someone who will not get better from their illness, it’s important to start thinking about palliative care. Palliative care is not only for people who have cancer, or just about sending someone to hospital or a hospice. During the National Indigenous Palliative Care Needs Study research one of the most common things people said was that they wished they had known much earlier about palliative care – and the sooner you contact them, the better.

Getting in touch with the palliative care team in your area doesn’t mean you have to start using their services straight away, or that you have to give up your own doctor.

What it will do is give you useful information to help you and your family in making decisions and give you a chance to start getting to know the team, so if you do decide you want their help, they won’t be strangers. Palliative care workers are specially trained to care for people and families in your situation, but your own general practitioner (GP) or specialist can also become part of your palliative care team.

If you feel you might want to use a hospice from time to time, the palliative care team can also arrange a visit well before you need to use it, so it will not be an unfamiliar place.

Ideally, your specialist, GP or Aboriginal Medical Service (AMS) doctor should put you in touch with palliative care when the family is told that the sick person will not get better. However, palliative care is a new field and some doctors do not know a lot about it. If it is not offered, ask your doctor or Medical Service for information or to find out for you.

You can also find out about palliative care services in your area by contacting the palliative care organisation in your state or through the national body, Palliative Care Australia. Contact details are on the back cover of this magazine.

Indigenous Palliative Care Resource Kit

The Wodonga Institute of TAFE, in partnership with Mungabareena Aboriginal Corporation and Mercy Health, has developed a comprehensive resource kit (including practice principles) to help mainstream palliative care services to give culturally appropriate palliative care to Aboriginal and Torres Strait Islander peoples. To get copies of the kit, please phone 1800 020 787 or email palliativecare@health.gov.au. More information is on the project website at www.indpac.org.au.

“I’d just have to ring and she’d be there”

Pat Morris lives on the mid-north New South Wales coast. For almost three years, she nursed her son, Tom, at home through his illness from lung cancer. Pat says she’d gladly do it all again, even though she carried the load largely on her own.



Left to right: Sue, Pat and Joel.

Sue Thompson is a palliative care nurse who became involved about 12 months after Tom became sick. By this point, Tom could do almost nothing for himself, Pat says, except “sit on the bed and make you laugh”. Tom’s doctor, a family friend, urged her to get help from the Palliative Care Team at Community Health in Kempsey.

As Sue says, “Caring for someone who is sick is a pretty big ask. It’s 24 hours a day, seven days a week. Tom’s condition and his pain were getting worse – it was getting hard for Pat to manage him, and Pat had health problems of her own.”

At first Pat wasn’t sure. She felt she should be able to look after her son herself. “I thought about it a few days. I thought they’d be stuck up people, and my house wasn’t what you’d call real clean because I was looking after Tom all the time. Then I thought, well they can’t be all that bad. If they’re going to come around and look at sick people all the time, they must be pretty good. They wouldn’t judge me for what my house is like.”

Sue came over to assess what Tom needed as a patient, and what Pat’s needs were. At first equipment for Tom was needed, but over time it became more difficult for Pat to care for him.


“I had to start looking at how to support Pat and help her get through it as well,” Sue said. “That’s when we started to look at what services we could get that would help Pat with the hands-on care – showering Tom, cleaning – that’s one less stress on Pat.”

Sue’s search for support for Pat led to Booroongen Djugun Aboriginal Corporation. Booroongen combines an aged care facility, community-based services, and a training college for the Kempsey area. Sue and Pat were amazed how quickly they responded: “We rang up on the Friday and Kerry was here on the Monday morning!”

Kerry Wade is the Community Aged Care Packages (CACPs) Coordinator at Booroongen. She was able to put support services in place in a just a few days. A male carer came in to bath Tom, support workers started coming regularly to clean up and mow the yard and help Pat with the cleaning, and to provide company and transport for Tom when needed. A ramp was put in for wheelchair access. Later, a hospital bed was provided.



*(Left to right)
SueThompson,
Pat Morris,
Joel Chapman,
Paula Hicks,
Vicki Hope*



Meanwhile, Pat continued to care for Tom and to give his pain medications, with support from the Palliative Care team. “Sue was fantastic. I’d just have to ring her and she’d be there,” says Pat, “and Tom had a lot of faith in her. If anyone else gave him a needle, he’d always say ‘Sue would do that better!’”

As well as home visits and liaising with the client’s doctor, Sue’s job is to advocate for her clients. “I was talking to all the different services – being the resource person and keeping it all together, keeping track of everything and communicating with everyone, always on behalf of what Tom wanted.”

At times Pat and Tom both needed a break. Sue arranged short-term respite care at Kempsey Hospital, which has special rooms reserved for palliative care patients and families. With a bathroom, kitchen access, dining room setting, TV and sofa bed, family members can live in, or visit 24 hours a day.

Sue and Pat were amazed how quickly they responded: “We rang up on the Friday and Kerry was here on the Monday morning!”



Left to right: Vicki, Paula and Sue – Palliative Care Team.

Pat and Joel, the family friend who helped care for Tom in the last few months, described it as ‘a fantastic place to stay’, and said they felt no barriers from the hospital or the staff. “Everyone was really nice to us”, said Joel. It was at the hospital that Tom passed away in March 2004, after a short admission at his own request.

All of the palliative care team – Sue Thompson, Vicki Hope and nurse consultant Paula Hicks – worked with Tom at some point, and remember his special sense of humour. Strong bonds remain and Pat is still a client, calling Sue whenever she needs to.

Tom passed away just two months before Pat gave this interview. Although her loss was very recent, Pat wanted to share her story. She hopes telling about her good experience of palliative care might help someone else.

Planning ahead

Planning ahead for the funeral arrangements you want and the costs involved can take a lot of pressure off later. It’s a good idea to talk to two or three funeral directors. They should give you written information about what is available, the prices and any other costs. Planning ahead gives the family time to think about all the options and how the expenses can be managed.

When the person passes away and you have chosen a funeral director, they should give you a written estimate of all the charges and expenses once they get your instructions. In some states and territories, financial assistance may be available through a local or regional land council. It is also possible to arrange a prepaid funeral.

For information, contact the Australian Funeral Directors Association on 1300 888 188 (free call except from mobiles) or website: www.afda.org.au.



Kerry Wade with interviewer Kerry Welsh at Booroongen Djugun

Working Together

One of the biggest barriers to Aboriginal and Torres Strait Islander people accessing palliative care is lack of knowledge – on both sides.

Many community members haven't heard of palliative care and community organisations may never have had any contact with a palliative care service. On the other side, palliative care workers often do not know very much about the Aboriginal community, or where to start to make contact.

In Kempsey, on the New South Wales mid-north coast, palliative care nurse Sue Thompson didn't have much opportunity to work with Aboriginal communities until she nursed Tom Morris (see Tom's story on pages 4-5). She found it a huge learning experience, and the starting point for working with local community organisations, such as Booroongen Djugun Aboriginal Corporation which provided home and community care services for her client.

"I learnt about families and about who to deal with in the family, how many people may be involved, and I learnt more about the Aboriginal community and the services, the programs they are running and what they can do for people," Sue said. It opened a door to becoming more involved with the community.

For Kerry Wade, the Community Aged Care Packages (CACPs) Coordinator at Booroongen Djugun, it was an opportunity to learn about palliative care and to work together with another organisation.

"That was a new field to us, when I put the service in. We did our area, the home care side. The medical area took care of theirs, and what palliative care had to do, they took care of that area. I think everyone complemented each other, and that's how things get achieved," Kerry said.

From this beginning, new relationships are building up in the community. Booroongen has invited the palliative care

team to come to network meetings of all the Aboriginal Home and Community Care (HACC) services for the entire region to talk about the palliative care service. Booroongen also runs a training college, and now there are discussions about a combined course to train volunteers in palliative care.

Contact has also been made with the Durri Aboriginal Medical Service in Kempsey, and that has led to an invitation to attend Health Partnership meetings with the medical services in the region.

The palliative care team – Paula Hicks (Palliative Care Nurse Consultant), Sue and Vicki Hope (nurse) – is taking a gentle, but persistent approach to building relationships and raising awareness.

"Really, it's word of mouth," says Paula, "and saying that we're willing. We're not saying 'hey, you need us'. It's ringing up and saying 'We're in health, we have this service. Can we come one day and tell you about it?' Through the meetings we're starting to find out what people need and how we can help. Now we are confident that

people want us and want to know. People are seeking us out."

They have found many ways to help. In cases where the family might be unsure about having a non-Aboriginal person visiting their home, the palliative care nurse might go with an Aboriginal worker at first, or stay right in the background and just provide support and advice over the phone.

"We want to support our whole community – everyone. We understood people may not be keen to access our service, so we are looking at ways of reassuring people, letting people know about the service and trying to build bridges."

"In cases where the family might be unsure about having a non-Aboriginal person visiting their home, the palliative care nurse might go with an Aboriginal worker at first, or stay right in the background and just provide support and advice over the phone."

"We want to support our whole community – everyone."

A sister's story

Peggy Hampton is a home care worker with Wangary Home Care in Western Sydney, helping to look after the 100 clients on Wangary's books. Depending on what the client needs, she might help them with shopping, housework, or personal care like showering and dressing. When Peggy's sister Connie became ill, she was able to help her father, Alf, giving Connie this same support at home as one of her clients.

Connie was 37 when she was diagnosed with an aggressive form of breast cancer in December, 2000. Her young son, Joshua was four years old. Her doctor at Daruk Aboriginal Medical Service referred her to specialists at Westmead Hospital who diagnosed the cancer and referred her on to the Nepean Cancer Clinic for treatment.

For the next few months, the family looked after Connie. "Mainly, it was just Dad and myself and my three daughters. He provided all the meals, did the washing. Really, he's the one who did the bulk of all the caring at home," remembers Peggy.

Peggy recalls the demands on the family: "It's not just the physical load. It's the emotional and mental load that you have to carry, because there are so many people in the family that you're looking after. Mainly, the person I was concentrating on was Connie, her welfare emotionally and mentally.

I wanted to make sure I was doing what she wanted."

"Judy was very kind and patient. She went above and beyond – she was like a friend really. Connie needed that support."

In Connie's case, palliative care services did not play an important role until the last stage of her illness. For several months, her pain relief was managed by her own doctor, Dr Judy Meldrum, from Daruk Aboriginal Medical Service, who came to home regularly while the family did the rest.

"Daruk were the biggest support from word go. Judy

was very kind and patient. She went above and beyond – she was like a friend really. Connie needed that support."

Then Connie went downhill and her doctors wanted her in hospital for medical care. There the hospital's Aboriginal Liaison Officer was a great support. "While I was at the hospital I was always looking for the Aboriginal worker. If I had any questions or wanted to find out anything I'd go to her," Peggy said.

The hospital stay was only for a couple of weeks, as the illness progressed quickly. Finally, Connie and her family wanted her to come home. When Peggy told her doctor and nurse, she was referred to the palliative care nurse.

"I told the palliative care nurse that Connie was going home tomorrow and I'd like a hospital bed to make it easier for Dad and me to be able to help her."

The response was immediate. "Once she knew what we wanted, she just went straight in and did it. We got the hospital bed, the commode, a chair – all the equipment we needed, because of that palliative care nurse. She faxed it and rang through straight away to Mt Druitt Hospital. Mt Druitt got the information and I went there and picked up some things, and the hospital brought the bed out. Everything was set up there before Connie came home."

At the last minute it looked as if, after all, the family might not be able to bring Connie home as she was too ill for Peggy to take her home by herself and no ambulance was available. Peggy had the presence of mind to ask to speak to an Aboriginal Liaison Officer. With her support, a private ambulance service was arranged.

"She spoke up for me. It was a very emotional time. It was them that helped me get her home."

Connie passed away in August 2001, just two days later. She was at home, as she wished, with her family.



The Hampton family. Back row left to right: Teagun; Nathan; Taleah; Shannon; Koorine. Front row: Alf holding Josh and Jasmine

Carers need care too!

If you are a carer, you're not on your own and you shouldn't be. There are a lot of resources to help carers.

Commonwealth Carer Resource Centres in each state and territory can refer you to services and give you practical information to help you, all for free. Contact Commonwealth Carer Resource Centre on 1800 242 636 (free call except for mobile) or visit the website <http://www.carersaustralia.com.au>.

Reaching out to communities

Karinya is a small palliative care inpatient unit in the David Berry Hospital, just outside the small town of Berry in the Shoalhaven region on the New South Wales south coast. The main population centre is Nowra, about half an hour's drive to the south.



Social worker, Peter Lawrence divides his time between *Karinya* and the Shoalhaven Palliative Care Team at Nowra Community Health Centre, where he works as a counsellor.

The region has a large Aboriginal population, and Peter would like to see more Koori people taking advantage of the resources and services that the region's palliative care services can offer.

"My feeling is there are a lot of Koori families who would benefit from palliative care. People can come into *Karinya* as public patients, so it's free.

We have nurses, a physiotherapist, an occupational therapist, a pastoral care worker, a social worker - all laid on. It could be just a week, to give the family a break or for symptom control, or for end of life care."

Peter is working with some Aboriginal families, but feels there are more who either aren't aware of the service or who may be reluctant to use a mainstream service.

"It's hard to have mainstream services suit your needs perfectly, and I think it's cultural fit that we're probably struggling with. It's finding a way that the cultural experience of Aboriginal people can be somehow met in a more fitting way."

Peter recognises that a lot of people, not just Koori people, have some fears about *Karinya* because they feel it is a place where people go to die. "That's how people feel in the community, unless they've been here. The families that have been here and used the resources, Koori or not, mostly say: 'It's wonderful'."

One way to break down barriers was to invite people to come and see for themselves. First the team approached the South Coast Medical Service Aboriginal Corporation and the Koori Healing Service in Nowra and spoke with the organisers of the forthcoming Safe Communities conference to ask if they could make a presentation about palliative care.

"They were really happy about that, so we had a workshop session and talked about the services that we offer and ways it might be able to be made more 'user friendly' for Aboriginal people."

At a follow up session the next day, a proposal was put forward to have an open day at David Berry Hospital, focussed on *Karinya*. The idea was supported by the community, so Peter started contacting the local elders' groups. Many of the elders accepted the invitation to come and visit *Karinya* and enjoy a tour, a barbecue and a yarn about palliative care.

The open day was held during National Palliative Care Week in May 2004 and proved quite a success. Some of the visitors had been born at David Berry Hospital and one family remembered driving down in a horse and sulky from the coastal town of Kiama. At one time the David Berry Hospital was the only hospital in the region that would accept Aboriginal patients; even so some spoke of painful experiences they had had there in the past.

The open day was a first step towards opening doors. "A lot of people were feeling it would take time. Transport was raised as a concern, and the main thing was to have Aboriginal people working here. That was a sadness for them, I think. They saw that as a key to Aboriginal people feeling at home."

"It's that feeling comfortable, feeling safe - having a climate where people know they will be accepted and treated fairly and in a caring way. I think they felt that was the most important bridge to cross."

Cultural Safety

The concept of 'Cultural Safety' was pioneered in New Zealand by nurse and nurse educator Dr Irihapeti Merenia Ramsden. It means:

"An environment which is spiritually, socially and emotionally safe, as well as physically safe for people, where there is no assault, challenge or denial of their identity of who they are or what they need. It is about shared respect, shared meaning, shared knowledge and experience, of learning together with dignity and true listening."

"Unsafe cultural practice is any action that diminishes, demeans or disempowers the cultural identity and well-being of an individual or group. Past unsafe cultural practices are a major factor in Indigenous peoples' abhorrence and distrust of research and service delivery in general."

Things have really changed

Nola White is the Nurse Unit Manager of the Indigenous Health Service at Inala Community Health, in an outer suburb of Brisbane. Over a lifetime career in nursing, and through her own family experiences, she has seen huge changes in the care of people who are terminally ill.

“When I was a very young nurse in the 60s at an outer suburb hospital of Brisbane at Ipswich, nursing terminal patients in the hospital system was really traumatic. We used to nurse them just in a ward, and at the end they used to put them in a different room, or if there weren’t rooms available, they just put a screen around them. It seems terrible, but that’s the way it was. There wasn’t a lot of family support. They only came up at visiting time. To me, looking back, it was a very sad time.”

Mum’s story

“When my stepfather got cancer, in the late 70s or early 80s, I remember my mother nursing him at home. It was really hard for her. There was no support, because it was a rural area, and Mum would just care for him 24 hours a day. He was in a lot of pain and he wasn’t getting any pain relief, just Panadol or nothing at all. Mum didn’t say a thing to me about how difficult it was at the time. There was no offer of any sort of palliative care, or even pain relief for him. The doctor didn’t do home visits.

“She was in a housing commission house, and afterwards she had to move out of there because his spirit was still there. It was really difficult for them in those days.”

The cousin who had cancer still enjoyed a drink and a smoke.

A cousin’s story

A couple of years ago, Nola’s cousin learned

he had cancer. His brother became the main carer. As a nurse with a lot of experience of terminal cases, Nola suggested they think about palliative care.

“They said ‘no, we’ll be right’.”

The cousin who had cancer still enjoyed a drink and a smoke. “He thought he wouldn’t be allowed to have those little luxuries if he went into palliative care.”

Things became harder when her cousin’s condition worsened and the brother who was carer had a stroke. He could no longer help with the heavier work, such as bathing his brother. Again, Nola suggested palliative care: ‘Just let them come out and introduce themselves and let you know what they can offer’, and the brothers agreed.

“The Palliative Care Home Team from Mt Olivet¹ came out. They had a male nurse, which was really

culturally appropriate, and it was good, and then they agreed to have the service.” From that point the family received home care, and from time to time the brother who was ill went into Mt Olivet hospital for respite care.

“He’d be in and out, but it was his decision when he wanted to go in, and it was good because the palliative care team would allow him to be admitted on his terms. When it does become a lot for the family it’s good to have that relief in hospital for a while.”

Nola’s cousin was admitted to hospital at the final stage of his illness. The family had talked about the options and decided it was best that he should have his last days in hospital.

“They did feel comfortable with that service. I think it’s because I suggested it, and the experience I had had with them, being so kind to other Aboriginal people, and with cultural ways,” Nola said. “I think if I hadn’t suggested it, they probably wouldn’t have used that service.”

“It’s a new terminology now, palliative care. It’s been around for a while, but a lot of Aboriginal people don’t understand what it means, until you say it’s caring for people in a way that would be more comforting for them in their last stages of their care.”

Nola feels it’s important that families start thinking and talking about palliative care as early as possible. “It is a very emotional thing to talk about. I don’t think it will ever be easy for anyone, but people do have to talk about it.”



Nola White (left) with co-worker Annette Rabbitt

¹ Mt Olivet Community Services is a Catholic, non-profit health and aged care organisation that offers several health services including palliative care at its inpatient unit or through its palliative home care service.

Need financial advice?

Centrelink has a Financial Information Service that can advise on wills, enduring power of attorney, funeral plans and bonds, and how to administer a deceased estate. Contact Centrelink on 132300.

“There were people everywhere!”

Robert Cole’s twin brother, Malcolm, was well-known as a dancer, model, school counsellor, TV presenter and role model, and had travelled the world. Ten years ago, he came home to Townsville, dying of AIDS. Robert and his wife, Phillipa, nursed him through his final illness.

“Looking after him was very, very touching,” said Robert. “It was a big thing for me to have him home, and to know he was going to die at home. We were very, very close and I found it difficult looking after him at times, but luckily I had the support of my wife who was there with me all the time.”

Phillipa recalls: “We had a big five bedroom house. My Mum and Dad came and stayed with us, as well as all the brothers and sisters. We had upstairs and downstairs, and people were just everywhere, coming in all the time to help.”

Phillipa was grateful to have had a nursing background. Before Malcolm came home, the Coles got in touch with the AIDS Council, Blue Care¹, the Townsville Aboriginal and Islander Health Service (TAIHS) and the local palliative care doctor.

“It was palliative care, but we did it our way,” says Phillipa.

“The AIDS Council was really supportive. They supplied us with commodes, sheepskins, pillows, bed tables, shower access and all that sort of thing. They would phone to see if we needed shopping done, and would come in to look after Malcolm if we needed it.

“TAIHS actually came in with lunch every day. The community people supplied big pots of food for dinner every night. All we had to do was just look after Malcolm, because all the other stuff was taken care of, cleaning the house and everything.”

The palliative care doctor kept in contact with the Blue Care nurses, who visited at home, helped with showering, and looked after pain medication.

It was the first time the Blue Care nurses had cared for an Aboriginal and Torres Strait Islander man who had AIDS, Robert remembers.

“They weren’t sure what was culturally appropriate. It was good because they learnt something from us, and we learnt from them. The cultural way was probably different. They didn’t expect a lot of things that happened in our house.

“Even the doctor commented when my brother passed away. He said to my son, ‘Your uncle ought to be a very proud man because of the family support that he had around him’. He, as a non-Aboriginal and Torres Strait Islander person! I have not seen that before in our society. That was very touching for us.”



Robert and Phillipa Cole with grandson, Keneen Zaro-Cole

¹ Blue Care provides a range of care services throughout Queensland and in northern New South Wales, including palliative care nursing. People can refer themselves or be referred by friends, carers, members of their family, their doctor, or the hospital. There are similar services in other states (with different names). Refer to the back page for contact information.

“when I know I’ve done my absolute best for that family”

Helen Burns is a member of the Mt Isa Base Hospital Palliative Care Team. The service covers western Queensland and all its remote communities from the Gulf country right over to Lake Nash across the Northern Territory border.

Helen is part of a big team – a coordinator, two doctors, social workers, an occupational therapist, a dietician, and a counsellor, Blue Care nurses, and staff on the hospital’s medical wards.

“A typical day? No such thing! My job entails looking after the palliative care clients and their family from their first consultation when they’ve been referred to the palliative care unit.

“If they need oxygen, I’ll pick that up and take it to their home. Centrelink forms, accommodation, housing – I’ll chase all that up. I do everything and anything that I possibly can.

“Some of the beds on the medical ward are allocated to palliative care. I visit them daily when they’re on the wards, or however many times that patient needs. At the final stage I may visit a lot more frequently, to see how the patient and their families are coping.

“If they are in the outlying communities, such as Doomadgee we will have a video conference. We can talk to the whole family and the doctor from the community, and the doctor here. Quite often with Indigenous families it might just be the first consultation, but we end up having a big meeting. We cover the whole of our district – Mornington Island, Normanton, Cloncurry, Doomadgee and Dajarra.

“The biggest challenge is earning the people’s trust from the communities, and me being a young person, people think ‘oh, she don’t know’. That’s fair enough for the elders to think that; they’re looking at me as a young person, but you start talking to them and you can feel them start to trust.

“A lot of our elders are very proud people. They want to die with their dignity and everything still intact, and their independence. Independence is a big thing.

“I think they should have more Aboriginal liaison officers within palliative care. There are only two of us Australia wide¹, and I don’t know how the other palliative care teams across Australia go about it when they have an Indigenous client. Personally, I think they need a lot more, just to make the people more aware. Aboriginal patients relate ten times better with their own people than they do with non-Aboriginal people.



“My motto is I treat my patients how I want my family to be treated, and I don’t treat any different, whether they are homeless in the river bed or whether they live in a flash house in the community. I’ve seen both sides of the fence, and I think I probably went more out of my way for the guy in the riverbed.”

“The thing that I enjoy most at the end of the day is when I know I’ve done my absolute best for that family, and they come back and tell me that they really appreciate how I’ve helped them. That gives me my greatest pleasure, knowing that I was able to help a family and support them in their time of need.”

¹ The other, an Aboriginal Health Worker based at a hospital within a palliative care team, is Bev Derschow in Darwin (see Bev’s story on page 12). Paul Munn, an Aboriginal Health Worker who coordinates palliative care for his community at Yarrabah in Queensland is community-based, rather than employed within the palliative care team.

Unfinished Business

Helen Burns did work with someone who lived in the river bed. He had been sent back to Mt Isa from Townsville with medication that he didn’t know how to use properly. The palliative care team organised his medication and Helen would visit him in the river bed regularly to check on how he was going.

“Every day he would come to the Emergency Department to have his medication as he was homeless and had nowhere safe to store it. I talked to pharmacy because we were storing his fentanyl patches. They were quite fine with it. They’d stocktake it, so when his tablets or his patches ran out, they’d say, ‘Oh, can you chase up a script?’ He had a drinking problem so I explained to him how drinking could affect his medications. Once he understood that he was happy to co-operate. We worked out a plan with the palliative care doctor so that he could still have a drink, but it was to be regulated so that it wouldn’t interfere with his medications,” Helen said.

The palliative care team helped this man with some cultural ‘unfinished business’. He had not been back to his home community in the Gulf since he was 16. Towards the end, the team arranged for him to go back for a visit. An Aboriginal Liaison Officer flew with him and stayed overnight, then brought him back the next day. It was really important to this man to go home once more to visit his homeland and see his family. He was able to pass away with dignity as he had made peace within himself, his family and his community.



Palliative care in the Top End

The Top End Palliative Care Team, based at Royal Darwin Hospital, looks after people throughout the northern part of the Northern Territory and serves one of the largest regions of any palliative care service in Australia. It is one of the few that has a dedicated Aboriginal health worker who works only in palliative care. That role is filled by Bev Derschow, who works with rural and remote clients.

Bev is originally from Western Australia, and has trained as an enrolled nurse. She first became interested in working in palliative care while working at Royal Darwin Hospital. She felt that the system wasn't fully meeting the needs of Aboriginal clients, but was impressed with the approach that the Palliative Care Clinical Nurse Consultant (CNC) took.

"I liked the approach of the CNC because she listened to people. She understood the importance of working with family, as well as advocating the needs of the clients, and she was better able to assess the needs because of that relationship she had with families."

Bev explains: "Most of our Aboriginal clients are from rural and remote areas. For informed consent, the family needs to be involved, especially around death and dying time, because at different stages of that person's illness, there might be different consents to be given by different people. It's quite simple to ask the family or the client who is the right person to talk to and make sure that the right story is getting through to those people."

The main focus is on making sure that the client and their family are fully informed about their options, and respecting their choices.

A client might decide not to have an operation because it is against the family's wishes, or because if something went wrong, other family members might be 'blamed' according to traditional customs and this could lead to pay back. Getting it right is really important.

"It raises complications for professionals. Sometimes they think that if they were in that situation, they might choose something else. They might choose chemotherapy or radiation therapy to prolong their life, where a traditional Aboriginal person may just want to return home and spend what time they have with their family in country," Bev says.

Although some choose to stay in town for care, many of her clients want to go home to their own country, and the service does everything it can to support that.

Like other palliative care services, providing special equipment for care at home is an important part of the service. Bev's work also includes a range of other cross-cultural work, liaison and advocacy, such as helping clients who speak little English to find accommodation or deal with Centrelink and other government departments.

Getting clients home can present unique challenges. Normally, someone who has just had a chest drain removed wouldn't be able to fly – but compared with many hours on a bus to the next major town, and perhaps many more on a bumpy dirt road, flying is by far the better option. Sometimes Bev has to be a strong advocate for her clients and find creative solutions.

Once home, the client's choice may simply to be outside, under a tree. "Quite often that can be confused with family not caring for the client," Bev says, "but they have to remember that people don't have to be neat, clean and tidy and tucked into a bed when they're dying. It's the client and family's choice. It doesn't matter in what circumstances they are cared for if it's important to that person's spiritual well-being, and it helps the family with grief and bereavement after they have passed away."

When Bev started her job, the case load went from about 6-10 people in rural and remote communities to between 30 and 40. "Having an Aboriginal person in the palliative care team made the clients and family more comfortable in accessing our service."

Good experiences of palliative care, also helped. "The demand is growing. It increases our workload, but it shows that what we are doing is working."

"What I find rewarding is that this is such an important part of a person's spiritual journey, and for the family and the client to allow me to be involved, that is the greatest joy I get out of palliative care. It's a real honour for me to be involved in such an important time of people's lives... and to know we can and we are making a difference.

"The system can work. We've shown through hard work and advocacy that systems can work and be flexible... with a bit of a push from us."

"It's a real honour for me to be involved in such an important time of people's lives... and to know we are making a difference."

A flight to Inverway

Elaine Tiliakos's mother was one of the Stolen Generation. As a child she was taken from her family on Wave Hill Station in the remote north west of the Northern Territory. Her sister remained, and grew up as a traditional Gurindji woman, living on Inverway station in the northern Tanami Desert, close to the Western Australia border. In the traditional way, this sister was also Elaine's mother and when she became ill, Elaine was there for her.

A cyst on the lung was first noticed in late 2001. It isn't clear why there seemed to be no follow up, but it wasn't until late 2003 that Elaine's mother was brought to Darwin for treatment. By then she was seriously ill and did not have much time. Her daughter, Mageline¹, who is also Elaine's sister in the traditional way, came with her.

The next weeks were a chaotic and difficult time for the whole family. Elaine is a pensioner, while Mageline and her mother had worked on CDEP² in their own community. Although a special payment could have been arranged because of the circumstances, the bureaucracy wouldn't budge – so money was tight, transport to and from the hospital was difficult, and no accommodation had been arranged for Mageline. The family desperately needed financial help.

"No one could help Mum and Mageline," Elaine recalls, "It was like a brick wall".

Then the social worker at the hospital put her in touch with Bev Derschow, the Aboriginal Health Worker on the Palliative Care Team (see Bev's story opposite).

"Bev came straight down to us in the ward. It was a great relief. The first time I met her I was in a real dither about everything. I was just about in tears, and she came up and she just sort of eased everything off me. She said 'Don't worry, I'll sort it all out, and I'll get back to you and let you know what's happening and where we're going from here'.

"It made a lot of difference. She did all the paperwork, all the talking to the necessary people to get things done. When Mum knew she was dying, Bev pushed the doctors and arranged for her to fly back to Katherine from Darwin, and then from Katherine to Inverway. Even little things like the wheelchair, she arranged. Every little detail she arranged, everything."

"It was very important to Mum to go home. She knew she was dying, but she didn't want to stay here. They didn't want her to fly. The doctors spoke to Airmed and they said they could fly at a certain altitude and that was arranged. She was able to go home through the help of palliative care – Bev and the doctors."

Elaine's mother was flown to Katherine, where she stayed for two weeks until able to go home to her own community. She passed away on Inverway in early January, 2004. Elaine attended her traditional funeral at the community and then kept a promise to her mother. With help from Bev, she brought Mageline back to Darwin where she gave birth to a baby girl in May 2004.

¹ Pronounced like 'Magdelen'

² Community Development Employment Program – equivalent to 'Work for the Dole'



Financial help

If you are caring for someone full time in their home, you may be entitled to a Carer Payment, and/or Carer Allowance through Centrelink. Claims for Carer Payment and Carer Allowance can be lodged by phone or fax. You may be able to get the payment approved sooner if you put in an 'Intent to Claim'. This can be done on the Centrelink website (<http://www.centrelink.gov.au>) or phone Centrelink on 132717.

If someone who was a Centrelink customer passes away, their family or the people looking after their affairs may be able to get a bereavement payment, for example to help pay for funeral expenses. This can be done very quickly. The husband or wife of the person who passed away may also be able to get a bereavement allowance for up to 14 weeks. The Centrelink booklet, *Are you needing help after someone has died?* provides information about payments and services you may be able to get if you need help after someone has died. Contact Centrelink on 132717.

If you need help, ask if there is an Aboriginal Liaison Officer or a social worker who could help you find out about these benefits.

A story from *Elcho Island*

Joe Djendulu's story shows how critical it is to have good communication with the family, especially where there are language barriers, and how important it is for the family to feel they can relate well to the palliative care team.

Joe Djendulu is a senior Yolgnu man whose home is Galiwin'ku, on Elcho Island off the Northern Territory coast. He is the head of a large extended family. When Sebastian, a young member of that family became ill with cancer, he and other family members moved to Darwin to be with him and look after him.

Speaking through interpreter Wendy Gaypirra, Joe talked about how Bev Derschow, the Aboriginal Health Worker at the Top End Palliative Care Service, helped his family, especially Sebastian and his mother Judy.

"Bev was the right person to work with the families, sit with the families, talk about Sebastian's sickness... giving all the information to the families and sharing to the families the story about Sebastian. It was everyone working together to care for Sebastian.

"Half of the families was living in Darwin, and half of the family was living at Elcho. Bev used to fly over to Elcho and share the same stories about Sebastian. She would stay there for two or three nights, and fly back and feed back to the families who were living in Darwin. That's how Bev got involved with

Sebastian and all the families, and the families were very, very kind to Bev."

Sebastian's illness lasted some three or four years, and Bev's role was so important during that time, she was adopted into the family. It was she, rather than the doctors that the family felt they knew, and who they could turn to for help. They see the relationship as going two ways.

"She understands culture and traditional ways, because the family teach her. It's very important that Bev has to know the culture of the Aboriginal people



Wendy Gaypirra (front left), Joe Djendulu (front right) and his wife Daisy (centre) with other family members

too. She gives all the information back about the person, and we have to give her back too, our culture and everything. That's how it should be, two ways."

Towards the end of his illness, Sebastian was taken to Adelaide for treatment. The family feels they had said they did not want him to go, but in Bev's absence the decision wasn't communicated properly back to the hospital.

Wendy, who is now an interpreter at the hospital, says "At that time, I wasn't working as an interpreter. If I should have been there, interpreting for the doctor, they would just say to me 'can you tell the doctor not to send him'."

Sebastian passed away in Adelaide. Although it was a sad outcome, the family remains very grateful to Bev for what she did for the family and the sick boy.

"She has been working with the family side by side, together, and that's why she has been adopted into the family. The family is really proud of Bev and what she has done."

Palliative Care Courses

Flinders University (South Australia) and Charles Darwin University (Northern Territory) now offer a distance education topic in Indigenous Palliative Care for post-graduate students.

Flinders University also has a post-graduate course in palliative care in aged care, offering graduate certificates and graduate diplomas.

For further details contact:

Course Administrator
Palliative Care in Aged Care Education Program
Department of Palliative and Supportive Services
School of Medicine, Flinders University
GPO Box 2100, Adelaide, SA 5000

Telephone: (08) 8275 1603

Fax: (08) 8374 4018

Email: pallcare@flinders.edu.au

Learning about the palliative approach

Are you working in health and interested in learning more about palliative care? You could be eligible to go on a special work placement.

A national program called PEPA – Program of Experience in the Palliative Approach – has been set up in each state and territory. It is funded by the Australian Government through the National Palliative Care Program.

PEPA aims to give people who work in a primary care setting the opportunity to learn first hand how palliative care specialists care for their clients and families. It is open to Aboriginal health workers, nurses, counsellors, volunteer program managers and other allied health workers.

The program offers a placement of up to ten working days at a palliative care service, with all travel and accommodation costs covered, and can also cover the cost of filling the person's position while they are away.

PEPA's National Coordinator, Linda Barrett says the main purpose of the placement is to offer an experience of palliative care. "It's to gain exposure and experience. We're not looking at making people into palliative care specialists. It's to give them an experience of the palliative approach to care, how it uses an inter-disciplinary team, and to understand the change of focus of care."

Most people who work in health are naturally focussed on helping the patient get well, or manage a disability or injury. In palliative care, the emphasis is more on quality of life, comfort, symptom control and the needs of the patient and family.

In many cases, the care of a palliative care patient is given by their own family and local doctor or health service, so the program aims to increase general awareness of the palliative approach. The PEPA program aims to match the worker with a suitable host site, so as well as a good

experience, the person will gain contacts and a network of support for the future.

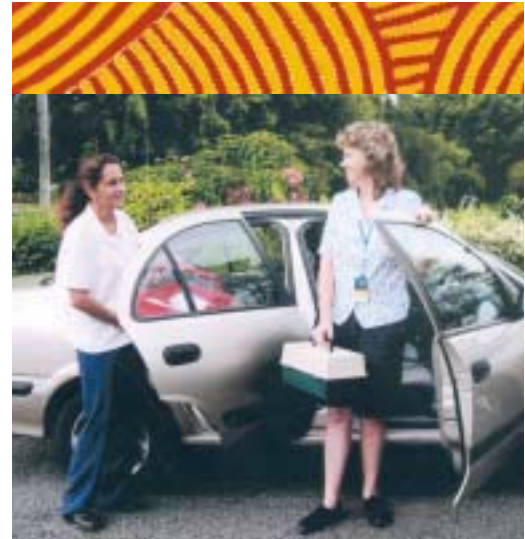
One Aboriginal Health Worker has completed the program, and two more have applied. Kamille Bligh, from the Queensland town of Emerald, did her PEPA placement at Gordonvale Hospital (a Centre for Excellence in Palliative Care, see story page 2), near Cairns.

Kamille was interested to learn more about palliative care, partly because of experiences in her own close family. "I wanted to get more experience, to see what it was all about, and to work in another community with some other community workers and with registered nurses."

"They were very beautiful people, very helpful, and very kind to me. I learned how to support the family and the friends of the patient. The ladies up at the Cairns Base Hospital were wonderful too. They took me through the unit where they do the chemotherapy, and all of that. There was so much to take in!"

In fact, after watching the registered nurses working with the health workers from nearby Yarrabah community, Kamille decided on something she had been thinking about for a while – to go ahead and train as a nurse herself.

The PEPA program will be available until at least mid-2005 and later in some states. For more information, contact the PEPA Coordinator in your state or territory.



Kamille Bligh and registered nurse Denise Reghezini pay a home visit

For more information about palliative care activities being progressed by the Department of Health and Ageing under the National Palliative Care Program, please contact the freecall inquiry line on 1800 020 787, or visit www.palliativecare.gov.au.



PEPA contacts:

Victoria:	Allan Havelock (03) 9616 1459
New South Wales:	Fiona Jamieson (02) 92826447
South Australia:	Marlene Anderson (08) 8226 6428
ACT:	Sue Wood (02) 6273 0336
Queensland:	Gordon Poulton (07) 3636 1449
Western Australia:	Helen Walker (08) 9382 3774
Tasmania:	Linda Barrett (07) 3636 1449
Northern Territory:	Julie Barnes (08) 8922 6770
National Coordinator:	Linda Barrett (07) 3636 1449

Many Ways of Caring

The Central Australian Palliative Care Service is based in Alice Springs. It covers about one million square kilometres in the south of the Northern Territory and the cross-border regions of South Australia and Western Australia. Much of it is Aboriginal land, dotted with remote communities and outstations. A number of different languages are spoken and cultural practices vary widely.

Ofra Fried – a palliative care doctor

Dr Ofra Fried¹ is the palliative care doctor in central Australia. It is a small team, with just one doctor and two nurses. About half of the palliative care clients are Aboriginal people who come from many different kinds of life situation.

“For many of our Aboriginal clients there is a wish to remain on country, or to return to country for ‘finishing up’. Their country is likely to be some distance from Alice Springs, and that raises issues about the kind of care that will be provided, who will provide it, and the medical and nursing care that is needed,” Ofra says.

Out bush, medical and nursing care can be difficult to access, but there can be problems in town too. “They may live in town camps, there may be issues of poverty, over-crowding, lack of facilities. Houses aren’t as warm, even access to electricity or basic services can be an issue.”

In 1998, Ofra initiated *Many Ways of Caring*². Four artists, each from one of the main language groups of the area, produced special paintings of what they felt was important about ‘finishing up’.



“A woman is sick, and whitefellas and Anangu [Aboriginal people] are in a meeting, saying ‘take her to hospital’. There are many meetings talking about the right thing to do. We see her travelling to hospital. This painting is about when a decision is made whether to take the sick person for care in the hospital.”

On the right of the painting, the sick person is surrounded by Aboriginal and non-Aboriginal people, all in the shelter of a windbreak.

Many Ways of Caring: The Aboriginal Palliative Care Paintings Project



Dr Ofra Fried

The painting behind her is called ‘Unfinished Business’. The artist was a young man who began painting while in hospital, getting palliative treatment so he would be well enough to be managed at home in a remote community. His family helped him with this painting but he became too ill and passed away before completing it. Afterwards it was sent to Alice Springs and shown in a special exhibition of works by palliative care patients. Even unfinished, the painting reflects that the young man was able to pass away in his own community and culture.

“Many of the health care providers such as myself are non-Aboriginal people, so we have to work together in a cross-cultural way to give people and their families the best quality of life during that difficult time in their lives.”

Sadly, one of the artists (whose painting is shown below left) later became

one of Ofra’s palliative care patients. She was a bush woman who had both a strong Christian and traditional background. “All of these influences were important for her final care... For example, she would often have Christian hymns playing on a tape by her bed... I met a ngangkari, the traditional healer, at her bedside, and she received traditional support and care from family and community members who came in from the bush... all of this needed to come together for her.”

Ofra said of this learning experience, “It’s about not making too many assumptions about what people’s needs are and being prepared to work with whatever is happening and whoever is part of the care situation... I can’t do some of the support work that family members can do, the ngangkari did, the people who came from the community did – I can do my job as a doctor and try to be flexible enough to not get in the way of other people doing what’s important for them and the person who is sick.”

Ofra says it’s very important to offer ‘culturally safe’ care. “Cultural safety is about people being able to access services from people of another culture without giving up what’s important from their own culture.

“In other words, you’re not the boss of the decision-making. You’re a service provider, and you do things on the terms of the person who is sick. In our society, health care workers have a great deal of power. We’re used to making decisions for people. We have to be really aware of what we’re doing. It’s about respecting difference and being aware that everybody has their own uniqueness.”

Linda's story

Linda Bray works as an Aboriginal Liaison Officer and interpreter at the Alice Springs Hospital. Her mother was an artist who took part in the *Many Ways of Caring* project. She was born at Ernabella in South Australia. Her country was at Pukara and this was the country she often painted.

Linda's mothers' working life was out on stations, and at hotels in Kulgera and Wauchope, her children coming with her and learning about bush life. She also taught Linda's children.

She finally settled at Mutitjula, the community near Uluru (Ayers Rock), and began painting there. "Her country is in the painting. That's our people," Linda explained.

When Linda's mother was brought to Alice Springs for treatment, she had been ill and in pain, but had not told her family. She had only a short time to live, and decided to stay in town with Linda to be cared for. Linda rang her mother's sister at Mutitjula, and asked her to come.

"They got there that night. Mum knew her sister was coming to visit her and she cried and they hugged each other."

"She had a lot of her family around her: my sister, my five children, my sister's children and her two sons. They were all there, all at home. Everyone was outside, sitting, talking about home and what's going to happen."

"I had the palliative care and the doctor [Ofra Fried] coming to her every day. They were a lovely team. They make you feel good. I really appreciate them. They was always coming home, checking if I needed any help."

"She was glad to know everybody came. I had a lot of ngangkari coming in from way out bush. Her brother came as well, and brought ngangkari man, and her other sister from Mimili, cousin sisters were all at home. We had prayers every night. The Ernabella Choir came – it was so lovely.

"She said to me 'I'm glad I'm back here in town'."

Linda's mother asked to be buried at Mutitjula, and when she passed away the family went there for sorry business.

"We took Auntie back home to Mutitjula with us. Everyone was waiting there. All the family was at the sorry camp and we all went back there.

"The next day we had to go around the community with brushes of leaves to cover Mum's tracks where she lived, at the clinic and at the shop. We had to cover all our tracks and the house where she was staying. We had to clean all that out, go through every room in the house, getting all the spirits out. Then we danced and finished. That was 'finish off' they call that."



Many Ways of Caring (continued)

Another patient was a teenage girl who had leukaemia. Her treatment in Adelaide had failed, and she returned to Alice Springs Hospital, needing very complex treatment for her condition.

When Ofra first saw her with her mother, she wouldn't speak to anyone and was very withdrawn. This could have been usual cultural behaviour toward an older woman, but Ofra had a gut feeling that she was really depressed...

"It was a matter of getting the right story – it always is. I asked permission to speak to her on my own, and then she was able to tell me what she really wanted. It was to be with her grandmother, who lived on a community about 700 km from Alice Springs. What it boiled down to was that she needed to go home."

It was very difficult because of her complex care needs, but not impossible. Many people had to be involved – the palliative care team, various departments in the hospital, the Aboriginal liaison team, organising transport to the community, and nurses and Aboriginal health workers. Fortunately a doctor was based at that community.

"When I told her it was going to be possible for her to go home, this young woman suddenly brightened up and stopped being depressed. She was really happy because what she really wanted was going to happen. She went home, and it was good. It worked out well."

¹ Dr Fried completed her master's thesis in Public Health, *Cross cultural issues in the medical management and nursing care of terminally ill Aboriginal people in central Australia*, in October 2000

² Pamphlets, posters and a booklet about the *Many Ways of Caring* paintings were first produced in 1998/99, and a new edition was produced in 2004.



Glen Sharpe,

Aboriginal Liaison Officer and Interpreter

Glen Sharpe grew up at Jay Creek, near Alice Springs. He speaks Luritja, Western Arrernte, Pitjatjantjara and English.

"We mainly do interpreting. The doctors, usually they ring up when they need us, like if they have a patient when there's a language barrier... so we come in and make them understand what the doctor's saying and that really helps them as well.

"Even ourselves – sometimes just being there as an Aboriginal person, when they see someone like me, they feel more comfortable and they want to speak. Well, they look up to me. I am traditional, and I've worked here and know the area and know the people.

"Like when they get shamed with the doctors or nurse or community worker, I just tell them that these are good people. 'They're here for you, they've come to help you' and that way they are building relationships.

"The hardest part is when you have to tell the patient that they're not going to get better, they'll have to be in palliative care.... When they come to hospital, they're thinking 'oh, I'll get better, the doctors will make me better'. That's the hardest part, the first part. But when you explain it to them that there are people there to help you, they're going to take care of you, whatever you need... sometimes it make them feel better.

"When I'm working here I try not to get involved with the patients, try not to get caught in the emotions. Because that way, I feel that my work helps them too. They need someone who's going to be straight, not get caught – tell them these are all the helps they can get and giving them options.

"Ngangkari [traditional healer] – that's the first one they ask for. Most of the time when the ngangkari's come in and fix them, they feel all right. After that they're pretty much lively and doing things and talking normally. It helps them.

"It helps the family. It calms them down and makes them more relaxed, instead of being stressed out and wondering what's going to happen. Most of the families they get frightened if the wife or husband in palliative care pass away, then families will be after them for payback.

"Before when I wasn't working, I've seen a lot of people going for payback and it wasn't really necessary for them to do that. They didn't understand fully what had really happened. It's more better now. We can explain it to them in their own language.

"I think one problem I see is there's nothing out bush in communities, where they should have community based palliative care, where they can help them at home. Passing away in different areas is not right for them, spiritually. They should be in their own country. That's what I see."

The Aboriginal Liaison Team

The palliative care service in central Australia relies a great deal on the Aboriginal liaison team at the Alice Springs Hospital to support and interpret for many clients.

Eighty per cent of patients at the hospital are Aboriginal. As well as the usual role of Aboriginal liaison officers (ALOs), the team double as interpreters in the many languages of central Australia.

Senior Social Worker, Lorraine Schmidt manages the Social Work and Aboriginal Liaison teams.

"The first thing for them is to speak languages of central Australia. Most of the ALOs speak quite a few languages. We had one particular ALO who spoke nine languages!"

At the moment we have Luritja, central and western Arrernte, Pitjatjantjara, Anmatyere, Alyawarre. Warlpiri is the main one we are missing for now.

"They also do practical welfare things like helping people with their banking, Centrelink queries. They do

emotional support. They attend and facilitate family meetings where there are decisions to be made. Often they liaise with communities and provide information to them about what's happening in the hospital.

"Their role is to be cultural brokers too – explaining Aboriginal culture to the staff here and also explaining parts of hospital culture to patients."

Lorraine grew up in Melbourne. Her mother was born in central Australia but was taken away as a child. Back in Alice Springs, her role includes working with grief and loss.

"I feel that there are just so many layers to grief, and when you peel away one layer, you expose another.

"Aboriginal people have so many deaths to deal with, and that's what we find with our team here. We have five liaison officers. They have to take a lot of time off to go to funerals.

"We try to be flexible – we can't exist without them. If we don't have interpreters there's no such thing as informed consent. They're a really integral part of the support in the hospital."

Annie Milgan Health Worker...

The Kimberley Palliative Care Service, in north-west Western Australia, covers a region about twice the size of Victoria. There are about 15,000 Aboriginal people, of a total population of around 30,000. More than half live out bush. The only full time palliative care worker is Coordinator, Wendy Scott, based in Broome. Our stories come from the Derby area, about 2000 kilometres from Perth.



Annie Milgan lives in Jarlmadangah Burru, a community of around 70-80 people approximately 135kms north east of Derby. She works for the Derby Aboriginal Health Service (DAHS) and has 20 years experience as a health worker. A DAHS doctor visits the community each week.

Annie first learned about palliative care at a workshop in 2003.

“It made me really think. A lot of our people have gone to nursing homes when they are really, really sick, and they finish up [pass away] in nursing homes,” Annie said.

“It’s really got to come from their heart where they are going to finish up. I know some of the old people said ‘I’d like to finish in my country’, but the old people never had options before... I know we were never giving them a chance... where they want to be. We kept pushing them back to hospital or nursing home. Annie felt it was really important for people to be able to come home to their families, where they would be loved and cared for. She went back to Jarlmadangah and talked to people in the community.

“You know, we’ve got to think about our old people. This is their home and their dreaming, and they know this place. We were taught by old people.”

Families are often not aware that they could choose to have the patient come back to their own community. This may not even be considered by hospital staff – especially if the patient needs complex medical care which can be difficult to manage in a remote community. The family may be reluctant too. Some people say, “we don’t like to see our old people pass away in front of our eyes”, and there are traditional customs as well. Annie explains, “when the person passes away at home, well the family has to move out and they can’t go back to that house.” This is a big factor for many families in central, western and northern Australia.

Annie would like to see a lot of changes – such as education and training in how to care for someone who is very ill, so instead of relying on nurses, health workers

and community members would know what to do. She would also like palliative care equipment, supplies and information to be available. Another thing she would like to see in her community is a building being used to care for people in the final stage of their illness, so that families won’t have to move out of their homes.

“We have to listen to the old people, their choice. We’ve got to give them a chance, where they want to be... because they are feeling in their heart it is their country and their family that are close to them.”

A video for remote communities

The idea for a video that could be shown in the communities to teach people about palliative care came from Wendy Scott, the Coordinator of the Kimberley Palliative Care Service. It was funded by the Caring Communities Program¹.



The video shows how someone can be helped to come home, even to a remote community, and be looked after by their family before they pass away. The video explains about palliative care and tells the story of a mother who is very sick, and her daughter, played by local people acting the parts. The family decides to look after the mother at home, in the community. At different stages of her illness, Aboriginal health worker Annie (who plays herself) and the nurses help the family and explain the choices they can make.

Wendy came up with the idea because, like Annie, people in communities have not heard of palliative care. As Coordinator of such a huge region, she needs a network of people based in communities who can support clients if they come home. She plans to show the video at clinics and women’s centres.

Annie hopes the video will be widely shown in communities throughout the Kimberley, so that people can think more about looking after old people on their own country. Above all, she would like to see the old people given a choice about where they wish to spend their final days.

For information about the video, contact the Kimberley Palliative Care Service on (08) 9192 9295.

¹ funded by the Australian Government Department of Health and Ageing through the National Palliative Care Program. Information is available from www.pallcare.org.au/caringcommunities

Photo: actors Rachel and Elizabeth Watkins (left) with Wendy Scott, Kimberley Palliative Care Coordinator.

... a nurse... *Helen Leamy*

Helen Leamy is a registered nurse, working with the Derby Aboriginal Health Service (DAHS).

She fulfils many roles, including Enhanced Primary Care Coordinator and Child Health Nurse, and when needed, she also provides palliative care nursing for Aboriginal patients in Derby and the surrounding region.

During working hours, Helen's palliative care work is covered by her job with DAHS; out of hours, it is paid for by the Kimberley Palliative Care Service administered from Broome. She is one of a small team who together provide palliative care nursing in the Derby area.



Although many cases go well, Helen feels palliative care services could do a little more to meet Aboriginal people's needs in remote communities.

"We haven't educated the community that it's okay for a palliative care person who wants to die in their own country to do that. Aboriginal people are so used to whitefellers stepping in and taking over. When he gets too weak – off to hospital! The thought, or the option, hasn't been put to them," Helen explained.

"We've certainly come a long way, but patients are still coming in and dying in hospital, or down in Perth without any thought about them dying in their country,

We got her family on the phone... and she seemed to snap out of it a bit, once she heard a family voice.

"I had one old man say to me over the wet season, 'when the roads dry up, I want to go back to my country one more time' and unfortunately, for a number of reasons, he stayed in hospital and it was just like he died of a broken heart. He never got back there and that made me really sad. Those are the sort of areas that we could work on better."

and I think we need to educate Perth hospital doctors as well as the staff here. They feel much more secure having them in hospital with all the buttons and bells and equipment... and you have to have the community happy with that as well. It's no point sending someone back if the community are unhappy with it.

A recent case went really well because of timely action. A patient with kidney disease was very ill in a Perth hospital and was non-responsive. She wasn't going to have more treatment, and the doctors were going to send her back, to Nambala Nunga nursing home. Helen heard about her case and spoke to the GP at the health service. "We got her family on the phone and got the nurses to put the phone to her ear, and she seemed to snap out of it a bit, once she heard a family voice." Doctors arranged to fly the patient back to her community, and the nurses took out a bed and other equipment to make her comfortable, and visited every couple of days. Back in the community, the patient was able to see all her relatives and friends from other communities. When she was ready, she was admitted to hospital where she passed away.

"Every case is different. We're very flexible. We go by what the family wants, and gently try to find the right time to talk – like, 'as Mum gets weaker, where would you like her to go?' or 'in the event she had a heart attack, do you want the ambulance to come, or are you happy for the nurses to come and give some pain relief?'" Talking about what might happen is important because when the time comes, it is important that the family isn't fighting and everyone has agreed about what to do.

Information about caring at home

All palliative care services will be able to give you information on a range of issues that will be very helpful.

The Palliative Care Councils of South Australia and Western Australia have produced two excellent booklets called *Palliative Caring at Home*.

They cover the practical issues involved in caring for the patient at home and answer many questions carers might have about what to expect and where to go for help, such as where to get equipment, counseling, financial help or other information. The practical information in these booklets would be helpful to Indigenous people anywhere in Australia. Copies are available from the Palliative Care Council of South Australia or Palliative Care Association of WA Inc (see contact details back cover).

Centrelink's booklet, *Are you needing help after someone has died?*, also has helpful, practical information about what to do and who to contact after someone has passed away, where to get financial advice, and information about payments and special benefits. You can download the booklet from the Centrelink website, at <http://www.centrelink.gov.au/internet/internet.nsf/publications/hd001.htm> or contact Centrelink on 131021

... and a carer... *Pamela Hunter*

Pamela is a Senior Aboriginal Health Worker and has many years' experience in health. Her husband was diagnosed with bowel cancer about five years ago.

The disease went into remission for two or three years, but then came back in a very aggressive form. Pamela was her husband's sole carer, as well as mentor, assistant and everything, rolled into one.

For the first two years the couple travelled a lot between Derby and Perth, for chemotherapy and other specialist treatment. This journey meant a two hour plane flight, 2-3 weeks of daily chemotherapy, and returning again just four weeks later to start all over again. It was draining, and hard for someone who was so ill.

In the end stage, the travel, treatment and missing home all took a toll, and Pamela's husband decided against further chemotherapy. He was in Sir Charles Gardener Hospital when they made the decision to return home. While waiting for a Royal Flying Doctor Service return flight, Pamela spent the time observing and learning how to turn him and use the equipment, knowing she had a big job ahead of her.

Pamela's health background helped, but it was important for her husband to take charge of the decision-making. "Initially in his illness, he was just doing as the doctor said. I used to say to him, 'It's your body, and you really have to know what they're saying, so ask questions all the way'. We asked a lot of questions throughout, and I think it gave him a lot of confidence. We were actually in control of things down there, in the city if you please! I'd never have believed that in the beginning."

It was in Perth they first came into contact with palliative care and the pain management concept. Back in Derby, they met with Helen Leamy and the rest of the local palliative care team, which is made up of several people who put part of their time – always juggling daily work and personal commitments – towards palliative care.

"I was just so happy when I heard it was Liz and Helen, whom I've known for many, many years. That familiarity gave me a lot of strength... We had a deadly team around us all the time, helping us to make decisions. As a team, it was quite a strong voice. When we felt we were losing control, we could always call on the palliative care team to step forth and say, 'hey, what's going on here?'"

By Christmas, 2002, her husband was ready to come home, but was confined to a wheelchair. The team offered practical support and organised the equipment,

including a hoist, air mattress, a pump for pain medication, and an electric bed sent up from Perth. "I knew I was strong enough to do the work – and I did do it – but the most practical thing was getting the mechanical stuff there at home, and them being there when I needed them."

"They offered us a lot of love and a lot of empathy.

It was Helen Leamy's husband, Kerry who eventually installed a wheelchair ramp, when no one was willing to fund it, and this made it possible for Pamela's husband to come home. Pamela remains eternally grateful for that, and for all the other support she received both in hospital and in the four months that she cared for her husband at home.

"It's a bloody hard job, and you can't do it on your own..."

"It's a bloody hard job, and you can't do it on your own. I really, really don't feel that people

should be put to the test of having to do it on their own. I would be saying straight away, 'go and see the palliative care team'."

It helped her that the team members were local people. "That is going to really help any Aboriginal family, or any family at all, the fact that they're known locally. I knew these girls for many years and so I was quite happy to have them alongside of me to help me through it. I could trust them, and I know they gave me trust back.

"I think it helped with closure as well, you know? When we came back to Derby we had this team, and they stuck with me throughout, and when it came to closure I knew that if I come up against a brick wall and didn't know how to handle this or that, I had the team to fall back on. Helen was right there.

"After he passed away... to a certain stage you want people around, after that stage you just want to cut off – so I just packed up and went to Perth for three months, but when I came back, they were still here, still inquiring about my welfare.

"Working in the health field, initially, palliative care, to me, was just like a word – as in any other kind of care we deal with in our work. Having been through the experience of what palliative care is, I'm just totally happy to be able to contribute anything and sing the praises of the palliative care area."



Contact Information

Where to get information about palliative care...

Information about palliative care in your State should be available through your State Health Department, your local Community Health Service or Aboriginal Medical Service (or community controlled health service), your local hospital or local doctor. In addition there are Palliative Care associations in each state which have very good information about palliative care services and issues for carers.

Palliative Care Australia (National Office)

Phone: (02) 6232 4433
Email: pcainc@pallcare.org.au
Freecall: 1800 660 055
Website: www.pallcare.org.au

Australian Capital Territory

ACT Palliative Care Society Inc
Phone: (02) 6273 9606
Email: acthpc@bigpond.com.au

New South Wales

Palliative Care Association of NSW
Phone: (02) 9282 6436
Email: info@palliativecarensww.org.au
Website: www.palliativecarensww.org.au

Queensland

Palliative Care Queensland Inc.
Phone: (07) 3394 3466
Email: info@pallcareqld.com
Website: www.pallcareqld.com

Tasmania

Tasmanian Association for Hospice and Palliative Care Inc.
Phone: (03) 6234 7577
Email: tahpc@associationoffices.com.au
Website: www.dhhs.tas.gov.au/palliativecare

South Australia

Palliative Care Council of South Australia Inc.
Phone: (08) 8291 4137
Email: pallcare@pallcare.asn.au
Website: www.pallcare.asn.au

Victoria

Palliative Care Victoria
Phone: (03) 9662 9644
Email: info@pallcarevic.asn.au
Website: www.pallcarevic.asn.au

Northern Territory

Top End Palliative Care
Phone: (08) 8922 6761

Central Australia Palliative Care
Phone: (08) 8951 6762
(No Palliative Care Association number)

Western Australia

Palliative Care Association of WA
Phone: (08) 9212 4330
Email: pcwainc@palliativecarewa.asn.au
Website: www.palliativecarewa.asn.au

Advice Lines

In some States there are advice lines that are free or at the cost of a local call. Some of these are for the general public and some are for nurses, doctors or health workers. For example:

Western Australia

Telephone advisory Services for Health Professionals in country areas
1800 420 102

(This line is staffed by CNCs from Silver Chain Hospice Service)

Doctors-on-call Line
1300 558 655

(Initiated by the Palliative Care Service, Sir Charles Gardener Hospital and funded by the Department of Health, WA)

Queensland

General Information Line
(operated by Karuna Hospice)
1800 772 273

For calls from outside Queensland ring Karuna Hospice directly
(07) 3632 8300

In many regional areas there are after hours advice lines for palliative care clients and their families. Information about these numbers is available from your local palliative care service.

Where to get information about Indigenous Health Organisations...

Information about local Aboriginal community controlled health services is available from the National Association of Community Controlled Health Organisations (NACCHO):

National Association of Community Controlled Health Organisations (NACCHO)

Phone: (02) 6282 7513
Email: pa@naccho.org.au
Website: www.naccho.org.au

If there is no community controlled health organisation in your area contact your State Health Department, Indigenous Health Unit, to find out about what Indigenous health services exist in your area or ask the Aboriginal Liaison Officer at your local hospital.

Note: These contact numbers change from time to time. If you are having trouble contacting the palliative care association in your state or territory, phone Palliative Care Australia (National Office).

Funded by the Australian Department of Health and Ageing