Our stories.

I Care for Palliative Care.
Aboriginal and Torres Strait Islander people should be aware that this document contains images and names of people who have passed away.
Our goal.

Our goal is to ensure that every person with a life-limiting cancer who needs specialist palliative care has access to it, when they need it, wherever they live in NSW.

The NSW Government can help achieve this by providing funding for:

- 10 additional full time palliative physicians, at a minimum
- 129 extra full time palliative care nurses
- Culturally appropriate specialist palliative care services for Aboriginal people

For more information on our I Care for Palliative Care campaign visit canact.com.au/palliative_care
When our loved ones are diagnosed with a terminal illness they deserve the best possible care and support. Palliative care gives patients and their families the quality time they need to make the most of the life that they have left. It enables them to have positive conversations about where and when they would like to die, when that time comes.

But, right now, that’s not always possible. It doesn’t happen because there’s a shortage of specialist palliative care services across NSW. There aren’t enough palliative care doctors and nurses to meet the needs of the community and many Aboriginal people are unable to access culturally appropriate palliative care.

I know how important this issue is to the community, and how further action from the NSW Government would be welcomed.

Patients, families, doctors and nurses, have begun sharing their personal and professional experiences of palliative care. They tell of the incredible strain placed on families when they are unable to access enough support; of the heartbreak experienced when loved ones can’t access pain relief when they need it most; of the impracticality of asking GPs to provide palliative care in already hectic medical practices; and of the high regard in which palliative care doctors and nurses are held by the community.

Many thousands of people have also taken the pledge calling on the Minister for Health to end the shortage of specialist palliative care. Almost a third of our state MPs — from across the political spectrum — have shared that they also care for palliative care, and as we continue to meet with MPs we know many more will show their support too.

This book shares some of the many stories, together with images of community and parliamentary support for palliative care. We hope that it will inspire the NSW Government to end the shortage of palliative care by funding more specialist palliative care doctors and nurses and culturally appropriate palliative care for Aboriginal people.

Sincerely,

Jeff Mitchell
Chief Executive Officer
Cancer Council NSW
November 2016
What is Specialist Palliative Care?

Specialist palliative care is for people who have a serious illness that cannot be cured and have complex pain and/or other physical, psychosocial and spiritual problems.

A multidisciplinary team
including specially qualified and experienced doctors and nurses who:

- Help to manage the person’s symptoms, for example pain, vomiting, shortness of breath or psychological distress.
- Give practical and emotional support to the carer and family during and after the patient’s illness.
- Support and advise primary care providers, such as the GP, to continue being involved in the person’s care.
- Offer care early in the illness, even alongside other therapies such as chemotherapy or radiation therapy.
- Support and advise primary care providers, such as the GP, to continue being involved in the person’s care.
Our
stories.
Mitch’s story

When Mitch’s mum, Dianne, learned she would likely die as a result of metastasised breast cancer, her doctor told her she need not suffer pain. Dianne died in 2015 aged 69, six months after stopping active cancer treatment. In the end, her family says she was in dreadful pain that could have been prevented with better access to palliative care.

Dianne lived outside a large town in regional New South Wales. Her primary carer was her 72-year-old husband, Tony, assisted by family. They also had assistance from Dianne’s siblings who travelled from Sydney and her sister in-law, a retired nurse who travelled from Queensland, to help Dianne during the final stages of her life.

At the time of her death, there was just one palliative care specialist nurse who doubled as a trainer for other nurses in the wider regional area.

Dianne’s son Mitch says the lack of palliative care specialist health workers in the region is “atrocious”.

“There is virtually no palliative care in this area,” he says.

The nurse, who was also responsible for coordinating training for other medical professionals wanting to deliver palliative care in the area, was “running pillar to post with his role”, says Mitch. “It was very much management in crisis”.

“Plus, he had to look after all the region. So, he was the lonesome bloke trying to cover all of that, which is an enormous job when you’ve got 65,000 people.”
“I feel so dreadfully sorry for (the nurse) with his role because he deals with a lot of frustration,” Mitch says, adding that while the nurse wanted to be more available, he didn’t have such capacity.

Dianne was a former special education teacher who lived her life helping others and once she stopped treatment for the cancer, had expressed a desire to stay at home rather than die in hospital.

“Mum’s pain in her last month was atrocious,” says Mitch.

The impact of her pain was excruciating for her dedicated family, her main carers.

“Look, it was awful and the thing is you don’t want to see people in pain. One thing mum’s doctor in Sydney had said was “you do not have to be in pain” and he was very forthright in that,” says Mitch.

But at the end of Dianne’s life, in those final few weeks, “she was in an awful lot of pain” despite the earlier medical advice that it need not be so bad, says Mitch.

“I feel that we let Mum down in that respect – and we didn’t, but it’s one of those silly things you think about,” Mitch says.

“You can only work with the cards you have in front of you but the system let Mum down. As a society we work hard on preventing cruelty to animals but the system allows our loved ones to suffer horrendously. It is not right. People living in regional areas deserve better.”
Confined to a wheelchair and dying, Doreen’s daughter Carolyn wanted to stay at home to receive palliative care, surrounded by her two little boys and family. Instead, Carolyn died in a hospital after the breast cancer she had endured almost a decade earlier then metastasised.

Carolyn, a former company executive, was a loving and caring person who was a great nurturer to her friends and family, says her mother Doreen, a retiree aged in her eighties.

Doreen would travel across Sydney to care for her daughter four days a week and struggled to get the medical help she needed to keep her daughter comfortable.

“She was confined to the wheelchair and she would fall asleep in the wheelchair and she would be falling forward and there was no one to lift her back into bed,” says Doreen, adding that Carolyn’s husband pared back his work before stopping work as her illness progressed.

“She dearly wanted to stay with her boys, she had had them for such a short time … she thought that when she went in hospital … she thought she was going into hospital for a couple weeks for a rest and then she said to me, so shocked, “They are not letting me home again”.

“Her husband did bring the boys in to see her every day but it is not the same as home.”

Carolyn had been taking her children out every day to the park with their bikes. Doreen says her grandson was upset when, as Carolyn’s illness advanced, that stopped.
He said, “Mummy, you don’t come to the park anymore” and they were really devastated. All she wanted to do was things with her children.”

Doreen says Carolyn received home care help but when it was time for palliative care, the options were limited and that upset and stressed her daughter in her final stages of life. Palliative care in hospital or home should be a choice, she says.

“Well I think it should be a choice – not just taken off to hospital. I am sure it is more expensive to be in hospital anyway. If we were provided the equipment at home to be able to be handled at home, we would have provided that care,” says Doreen.

“My daughter passed away last December. A dear friend of mine has just passed away and she said ‘no way am I going into a hospital’ and she got palliative care at home … maybe she didn’t need as much … maybe she didn’t need the physical care.”

Carolyn was focused on ensuring the wellbeing of her children as she was dying, but her mother says ...

... it would have been less mental stress on her daughter if she had been given the option to die at home with access to specialist palliative care.

“I just believe if she (my daughter) had adequate care she would have stayed at home with her boys and she would have had a much happier death.”
A cancer diagnosis and any mention of palliative care is troubling, but for Teena’s dad, Aboriginal community leader Frederick (Fred) Binge, extra hurdles that need not have been there, lay on his path.

When Fred was told by a doctor in 2013 that his liver cancer was terminal, while sitting on a bed, curtains pulled, in a packed regional NSW hospital ward with his daughter Teena, cultural sensitivities were absent.

“(The doctor) in the same breath said ‘you’ve got about three months to live’. Just like that,” says Teena.

“We sort of both just sat there stunned, in shock … and particularly for Indigenous people, a lot of that was … hard to take in because of the way it was delivered. There was no body language or sympathy that you could read or help prepare you for it.”

But any restraints or barriers in health care delivery were “because of the system, not because of the staff”, says Teena.

Palliative care can be a scary term for many Aboriginal people who may not be aware of what it means and how it can enhance life.

“When they mentioned palliative care, that was nearly as upsetting to Dad as telling him he was terminal,” says Teena. “He was like, thinking ‘I’ve only got a week to live’ and went back into the misconception, the myths told within community that once you’ve gone into palliative care, your journey will end very soon, and basically it’s a place where you go to die.”
Teena says such myths meant her father was at first resistant to palliative care but she just wanted him “to have some normality around a really not normal time”.

Teena persisted in convincing her father to talk to palliative care specialists and once he did, misconceptions eroded and they both tried to educate others about the facts.

“It was not just trying to alleviate any unfounded fears because of history and what’s been passed down and passed in community… but actually having to do that with a whole community, so that they can become a support for it, not tell him to not do it,” says Teena.

“That really pushed home to me how important it is for palliative care to get out to communities and tell them what they really do.”

The team was able to provide Fred with physical care and emotional care, which extended to his family as he was dying – two year after diagnosis – and afterwards.

“When he was very close to the end of his journey … they could talk to me about what I could organise for him to actually pass at home – what I needed to be aware of,” says Teena.

“(For) Aboriginal people, the fact you have to have police and ambulance come to pick up a body is distressing … (but) it can actually be an undertaker to do that if they pass at home.”

Without palliative care, Teena says Fred may not have had his wish to die at home fulfilled.

“They can support you and help you and in your darkest times – they’re like a shining light that can hold your hand and walk you through.”
A GP’s story

Frontline GPs who deliver palliative care in NSW are doing it tough, primarily because they don’t have the time, lack specialist training and often scramble themselves to gain the support they need to offer care to the dying and their loved ones.

For one Sydney metropolitan GP who takes on palliative care patients and does home visits on top of her hectic daily practice consults, the frustration is clear: she is one of few doctors to deliver palliative care. She does not have a formal specialist palliative care qualification but uses skills she gained from a stint in aged care as a trainee.

“I am not a physician of palliative care. I’m a GP. I know a little bit about a lot of things but not a lot of detail. There will be a certain point where I go: ‘Right, that’s reached the end of my knowledge. I need help’. And the key is knowing when to ask for help,” says the GP, who wishes to remain nameless.

The trouble is, the help is often not there because of a lack of specialist doctors and nurses and an uncoordinated team approach.

“There are not enough Clinical Nurse Consultants and accessible palliative care doctors. That would be helpful and that is where the gaps are,” says the GP.

“It’s all very well that I prescribe medication but I don’t bring it. So accessing that medication is really difficult for patients and I don’t know what some of the nurse consultants do,
but if you are affiliated with the hospital then the pharmacy at the hospital dispenses the medication and it can be brought out by the nurse.”

Family members are often left holding a script after a home doctor visit and are forced to leave the patient and find “ridiculously high doses of medication from a pharmacy somewhere”. “I think that’s really difficult,” says the GP.

Delivering palliative care is often not possible, unless the local GP spends her down time working at night after a full day seeing patients and keeping on top of essential paperwork.

“There are only so many palliative care patients that any doctor can see at one time, a) because of costs and b) because your patient times are booked up,” says the GP.

“If I come to work and there is only a 15-minute break all day, that is not enough time to see a palliative care patient, unless they come in to see me, and it is very rare that would be the case.

“So it’s, when do you see them? It’s 8 o’clock or 9 o’clock at night which is not necessarily appropriate for the patient, let alone your own personal lifestyle. But we all have patients where you will do that: they are very sick and so you will go at 8 o’clock at night a couple of times a week until they pass away. But you can only really do that one patient at a time otherwise there are not enough hours in the day and it’s just not sustainable.”
Ann’s story

“Don’t think there’s any such thing as palliative care here because there’s no money for it” are the words spoken by a nurse at a regional NSW hospital that stick in Ann’s mind when she remembers the death of her mother.

“I can remember the exact words,” says Ann, when recalling the conversation with a nurse overseeing patient care at the hospital where her mother passed away in 2014.

“I felt absolutely bereft … that was coming from the authority at the hospital,” says Ann.

Ann had spent three weeks by her 70 year old mother’s side when she was admitted to hospital with an infection and later died after several years living with cancer.

“I felt so very much alone and hopeless and helpless. All I could do was sit by Mum and be as supportive as I could and help her be as comfortable as she possibly could be, in the circumstances.”

Ann says her mother “made the most of whatever” throughout her life but continued to express her wish to return home from hospital, a wish she was unable to fulfil.

“Each day she would say ‘well we must be able to go home soon’. Her wish was to be at home. I’m not going to say that she wanted to go home to die or that she was saying ‘I want to die in my own home’ because she would not admit or accept the fact that she was dying. She just wanted to be at home.”
Ann was left to navigate the health system without direction while in distress as she tried to be her mother’s advocate. She says she tried to call a foundation operating in the local area that was helping support people with cancer but was told that once her mother was in hospital, there was nothing that could be done to get her back home. She just didn’t know who to approach for help.

Ann’s mother’s death was “not the ideal way to go” and was confronting for Ann because she was not given information about what to expect when her mother was nearing death – what her body would do and how she might be able to cope with it.

At the time of her mother’s death, Ann had left the hospital despite spending the bulk of her time there, by her mother’s side. Her absence at that time still causes Ann much grief.

“It was quite distressing (when her mother’s condition deteriorated),” she says.

“And the nurses said ‘we’ll call for family to come up’. I wasn’t thinking very rationally and I left the hospital. I’ve never been quite able to deal with leaving her alone.”

Ann says she will forever regret not being there at the time of her mother’s death but realises that it’s a situation many people must face.

“Wherever there’s a hospital, there will be people who will get into this situation, whether it’s just a tiny little hospital, you still need to have access to some palliative service.”
We Care for Palliative Care

Across NSW, people are taking action to show they care about palliative care

“Palliative care are so stretched with resources and staffing. They do a wonderful job. It’s fantastic. But there’s only so many of them. You can’t stretch them any further.”

Rosemary Grieve

“When you see your parent in agony, you realise that you can’t negotiate with this amount of pain and there is nothing you can do. It doesn’t matter whether it is at home or in hospital or in a hospice. For anyone in that situation, palliative care is absolutely essential, it’s a matter of basic humanity.”

Howard Dick

“I mean it was really amazing in the end because once they did come they come twice a day and they bring all this stuff and they do look after you and make it much easier for the family, not having to do so much personal care and watching the suffering of the family member.”

Belinda McIntyre
“I think the main message is there’s a positive side to palliative care that I don’t think people really know about. I think that message can be sold better.”

Brian Elton

“It would have been nice to utilise her doctor but he said that if anything happened we would have to call an ambulance and this most likely would have meant going to the hospital. So when he left we felt like we had been cut loose and I thought ‘oh my God’ now I am the medical carer as well.”

Jo Dodds

“My mother’s and our experience with palliative care has left me very passionate about the fact that palliative care is a subject that needs to be discussed when someone is diagnosed with a terminal illness.”

Kathy
Kerry’s story

Kerry’s daughter, Stephanie died after aggressive brain cancer immobilised her. She was aged 22. At diagnosis three years earlier, there were medical specialists aplenty. In death, no weekend doctors were on duty while she was in palliative care.

Her mother Kerry says her family’s cancer journey is like many others she’s heard about – “you get small glimmers of hope within a dark black cloud of fate”. Stephanie was a beautiful person who faced her illness with “incredible faith, perseverance and character”, says Kerry.

Stephanie went through surgery and treatment and when the cancer progressed, initially received medical care at home but was admitted into palliative care at a private hospital in 2014 when her health deteriorated and she lost the ability to talk and express her needs.

Kerry says hospital staff who cared for her daughter were “amazing” and “bent over backwards to care for her”, encouraging her family to pour love on her while they took care of her nursing needs “with much gentleness and kindness”.

“We could not fault them and would never speak ill of their standards of nursing and support,” Kerry says.

“We had access to pastoral carers, chaplains and were offered massages, which were all helpful.”

But Kerry says uncertainty about access to palliative care left her family scared. While Stephanie was extremely ill in hospital her family was repeatedly told that Stephanie’s palliative care wasn’t guaranteed when she needed it most, with inpatient care at the Sydney hospital caring for her usually lasting a maximum of two weeks.

“We were therefore often told that after two weeks we may have to be discharged,” Kerry says.
Stephanie was dying but nobody knew when she would pass away. Meanwhile, doctors weren’t available to provide specialist palliative care for her on weekends and Stephanie arrived at the hospital on the weekend of a public holiday, Kerry says.

“By then she was very sick and we had so many questions but no one to answer them,” Kerry says. “This was after having medical specialists who explained everything throughout Steph’s illness but here, access was very limited.”

Stephanie died 13 days into her stay at the palliative care facility.

**Services that are vital for people who are terminally ill and their families need improvement, because cancer patients need help throughout their whole journey, Kerry says.**

“We who walk the journey with our loved ones and do everything we can to make their life as comfortable as possible are going to walk away from the palliative care experience at some point and it needs to be seen as just as important as all the treatment and care that occurs during the illness,” Kerry says.

“I really want to emphasise that I was entirely grateful to the staff and their care of my daughter and us … we need to investigate staffing of these services to not only provide plenty of doctors and nurses to give quality palliative care but also to support them as they care for patients and families through very difficult circumstances. Some of the nurses were not much older than Steph and were impacted emotionally whilst having a lot of demands on their time in a busy ward.”

“We need to ensure facilities are available statewide in cities and rural areas to allow access for all, including the Aboriginal community.”
James’ story

In the throes of pain as she was dying at home, James’ wife, Fiona Murphy couldn’t get the specialist medical care she needed to alleviate her cancer pain for one reason: her pain didn’t fit into the system’s 8:30am to 5pm schedule.

Fiona died three weeks after being diagnosed with cancer in regional NSW and while she was able to access palliative care in her home during daylight before she died, it was unavailable outside office hours. Fiona’s husband, James, was by her side and administered every bit of pain relief he could, supporting her. At one point, he called an ambulance for help but paramedics too, were helpless because they had to wait for the palliative care team to be back on deck to ensure Fiona’s medication was at safe levels.

“It was freezing cold, middle of winter, so from about roughly 11 o’clock ‘til about sometimes six or seven o’clock in the morning she was just very agitated, very frustrated, in agony,” says James.

James and Fiona’s three adult children helped James during the day to nurse Fiona as her life came to an end. At night-time, Fiona’s pain would worsen.

“The palliative care nurse said ‘if you get into too much trouble, just ring an ambulance’. And the two ambulance drivers turned up and they said ‘our hands are tied, we’ve got enough stuff in the ambulance to knock her out for a month but we can’t administer anything because she’s under palliative care and she’s got the pump on’, “ James says.
“Well, I said ‘the nurses left all of that and you can read up all of what she’s on and what she’s got and everything else’ and he said ‘no we can’t do anything – all we can do is take her to Emergency and they’ll have to wait for palliative care’, to find out what she’s on and what she’s not on. So … she could go down there for three or four hours and just be in an agitated state and no-one will look after her at all.”

James says that despite the palliative care service being restricted to office hours, one specialist nurse visited Fiona one night in her own time, to fix a tube she had pulled out of her body.

James was given instruction as to how to administer pain relief but sometimes, the drugs didn’t work well or took hours to reduce Fiona’s distress.

“We were sort of left to our own wits,” says James.

“It was only two weeks prior to that date that palliative care was cut from a 24-hour operation to an 8:30 to five o’clock operation, so there was no one coming out of a night time,” he says.

Fiona wasn’t too bad during the day. She was agitated and everything else but she wasn’t too bad of a daytime. The medication they gave her seemed to calm her down a bit but come about 11 o’clock at night, she just got all erratic.”
Every death is different but when specialist palliative carers are on the frontline, a distressing death can be made easier. For Nicole, of Sydney, hospital palliative carers were on hand when her husband Blake died in a physically confronting way, by bleeding out.

Despite the horrific circumstance Nicole faced as she stood alongside her husband as he died in this way, she says she felt supported by specialist palliative care staff who were there to help him and to help her.

This was not the case with the death of Nicole’s mother, who died under the care of a geriatrician in a hospital ward following a stroke, with doctors providing “their version of palliative care remotely” with no explanation of what was happening to her. The family had been advised she could not access a specialist palliative care facility, Nicole says.

“Blake (Nicole’s husband) was four days in a standalone palliative care ward with 24-hour access, specialised staff,” says Nicole.

“We had the chaplain pretty well on our case, on call, we had (the doctor) on the case, on call the whole time. We had staff who did this, day in and day out. They knew what they were doing. They knew to tell me ahead of time (what to expect).”

Blake’s death was harrowing for Nicole as she was with him while staff helped him. The death of Nicole’s mother, while more peaceful, was not as well supported, she says.

“I felt more supported in his passing than I did in hers.
I had to run out at one point and say ‘I need someone from palliative care’ and they said ‘they don’t start until nine’ and this was about a quarter past seven in the morning.

I believe there is a huge difference.”

Nicole says that while it’s recognised that “it takes a village to raise a child”, we forget that “it actually takes a village to support someone when they pass as well”.

“Someone passing away in a hospital shouldn’t be a statistic. It shouldn’t come down to a statistic. I understand that palliative care is a very new realm of medicine … it’s still not given the respect it deserves,” says Nicole.

Nicole says palliative care can provide very good support for family and community around the person who is passing.

“I think the flow on effect of that is a greater acceptance of that person’s passing,” she says. “The support for their family and friends and community and co-workers and from that, I think we end up with greater social awareness. You end up with people managing the process of grief better. For me, I don’t think palliative care is wholly and solely around symptom management and pain control – I think it has many layers and they all have value.”

Nicole says her experience of palliative care shows her that good specialist care enables comfort for the patient and loved ones.
Rosemary’s Story

Waiting 10 days for a family member to receive palliative care can be heart-wrenching but for medical practice manager Rosemary, the ramifications are widespread. Rosemary, from a nursing background, works in regional NSW and sees first-hand how stretched services drag everyone down.

There is a ripple effect with a lack of services. When a patient is suffering and not getting access to care when they need it, families reach for help. GPs go above and beyond to help them but have their own time restrictions. Palliative care specialists get the call but often simply don’t have enough hours in the day to reach everyone. The result: a lot of people in pain.

“That does happen fairly often,” says Rosemary.

“We had a young patient, (aged) 21 ... his regular GP was overseas and we had GPs looking after him. He became very ill and the family rang palliative care because that’s what they had been asked to do,” she says.

“They were told ‘well in 10 days, the doctor can come out, the nurse can come out’ and they were just devastated. This family came into the clinic and they were just inconsolable (saying) ‘what are we going to do, how are we going to manage him?’

“One of the GPs saw them and spoke to palliative care and they actually got him to go out that day. Obviously this guy needed it, but that was potentially at somebody else’s expense because they didn’t have extra specialists on board to do it.”
Palliative care is hard to access if people don’t try to tap into services early because ...

... there are not enough specialist staff available, says Rosemary.

“It’s very hard for them to get it when they need it if they leave it too late.

“Palliative care is so stretched with resources and staffing. They do a wonderful job. It’s fantastic. But there’s only so many of them. You can’t stretch them any further.

“It’s so under-resourced. They just haven’t got the time to spend with everybody and the palliative care people, you do feel for them and you know they’re stretched.”

The impact on palliative care teams unable to reach everyone is devastating, Rosemary says: “It’s absolutely dreadful. They do what they can and they bend over backwards to help a person to get any resources they can but I think they’d be devastated that they can’t help everybody but there’s only so many of them.”

Palliative care is often effective when families get help in their homes to fulfil patient wishes of dying at home but there are many people, particularly local Aboriginal people, whose wishes aren’t fulfilled because resources aren’t there, she says.

“Aboriginal Australians, I don’t know how they manage … trying to get them to services is so hard but also trying to get services for them (is hard). It’s just that the clinics are so booked up.”
Throughout NSW, MPs from across the political spectrum have shown their support for palliative care by having their photo taken holding the I Care for Palliative Care pledge. As local community members continue to meet with their MPs, many more will join their colleagues in expressing their support for palliative care.

Adam Crouch
Member for Terrigal
Liberal Party

Chris Gulaptis
Member for Clarence
The Nationals

Damien Tudehope
Member for Epping
Liberal Party

David Harris
Member for Wyong
Australian Labor Party

David Mehan
Member for The Entrance
Australian Labor Party

Geoff Lee
Member for Parramatta
Liberal Party
Geoff Provest  
Member for Tweed  
The Nationals

Greg Piper  
Member for Lake Macquarie  
Independent

Guy Zangari  
Member for Fairfield  
Australian Labor Party

Jai Rowell  
Member for Wollondilly  
Liberal Party

Jamie Parker  
Member for Balmain  
The Greens

Jenny Aitchison  
Member for Maitland  
Australian Labor Party

Jo Haylen  
Member for Summer Hill  
Australian Labor Party

Jodi McKay  
Member for Strathfield  
Australian Labor Party

Jonathan O’Dea  
Member for Davidson  
Liberal Party
Julia Finn  
Member for Granville  
Australian Labor Party

Kevin Anderson  
Member for Tamworth  
The Nationals

Lee Evans  
Member for Heathcote  
Liberal Party

Mark Speakman  
Member for Cronulla  
Liberal Party

Tania Mihailuk  
Member for Bankstown  
Australian Labor Party

Thomas George  
Member for Lismore  
The Nationals

Tim Crakanthorp  
Member for Newcastle  
Australian Labor Party

Trish Doyle  
Member for Blue Mountains  
Australian Labor Party

Yasmin Catley  
Member for Swansea  
Australian Labor Party
We Care for Palliative Care

“Palliative care supports the family to know more about what’s actually going on for the person who is sick. But also just being able to stay at home and be in their own home and not have to be in a hospital and to be able to be more comfortable in their own environment.”

Belinda McIntyre

“No-one should have to die in agony, or have episodes of agony, simply because the system fails, particularly after hours. The availability of palliative care staff is something that can and should be managed well.”

Howard Dick

“I guess there is comfort in knowing that he is under the best care … for someone like your father who has provided for you for your whole life, done everything for you and then in the final days of his life, everything is out of your control and you cannot provide the same level of love and care that they deserve in their last few days in this world.”

Christina Watts
Leonie’s story

Wiradjuri junior Elder, Leonie McIntosh, was in the final throes of her PhD thesis when diagnosed with brain cancer after having difficulties navigating her computer while at work in regional New South Wales in 2015.

Leonie, aged 41, has two children, a 16-year-old daughter and a four-year-old son. The diagnosis has up-ended her work, study, family life and her community role. She can no longer drive or help others as much.

“I guess life isn’t as fun as it used to be,” says Leonie.

Access to local palliative care and the Aboriginal Health Service has brought about some welcome changes to Leonie’s daily life … giving her the opportunity to re-engage in cultural activities and take time to connect to her world, especially her son.

“My prognosis is long term but at any time I could have a seizure or something could go wrong, so we always hope that we’re going to beat this thing,” says Leonie.

“The palliative care team come one or a couple of hours each week and they take me to a park, me and my son, and we go and he does kid stuff, explore the wild and have fun. They can take me shopping, if there is something on that day, we can go to that. You know, it’s just a chance to do normal stuff outside of specialists.”

Leonie has tapped into a health diary service offered to Aboriginal patients to help alleviate some of the stress involved in managing multiple medical and allied health appointments.
“Without that, I really wouldn’t have coped with the first six months of getting back from hospital and all of that stuff,” Leonie says.

Access to emotional support has been reassuring for Leonie: “Not only are they good for those practical things, they are also really emotionally supportive and so it’s good to just have a normal yarn with someone”.

“If (the nurse or volunteers) recognise any changes in my voice, they come and meet me,” Leonie says.

“They’ll ring me up and if I need them, they’ll come straight around. Or I can ring them 24/7… There was a time when I was quite ill, so my daughter, I think she rang palliative care nurse and they told her what to keep an eye out for.”

Leonie says the team also helped her plan ahead in a practical way.

“I don’t have a formal will … I didn’t know about the ambulance care plan … when you get cancer you don’t know about any of that kind of stuff and if you’ve got a really good palliative care team they can make it less confronting and less scary,” Leonie says. “I’m only forty-one, I never thought of dying.”

**Palliative care has enabled Leonie to find life’s sweet spots.**

“I’m slowly getting myself back into the bush and walking. I get very fatigued from the medications and stuff. It’s been quite a challenge but I still walked maybe 2 or 3 kilometres a day since diagnosis, when I’ve been well.”
Jennifer’s story

Waiting too long for palliative care causes needless pain for patients and families. For Jennifer Creal, timely pain management for her husband Christopher was lacking because of a two-week wait for specialist palliative care during a crucial time in his illness.

The Creals lived on a farm in regional NSW when Christopher’s active cancer treatment stopped and ...

... they were left waiting for a palliative care assessment and vital help from the palliative care team.

Christopher had cancer of the larynx that spread to his lungs and underwent surgery in Sydney, also travelling to a regional hospital for chemotherapy. Once the couple realised his health was ailing, they focused on maintaining his quality of life.

During two weeks of waiting for palliative care, Christopher’s health declined rapidly and he was taken to hospital by ambulance, in pain, in 2013.

Christopher’s oncologist had earlier referred him to a palliative care team. After a week at home without action, the team told Jennifer on the telephone that “yes, yes we are coming” but two weeks later, without an assessment or visit, his pain was out of control.

“They (the palliative care team) kept in touch and to be fair, Christopher’s cancer progressed very rapidly but at the end of two weeks I couldn’t control the pain and he was admitted to the Palliative Care unit at our local hospital,” Jennifer says.

Christopher died in hospital within three weeks of completing his chemotherapy and while specialist palliative care was helpful when he was able to access it, prompt attention would have benefited the Creals immensely.
“If we could have seen somebody in that first week and got him onto proper pain management – I am not saying it would have been the answer – but it would have been nice for me and the family because they were all visiting from Sydney,” Jennifer says.

People should have the sort of death that they want, says Jennifer, who believes that having family around when a loved one is dying is important. Pain doesn’t only impact the patient: “It is really about controlling the pain and that is what is worrying, if you cannot control the pain, it is really difficult to watch”.

The care was great when Christopher received it.

“The local palliative care unit is fantastic,” Jennifer says. They have a unit which has a little annex where you can sleep, a fridge and a microwave – everything to make life comfortable and I did stay there a lot – I mostly stayed there actually and I am lucky to have a wonderful family. They were a great support.”

But timely palliative care at home would have been the right fit for Christopher, says Jennifer, whose brother died in palliative care at home.

“It would have been nice, and he would have liked it as well, if he had just been at home. I had a brother who died a few weeks after my husband (in another town) and he was nursed at home.”
“Despite having a terminal illness, there was no discussion about what would happen at the end, none whatsoever. And that’s just not the way it should be, that’s not the way it should be at all. It meant that she suffered without her medication and got sick again, she needn’t have.”

Kathy

“In the end, the only aspect of this terrible disease Rick could control was where he would be when it eventually ended his life. Rick wanted that place to be at home. Without palliative care, I would not have been able to make this happen.”

Carolyn Keast

“... looking back at the experience you should be able to think ... we did the best that we could; we provided the care and love that that person needed. You do not want to look back on that time negatively when it is such an important period of time.”

Christina Watts
“One of the scariest things for us as a family was the sense of fear around a short term offering of support. We were informed that the inpatient care was usually for a maximum of two weeks. We were therefore often told that after two weeks we may have to be discharged.”

Kerry Moss

“A lot of people think palliative care is just about the person that’s dying. It’s not. It’s about the whole family – allowing them to come into that area and grieve.”

Deb Cotter

“I don’t think she wanted to die in a nursing home. To get back home to look at her garden, potter around, make a cup of tea and sleep in her own bed was very, very important for her besides the emotional factor just being at home was much better for her.”

Alison McMorland
Belinda’s story

Faced with a wait of at least two months for an appointment to see a specialist doctor to investigate constant pain, Belinda’s mother drove several hours from regional NSW to take her father to seek help at a clinic near her home in Sydney, where he was told he had oesophageal cancer.

“He was in constant pain, all day and night, and the best they could do, in July, was to tell him he could get an appointment in September,” says Belinda. “He said himself that he would have probably been dead by then without even knowing what was wrong.”

After reacting badly to chemo treatments early on, he was admitted to hospital where his oncologist was based, and spent more than a month there. “My mum would have to drive for an hour-and-a-half just to get there to see him,” says Belinda.

When her father got sicker, access to much-needed palliative care at home was essential because of the long drive to the regional hospital from the family farm, and his wish to stay at home. It also became difficult to get help from their family GP when Christmas time was upon them.

“Around Christmas time, he was very sick and that was when my mum wasn’t really coping. The GP basically said he was going on holidays and there was no way we could contact him and that’s it,” says Belinda. Thankfully the palliative care nurses helped to find an alternative GP to communicate with and even assisted with communications with the funeral home.

Belinda’s father received palliative care at home but the family found some aspects of the service complex and stressful, in particular getting access to medication when it was vitally needed.
“The nurse would come and tell you what she thought he needed, but then she had to go and ring the palliative care doctor and confirm that’s what he needed. Once confirmed, you then had to go and get a script from your GP who by that stage of the illness, didn’t really know what was going on because he wasn’t even seeing you anymore,” she says.

“When you live in the country, it’s not that easy. My mum has to drive 40 minutes to go to a chemist, to get there and back.”

Belinda says she had no complaints about the care her father received when he was dying but the issue with obtaining medication prescribed after these visits was difficult due to their location.

“My Mum couldn’t have done without the palliative care team and they really were great. They came out there twice a day to care for him and provide resources, personal care, training for us and advice. In the end he did die at home,” she says.

“The nurses were very kind and helpful with answering our questions and helping us to be more aware of what was happening, and how to help him be comfortable. When you haven’t been through something like this before, it really helps having people around who can help you understand what is going on, and help prepare you for what is to come.”

Belinda says it was important for her father to be able to die at home but specialist care was lacking at a crucial time in his illness. The specialist palliative care doctor was available to visit Belinda’s father just once when he was dying. “I think we need more doctors especially, because, as I said, my dad saw a palliative care doctor only once.”
Juliette’s story

At the time of eminent Sydney head and neck surgeon, Professor Chris O’Brien AO’s death as a result of a malignant brain tumour, the words palliative care hadn’t been mentioned in his orbit. Death was the “elephant in the room”, says his family.

“We were in fight mode,” says Juliette O’Brien, Chris’ daughter.

“He was constantly going from scan to scan and the hope was always that this next thing would work. Until the very end, in fact for me it was the final hours, we were still hoping to find that solution, that miracle, and holding onto that. I don’t think we ever did reach a point of actually saying the words ‘palliative care’.”

Gail O’Brien, Chris’ wife, says while they acknowledged the disease would end his life, they didn’t talk about palliative care or death other than discussing plans for his funeral service about one week before he passed away.

“It’s like it was the elephant in the room,” says Gail. “Hope is what kept us all going, so that is what we focused on. We needed to keep holding on to hope. But in hindsight, we should not have done that at the expense of also preparing.

“It would have been very helpful to me to have some sort of facilitator or conduit to say to me ‘Gail, when you are ready, we need to talk about this. You may be the lucky ones but the survival rate is not good, so let’s talk about the possibilities and the options.”
“I really think palliative is such a scary word to people. Maybe we could use another word. [‘Palliative’] spells death to everybody.”

Professor Chris O’Brien was diagnosed with cancer in 2006 and died in 2009 after being rushed from home by ambulance to RPA, the hospital where he worked and died, encircled by his family. In a book Juliette wrote about her mother, This is Gail, she detailed the traumatic day when Chris was struck by a sudden burst of ill health at home and Gail struggled to get morphine to alleviate his pain. Eventually, intensive care paramedics were called and Chris was transported to hospital.

There was no understanding of the pain Chris might be in toward the end, says Juliette. And the word palliative is problematic: “Palliative has a bad branding issue because it’s become a word that terrifies people.”

The idea of having a facilitator other than the oncologist or GP to prepare the patient and family for dying is a good one, says Gail.

“The timing of that conversation is critical. It does need to prepare the patient and family, so that they are better equipped physically, mentally, emotionally and even spiritually,” says Gail. “And in some ways, it might also give the patient permission to stop fighting – that it’s ok to succumb gracefully.

“None of us thought about talking about it,” Gail says. “We didn’t know what we didn’t know”.
Melanie’s story

“I just want to go home, let’s just go home, you can look after me there and stay with me” are the words etched in Sydney woman Melanie’s mind when she recollects the death of her father Robin as he sat in a hospital shortly before his death.

The system did not afford 68-year-old Robin the option of dying comfortably at home in palliative care, surrounded by his family. He died in hospital six months after being diagnosed with advanced, aggressive prostate cancer.

Robin’s daughter Melanie was his main caregiver during his illness and says when it was clear her father was going to die soon, she just wanted to take him home: “And he wanted that”.

“I said ‘look, I’m smart. I’ve followed the medical condition of my dad. I have watched the nurses inject him with everything. I know the process. I can manage this. I have the time if you can just let me take my dad home, teach me how to look after him, I’ll do it. And if he needs to get carried to the bathroom once a day, just send someone over once a day to help me carry him or teach me how to lift him up in the bed. I’m strong’, says Melanie.

“The capacity was there – my mum was there; I was there. We are two very strong, able people. To look after him 24/7, all we needed was just a little bit of extra support to guide us.”

Robin had been treated with radiotherapy, chemotherapy and thalidomide but his cancer progressed rapidly and he spent the last three weeks of his life in hospital. Melanie says it would have been better if Robin had been able to be transported home towards the end.
“That would have made such a big difference,” says Melanie.

His bedroom looked out into a beautiful garden courtyard. That was his home where we spent so much time together. And I just had this vision of him dying in bed with all of us there around him, looking out into the sunny garden.

“And that is what he wanted. That’s what he wanted when he asked me to take him home.”

Melanie says she doesn’t want other families to feel the guilt she feels about her father not getting the care he wanted at the end of his life.

“I know if he was in a position to tell his story, he would have said the same thing … for all the other families who are stuck in our position in the future,” she says.

“I don’t want anyone to feel that guilt. It shouldn’t be put onto the families either.

“I still live with that guilt.”

Melanie says her family just needed a little bit of assistance: “We just needed a bit of extra help. We could have managed.”
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The Cancer Council NSW campaign goal is based on a recommendation from the Australian and New Zealand Society of Palliative Medicine and workforce data from the Australian Institute of Health & Welfare, current as of October 2016. It is subject to change as new data becomes available.