The NSW Government plan to increase access to palliative care

2012-2016
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Foreword

Honouring people’s choices about the end of their lives

In *Julius Caesar*, Shakespeare reminds us that “death, a necessary end, will come, when it will come”. At some stage each of us will die, as death is a fundamental part of the human condition. There is still so much we do not know about death and dying, and human beings have always struggled to understand exactly what it means.

On the other hand, enormous advances in medical sciences and technologies have given us a better understanding of what it means to live with a complex terminal condition and how to manage the pain and physical suffering that is often associated with it.

Each individual faces the end of their lives differently. Depending on their life histories, their family situations, their cultural and religious backgrounds and beliefs, their medical histories and their own personalities, they have different needs and expectations.

However, everyone should be able to take some control of the last part of their lives and be able to make decisions about what medical treatment is provided and how it is delivered and managed; about the way in which their pain is ameliorated; and about the places and circumstances in which care is delivered.

Palliative care is that part of modern medicine which deals with such questions and it is the policy of the NSW Government, set out in this new Plan, to ensure that everyone has access to quality palliative care regardless of their economic or social circumstances, their geographical location or their medical condition.

NSW already has good palliative care services in both the public and private sectors delivered by a variety of organisations, but there is an inadequate number and they are not available equally to all communities.

This Plan seeks to enhance those services and to draw upon and expand the skills of the multi-disciplinary teams who provide such care. In addition we are seeking to involve families more directly in the provision of palliative care to their loved ones and thus make it possible for more people to have a real choice about being able to die at home in an environment of love and comfort provided by those closest to them.

This represents a great challenge, but one which we are determined to meet. Above all, it requires us to be intelligent and flexible in our thinking and to commit ourselves to supporting the right of people to make real choices about how their last days are spent by mobilising the skills, expertise and love of families, carers and dedicated health workers to ensure that our necessary end can be faced as painlessly as possible and with the dignity to which we are all entitled.

Hon Jillian Skinner MP
Minister for Health
Minister for Medical Research
The NSW Government has committed an additional $35 million over the next four years to improve access to care and support for people who are dying, their families and their carers.

The NSW Government will develop new models of care, foster new partnerships and establish linkages across services and sectors to develop an integrated network of primary care, specialist palliative care, aged care and community services.

To do this we will work with people living with a life-limiting condition, carers, community members, GPs, nurses, allied health professionals, Medicare Locals, Local Health Districts (LHDs), specialist palliative care providers and the NSW Agency for Clinical Innovation (ACI), a clinician-led organisation tasked with developing new models of care and improving patient outcomes.

To accelerate progress in putting these important strategic improvements in place, public, private, community and non-government organisations (NGOs) will be invited to submit proposals for community-based palliative care initiatives that will help achieve the actions listed in this Plan.

NSW Health will be open to considering a range of service proposals that address the key strategic objectives identified as part of this Plan. These action areas are as follows.

1. Expanded community-based palliative care services, especially in rural areas and for special needs populations

Adopting innovative approaches, the NSW Government will expand community-based services and extend the mix of organisations currently responsible for palliative care to include new providers, particularly among NGOs and private providers. New and existing services will be encouraged to form partnerships with LHDs and Medicare Locals.

2. Integration of primary care, aged care and specialist palliative care services across the state

The NSW Government will drive greater integration across services in the state. Linkages will be encouraged between specialists and GPs, community nurses and others. Medicare Locals will have an increasing role to play and referral pathways between services and residential aged care facilities will be strengthened.

The ACI will, through the newly formed Palliative Care Network, promote the adoption of best practice by service providers and maximise use of resources.

3. Expanded support for families and carers

The NSW Government will extend support for families and carers of people receiving palliative care. This may include increased access to information, advice and support, after-hours telephone support and access to other assistance with day-to-day living such as domestic help.

The Government acknowledges that information and appropriate support services are integral to maintaining the health and wellbeing of the carer and supporting his or her capacity to continue in their caring role for as long as they choose to do so. Links between carers, carer support officers and volunteers will be strengthened to ensure that they receive timely and targeted assistance.
4. Extended capacity of palliative care services in NSW

The NSW Government will build workforce capacity through support for the training, employment and retention of specialist palliative care physicians, nurses and allied health workers (including those specialising in paediatrics), GPs, indigenous palliative care workers and volunteers.

We will include palliative care education as part of general medical, nursing and allied health education and training.

LHDs will be encouraged to participate in the Program of Experience in the Palliative Approach. This national program provides opportunities for health professionals to enhance their knowledge and skills with input from experienced specialist staff.

LHDs will also be encouraged to support enrolment of palliative care services in the National Standards Assessment Program.

Jenny Potts’ story

I am a volunteer in my local area and visit patients in hospital and also do home visits. I do have a genuine empathy for people, and probably identify quickly when folk want to talk or just have company. I get pleasure in chatting to patients and giving them gentle foot and hand massages, generally easing their pain a little if possible. Through house visits I am able to let the carer have a little respite, whilst being company to the patient.

Doing house visits enables me to become a little closer to the patient and with one lady we had lots of laughs and discussions about similar trips we had done. We both loved the same music and would just sit and listen to it together. She also loved her weekly foot and hand massage. I would come from these visits with a feeling of making someone more comfortable. With some patients, I find I build a rapport with them and they often open up to me and confide in me, when they may not tell family or friends. I have been volunteering for over six years now in this field, and I think I have learnt so much, and feel it has made me a much more tolerant and caring person.

Jenny with her Quiet Achiever Award presented to her by the Scope Club of Ballina in October 2012 in recognition of her community work.
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What is palliative care?

Palliative care provides treatment and care for people who are dying and supports their families and carers. It neither hastens nor postpones death, but affirms life and approaches dying as a normal process.

Elements of palliative care include:
- relief from pain and other distressing symptoms
- enhancement, as far as possible, of quality of life
- psychological and spiritual care
- support to help patients live as actively as possible
- assistance for families coping with illness, death and bereavement.

Palliative care may start early in the course of an illness and evolve as a person approaches the end of his or her life.

Palliative care can be provided in a range of settings and can involve doctors, nurses, allied health workers, volunteers, families and carers. They will often work in networked teams to allow best access to high quality care.

These networks include primary care providers (including GPs, generalist community nurses and allied health workers), tertiary care providers (including public and private hospitals and specialist hospices), community support services and aged care services.

One of the greatest challenges is ensuring people across NSW are able to access palliative care as close as possible to their home and family.
**Palliative care services in NSW**

The NSW Government currently spends at least $86 million a year on specialist palliative care delivered in a range of settings: public and private hospitals, hospices, community clinics, residential aged care facilities and in the home. Many more millions are spent on providing palliative care to patients in general hospital beds and in community settings.

Rural specialist palliative care services are predominately small, nurse-led teams (Figure 1). After-hours access to specialist palliative care services is limited outside metropolitan areas. Not all specialist palliative care services have direct access to a palliative care physician (Figure 2).

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**Figure 1: Nurse-led palliative care services**

Source: NSW Ministry of Health, Palliative Care Role Delineation Framework – 2009/10 mapping activity
Inpatient palliative care

There are 300 specialist palliative care beds located in NSW public hospitals, affiliated hospitals and other facilities in the NSW health system. Care is also routinely provided in non-designated palliative care beds.

In 2008-09, there were 19,800 palliative care hospital admissions both in designated and non-designated beds, almost all in public hospitals.

Specialist paediatric palliative care physicians have admitting rights to their base facilities but report limited use of inpatient beds, compared to outpatient consultations and home visits.

Palliative care teams have a significant role advising other health professionals on the care of patients admitted to hospital for other reasons.

Seventy-one per cent of palliative care admissions in 2009-10 were cancer-related, but the number of non-cancer palliative care admissions is rising (increasing by 65 per cent between 2002 and 2009).

Community-based specialist palliative care services

Community-based specialist palliative care services provide care at home, or as close to home as possible, including in residential aged care facilities and in clinics. In NSW in 2010-11, there were about...
100,000 visits to the home by dedicated community palliative care services.

People receiving specialist palliative care made 144,585 visits to hospital clinics in 2009-10 and an unknown number of visits to consulting rooms or stand-alone day clinics.

**Primary care services**

In addition to the important role of specialist palliative care services in both hospital and community settings, much of the care provided to people who are approaching and reaching the end of their life is provided by primary care services or other medical specialists.

Primary care services are provided by GPs, generalist community nurses and allied health workers.

Community support services are provided by public community support agencies and NGOs. Adopting a palliative approach ensures better symptom management and communication on the options available.

The Australian Government has direct policy and funding responsibility for GP services. The engagement of GPs within community-based palliative care service networks is an ongoing challenge.

There are problems with accessing GP services in some areas of metropolitan Sydney; however, in other metropolitan areas the supply of GPs is adequate. In rural NSW, a shortage of GPs has contributed to their reduced capacity to participate in shared care arrangements for patient care.

The NSW Ministry of Health will be developing and strengthening links between LHDs and Medicare Locals, the bodies locally responsible for ensuring adequate access to primary health care services.

**Paediatric palliative care**

Children receive palliative care from GPs, nurses and allied health workers via a mix of community-based services and specialist paediatric palliative care services in conjunction with families and carers.

About two-thirds of children who are dying of a life-limiting illness in NSW are supported by specialist paediatric palliative care services provided through The Children's Hospital at Westmead, Sydney Children's Hospital and John Hunter Children's Hospital.

These hospitals’ specialist teams also provide hospital-based consultancy services and consultation to community palliative care services and primary care service providers.

Under the “Pop Up” teams model, a specialist palliative care service supports a local team of health professionals. This team can be quickly mobilised around the child and family to provide support for the duration of the child’s illness and for the family in bereavement.

The NSW Paediatric Palliative Care Planning Framework 2011-2014 outlines the plan for further development of these services.

**Aged care services**

About 10 per cent of all deaths in NSW take place in residential aged care facilities. When needed, a palliative approach to care is provided by aged care staff, GPs and, in some instances, aged care palliative care liaison nurses. The population of these facilities is expected to increase by 70 per cent in Australia over the next three decades.
I have motor neurone disease, which was diagnosed in June 2011. I receive palliative care services from Calvary Hospital and from my first diagnosis was overwhelmed with people willing to help. Frank, my palliative care consultant, was good at linking me in with other services, was concerned with my emotional and physical health and has a good knowledge of motor neurone disease.

Motor neurone disease has phases of incapacity that impact on different areas, and they are not the same for everyone. Frank’s role was “pre-emptive” – getting me access to services and support before they became a problem, and organising and lining up services for me.

For example, after two rapid sleep studies, I now have access to equipment to support my sleep. This will increase my life expectancy. I am meeting with the gastroenterologist who will talk through my options when chewing and swallowing become too difficult.

It’s a challenge to dissect all the information, especially at the time you are first diagnosed and mentally are in a bit of a daze. It’s all a bit overwhelming and you are not sure who to turn to, as there are lots of people acting in your best interest. I think there should be more literature – we were given information verbally, and occasionally hand-written notes, but it would have been great if we had received literature on what the palliative care service is, how it fits into the hospital organisation, who does what and what the options are.

My advice to others embarking on a similar journey? Don’t panic. And accept people who are offering their services, even if you think it’s too early.

And if you have a doctor who is not listening, change. Fortunately I have had a good experience.
Support services

Bereavement services
Bereavement counselling and support is recognised as a routine part of palliative care, although few services employ dedicated staff. Most bereavement support is provided by nurses and social workers.

Respite for carers
Carers are frequently required to take an active role in caring for a loved one at home, managing pain and medications, providing hygiene care and supporting general activities of daily living. Carers are also often called upon to be involved in stressful end-of-life care decisions. There are limited respite services available for carers, especially respite care that can be provided in the home. There is also limited aggregated information about the extent of services that are provided.

Volunteer services
Volunteers provide a range of support for patients and/or their carers and families. These services may range from direct practical assistance through to telephone support and counselling. Volunteers may be members of NGOs or operate as part of local palliative care service networks. Most LHDs have volunteer programs and employ at least a part-time dedicated volunteer coordinator. These programs vary in size and can fluctuate in activity. There is a need to support volunteers working in this area.
Palliative care services in NSW

Equipment
Timely access to equipment ranging from mobility aids to therapies such as oxygen is particularly important to support people to die at home. Many LHD services report insufficient access to equipment.

E-Health and telehealth
Technology will play an increasingly important role in linking patients and their primary and tertiary care providers when they may be distant from each other or unavailable at certain hours.

E-health provides enormous opportunities for health professionals to increase productivity and improve patient care, particularly through access to reliable information about a patient’s medication regime and medical history. This is important for palliative care services as patients may be prescribed medication by a number of health professionals. Two of the most significant enhancements in this area are the Australian Government’s Personally Controlled Electronic Health Record and telehealth, which is already used extensively by NSW Health. Palliative care services can benefit significantly from a wider use of technology. Health professionals need to support their patients and colleagues to appreciate the benefits and opportunities afforded by innovation in this area.
The gaps

Access is difficult

Of the 13,000 people in NSW who die of cancer each year, about two-thirds receive specialist palliative care. A similar number of people die of other conditions where death is predictable. Only about 10 per cent of these people receive specialist palliative care in their last year of life.

While there are many well-established palliative care services and health professionals delivering them, some people and their families find it difficult to access these services. It is important that people are aware of palliative care services. People living with a life-limiting condition, their families and their carers will be informed that palliative care may be an appropriate choice for them.

As shown earlier, both specialist and primary care services are not uniform across NSW, with people in regional and rural areas particularly affected.

For some people, lack of local access may involve travel for specialist palliative care, creating practical, emotional and financial problems. Access to GPs, particularly after hours, creates a significant gap for people wishing to remain at home. Support often depends upon the goodwill and commitment of palliative care staff who live and work in these communities.

Access to federally funded services such as Home and Community Care and aged care packages is also a gap for community palliative care patients.

Gaps in assessment skills and referral processes often mean that the recognition that a person is dying does not occur until very late in their life, leaving them and their family and carers very little time to come to terms with the approaching death and denying them the time to consider options such as dying at home.
Being able to die at home

Most people in Australia say they want to be cared for and die at home (Figure 3).

Yet across Australia, only 16 per cent of people die at home, 20 per cent die in hospices, 10 per cent in nursing homes and more than half in acute care hospitals.

There are a number of reasons why more people do not get to die at home, including:

- both specialist and primary community palliative care services are limited in rural areas and in some metropolitan areas
- there is a lack of 24-hour advice and support for families, carers and health professionals, especially in rural NSW
- there are fewer incentives for GPs to provide home visits or extended consultations
- GPs and palliative care professionals are not adequately supported to provide coordinated and high quality palliative care support in aged care homes
- hospitals and community-based services are not coordinated well enough to allow people to move quickly and easily from home to hospital and back again as their needs change.

Figure 3: Place of death

Culturally appropriate care

While almost one-third of people supported by specialist palliative care services are born overseas, palliative care services may not be culturally appropriate for people from culturally and linguistically diverse (CALD) communities.

Similarly, Aboriginal and Torres Strait Islander people may have different cultural understandings of concepts such as kinship and family relationships, place, healing, communication styles, and death and dying.

It is important that culturally appropriate services are available to all people who wish to receive this care.
Murray Rose was the greatest swimmer in the world in the 1950s and early 1960s, setting 15 world records and winning four Olympic gold medals. In January 2012, he was diagnosed with acute leukaemia.

After initial treatment in hospital, Murray and his wife, Jodi, decided he would like to die at home. Less than three months later, he did so, with Jodi and their 22-year-old son, Trevor, at his side. Jodi Rose tells his story.

When Murray was diagnosed, the leukaemia was very advanced and we knew we only had a matter of time. We were blessed to have those months, because he was able to prepare himself and accept the inevitable.

Originally, Murray was thinking of going into a hospice. I had told him early on that I was not afraid, that I knew home was the best place for him to be, to pass. Murray felt a sense of comfort being where he belonged. In ancient times, death was a very sacred chapter and people took great care to see this passage through with dignity and honour.

Some of the research I did online suggested that to care for a loved one at home eases emotional issues after they pass. I am left with the knowledge that, though it is a painful and terrible loss, what I did was right for us. I have no regrets about the road we chose.

The doctors from Sacred Heart Palliative Care, Darlinghurst, would come a few times a week and take blood. They had staff on call regularly to answer questions. Without their gentle training, there is no way I could have administered medications like morphine.

I found strength that Murray could be at home. Since he recognised I was coping, he allowed me to do things for him. To surrender to such support is a sign of character and trust.

It is a vital role of any progressive society to assist people to help their loved ones die at home. And for a carer to feel that if they are able (and we know not everyone is comfortable or will feel right in this role) they are supported.

There is no way to do it alone. I will forever feel a great debt to the Sacred Heart staff and their role in allowing a point of peace through this great transition.
The NSW Government currently spends at least $86 million annually on specialist palliative care services administered by the NSW Ministry of Health and LHDs.

Over the next four years, an additional $35 million will be allocated to increase access to palliative care for people who need it across NSW.

To do this, we are keen to collaborate with people living with a life-limiting condition, carers, community members, GPs, nurses, allied health workers, Medicare Locals, LHDs, specialist palliative care providers and with the ACI.

We will develop new models of care, foster new partnerships and establish linkages across services and sectors so that the people are served by an integrated network of primary care, specialist palliative care, aged care and community services.

We will support the development of robust primary care and specialist services available in the community, to help ensure that wherever possible more people can be supported to achieve their wish to die at home with their families and loved ones.

Strong and effective local, regional and statewide networks of primary care, aged care and specialist palliative care providers will ensure that all people in NSW have access when needed to high quality care as they approach and reach the end of their lives.

To accelerate progress in putting these important strategic improvements in place, the NSW Government will invite public, private, community and NGOs to provide proposals for community-based palliative care initiatives that will help achieve the actions listed in the following section.
NSW Health will consider a range of proposals that address the key strategic objectives identified as part of this plan. The action areas are as follows.

1. **Expanded community-based palliative care services, especially in rural areas and for special needs populations**

2. **Integration of primary care, aged care and specialist palliative care services across the state**

3. **Expanded support for families and carers**

4. **Extended capacity of palliative care services in NSW**

These actions will be carried out over the course of the next four years.

**Models of care for palliative care services**

The ACI will work to develop models of care for palliative care services. Under these models of care, palliative care services will:

- take a multidisciplinary approach to care involving family members, carers and all appropriate health care providers
- in the case of community-based services, have formalised links with a specialist palliative care service
- have the capacity to provide, or be networked with a service to provide, after-hours support and advice from health professionals
- use innovative technology such as telehealth and e-health to share information
- have broad access to clinical networks
- provide comprehensive assessment, case management, coordination and clear communication across care settings
- ensure coordinated and integrated services across settings
- work in partnership across government, non-government and community services
- provide coordination of health care with other services such as carer respite and home care services
- tailor services to the target population and setting, particularly when addressing cultural needs
- offer dynamic models that can respond to the needs of individuals in rural or remote areas
- provide an explicit, easy to navigate process for the transfer of individuals from acute to palliative services, with the individual informed and involved in decisions
- have a data-driven culture aimed at clinical practice improvement
- promote formal relationships between primary care services and specialist palliative care services to achieve a more integrated and coordinated approach
• initiate linkages between palliative care service providers and networks of Aboriginal health professionals and Aboriginal community-controlled health services

• initiate partnerships between palliative care services and CALD health and community services

• integrate state-based programs with work being done in palliative care services by the NGO, federal, primary care and community-based sectors

• use the National Standards for providing quality palliative care for all Australians as a benchmark to guide service development

• work in partnership with palliative care research bodies to ensure an evidence base for all features of a model of care

• expand community-based palliative care services, especially in rural areas and for special needs populations.
Laurence Perrin’s story

Laurence was the husband and carer of Christine, who was 53 when she died. They were parents of five children.

Christine’s primary diagnosis was breast cancer with secondary sites in the liver and bones. Christine and Laurence made a decision early on that Christine would be cared for at home once the chemo was to be stopped, and that Laurence would support her.

Key factors supporting the decision to care for Christine at home were having access to palliative nursing care and pain management.

Palliative care nurses would come and visit Christine at the house – initially once a week and later twice a day. The nurses were very experienced and the quality of their service very high. They were able to give a detailed explanation of Christine’s situation and what to expect. Laurence had a very good experience with the nursing staff and they made an enormous difference to Christine during her time at home.

The home option was the best for their family and friends, as the family was in control of her care and she remained in familiar surroundings with access to all the home facilities, privacy and access to nature and the garden even when she was completely bed-bound. It also enabled family, friends and neighbours to pop in for a three minute chat or to return if Christine was sleeping. Being at home meant there was no feeling of institutional care, even though those skilled were at hand when required. It was less stressful to have Christine at home and it benefitted her, as well as her family.

Christine was a member of a Cancer Support Group at the Sydney Adventist Hospital, which was an excellent source of support and information. The sharing of information and experience was invaluable as was being supported in gaining access to the relevant medical skills and contacts for specific issues.

But there were areas open to improvement. For example, Christine and Laurence had access to a 24-hour helpline. This support experience varied – during office hours it was well supported with experienced staff, but the night support was inconsistent.

As there was no electronic database with all Christine’s information, it needed to be kept in physical files at the house, and these were the primary source of information for doctors and nursing staff during the palliative care phase. If a nurse required any information, they needed to consult the files at the house. There is a need to establish an easily accessible electronic database.

Home-based palliative care is the most compassionate and special care any patient and their family can experience if it is practically possible.
1. Expanded community-based palliative care services, especially in rural areas and for special needs populations

Supporting system linkages

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<tr>
<th>Action</th>
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<tr>
<td>Ensure information about the provision of palliative care is available to people living with a life-limiting condition, their families and their carers</td>
<td>LHD</td>
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<tr>
<td>Develop models of care for palliative care services</td>
<td>ACI</td>
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<tr>
<td>Strengthen access to multicultural health workers and interpreter services to facilitate delivery of culturally appropriate services</td>
<td>LHD</td>
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<tr>
<td>Support the ongoing training of volunteer palliative care workers and carers</td>
<td>LHD</td>
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<tr>
<td>Work with members of Indigenous and culturally and ethnically diverse communities to deliver culturally appropriate information and services</td>
<td>LHD</td>
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<tr>
<td>Work with all health sectors treating people with chronic disease to strengthen appropriate referral pathways between these services and dedicated palliative care services</td>
<td>LHD</td>
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Supporting specialist community-based palliative care

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<tr>
<td>Progressively introduce new community-based specialist palliative care services to address current gaps – this process will begin with the purchasing of service components</td>
<td>Ministry of Health (MoH)</td>
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<tr>
<td>Support the expansion of existing community-based palliative care services where services exist but cover the population incompletely</td>
<td>MoH</td>
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<tr>
<td>Support the expansion of after-hours telephone support for health professionals as a means of ensuring continuous access to specialist advice</td>
<td>MoH</td>
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Supporting palliative care in the aged care sector

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<tr>
<td>Support residential aged care facilities to provide palliative care to all who need it</td>
<td>LHD</td>
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2. Integration of primary care, aged care and specialist palliative care services across the state

Supporting system linkages

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<tr>
<td>Work with LHDs to strengthen existing relationships between community and hospital-based specialist palliative care services and formalise these arrangements to promote a more integrated and coordinated approach</td>
<td>ACI</td>
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<tr>
<td>Promote linkages between specialist palliative care services and networks of Aboriginal health professionals and Aboriginal community-controlled services</td>
<td>ACI / LHD</td>
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<tr>
<td>Reinforce and support relationships between GPs, community nurses and dedicated palliative care services through strategies such as reciprocal representation on LHD and Medicare Local planning committees in order to establish formal links between them and to promote a more integrated and coordinated approach</td>
<td>LHD</td>
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<tr>
<td>Promote linkages between dedicated palliative care services and CALD health workers</td>
<td>LHD</td>
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<td>Promote linkages and formal relationships between LHDs so that those LHDs with fewer resources are supported</td>
<td>ACI / NSW Palliative Care Network</td>
</tr>
<tr>
<td>Increase adoption of shared care as a desirable model of care between GPs, community nurses and dedicated palliative care services as well as between specialist palliative care and other health specialist services</td>
<td>ACI / NSW Palliative Care Network</td>
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<td>Examine the most appropriate situations to adopt the “Pop-Up” model of care for paediatric services for adults</td>
<td>ACI / NSW Palliative Care Network</td>
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### Supporting specialist community-based palliative care

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<tr>
<td>Work in partnership with palliative care research bodies to ensure an evidence base for all features of a model of care</td>
<td>ACI</td>
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<tr>
<td>Refine the use of telehealth within palliative care service models of care, especially for patients in isolated areas where this form of communication may need to be relied on for all consultations and contacts</td>
<td>ACI</td>
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### Supporting palliative care in the primary care sector

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<tr>
<td>Work in partnership with Medicare Locals to develop coordinated primary health components of palliative care, with clinical and educational support from specialist dedicated palliative care services</td>
<td>MoH / ACI</td>
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<tr>
<td>Strengthen relationships between specialist palliative services and residential aged care facilities through evidence-based strategies known to build capacity and result in a more integrated and coordinated approach to residents’ care</td>
<td>LHD</td>
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3. Expanded support for families and carers

Supporting system linkages

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<tr>
<td>Establish linkages between local carer programs and palliative care</td>
<td>LHD</td>
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<td>volunteers</td>
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<td>Make representations to the Australian Government and the NSW</td>
<td>NSW Minister for Health</td>
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<td>Minister for Disability to improve access to Home and Community</td>
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<td>Care services for palliative care patients</td>
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<td>Ensure advance care planning features in all forms of the NSW</td>
<td>ACI</td>
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<td>models of care for palliative care services under development</td>
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</table>

Supporting families and carers

<table>
<thead>
<tr>
<th>Action</th>
<th>Lead</th>
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<tbody>
<tr>
<td>Provide families and carers with access to culturally appropriate</td>
<td>LHD</td>
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<tr>
<td>information and services, while taking care to meet the particular</td>
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<tr>
<td>needs of children</td>
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<tr>
<td>Expand after-hours telephone support services for people living with</td>
<td>MoH</td>
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<tr>
<td>a life-limiting condition, their families and their carers</td>
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<tr>
<td>Increase access by people with life-limiting conditions to domestic</td>
<td>MoH</td>
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<tr>
<td>assistance programs to sustain families and carers</td>
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<tr>
<td>Include planning for equipment provision in the delivery of</td>
<td>LHD</td>
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<tr>
<td>palliative care services</td>
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<tr>
<td>Include people living with a life-limiting condition and their</td>
<td>ACI</td>
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<tr>
<td>families and carers in discussions about their preferences for care</td>
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<td>in all models of care</td>
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4. Extended capacity of palliative care services in NSW

Supporting system linkages

<table>
<thead>
<tr>
<th>Action</th>
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<tbody>
<tr>
<td>Manage the development of a palliative care population planning tool to estimate current unmet need, as well as to accurately predict future requirements</td>
<td>MoH</td>
</tr>
<tr>
<td>Oversee the improvement of data collection in all palliative care service sectors, but particularly in the community sector</td>
<td>MoH</td>
</tr>
<tr>
<td>Establish mechanisms to improve the transparency of reporting outcomes, in line with the move to national activity-based funding</td>
<td>MoH</td>
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<tr>
<td>Review and introduce referral criteria and guidelines for access to specialist palliative care services</td>
<td>MoH / ACI</td>
</tr>
<tr>
<td>Develop a palliative care minimum data set for adults and paediatric services</td>
<td>MoH / ACI</td>
</tr>
<tr>
<td>Support the development and implementation of systematic collection and evaluation of data on key care and service outcomes</td>
<td>MoH / ACI</td>
</tr>
<tr>
<td>Promote sharing of best practice between service providers across the state</td>
<td>ACI / NSW Palliative Care Network</td>
</tr>
<tr>
<td>Support education of health professionals and the development of state-wide tools to assist them with early referral to palliative care</td>
<td>ACI / NSW Palliative Care Network</td>
</tr>
<tr>
<td>Develop strategies to promote service users’ adoption of electronic personal health records, to support safe care coordination across health services, particularly in relation to medication management</td>
<td>ACI / NSW Palliative Care Network</td>
</tr>
<tr>
<td>Implement the new NSW Health policy framework ensuring advance care planning is integrated into all aspects of care for people with life-limiting chronic illness</td>
<td>MoH</td>
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The NSW Government plan to increase access to palliative care 2012-2016

Supporting specialist community-based palliative care

<table>
<thead>
<tr>
<th>Action</th>
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<tbody>
<tr>
<td>Encourage self-assessments by all LHD specialist palliative care services using the National Standards Assessment Program</td>
<td>MoH</td>
</tr>
<tr>
<td>Improve regular access to professional development for doctors, nurses and allied health workers in palliative care</td>
<td>MoH / Health Education and Training Institute (HETI)</td>
</tr>
<tr>
<td>Initiate inter-professional working groups to address issues arising from the National Standards Assessment Program self-assessment process and to foster best practice</td>
<td>ACI / NSW Palliative Care Network</td>
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Supporting palliative care in the primary care sector

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<tr>
<th>Action</th>
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<tbody>
<tr>
<td>Encourage LHDs to participate in the Program of Experience in the Palliative Approach, a national program focusing on training of the health workforce in the palliative approach</td>
<td>MoH</td>
</tr>
<tr>
<td>Advocate for increased palliative care content in general medical, nursing and allied health education and training</td>
<td>MoH / HETI</td>
</tr>
<tr>
<td>Improve regular access to professional development for doctors, nurses and allied health workers in palliative care</td>
<td>MoH / HETI</td>
</tr>
<tr>
<td>Examine Emergency Department screening tools to identify patients for whom the palliative approach may be appropriate</td>
<td>ACI / NSW Palliative Care Network</td>
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Supporting families and carers

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<tr>
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<tr>
<td>Involve people living with a life-limiting condition and their families and carers in improving palliative care services</td>
<td>MoH / ACI</td>
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</tbody>
</table>
Jay’s story

Jay lived life to the full. At 39 he was diagnosed with squamous cell carcinoma and had surgery then ongoing chemotherapy and radiotherapy. He was in a lot of pain and had very little sleep, as it was difficult for him to sit or lie down.

Jay was referred to the palliative care nurse in the rural town where he lived. The facility was small, with limited resources, and they couldn’t provide the care he needed. He was offered care in a hospice in Sydney for two weeks. Once there, his pain eased and he could lie down and get a good night’s sleep for the first time in three weeks. His mood lifted and his family – he was one of 14 – felt like they had their brother back again.

At the hospice Jay had counselling and planned his end-of-life care. He talked about dying with the staff there. He was transferred back to his home town a week before Christmas, and was able to be with his family in his sister’s care for 10 days before he went back to hospital. Jay died peacefully and his family was very grateful that he received palliative care services.

The cover of Jay’s funeral service booklet that shows a photo of this much-loved brother and friend who died on 25 January 2011.
White-water rafting and palliative care

For my late wife, Gloria

If I had understood (when down the river
you and I went swirling in that boat)
that there were those who knew the ways of the water
and how to use the oars to keep afloat
  I might have been less deafened by the worry,
less stunned by thoughts of what lay up ahead
(the rocks, the darkness threatening to capsize daily),
if I had only realised instead
that help was all around me for the asking
  I never asked, and therefore never knew
that such additional comfort could have helped me
in turn to be more help in comforting you.

I’d have found it easier then to simply hold you
instead of bobbing to and fro so much,
for it was you who seemed to be more tranquil
and I whom death was reaching out to touch.

If only I had had sufficient knowledge
in that white-water rafting I’d have learned
that there were those around us (with life jackets)
to whom I might have, in that turmoil, turned.

Instead, because I had not thought of rivers,
or rocks, or rapids, and gave way to fears
that seeking help might make a man less manly
and liable to betray himself with tears,
I was less useful then, as twilight deepened,
than I might well have been, had I but known:
however wild the waves that roll around us
no one need to live (or die) alone ...

Bruce Dawe