

NSW Health

End of Life and Palliative Care Framework 2019-2024

NSW GOVERNMENT

Acknowledgements

NSW Health would like to acknowledge and thank the thousands of individuals, clinicians, service providers, academics, consumer groups, peak bodies and others individuals and groups who shared their views, knowledge and expertise towards the development of this NSW End of Life and Palliative Care Framework ('the Framework').

The Framework builds on the substantial work and consultations carried out over previous years in relation to end of life and palliative care in NSW. This includes the work of the Agency for Clinical Innovation (ACI), the Clinical Excellence Commission (CEC), the Health Education and Training Institute (HETI), the Cancer Institute NSW and Palliative Care NSW. This Framework has also benefited from the expert advice and guidance of members of the End of Life and Palliative Care Framework Steering Committee.

Cover photo: Givenworks

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A message from the Minister



Every day in our lives we make choices and those choices should not stop when we are approaching the end of our lives. When people reach the end of their life they should have the option of being surrounded by family and friends in an environment where they are the most comfortable and receive the best support possible.

The NSW Government invests more than $210 million each year in palliative care services. But we can always do more and that's where this End of Life and Palliative Care Strategic Framework comes in. This Framework sets out the future of palliative care in whatever environment it takes place.

In 2017 we heard from more than 2000 people across the State who participated in the NSW Palliative Care Roundtables or responded to a Palliative Care survey.

We heard many personal and transforming stories which highlighted that:

- care at the end of life should be person centred,
- service delivery should be flexible,
- care should be integrated and well-coordinated,
- additional resources and training is needed for staff; and
- the role of carers and support services should be recognised.

In response to this feedback, the NSW Government committed an additional $100 million over four years (2017-18 to 2020-21) to improving end of life and palliative care services.

At the heart of this Framework is the focus on people. And that starts with every one of us having what can be a difficult conversation with our family and friends around death. We know that death can occur at any time and sometimes unexpectedly. This Framework encourages all of us to have open conversations with loved ones ahead of time to ensure we all get the care we want and need when the time comes.

The community deserves to have the utmost confidence and choice in their end of life and palliative care. I am incredibly proud that the NSW Government has increased palliative care funding to record levels to meet the needs of our community.

Brad Hazzard
Minister for Health

A message from the Secretary



One of NSW Health's strategic priorities is to promote choice of care for individuals approaching the end of their life. It is important that we create a health system that supports individual preferences, which means continuing to improve access to consistent and high quality end of life and palliative care services.

I am pleased to share the End of Life and Palliative Care Strategic Framework, which will assist NSW Health services to provide high quality care for individuals approaching the end of their life, with their families and carers well supported. Over the next five years, the Framework will guide change in our health system to achieve this objective. The Framework sets out priority areas for improvement where people and services must work together to enhance support and care for people at the end of life in NSW.

It is important that everyone is involved. Each role needs to be acknowledged and supported to provide high quality person-centred care. This includes individuals, family members, carers, professionals, volunteers and members of the local community. The Framework will guide services and support to be more culturally safe and responsive to the unique needs of people and population groups.

Some of the Framework's actions include working with partners to develop consistent approaches for advance care planning, improve access to bereavement support for families and carers, the development of a state-wide workforce strategy and looking at how we can design spaces, use technology and equipment in community and acute settings. A new End of Life and Palliative Care governance structure will also commence to oversee progress of the Framework's actions.

Making this Framework a reality requires effective collaboration across the NSW health system including between service providers, policy makers, clinicians and program managers. Equally, end of life and palliative care could not be provided without the actions and support of non-NSW Health partners including community bodies, primary health care providers, aged care providers and more.

My hope is that everyone in NSW receives the best possible care as they approach the end of their life, and that families, carers, volunteers and staff are supported.

Elizabeth Koff
Secretary, NSW Health

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Introduction

How people approach the end of their life is highly individual and a deeply personal experience. As people enter this phase of their life, they, their families and carers should be able to make decisions about the care they want, how it is delivered, and the places and circumstances it is provided.

At the heart of this NSW End of Life and Palliative Care Framework ('the Framework') are individuals, and their families and carers. All individuals should have access to the best possible end of life and palliative care – no matter where they live, their condition, age or who they are.

The care they receive should also be based on their individual needs and preferences. There is strong and growing evidence around the benefits of a person centred approach to end of life and palliative care.

Person centred care contributes to:

- better outcomes for individuals, their families and carers
- an improved quality of life
- a more positive experience for people.[1, 2, 3, 4, 5]

A person centred approach is supported by care delivered according to individual needs and preferences and in partnership with the person, their family and carers.

In NSW there are areas of excellence and innovation in end of life and palliative care but more work is needed to make sure everyone can access and receive this care.

This Framework acts as a guide for those working within the NSW health system.

In this context, the NSW health system refers to all publically funded health organisations. It includes the NSW Ministry of Health, Local Health Districts, Speciality Health Networks, Pillars (Agency for Clinical Innovation, Bureau of Health Information, Cancer Institute NSW, Clinical Excellence Commission and Health Education Training Institute), state-wide health services, shared services and any other organisation publically funded by NSW Health.

To support implementation of the Framework, the NSW Ministry of Health will provide additional guidance. This will include providing key accountabilities for Local Health Districts and Speciality Health Networks, Pillars and the NSW Ministry of Health.

Ultimately the Framework aims to not only improve access to the best possible end of life and palliative care, it also aims to encourage people to talk more openly about death and dying as a normal part of life.

This Framework sets out the **vision and direction** for end of life and palliative care in NSW. It aims to create **a renewed drive** for people and services to work together in **providing accessible, high quality end of life and palliative care**. This includes working in partnership with people receiving the care, their families and carers.

The context

With an ageing population comes a rise in the prevalence of chronic diseases. This means the demand for end of life and palliative care services is increasing and continues to grow.[6]

The NSW Government recognises the increasing demand for end of life and palliative care and has invested in initiatives to increase the capacity of the NSW health system to provide end of life and palliative care.

One of the challenges in preparing for the increased demand is the variance in models of end of life and palliative care provision, and needs of different communities, across Australia. Each state and territory has a different approach to planning and delivering publicly funded services; local services have different delivery practices and structured health care systems. They also have varying demographic profiles, geographic location and differing demands for particular types of services.[7]

Integrating end of life and palliative care

In 2017, the NSW Auditor-General reviewed palliative care services in NSW. The report acknowledged the multiple initiatives aimed at addressing the issues affecting palliative care service delivery and planning. It also identified specific areas for improvement, including:[8]

1. Performance monitoring
2. Coordination of statewide planning and evaluation
3. Systematic planning
4. Consistent data collection and use
5. Engaging stakeholders.

To address these, the Audit Office recommended NSW Health develop an End of Life and Palliative Care Framework.



Photo: shapecharge

Talking about death and dying

To ensure truly person centred end of life and palliative care, we need to talk about what matters most to us in living and dying.

Having conversations about death, dying and bereavement can be difficult. It may even be considered by some to be a taboo subject. Even though we all have different beliefs and thoughts around death there is one thing we have in common - dying and death will be a significant part of our lives and most of us will experience losing people we love and care for during our lifetime.

The approach

The Framework integrates key principles from multiple strategies, guidelines and standards related to end of life and palliative care as an overarching 'umbrella'. It will also guide the future direction of state-wide policy and strategy relating to end of life and palliative care.

The Framework has also been informed by international, national and state policies, as well as relevant strategies.

The Framework builds on the extensive suite of existing tools and documents. This includes:

- The Agency for Clinical Innovation's (ACI) Palliative and End of Life Care: A Blueprint for Improvement
- The Clinical Excellence Commission's (CEC) AMBER Care Bundle
- NSW Health Education and Training (HETI), SHAPE end of life conversations, Verification of death, and Managing Death and Death Certification eLearning modules
- NSW Health Advance Planning for Quality Care at End of Life: Action Plan
- NSW Government Plan to increase access to palliative care 2012-2016
- NSW Health Leading Better Value Care Program.

The Framework is supported by other current key documents relating to quality for end of life and palliative care, which services adhere to. These key documents include:

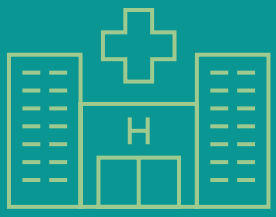
- Principles of the National Palliative Care Strategy
- National Safety and Quality Health Service (NSQHS) Standards and the National Consensus Statement: essential elements for safe and high-quality end of life care
- National Palliative Care Standards
- EQuIP5: Linkage with Standards for Providing Quality Palliative Care for all Australians.

Snapshot of end of life and palliative care in NSW



33,000

Each year, there are approximately 33,000 predicable deaths* where a person could benefit from some form of end of life care.



50%

Nearly 50% of deaths occur in the acute care setting.



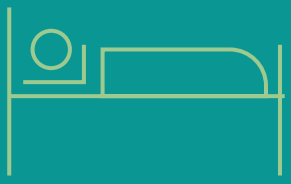
36.8%

In 2018, 36.8% of older Australians accessing health services had at least one advance care directive documented in their health record. This was higher than the national result of approximately 30%.



1,610 volunteers

In 2018, there were 1,610 palliative care volunteers and about 44 palliative care volunteer services.



11,400 packages

11,400 Last-Days-of-Life home care packages were delivered to 7,983 people in the last five years.



$210m

More than $210 million spent annually on palliative care services.

Including:



2012: $35m investment to improve access to palliative care including home support packages and support for Palliative Care volunteers.



2014: $32m announced for further investment in Last-Days-of-Life home support, flexible funding pool and after-hours helpline.

On top of the annual investment in palliative care, the Government has committed additional funding:



2017:

$100m investment for enhanced Palliative Care services over four years.

* Provided by Professor K Eagar (2018) Palliative Care Outcomes Collaboration, University of Wollongong.

Who is this Framework for?

The Framework is designed for use by the NSW health system, including service providers, policy makers, clinicians and program managers. It provides direction and advice for all NSW Health funded staff regardless of their profession, discipline and level of expertise.

The Framework applies across all settings where end of life and palliative care is provided. This can range from people's homes, specialist palliative care units, residential aged care facilities and acute care facilities including intensive care units, emergency departments.

It is relevant to all clinical specialties, including (but not limited to) paediatrics, neurodegenerative and specialties relating to chronic conditions, as well as in the care of the elderly and people with a diagnosis of cancer.

NSW Health collaborates with a wide range of organisations and service providers who also have a role in providing and supporting end of life and palliative care. This includes the aged care sector, non-government organisations, the community, primary health care and other government departments who also support individuals who are approaching and reaching the end of life, their families and carers.



Photo: Jasmin Merdan

The scope of end of life and palliative care

The terms 'end of life' and 'palliative care' hold different meanings to different people. There are many different definitions; it is important to understand the meaning of these terms in the NSW setting. In this Framework, 'end of life' and 'palliative care' refers to the following:

Care that **optimises the quality of life** for individuals, their families and carers approaching and reaching the end of life, **reducing suffering and promoting dignity**. It is for those with a life limiting condition and often for those in the last year of life. However, care may also be needed for either shorter or longer periods depending on the individual needs of the person, and their families and carers.

All care provided to people who are approaching or reaching the end of their life should consider **individual needs and preferences***.

A phase of life

End of life is a part of life, everyone will experience. End of life is the timeframe a person lives with, and is affected and/or impacted by, a life-limiting condition, even if the prognosis is ambiguous or unknown.[9] This will be different for each person.

An approach to providing care

End of life care is provided when a person is 'approaching the end of their life'. Palliative care is an approach that improves the quality of life of an individual and their families, facing problems associated with life-limiting illnesses. This is through the prevention and relief of suffering, by means of early identification, assessment and treatment of pain and other symptoms – physical, emotional, psychosocial and spiritual.[10]

Typically, end of life care is provided when a person is likely to die within the next 12 months due to progressive, advanced or incurable conditions or old age.[11] This will vary for each individual. It can be difficult to identify when a person is entering this phase of their life, but it is necessary care is focused on their individual needs and preferences.

People approaching and reaching the end of their life require varying levels of care and support, and their needs will fluctuate and change. Services need to be responsive, coordinated and flexible in meeting these changing needs.

It is important to recognise for some families and carers, support and care needs may not end with the death of their loved one. Bereavement and counselling services are some ways ongoing care may be provided.

* Refer to glossary

Providers of end of life and palliative care

Many people and organisations provide care and support to people approaching and reaching the end of their life. General practitioners, community based providers, residential aged care facilities, religious groups, support groups, friends and neighbours, all play a role.

All NSW Health staff have a role in providing care and support to people approaching and reaching the end of their lives. This may also include support to family and carers. People with more complex needs should be able to access care provided by specialist palliative care services.

These are provided by professional multidisciplinary teams or services whose staff have advanced training in palliative care. Specialist palliative care may provide consultation services to support, advise and educate specialist and non-specialist teams to provide end of life and palliative care to people with less complex needs.[12]

As the population continues to age, more people will need end of life and palliative care. This involves timely access to specialist support, if and when, it is needed. NSW Health's partnerships with aged care and primary care will be essential to ensure high quality care in hospital, community and aged care settings.



Photo: xavieramau

The Vision

All NSW residents, their families and carers have access to and receive the best possible end of life and palliative care, based on their individual needs.

This care places the person at the centre, where their preferences, values, beliefs and dignity are respected, and quality of life matters most.

For individuals, their families and carers

People, their families and carers receive individualised care based on their unique needs and preferences.

For service providers and clinicians

Service providers and clinicians have the necessary skills and knowledge to provide individualised, high quality end of life and palliative care.

For the general community

People are supported to have conversations about what is important in living and dying well.

For the health system

The NSW health system delivers high quality end of life and palliative care, supporting residents of NSW, their families and carers to receive the best possible end of life and palliative care, based on their individual assessed needs.

Changing the conversation

Families and carers may have to make decisions about the care their loved one receives. If people have not made a plan for their choices, this can be distressing for families and carers, as they are not sure they are making the right decisions for their loved ones.

Having open conversations about death and dying allows people to consider how they feel about different options for end of life care, how they would prefer to live their final days, and how they want their lives to be celebrated and remembered.



Photo: Atilla Csaszar

What underpins the Framework?

There are a number of key assumptions that underpin the Framework. These have been identified through consultation with key stakeholders, including individuals, their families and carers, clinicians, service providers, peak bodies and experts.

Individuals, their families and carers are at the heart of the Framework

Everyone in NSW should be able to access quality end of life and palliative care when it is needed, regardless of their geographic location, age, condition, socio-economic needs, cultural and religious background, or languages spoken.

Each person's care should be unique, holistic, and respectful of their preferences and dignity. The care should be provided on the basis of assessed need, be flexible, and adopted in response to the individual's own changing care needs.

Families and carers (and those who support them) should be recognised, valued, and supported. They should be involved in planning and providing care, and receive the services and support they need to carry out this role.

Everyone in the NSW health system has a role and responsibility in providing end of life and palliative care

This can be demonstrated in many different ways, such as engaging people in conversations about death and dying, through to caring for someone who is approaching and reaching the end of their life.

Individuals and communities are engaged at all levels

The Framework assumes involving people, families and carers in their care, and in the design of services and systems is a key part of ensuring services meet their needs. This may be at a community, service or individual level.

Community engagement assists people to understand what end of life and palliative care is, the different stages of care, and the services available both generally, and in the local community. It should also help health professionals and services to understand the specific needs of their communities and develop appropriate services.

While many people are reluctant to talk about death and dying, these conversations across the community and with health professionals should be encouraged and normalised.

Care is evidence-based

Care provided to individuals, their families and carers, is to be high quality, based on evidence and delivered by capable staff skilled in caring for people approaching and reaching the end of their life.

Continuous quality improvement, research and innovation at local and state levels is essential to continually develop and evolve end of life and palliative care.



Photo: Caiamage/Tom Merton

Priorities

The priorities are the things you have told us are important to you.

This Framework is built on what you have told us throughout consultation, palliative care roundtables across NSW, and survey of 2,000 people.

01 Care is person centred

Care should be based on the unique, holistic needs and preferences of the person receiving care. It should respect their preferences and their dignity. The individual, their families and carers are equal partners in the decisions relating to their care and treatment. Provision of care should be on the basis of assessed need and be flexible in response to the person's changing needs and preferences.

02 There is recognition and support for families and carers

Families and carers play a pivotal role in the end of life and palliative care service system. It is essential their role is recognised, valued, and supported. Health services should support families and carers to be involved in planning and providing care, and to access the services they need to carry out this role.

03 There is access to care providers across all settings who are skilled and competent in end of life and palliative care

End of life and palliative care can be delivered in multiple settings. It must be supported by a skilled and competent workforce.

04 Care is well-coordinated and integrated

People needing end of life and palliative care may receive care from multiple services across a number of settings. Care should be delivered in an integrated and well-coordinated manner with seamless transitions between services and settings.

05 Access to quality care is equitable

There can be significant variation in access to end of life and palliative care services across NSW. There are groups across NSW who need greater support to access end of life and palliative care services.



Photo: Marilyn Nieves

Priority 1
Care is person centred

Care should be based on the unique needs and preferences of the individual as an equal partner in decisions relating to their care and treatment. Each person's care should be based on assessment and care plans that are regularly reviewed and updated as needs and preferences change. People should be kept well informed about their care and services available to them, with advocates such as families or carers involved and able to represent the person's preferences when they can no longer communicate themselves.

"Patients are the centre of all care and care should be tailored to meet the individual needs of the patient, not the patient 'meeting the needs of the health system."

Health care practitioner
at Palliative Care Roundtable

What you told us

Overwhelmingly, you said NSW needs an end of life and palliative care person centred system where people, their families, carers and support networks have access to the services and supports they need, in a way that is flexible, adaptive and provides choice and control. This means:

- Care is **flexible** and based on the wishes and preferences of the person approaching or reaching end of life
- There are options for care that **empower** people to make their own choices in relation to the care they receive, including where they receive care
- Processes are in place to **fully inform** individuals and their families of the service options
- There is support to enable individuals and their families to **make choices and care decisions**. This helps people to receive holistic care, with social, cultural, emotional, physical, medical and spiritual factors all considered and supported.



Photo: stevecoleimages

Why this is important

Research demonstrates person centred care can have a significant impact on the quality of care.[13] It can:

- Improve the **experience** people have of care and help them feel more satisfied
- Encourage people to be more **involved in decisions** about their care so they receive services and support that are appropriate for their needs
- Positively impact on people's **health outcomes**.

There is consensus end of life and palliative care should be designed around the individual, their families and carers, and respect their unique needs and wishes. The need for person centred care is articulated in multiple national standards including the Palliative Care Australia (PCA) second National Palliative Standard which states '*the person, their family and carers work in partnership with the team to communicate, plan, set goals of care and support informed decisions about the care plan*'.[14]

The Essential Elements for Safe and High Quality End of Life Care also emphasises that care should be fundamentally 'patient and family centred' and the National Safety and Quality Health Services Standards require services to partner with consumers.

Person centred care is not just about the provision of services. It is also about the way professionals and people think about care and their relationships. Person centred care is a way of thinking and doing things that sees the individual as a partner in planning, developing and monitoring care to make sure it meets their needs. This means putting people and their families at the centre of decisions to get the best outcome.[15]

Caring for young adults with life limiting conditions may differ to caring for adults. Young adults can experience disease differently according to their evolving physical, emotional and cognitive development. People providing end of life and palliative care must be aware of and responsive to each young person's preference and need for support and care.



Photo: Leo Partrizi

Examples of what has been already done

- Advance care planning training and educational resources have been developed to support providers in having end of life conversations with people by explaining and assisting them in the Advanced Care Planning process
- A free online course was developed to assist health professionals conduct effective end of life conversations with patients, families and carers – Supporting Health Professionals in Advance Care Planning and End of Life (SHAPE) Conversations
- The 'Making an Advance Care Directive' template was developed and evaluated to ensure it is useful to people and their families
- The NSW End of Life Implementation Advisory Committee developed the Advance Planning for Quality Care at End of Life: Action Plan 2013–2018
- NSW Health provided funding to increase the number of clinical staff to support rural and remote palliative care patients
- The NSW palliative care after-hours helpline was established to provide better after-hours support
- A 'last days of life' toolkit for health professionals was developed to better support them in caring for people approaching the end of their life
- The 'last days of life' home support service has provided over 10,000 packages to care for people in their home
- Senior Aboriginal Health Workers were employed to establish culturally appropriate Aboriginal services and improve access to end of life palliative care for Aboriginal communities.

NSW Health will work collaboratively to:

- Advocate for and promote the uptake of advance care planning, discussing people's individual preferences for care. Discussing people's individual needs is not necessarily a single conversation, but may require multiple discussions with the person's journey evolving as their needs and preferences change
- Support partnerships in the development of consistent approaches for advance care planning, for example with the aged care, community and primary care sectors
- Develop measures that allow individuals, families and carers to provide timely feedback about their experiences and outcomes (patient reported outcome measures – PROMs, and patient reported experience measures – PREMs)
- Involve people approaching the end of life, their families and carers as partners in their own care and decision making
- Involve people approaching the end of life, their families and carers in planning, designing and evaluating end of life and palliative care services.

Priority 2
There is recognition and support for families and carers

Families and carers play a pivotal role in end of life and palliative care, providing ongoing support and care to people. It is essential their role is recognised, valued, and supported. It is important they are involved in the planning for and provision of care, and they receive the services and support. This includes personal and home care, counselling and respite.[16]

> "Families and informal carers provide by far the greatest amount of care for people who are living with a life-limiting illness...
>
> If they weren't there, our health system could not afford to provide the care that families and informal carers provide."
>
> Health care practitioner
> at Palliative Care Roundtable

What you told us

The importance of recognising the role of families and carers, actively engaging with them, and keeping them fully informed as partners in care was consistently identified as critical to supporting the health system to work well. It was also acknowledged as an area that is working well in the end of life and palliative care system.

You said carers and families require more practical support services to help them better care for their loved ones, including:

- Practical assistance to help manage and ease the burden of day-to-day caring responsibilities (e.g. washing, cleaning, transport, accommodation during treatment away from home)
- Access to targeted resources, information, and advice to help navigate the system – particularly in regards to accessing services, as well as encouraging access to local support networks
- Support for carers including access to trained palliative care staff, 24 hour phone support, overnight care and access to medication and equipment
- Access to respite care that is flexible (e.g. in-home, day care, clinics, short-and long-term respite) and available to carers when they need it to help support care at home and prevent unnecessary hospitalisations
- Support through the bereavement and grieving journey, particularly support that normalises the grief process.

Why this is important

Families and carers play a significant role in caring for their loved ones as they approach and reach the end of their lives, regardless of where death actually occurs.[17] They provide physical, emotional, social and spiritual support and care.

It is important their role is valued by health providers by working with them to understand what they are willing and able to provide.[18] Families can experience stress due to the uncertainty of their loved one's condition, a perceived lack of support[19] and questions about how to provide care.

Access to good quality information is central to coping and is essential for families and carers as it helps them better manage their role in caring for their loved one.[20] Continued support through the grieving process is also important. Evidence shows people who experience complicated grief are more likely to have poor health, psychological and social outcomes.[21]

Examples of what has been already done

- The NSW Paediatric Palliative Care Programme has been developed to provide care and support to children or young people who have a life threatening illness and their families
- In some local areas there has been increased bereavement counselling services as well as models of care focusing specifically on palliative care bereavement support for families and carers
- Multiple information technology methods have been developed for families and carers during the end of life period. This includes access to care related information via email and a loaned tablet device.

NSW Health will work collaboratively to:

- Support the health system to engage and understand the role of families and carers in end of life and palliative care
- Develop standard resources to support families and carers including multicultural resources
- Improve access to bereavement support for families and carers.



Photo:davidf

Priority 3

There is access to care providers across all settings who are skilled and competent in caring for people requiring end of life and palliative care

Many health care professionals, families, carers and volunteers are involved in providing care to people who need end of life and palliative care.

Specialist palliative care services are available across NSW for people who require specialist care.

However, not all people need, or want, access to care provided by specialist palliative care services.

Some people approaching end of life have uncomplicated needs, that are both straightforward and predictable. In many cases these needs can be met by providers not based in a palliative care service. However, it is critical these providers can access specialist palliative care services for advice and guidance if and when needed.

"A highly skilled palliative care workforce is critical to reduce the pain and distress of life-limiting illness. As the population ages we will need more people who are able to provide this critical support."

Health care practitioner at the NSW Palliative Care Roundtable



Photo: Johnny Greig

What you told us

The broader workforce needs to have the skills and knowledge to provide care to people approaching and reaching the end of life and have access to specialist advice and resources when needed. You highlighted the need for:

- **Recognition** of the role of specialist palliative care, as both a discipline and a critical service provider for patients with complex needs who are approaching and reaching the end of life
- **Greater integration** between primary care and specialist palliative care services, including the use of multidisciplinary teams, with clearly delineated roles for all care staff
- **Appropriate staffing levels and mix** to ensure quality care support for staff. This could be supported by incentives, **including scholarships to encourage more specialists** to work in areas where there is an absence of specialist palliative care services, particularly in rural and remote areas
- **Workforce planning** to ensure staffing models meet both current service gaps and increased future levels of care for individuals approaching and reaching the end of life. Planning should support more creative and innovative structures and staffing models for the care of people approaching and reaching the end of life
- **Recognition of the role of volunteers** in supporting end of life and palliative care, including in respite care, transport services and home visiting. There is an opportunity to extend the role of volunteers by developing a targeted volunteer program and resourcing strategy
- **More education and awareness** of the differences and interaction between specialist palliative care and other services providing care to people who are approaching or reaching the end of life
- Additional education, **training and support for GPs** about end of life and palliative care, including training in end of life and palliative care planning, advance care planning, and care coordination
- **Education and training** on end of life and palliative care to support the delivery of care to people approaching or reaching the end of life in all care settings, including training for other specialists, practice nurses, registered nurses and allied health professionals
- **Tailored training, education, and resources** to enable family members and carers to provide care where appropriate.

In NSW, paediatric palliative care is provided through a networked approach across hospital and community services. **Multidisciplinary teams provide timely, well-coordinated support to children and their families** throughout the duration of the child's illness, including bereavement for families. Where possible, **support is provided to children at home or as close to home as possible.**



Photo: Tobias Titz

Why this is important

The need for end of life and palliative care will continue to increase as the population ages and people live longer. Current models of care use a mix of specialist palliative care providers, many based within hospitals, and generalist community services. However, individual preferences and funding constraints point to an increasing need for service delivery in the community, within homes, in rural and remote locations and in residential aged care facilities. In addition, an ageing workforce and shortages of trained clinical staff in specialist palliative care is placing increased pressure on services to meet rising demand.[22]

Examples of what NSW Health has already done

- There has been a significant increase in staff to expand palliative care service capacity, including clinical directors, medical specialists, clinical nurse consultants, clinical nurse specialists and community palliative care nurses
- There has been an increase in staff training and education on end of life and palliative care including specialist short courses, conferences and postgraduate study. There has also been investment in scholarships for staff in rural and regional areas and increased on-the-job training in end of life and palliative care
- There has been an exploration of collaborative partnerships between primary care and the non-government sector as a way to enhance workforce skills
- Additional information technology resources and equipment, telehealth equipment and medical equipment have been rolled out
- Community pharmacists are being supported to improve care for people with palliative care needs, including improved access to medicines and medication management
- A local version of the AMBER care bundle was developed to provide a systematic approach for the multi-disciplinary team to follow when clinicians are uncertain whether a person may recover and are concerned that they may only have a few months to live.

NSW Health will work collaboratively to:

- Develop a state-wide workforce strategy for end of life and palliative care, which identifies and addresses needs across Local Health Districts and Speciality Health Networks, especially in rural and remote areas
- Enhance investment in the end of life and palliative care workforce, including allied health and Aboriginal health workforces
- Advocate for increased end of life and palliative care content in clinicians' training and education
- Facilitate opportunities and increased training and educational resources for care providers to broaden the understanding of people's diverse end of life and palliative care needs
- Work collaboratively with the Commonwealth and other partners to promote training and education on end of life and palliative care for people in the primary, aged care, and not for profit and private sectors
- Support volunteers by providing them with training and education about end of life and palliative care and reinforce their role as part of the multi-disciplinary team.

Priority 4
Care is well-coordinated and integrated


Photo: Sean Shot

People needing end of life and palliative care may receive care and support from multiple services across a number of settings. It is critical care is integrated and well-coordinated to ensure better experiences and outcomes for individuals, their families and carers, a seamless transition between services and settings, and efficient use of resources.

Commonwealth and state governments are currently investing in activities to improve coordination and integration across the health care system, which includes end of life and palliative care. This creates an opportunity for NSW Health to leverage and share available resources.

"Coordinated and collaborative care is more likely to be effective [and] result in a reduction of errors."

Participant at the
NSW Palliative Care Roundtable

What you told us

Across the state, there were examples of strong relationships and good collaboration between service providers at a local level. On the whole, providers deliver integrated, coordinated care for their patients.

However, there was also recognition more work is needed. In particular, there is a need for:

- Greater **collaboration amongst care providers**, including working in partnership and facilitating communication between GPs and other service providers
- Establishing local **interdisciplinary teams**, encompassing GPs, primary care services, medical specialists, palliative care staff, allied health professionals, social workers, support services, and Aboriginal Health Workers
- **Developing service provider networks** of a number of multiple, connected organisations
- **Increasing recognition of individuals, families and carers** as an integral part of the team
- Assigning **care coordinators** to help people, carers and families navigate the system and the available services and providers, to ensure there is no duplication of services and individuals don't need to be reassessed each time they engage with a new service
- **Shared case management** across services with case conferencing to facilitate high quality care and clear, honest and open communication between all parties
- Consistency in **information and data** collection, recording, reporting and sharing, with health records shared across service providers in real time to support flexible and coordinated care
- Better adoption and use of My Health Record by all providers across all settings, ensuring current **patient information** is accessible to support continuity of care
- **Consistent clinical documentation**, building on work underway in some areas to standardise forms, clinical documentation and assessment tools. Common guidelines, checklists and assessment and monitoring tools will improve the continuity of care provided to patients approaching and reaching the end of life.

It is important multidisciplinary teams and/or services work together to ensure high quality end of life and palliative care. This includes all health care professionals, carers, volunteers, and families. Each team, service, family member and professional has unique skills and experiences that can enhance care. A highly skilled and collaborative workforce will provide better outcomes for individuals by sharing responsibility for the person receiving care.

Why this is important

People often receive care from a range of organisations with different systems, roles and approaches to managing end of life and palliative care. Interdisciplinary teams are made up of health care providers with varied experience, values and perspectives on planning and providing end of life and palliative care.[23] When services are not integrated, people experience fragmentation, duplication, gaps and delays in their care.[24] Coordination, communication and clarity of care goals between providers can improve care experiences, optimise resources and reduce unnecessary hospital visits.[25]

Examples of what NSW Health has already done

- The ACI developed 'Palliative and End of Life Care – A Blueprint for Improvement', a flexible guide for health services to meet the needs of people approaching and reaching the end of life, their families and carers. The Blueprint can be implemented across all care settings and provider types
- Multidisciplinary palliative care teams have been set up to support patients, their families and carers in all settings
- The NSW Government signed and implemented the Bilateral Agreement on Coordinated Care with the Commonwealth Government which includes agreed work to better coordinate and integrate end of life and palliative care services
- Partnerships have been, and continue to be, explored, developed and implemented with primary care and the NGO sector.

NSW Health will work collaboratively to:

- Continue to promote clinical excellence that addresses co-ordination in end of life and palliative care by providing input into national standards relating to end of life and palliative care
- Promote increased information sharing between care providers across settings through the development of standardised documentation and tools relevant to end of life and palliative care
- Test new models of care at a state and local level to deliver better co-ordinated and integrated end of life and palliative care to people, their families and carers
- Develop resources to help care providers recognise triggers for when consultation with, or referral to, specialist palliative services is needed
- Work with digital partners to identify ways to improve end of life and palliative care data collection across NSW
- Work with Commonwealth partners to further develop shared priorities in end of life and palliative care, such as in the disability, aged and primary care sectors. This includes supporting linkages between specialist palliative care services and primary health services.

Priority 5
Access to quality care is equitable

People in NSW come from diverse social, cultural, spiritual and economic environments and backgrounds. This means there can be significant differences in equity of access to end of life and palliative care services.

Equity is essentially about fairness. In this context, it is about ensuring needs based access to health services. Everyone in NSW should have equitable access to quality end of life and palliative care. This involves understanding the different needs of people and communities, and enabling flexible access and resourcing to provide quality care.

> "Every individual is different and has different needs, so flexible access allows for delivery of person centred care and for patients to be more in control of their health care."
>
> Response to the NSW Palliative Care Survey

What you told us

All people should have equitable access to high-quality care and support irrespective of age, geography, diagnosis, care environment or personal circumstances.

For individuals approaching and reaching their end of life, as well as their families and carers, to have equitable access to care you suggested there needs to be a greater focus on:

- Improving access to services able to cater for **all age-groups** rather than focusing on patients aged over 65 years. This includes paediatrics and young adults
- More services and support for individuals and families with **diagnoses other than cancer, including those with a chronic or neurodegenerative disease**
- The use of **alternative care models** to provide services to individuals approaching and reaching the end of life in rural and remote areas including, for example, greater e-health and telehealth services
- **Developing a diverse workforce** in terms of knowledge, skills, language and beliefs. The workforce should reflect the cultural, social, spiritual and economic diversity in the community.

Why this is important

It is important everyone in NSW can access quality end of life and palliative care, regardless of their geographic location, age, socio-economic needs, cultural and religious background, gender identity, sexual orientation or languages spoken. Under the National Palliative Care Standards, services should have clear admission criteria that are transparent and non-discriminatory.[26]

People relate to death and dying differently, often based on personal experience, culture and history. This is particularly important to consider when recognising the needs of Aboriginal communities.

There are a number of challenges people face in accessing end of life and palliative care services, particularly in rural and remote regions.[27] People who live in rural and remote areas often have fewer services close to home and may have to travel away from home for care, away from their support networks.

There are groups who may need additional support in accessing end of life and palliative care. People from the following populations may require additional support to access services:

- People from culturally and linguistically diverse (CALD) backgrounds
- Aboriginal communities
- Paediatrics
- Young adults
- People experiencing homelessness
- New migrants and refugees
- People living with a disability
- Care leavers and people affected by forced adoption or removal including the Stolen Generations
- People with a mental health condition
- People who are socially isolated
- People who identify as LGBTQI (lesbian, gay, bisexual, transgender, queer or questioning, intersex)

Access to end of life and palliative care should be based on individual and clinical need, regardless of background and circumstances.



Photo: Benoit Balanca

All cultures experience death and have their own unique traditions when dealing with bereavement. Preferences for care may be influenced by culture, spirituality, past experiences and community norms and practices. To improve access to quality care, end of life and palliative care providers need to ensure cultural safety in all services.

Examples of what NSW Health has already done

- Service capability in rural and remote communities has been strengthened and in some cases new services established
- Additional investment into rural and regional palliative care specialists, including additional relief positions
- Additional investment into paediatric palliative care
- Investment to improve access to end of life and palliative care services and information for people from culturally and linguistically diverse backgrounds
- Engaged with Aboriginal communities and Aboriginal Health Workers to create a culturally appropriate end of life pathway for Aboriginal community members
- Worked collaboratively with local communities to improve the knowledge of, and access to, end of life and palliative care for Aboriginal people
- Invested in additional Aboriginal Health Workers to provide culturally responsive end of life and palliative care services for Aboriginal communities.



Photo: franck reporter

NSW Health will work collaboratively to:

- Leverage population planning tools to guide and assist in service planning which reflects the unique needs of communities
- Ensure services and support are culturally safe and responsive to the unique needs of people and population groups who require additional support in accessing end of life and palliative care services
- Strengthen referral pathways to specialist palliative care teams by increasing awareness and knowledge of services
- Explore alternative ways care and support can be delivered across community and acute settings including consideration of appropriate design of spaces, technology and equipment
- Refine the use of telehealth to support care providers with end of life and palliative care, especially in rural and remote regions
- Develop data to allow increased local analysis and inform planning and service design.

Implementation and monitoring

NSW Health will measure progress towards achieving the vision of the Framework and its implementation. To do this, high-quality, accurate and timely data that can be used for analysis and measurement needs to be collected.

This data will also help to refine efforts to provide high quality end of life and palliative care. Currently, there is no single set of indicators for end of life and palliative care that can determine the impact of the Framework and measure progress of its implementation.

Establishing a core data set

NSW Health will establish a core data set for end of life and palliative care throughout the lifetime of the Framework. This will inform future service planning through a sustainable evaluation and monitoring process.

In the short term, there are existing measures NSW Health will continue to track and monitor, including:

- Admitted palliative care data
- Sub-acute and non-acute patient (SNAP) data
- Workforce trends
- Patient and family experience.



Photo: Leo Patrizi

A Multi-Year Plan

Below is an overview of a five year plan to develop and implement an effective end of life and palliative care monitoring and evaluation system in NSW.

Year 1

- NSW Health will provide health system leadership and guidance. It will establish a robust governance structure that will be overseen by the NSW Health Committee for End of Life and Palliative Care. The governance structure will include working groups based on the following:
  - Data and IT Solutions
  - Implementation of the Framework
  - Stakeholder and Consumer Engagement
  - Workforce
- The Committee and working groups will:
  - Develop a high level implementation plan for the Framework with key accountabilities for Health Services including Local Health Districts and Speciality Health Networks, Pillars, the Ministry and NSW Health funded partners
  - Establish a detailed evaluation and monitoring strategy for the Framework
- NSW Health will commence designing a comprehensive end of life and palliative care core data set. This may include mapping end of life and palliative care services across the state and assessing the use of existing data sets.
- NSW Health will review all existing policy guidelines relating to end of life and palliative care and update to ensure consistency with the Framework's overarching principles and priorities.

Year 2

- The Committee and working groups for End of Life and Palliative Care will engage with Local Health Districts and Speciality Health Networks, pillars and partners to support uptake of measures outlined in the Implementation Plan
- NSW Health will finalise the core data set for end of life and palliative care
- An initial evaluation of short term outcomes will be completed.

Years 3 to 5 – 2021-24

- NSW Health will work with Local Health Districts and Speciality Health Networks to increase alignment between service level agreements and end of life and palliative care outcomes
- NSW Health will evaluate the impact of the $100m investment into palliative care services and determine what further actions are required for the sustainability of the initiatives
- NSW Health will support Local Health Districts and Speciality Health Networks to implement the core data set
- NSW Health will review what data partner organisations provide
- NSW Health will evaluate the Framework's progress and uptake by Local Health Districts and Speciality Health Networks in their service planning.

Glossary

The Framework uses a number of terms which are explained below.

ACI Palliative & End of Life Care: A Blueprint for Improvement ('the Blueprint')

The purpose of the Blueprint is to provide a guide for health services and practitioners so they can deliver an integrated response to the needs of individuals (as well as families and carers) who are approaching and reaching the end of their lives.

Advance Care Directive

An Advance Care Directive is a way an individual can document what health care treatments they would like to have or refuse, should they find themselves in a position where they are unable to make or communicate decisions about their treatment and care. An Advance Care Directive in NSW can be spoken or written, there is not a specific form. An Advance Care Directive can only be made by an adult with decision-making capacity and if it is valid, it must be followed. Health professionals and Persons Responsible have no authority to override a valid Advance Care Directive.

Advance care planning

Advance Care Planning involves individuals thinking about what care they would like should they find themselves in a position where they cannot make or communicate decisions about their treatment or care. It can include the individual talking with family, carers and/or health professionals, developing an Advance Care Plan, appointing an Enduring Guardian or making an Advance Care Directive. An Advance Care Plan can be made by the individual or together with people that they trust and/or who are important to them. Where the individual is not able to make decisions, the Advance Care Plan can be made by their family with a health professional. An Advance Care Plan is not a legal document.

AMBER Care Bundle

The AMBER care bundle is a clinical care bundle developed at the Guy's and St Thomas' NHS Foundation in the United Kingdom and localised for use in NSW facilities by the Clinical Excellence Commission. The AMBER care bundle is a systematic approach for the multidisciplinary team to follow when clinicians are uncertain whether a person may recover. In these situation, the person is acutely unwell but has limited reversibility due to underlying poor health. The AMBER care bundle encourages clinicians, people and their families to continue with treatment, in the hope of a recovery, whilst talking openly about preferences and wishes, and putting plans in place in preparing for end of life. It is not a last days of life plan.

Bereavement care

The care and services offered to family members, carers and friends in response to the death of a loved one. It includes the process of helping people recover and heal from the loss.

Carer

A carer is an individual who provides unpaid, informal support and care to a family member, friend or neighbour who needs assistance because of disability, terminal illness, chronic illness and/or mental illness. The carer may or may not live with the individual.

Community

Community means different things to different people. A common definition of community is a group of people who:

- live in the same place or;
- have a particular characteristic in common or;
- share certain attitudes, interests or perspectives or
- have diverse characteristics and are linked by social ties.

Community may be defined similarly but experienced differently by people with diverse backgrounds

End of life

For the purposes of this Framework this refers to the timeframe an individual is clearly approaching the end of their life and is living with/ impaired by a life-limiting illness. This includes;

- the patient's last weeks or days of life, when deterioration is irreversible and
- when a patient is likely to die in the next 12 months

End of life care

The care delivered to improve the quality of life for people who have a life limiting illness, as well as their families and carers. End of life care ensures the appropriate support and palliative needs are provided to the person so they live as well as possible until their death. It recognises end of life care is the responsibility of everybody.

Family

This is an all-encompassing term that refers to the people who are closest to the individual and with whom the individual has an ongoing, personal relationship. This may or may not include immediate biological family, family of acquisition, blended families, same sex-partners, and family and friends of choice.

Individual needs and preferences

There are many factors that influence individual needs and preferences for care. This may be based on age, cultural background, language, ethnicity, gender, sexuality, personal upbringing, geographic location, family, colleagues and peers, friends, social situation, societal norms, and previous experiences.

Integrated care

Integrated care is the delivery of care that is seamless and effective and enables the patient, their family and carers to be central to care and treatment. Integrated care ensures the patient receives the right care, in the right places at the right times, which encompasses care from prevention to end of life care. It requires focus on better communication and connectivity of health care providers across all settings.

Life limiting illness or condition

A term used to describe an illness or condition where it can be expected the person will die prematurely as a direct consequence of the specific illness. This term can be used for people expected to die in the near future and also for those who may live for many years with a chronic illness or condition before dying.

Multi-disciplinary team

A multi-disciplinary team comprises a number of health care professionals from one or more organisations who play an integral part in providing quality care to the patient and creating improved health outcomes or experience. Dependent on the persons' condition and their needs, the team may be comprised of a range of health professionals such as general practitioners, medical specialists, nurses, and allied health professionals.

Palliative care

The World Health Organization defines palliative care as an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and assessment and treatment of pain and other problems, physical, psychosocial and spiritual.

Palliative care:

- provides relief from pain and other distressing symptoms;
- affirms life and regards dying as a normal process;
- intends neither to hasten or postpone death;
- integrates the psychological and spiritual aspects of patient care;
- offers a support system to help patients live as actively as possible until death;
- offers a support system to help the family cope during the patient's illness and in their own bereavement;
- uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;
- will enhance quality of life, and may also positively influence the course of illness;
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.

Person centred care

Person centred care is a way of thinking and doing things that sees the person at the centre of care. This means they are actively involved in and equal partners in planning and decision making around their own care and treatment. It acknowledges and considers each person has different desires, values, family and social situations and ensures care and treatment appropriately aligns with these factors.

Predictable deaths

More than 80% of predicable deaths are due to 5 causes: Cancers (30%), heart & other circulatory diseases (30%), respiratory diseases (9%), external causes (7%), stroke (7%). Only around 20% are not predictable, including stroke (7%), heart attack (5%), accidents and injuries (5%) and suicide (2%).

Specialist palliative care

Care given to patients with complex, unstable symptoms or high needs by either medical, nursing or allied health professionals who have formal specialist palliative care qualifications and often work exclusively within interdisciplinary teams with other palliative care health professionals. Specialist palliative care services can provide direct care to people and their families as well as provide education and advice to other clinicians providing end of life care. Not all people with a life-limiting illness require specialist palliative care services.

Volunteer

An individual who willingly and altruistically without any financial gain gives their time to benefit others. Volunteers can work in clinical and administrative areas or in the wider community. Volunteering can be either in a formal or informal capacity. Formal volunteering refers to activities organised through some sort of organisation in a structured way. Informal volunteers often work in less structured settings with less defined roles. It is also a term used to describe voluntary acts of helping and kindness to friends, family and neighbours.

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