

Queensland Health

Palliative and End-of-Life Care Strategy



Queensland
Government



Palliative and End-of-Life Care Strategy

Published by the State of Queensland
(Queensland Health), October 2022

This document is licensed under a Creative Commons
Attribution 3.0 Australia licence.

To view a copy of this licence, visit:
creativecommons.org/licenses/by/3.0/au

© State of Queensland (Queensland Health) 2022

You are free to copy, communicate and adapt the work,
as long as you attribute the State of Queensland
(Queensland Health).

For more information contact:

Queensland Health
GPO Box 48, Brisbane QLD 4001

Email PCReformProgram@health.qld.gov.au

Disclaimer:

The content presented in this publication is distributed by the Queensland Government as an information source only. The State of Queensland makes no statements, representations or warranties about the accuracy, completeness or reliability of any information contained in this publication. The State of Queensland disclaims all responsibility and all liability (including without limitation for liability in negligence) for all expenses, losses, damages and costs you might incur as a result of the information being inaccurate or incomplete in any way, and for any reason reliance was placed on such information.

SC2200148 10/22

Contents

A message from the Minister	4
Acknowledgement of Country	5
Stakeholder acknowledgements	5
Executive summary	6
Introduction	8
Defining palliative and end-of-life care	9
Policy context	10
International and national context	10
State context	10
Health equity for First Nations peoples	11
Queensland's journey so far	12
Investments in palliative care	13
Existing investment and innovation in palliative care	13
New investment in palliative care	14
Developing the Strategy	15
Who we consulted	15
What we heard	16
Better palliative and end-of-life care for Queenslanders	17
Principles	18
What the Strategy will deliver	19
Making it happen	20
Future areas for reform	26
Outcomes and evaluation	27

A message from the Minister



Life-limiting illness, dying, death, grief and bereavement are uniquely personal experiences. High-quality and accessible palliative and end-of-life care is a critical part of the health system. It improves quality of life for people with a life-limiting illness and can reduce unnecessary interventions and hospitalisations towards the end of life.

The Queensland Government has committed \$171 million from 2021–22 to 2025–26 to strengthen palliative care across Queensland. This funding is in addition to the existing and ongoing investment Queensland Health provides for palliative care across the state.

By 2025–26, this will result in an additional annual investment of \$66 million to fund more frontline nurses, doctors, and support staff, including bereavement counsellors. Over the next five years our frontline specialist palliative care workforce will increase by 87% across Queensland and more hospital, community and tele-support options will be available for all Queenslanders.

The *Palliative and End-of-Life Care Strategy* (Strategy) guides this investment to enable, strengthen and connect the system. The Strategy shows how we will collaborate to support access to existing, improved and new high-quality care and achieve Queenslanders' goals for care at the end of life.

Health equity is at the forefront of this Strategy. We are investing in more services and workforce in regional and remote Queensland to ensure we deliver accessible and culturally safe services for First Nations peoples, designed with community, to support a good death.

When developing the Strategy, Queensland Health consulted widely and reflected on the conversations and evidence that people presented to the Parliamentary Inquiry into aged care, end-of-life and palliative care about what they want and need for palliative and end-of-life care. I would like to thank our stakeholders, particularly consumers, their families and carers, for their input. The collective knowledge and lived experience we heard has directly informed this Strategy.

We know that improving Queensland's palliative care system will require ongoing commitment from all levels of government, the sector, and consumers. The Strategy and its supporting actions are the first step in the journey to create meaningful change.

The Australian Government has an important role to play in the provision of palliative care for Queenslanders. State advocacy is a key part of this Strategy, and we are committed to working closely with the Australian Government to ensure palliative care in the community is prioritised. This Strategy also enables us to meet our commitments under the *National Palliative Care Strategy 2018*.

This Strategy provides a path for us to achieve our vision: that Queenslanders with a life-limiting illness and their families receive equitable, compassionate, and high-quality palliative care that meets their individual needs, preferences, and goals at the end of life.

Yvette D'Ath MP
Minister for Health and Ambulance Services



Acknowledgement of Country

Queensland Health acknowledges the Traditional and Cultural Custodians of the lands, waters and seas across Queensland, pays respect to Elders past and present, and recognises the role of current and emerging leaders in shaping a better health system.

We recognise the First Nations peoples in Queensland are both Aboriginal peoples and Torres Strait Islander peoples, and support the cultural knowledge, determination and commitment of Aboriginal and Torres Strait Islander communities in caring for the health and wellbeing of our peoples for millennia.

Throughout the Strategy, the terms ‘First Nations peoples’ and ‘Aboriginal and Torres Strait Islander peoples’ are used interchangeably rather than ‘Indigenous’. Acknowledging First Nations peoples’ right to self-determination, Queensland Health respects the choice of Aboriginal and Torres Strait Islander peoples to describe their own cultural identities which may include these or other terms, including particular sovereign peoples (for example, Yidinji or Turrbal) or traditional place names (for example, Meanjin Brisbane).

Stakeholder acknowledgements



Throughout Queensland, complex palliative and end-of-life care services are coordinated and provided to health consumers, their families and carers across acute care and community settings.

The key role that dedicated volunteers, carers, families, non-government and peak body organisations play in the delivery of palliative and end-of-life care and support services is deeply acknowledged, as well as the support they provide to our Queensland Health staff delivering specialist palliative and end-of-life care services.

Executive summary

The Palliative and End-of-Life Care Strategy guides the Queensland Government's additional investment in palliative and end-of-life care. We heard directly from many stakeholder groups who informed the Strategy's vision, principles, goals, actions and outcomes.

“Our vision

Queenslanders with a life-limiting illness and their families receive equitable, compassionate, and high-quality palliative care that meets their individual needs, preferences, and goals at the end of life.”

The principles that guide palliative care reform are:

-  Care is high-quality, evidence-based and meets people's needs.
-  Care is equitable, accessible, and culturally safe for all Queenslanders, when and where it is needed.
-  Care is holistic and integrated across the continuum of care.
-  Information about palliative and end-of-life care is available to support informed decision-making.
-  People with a life-limiting illness, their families and carers are supported from the time of diagnosis, with support continuing for families and carers after death.
-  Life-limiting illness, dying, death, grief, and bereavement are recognised as a normal part of life and are planned for.
-  Care is person-centred, compassionate, culturally safe, and respectful of the preferences and unique cultural and spiritual needs of people with a life-limiting illness, their families, and carers.

Enhancing our palliative care system will take effort over time. This Strategy is an important step in the reform journey.

The principles are supported by goals for strategic change to palliative care across the health system. The Strategy's seven goals are:

-  **Access to quality services** – people with a life-limiting illness can access high quality, efficient and integrated palliative care services, at the right time and in the right place.
-  **Information about care** – people with a life-limiting illness, their families and carers receive information that enables and supports them to make informed choices about palliative and end-of-life care.
-  **Individual needs and preferences** – people with a life-limiting illness receive compassionate and high-quality care that is aligned to their preferences and is respectful of their culture, age, identity, emotional, and spiritual needs.
-  **Support for families and carers** – families and carers receive timely and compassionate support while caring for people with a life-limiting illness and during bereavement.
-  **Skilled workforce** – care is delivered by a skilled, supported, and multidisciplinary workforce that is accessible for people with a life-limiting illness, their families and carers.
-  **Data and research** – research and performance data are used to continually improve palliative care policy settings and services.
-  **Governance and advocacy** – state governance of this strategy drives action, accountability, and sustainability of funded services.

The Strategy includes 44 actions that will enable, strengthen and connect Queensland’s palliative care services. When delivered, the actions will achieve the Strategy goals.

The actions were directly informed by extensive consultation processes and align to the Queensland Government’s additional investment of approximately \$171 million to strengthen palliative care through the following initiatives:

- Develop a new Palliative and End-of-Life Care Strategy
- Grow Queensland Health’s frontline specialist palliative care workforce, supported by a workforce plan
- Invest in community-based services to meet local needs
- Enhance palliative care digital services and telehealth support
- Deliver 24/7 secondary consultation for palliative care practitioners
- Provide education and advocacy about dying, death and advance care planning

High-level outcomes of the Strategy



The Strategy will ensure palliative and end-of-life care is person-centred, compassionate, equitable and accessible to all Queenslanders. We know that a strong, collaborative effort is needed to deliver good care, and the Strategy responds to this need.



The Strategy is supported by the Queensland Health Specialist Palliative Care Workforce Plan. The plan outlines how we are growing our specialist palliative care workforce across the state to meet community needs.

Separate to palliative care investments, voluntary assisted dying will be available in Queensland from January 2023. This provides eligible people who are suffering and dying with an additional end-of-life option allowing them to choose the circumstances and timing of their death. Having access to both high-quality palliative care and the option of voluntary assisted dying provides dignity, choice, and care to those who are suffering.

Our commitment to palliative care reform has already started and the Strategy will drive better outcomes across the state.



Introduction

People with a life-limiting illness want choice in when, where and how their palliative care is provided. They also want support to make choices about their place of death and assurance that their families, carers and loved ones are supported.

A priority for Queensland Health is to ensure that all Queenslanders have access to high-quality palliative care and support at the end of life. The Strategy aims to strengthen the healthcare system to ensure this care is culturally safe, person-centred, equitable and accessible to everyone, regardless of where they live.

When developing the Strategy, we heard directly from Queenslanders through extensive consultation processes about what is needed to improve palliative and end-of-life care across the state. The feedback we received has directly informed the vision, principles, goals and actions outlined in the Strategy.

The Strategy is focused on Queensland Health, but all services across the state are encouraged to use the principles within the Strategy to guide their services. All Queenslanders have a right to a good death that is free from suffering, with the support of high-quality palliative and end-of-life care services. We know that a collaborative effort is needed to deliver this care and improve the palliative care system over time, and the Strategy reflects this need.



Defining palliative and end-of-life care

Palliative care and end-of-life care can improve quality of life and promote wellness for people living with a life-limiting illness, their families, and carers. Often, people associate palliative or end-of-life care with cancer, however, this care is appropriate for anyone living with a life-limiting illness, other chronic conditions, dementia, and non-malignant degenerative diseases.

Palliative care and end-of-life care may be required at any age, and the needs of children and younger people, their families and carers need to be considered. Considering people's cultural needs and ensuring culturally safe practices for everyone receiving care is also important. For First Nations peoples, the time before and after death, which may be referred to as Sad News and/or Sorry Business, are subject to customary practices and beliefs, which should be respected and accommodated during the palliative and end-of-life care journey. This Strategy responds to the diverse needs of Queenslanders and aims to ensure people receive compassionate palliative care and end-of-life care that is respectful of their cultural, spiritual, emotional, and physical needs and preferences.

This Strategy affirms that palliative care is a person-centred approach, which is consistent with the World Health Organization definition used in the *National Palliative Care Strategy 2018*. People with a life-limiting illness should be at the heart of their care, surrounded by their family, carers, community and supported by services, which may include one or more of a range of formal and informal supports.¹

¹ Australian Government Department of Health 2018, National Palliative Care Strategy, Australian Government Department of Health, viewed June 2022, <https://www.health.gov.au/resources/publications/the-national-palliative-care-strategy-2018>.

² Commonwealth of Australia 2017, National Strategic Framework for Aboriginal and Torres Strait Islander Peoples' Mental Health and Social and Emotional Wellbeing, Department of the Prime Minister and Cabinet, Canberra.

When we refer to palliative care and end-of-life care in this Strategy, we mean:

Palliative care

Palliative care is an approach that improves the quality of life of patients (adults and children) and their families who are living with a life-limiting illness, through the prevention and relief of suffering by means of early identification and correct assessment and treatment of pain and other problems, whether physical, psychosocial or spiritual.¹

End-of-life care

End-of-life care includes physical, spiritual and psychosocial assessment, and care and treatment delivered by health professionals and ancillary staff. It also includes support of families and carers, and care of the patient's body after their death. Voluntary assisted dying is another end-of-life option for people who meet strict eligibility criteria. People are 'approaching the end of life' when they are likely to die within the next 12 months. This includes people whose death is imminent (expected within a few hours or days) and those with:

- advanced, progressive, incurable conditions
- general frailty and co-existing conditions that mean that they are expected to die within 12 months
- existing conditions, if they are at risk of dying from a sudden acute crisis in their condition
- life-threatening acute conditions caused by sudden catastrophic events.

We recognise that social and emotional wellbeing is the foundation for physical and mental health, including for First Nations peoples. This Strategy also adopts a holistic view for palliative and end-of-life care. This includes supporting relationships between individuals, family, kin and community while providing care, and recognising the importance of connection to land, culture, spirituality and ancestry, and how these affect an individual.²

Policy context

International and national context

International and national palliative care strategies outline the importance of health systems providing high quality and accessible palliative care. This Strategy aligns with other strategies and describes Queensland's approach to strengthening palliative and end-of-life care services.

In 2013, the World Health Assembly adopted a resolution to include palliative care in all health systems, at all levels of care, and for the whole population.³

In January 2014, the Executive Board of the World Health Organization published policy directions recognising the need for palliative care and end-of-life care to be provided 'in accordance with the principles of universal health coverage' and for palliative care to be offered by all health systems.⁴ These policy directions were endorsed by the World Health Assembly in April 2014.

The Australian Government, in partnership with states and territories, leads policy development for palliative care in Australia. The national policy direction for palliative care is set through the *National Palliative Care Strategy 2018* (National Strategy) and supporting Implementation Plan. Queensland has committed to support the implementation of the National Strategy and ensure the highest possible level of palliative care is available to all people in Queensland. This commitment will be met by implementing the actions in our Strategy.

The Australian Government also has a key role in supporting palliative care in the community through primary care. We will continue to advocate to the Australian Government for increased investment, particularly across primary care and in community settings, to support the delivery of palliative care services in Queensland.

Palliative Care Australia is the Australian peak body for palliative care. The *Palliative Care Australia Roadmap 2022–2027* sets the direction Australia needs to take from now until 2027 to ensure high-quality palliative care is available for all who need it, where and when they need it.⁵ It outlines key areas to be prioritised across investment, support for carers, workforce, awareness campaigns about death, dying and palliative care, data and research, and palliative care in aged care. This Strategy aligns to these key areas.

State context

While the focus of this Strategy is palliative care and end-of-life care services, lessons from across the health system have been incorporated to improve access and equity of access to services. The report *Unleashing the potential: an open and equitable health system – Healthcare for Queenslanders in a pandemic ready world* explored lessons from the COVID-19 pandemic.⁶ It offers recommendations to progress reform across the continuum of care and create a health system:

- that is focused on consumers
- that is integrated across health providers

³ Humphreys, G 2013, 'Push for palliative care stokes debate', Bulletin of World Health Organization, vol.91, pp.902–3.

⁴ World Health Organization 2013, Strengthening of palliative care as a component of integrated treatment throughout the life course, World Health Organization Executive Board 134th session, Provisional agenda item 9.4.

⁵ Palliative Care Australia 2022, Palliative Care Australia Roadmap 2022–2027. Investing to secure high-quality palliative care for all Australians who need it, Palliative Care Australia, viewed June 2022, <<https://palliativecare.org.au/publication/palliative-care-australia-roadmap-2022–2027/>>.

⁶ State of Queensland (Queensland Health) 2020, Unleashing the potential: an open and equitable health system. Healthcare for Queenslanders in a pandemic ready world, State of Queensland (Queensland Health), viewed June 2022, <https://www.health.qld.gov.au/__data/assets/pdf_file/0029/1143479/Unleashing-the-Potential-an-open-and-equitable-health-system.pdf>.

- that supports a flexible and empowered workforce
- where clinicians, consumers and providers genuinely work in partnership, and
- where good ideas and practices are evaluated and shared across the system.

The new Strategy also builds on directions and actions from Queensland's previous *Statewide strategy for end-of-life care 2015*.⁷ Both strategies aim to strengthen the capacity of Queensland Health services to respond to the needs of people with a life-limiting illness and deliver high-quality palliative care services.

A key component of delivering quality services is making sure that the rights and interests of people with a life-limiting illness are protected and recognising the needs of people who may be vulnerable or at risk, including but not limited to, Aboriginal and Torres Strait Islander peoples, people with disability, people from culturally and linguistically diverse backgrounds, people with cognitive impairment, people experiencing homelessness, and older people. All people have the right to exercise choice to access palliative care services based on their preferences, and in the environment of their choosing. Appropriate advance care planning supports people to make and/or communicate decisions about their own life and the type of care and outcomes they would consider acceptable, and helps to ensure that their preferences are documented and respected.

Guidance and resource materials should be available to health professionals and others who care for people with life-limiting illnesses. Through information and education, professionals should have enhanced capacity to support decision-making practices, identify potential forms of abuse such as elder abuse, and to address issues.

This Strategy reflects these needs. It includes actions that strengthen person-centred palliative care services through greater collaboration, integration, and use of technology. The Strategy also contains actions that will help to develop a skilled workforce, through the provision of targeted information and professional development opportunities, to ensure staff are able to respond to the diverse needs of people with a life-limiting illness.

Health equity for First Nations peoples

End of life is a significant and sensitive time for First Nations peoples. It is a time that is subject to important customary and cultural practices and has meanings that are sacred to First Nations peoples.

This Strategy supports Queensland Health's First Nations health equity reform agenda. Recent amendments to the *Hospital and Health Boards Act 2011* and *Hospital and Health Boards Regulation 2012* have created the strongest legislative foundation for Queensland's public health system to achieve health equity for First Nations peoples and eliminate institutional racism across Hospital and Health Services. These legislative amendments and the release of the *Making Tracks Together – Queensland's Aboriginal and Torres Strait Islander Health Equity Framework* are placing First Nations peoples at the centre of healthcare design and delivery, including palliative care and end-of-life care services.

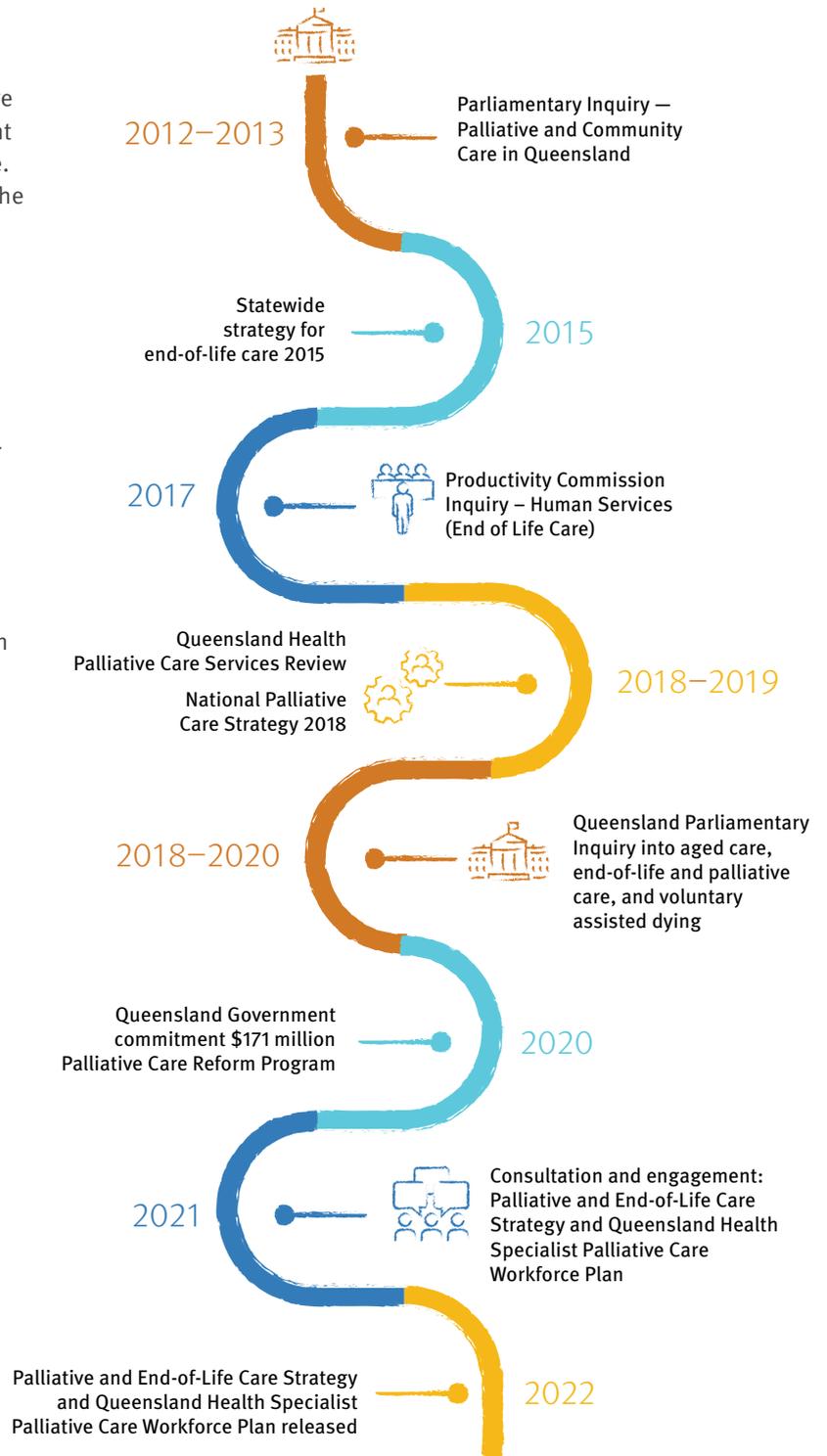
The Strategy prioritises investment in First Nations led culturally appropriate and family-centred models. It recognises the kinship ties among First Nations peoples and communities to deliver holistic palliative care. This is supported by the *Queensland Health Specialist Palliative Care Workforce Plan* (Workforce Plan) which builds the capability of palliative care services by growing the First Nations palliative care workforce across the system.

⁷ Queensland Health 2015, *Statewide strategy for end-of-life care*, Queensland Health, viewed June 2022, <https://www.health.qld.gov.au/__data/assets/pdf_file/0022/441616/end-of-life-strategy-full.pdf>.

Queensland's journey so far

In recent years, we have introduced new palliative care services and end-of-life care initiatives and committed more investment to improve these services across the state. We have also committed to working with the Australian Government and other states and territories to continually improve palliative care services through the National Strategy.

The *Queensland Health Palliative Care Services Review 2018* (Review) and the Parliamentary Inquiry into aged care, end-of-life and palliative care (Inquiry) sought feedback from thousands of stakeholders across Queensland. The findings and recommendations from these processes have informed the development of this Strategy, as well as extensive consultation and engagement undertaken in 2021.



Investments in palliative care

We have a track record of investing in palliative care to improve accessibility and equity across the state.

\$157 MILLION

approximate investment by Hospital and Health Services to provide palliative care services in 2021–22

\$17 MILLION

provided to Hospital and Health Services to deliver new palliative care services in regional and rural areas of Queensland across 2019–20 and 2020–21

\$13.3 MILLION

in 2021–22 to non-government organisations to deliver community-based care, training, and information and awareness services



Funding over four years from 2021–22 for Ambulance Wish Queensland

Jointly funding the **Specialist Palliative Care in Aged Care Project** for equitable access to specialist palliative care in residential aged care facilities

Funding the **Office of Advance Care Planning** to deliver education, advocacy and raise awareness about Advance Care Planning

Establishing **PallConsult**, a service that supports and builds capacity across Queensland for community-based clinicians

Funding for the **Specialist Palliative Rural Telehealth Service** to support the delivery of palliative care services in regional, rural and remote areas of Queensland

Funding for the **Paediatric Palliative Care Outreach Collaborative** to support the delivery of services for children in regional and remote areas

Funding for the **Medical Aids Subsidy Scheme - Palliative Care Equipment Program** to support the delivery of palliative care services at home

Funding **Palliative Care Queensland** to build community capacity through community development, engagement and awareness

We have service agreements with the following non-government organisations to deliver community-based and hospice services:

- Cittamani Hospice Service
- Ipswich Hospice Care Ltd
- Hopewell Hospice Services (Wesley Mission Queensland)
- Karuna Hospice Services Ltd
- Little Haven Cooloola
- Sunshine Coast Palliative Care Association Inc
- St Vincent's Private Hospital
- Toowoomba Hospice Association Inc
- Hummingbird House (Wesley Mission Queensland)
- Katie Rose Cottage Hospice



New investment in palliative care

We will invest approximately \$171 million in additional funds across 2021–22 to 2025–26 to strengthen palliative care services. By 2025–26, this will result in an additional annual investment of \$66 million per year. This funding increase is in addition to existing funding we provide for Hospital and Health Services, which will continue to increase over time. In 2025–26, Queensland’s total spend on palliative care is estimated to be close to \$250 million per annum.

The additional funding will be allocated to the following initiatives:

Initiatives	Total funding to 2025–26
Develop a new Palliative and End-of-Life Care Strategy	\$0.5 million
Grow Queensland Health’s frontline specialist palliative care workforce, supported by a workforce plan	\$102.5 million
Invest in community-based services to meet local needs	\$54.8 million
Enhance palliative care digital services and telehealth support	\$7.2 million
Deliver 24/7 secondary consultation for palliative care practitioners	\$4.3 million
Provide education and advocacy about dying, death and advance care planning	\$1.6 million

The investment will gradually increase over five years to ensure that services grow in a sustainable way and that workforce is available to fill new specialist palliative care workforce positions that we are creating.

Developing the Strategy

Who we consulted

People with a life-limiting illness, their families and carers, clinicians, peak bodies, advocates, and the palliative care sector told us what they want for palliative and end-of life care services, now and into the future.

Building on feedback received through the Review and Inquiry, we developed principles and goals, which align to the National Strategy and the previous *Statewide strategy for end-of-life care 2015*.

We invited stakeholders to participate in consultation opportunities, including workshops, targeted consultation sessions, Kitchen Table Discussions and Yarning Circles, or to provide feedback through email or a survey. We sought feedback on the proposed principles and goals, initiatives that were working well, and ideas about potential actions that could be included in the Strategy.

We heard from a wide range of stakeholders from across Queensland, including clinical and non-clinical representatives from the Queensland Hospital and Health Services, private clinicians, Primary Health Networks, Palliative Care Queensland and other peak bodies, training organisations, industrial unions, and consumers and carers.

We consulted:

- 142 consumers and carers across 14 towns and cities, including rural and remote areas, through Kitchen Table Discussions and Yarning Circles, facilitated by Health Consumers Queensland
- Queensland Health staff, including specialist palliative care clinicians, and nurses, physicians, and allied health practitioners, through multiple meetings with the 16 Hospital and Health Services and an internal survey
- Clinicians, nurses, allied health staff and consumer representatives through four workshops
- 49 representatives from 39 different non-government organisations, including palliative care service providers, peak bodies, Primary Health Networks, national peak bodies and aged and disease specific peak bodies related to palliative care, facilitated by Palliative Care Queensland.

We also held:

- Meetings with Queensland Health staff about the current workforce for palliative care, local workforce priorities and the development of the Workforce Plan
- A workshop focused on principles of good practice and models of care for designing and delivering First Nations led culturally safe community-based palliative and end-of-life care for First Nations peoples.

What we heard

The contributions from consumers and carers, the community, sector, and clinicians throughout the consultation process was invaluable. The information we received through the consultation process directly informed the actions and strategic directions contained in the Strategy and will also be used as a basis to enhance the palliative care system beyond the life of the Strategy. People told us what good palliative care should look like and how we must deliver essential change across the palliative care system in Queensland.

We collected and analysed a vast amount of feedback during our consultation activities and identified eight key themes that emerged during the process. These themes were:

- Bereavement support is a key aspect of care and should be provided from the time a person receives a diagnosis and during the provision of quality palliative and end-of-life care.

- Information needs to be timely and provided to patients, their families and carers at the right time.
- Compassion is a key aspect of palliative care and needs to be reflected across the principles and goals.
- Governance and accountability for the Strategy needs to be clearly articulated to ensure oversight of its implementation and monitoring.
- The importance of carers, families and other loved ones needs to be clearly outlined in the Strategy.
- There is a need for new investment and better ways to allocate funding and investment to fill gaps and strengthen service delivery.
- Growth, training and support for a multidisciplinary workforce that can cater to people's needs, including cultural and spiritual needs, is necessary.
- Awareness and education about the benefits of Advance Care Planning is required to safeguard individuals' preferences at the end of life.

"Increasing specialist palliative care workforce ensures skilled clinicians can support the generalist population but also deliver high-quality palliative care that meets people's needs." **Queensland Health survey response.**

"Support for carers is also very high on the list, as in my experience, the carers' needs are two-fold, during the end-of-life process, then the bereavement stage after. There are still fairly significant gaps for this support, especially for those who don't even know where to start looking. And the information isn't readily available." **Consumer, Kitchen Table Discussion, Cairns.**

"There is a need for recurrent funding for current models that are working well, such as PallConsult, Specialist Palliative Rural Telehealth Service, Paediatric Palliative Care Collaborative for sustainability." **Participant, Queensland Palliative Care Clinical Network Steering Committee engagement session.**

"There is an opportunity to review programs funded by the state to identify duplications, roles and responsibilities and what can be improved at a statewide basis and how investment can be allocated more efficiently." **Participant, Queensland Specialist Palliative Care Services Directors' Group.**

"It is important to recognise that bereavement support is a fundamental part of end-of-life care and supporting families and carers following the passing of a loved one." **Participant, Care at End of Life Collaborative engagement session.**

"There is a need for staff training and education ... all health and support staff [need to] understand palliative and end-of-life care, compassionate care, and culturally appropriate care." **Participant, Queensland Palliative Care Clinical Network Steering Committee engagement session.**

"There needs to be staff who have connections with our mob while in hospital, so we need to make sure that Aboriginal and Torres Strait Islander Liaison Officers are present. Need adequate staff numbers." **Consumer, Yarning Circle, Hervey Bay.**

"The Medical Aids Subsidy Scheme Palliative Care Equipment Program is amazing and now assists patients to be loaned the appropriate equipment ... It is much easier for the families." **Queensland Health survey response.**

Better palliative and end-of-life care for Queenslanders



Our vision

Queenslanders with a life-limiting illness and their families receive equitable, compassionate, and high-quality palliative care that meets their individual needs, preferences, and goals at the end of life.



Expanding services outside of southeast Queensland and facilitating more care at home are key focus areas under the Strategy. Investing in these services will support people to achieve their goals at end of life and reduce pressure on our hospital system. Partnerships across sectors, including with the primary health sector, will help us to integrate services and provide better care for people, allowing them to die with dignity.

People with a life-limiting illness, their families and carers are the foundation of the palliative care system. Many palliative care services are provided by families and carers with support from health professionals. Through this Strategy, there will be more support for people with a life-limiting illness, their families and carers to ensure they have better outcomes and are supported after a loved one's death.

The Strategy will help us to achieve this vision by including initiatives for improved models of care at the system level and the local level that improve palliative care experiences and outcomes for Queenslanders.

Growing and supporting our specialist palliative care workforce will be critical to achieving our vision. The Workforce Plan guides how a sustainable specialist workforce for Queensland will be established, developed and maintained over time to better meet the current and future needs of consumers and families.

Through the Workforce Plan and new investment, the frontline specialist palliative care workforce will be increased across Hospital and Health Services. An expanded specialist palliative care workforce will also support the primary care sector to build capability and their skills to support people to receive care in the community.

Principles

The Strategy has seven principles that guide the goals, actions and intended outcomes of the Strategy.



Care is high-quality, evidence-based and meets people's needs.



Care is equitable, accessible, and culturally safe for all Queenslanders, when and where it is needed.



Care is holistic and integrated across the continuum of care.



Information about palliative and end-of-life care is available to support informed decision-making.



People with a life-limiting illness, their families and carers are supported from the time of diagnosis, with support continuing for families and carers after death.



Life-limiting illness, dying, death, grief, and bereavement are recognised as a normal part of life and are planned for.



Care is person-centred, compassionate, culturally safe, and respectful of the preferences and unique cultural and spiritual needs of people with a life-limiting illness, their families, and carers.

Enhancing our palliative care system will take effort over time. This Strategy identifies the wide range of actions we must take to improve palliative care in Queensland, and is an important step in the reform journey.

What the Strategy will deliver

The Strategy has seven goals. These are what we expect to achieve by implementing the actions outlined in the Strategy.

Goals



Access to quality services

People with a life-limiting illness can access high quality, efficient and integrated palliative care services, at the right time and in the right place.



Information about care

People with a life-limiting illness, their families and carers receive information that enables and supports them to make informed choices about palliative and end-of-life care.



Individual needs and preferences

People with a life-limiting illness receive compassionate and high-quality care that is aligned to their preferences and is respectful of their culture, age, identity, emotional, and spiritual needs.



Support for families and carers

Families and carers receive timely and compassionate support while caring for people with a life-limiting illness and during bereavement.



Skilled workforce

Care is delivered by a skilled, supported, and multidisciplinary workforce that is accessible for people with a life-limiting illness, their families and carers.



Data and research

Research and performance data are used to continually improve palliative care policy settings and services.

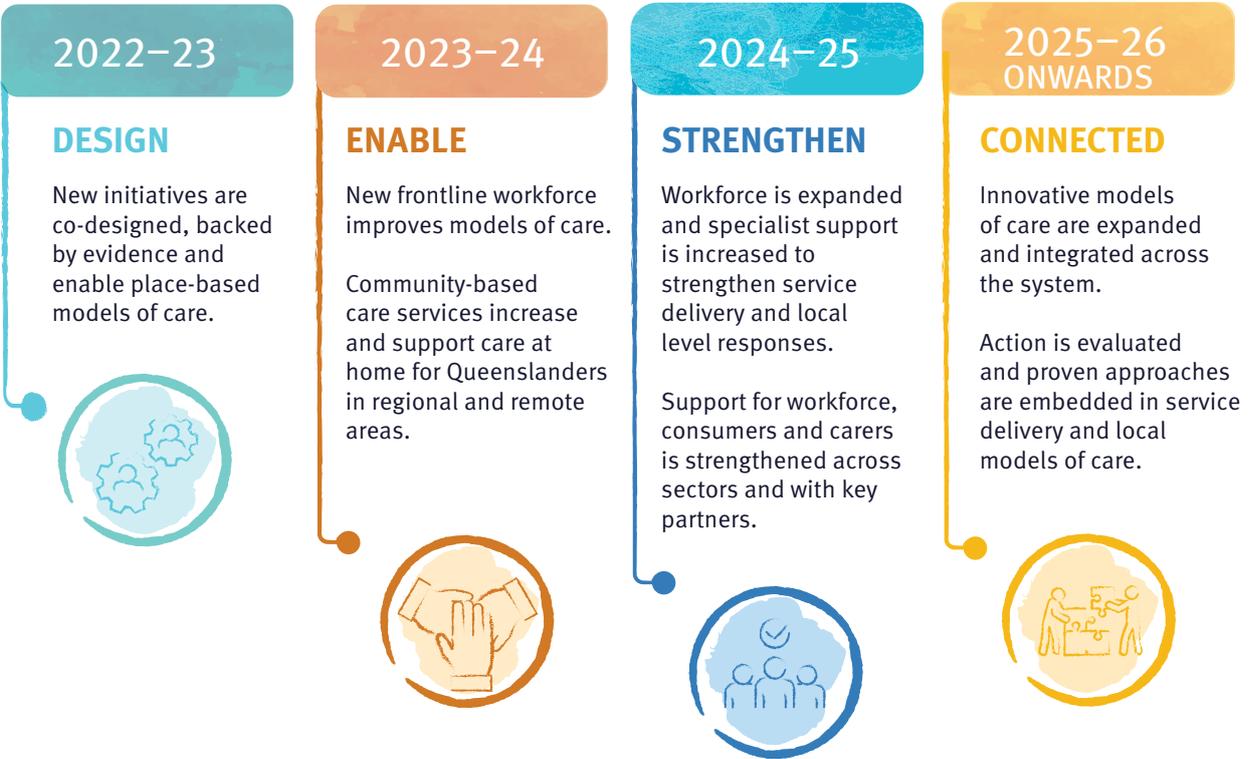


Governance and advocacy

State governance of this strategy drives action, accountability, and sustainability of funded services.

Making it happen

The Strategy aims to reform palliative care service delivery in Queensland through investment and policy to design, enable, strengthen and connect the palliative and end-of-life care service delivery system. This approach is outlined in the following diagram.



Actions

When delivered, the 44 actions outlined in this Strategy will achieve the Strategy goals for palliative care reform. Implementation of the actions will be staggered across the Strategy’s implementation period in alignment with the reform approach.

The actions focus on expanding existing initiatives and exploring new areas. The actions emerged from the consultation process and aim to improve outcomes for people with a life-limiting illness and to better support families, carers and loved ones.

Some actions from the Workforce Plan are also reflected in this Strategy as a skilled, multidisciplinary, and supported workforce is one of the most important enablers to delivering high-quality palliative care.





Access to quality services

Actions	Timeframe
Work with Hospital and Health Services to support implementing of new initiatives and palliative care services, including continuous improvement to support the delivery of high-quality palliative care.	Ongoing
Explore program enhancement opportunities for the recurrently-funded Medical Aids Subsidy Scheme – Palliative Care Equipment Program to support palliative care at home.	Ongoing
Support patient care choices by providing funding to non-government service providers, including hospices, to deliver palliative care services within the community, and support people to receive care, and die, at home.	Ongoing
Continue to provide funding for the Paediatric Palliative Care Outreach Collaborative to support the delivery of palliative care services for children living in rural areas.	Ongoing
Establish and promote statewide grief and bereavement resources for people of all ages, including vulnerable groups, and seek opportunities to standardise approaches to service provision in services provided or funded by Queensland Health.	Ongoing
Expand the Specialist Palliative Rural Telehealth Service to provide additional support and education to staff and support the delivery of palliative care in rural and remote areas of Queensland.	2023–24
Co-design improved models of care that support consumers’, carers’ and clinicians’, including ambulance officers’, needs for information, referral, clinical advice and after-hours support.	2022–23
Investigate digital healthcare access barriers and identify opportunities to pilot, scale and spread digital healthcare service delivery to enhance the quality of palliative care across the state.	2023–24 – investigate 2024–25 – implement/pilot initiatives
Showcase proven digital healthcare initiatives operating in Queensland that increase access and choice and reduce inappropriate or unwanted admissions to hospital.	2023–24 then ongoing
Deliver new community-based care services for consumers living in regional, rural, and remote areas outside South East Queensland to support people’s preferences to receive care closer to home.	Commencing 2022–23
Co-design and commission demonstration models of First Nations led community-based palliative care services for First Nations peoples, to support best practice care and social and emotional wellbeing, that can be evaluated and potentially scaled up and expanded in the future.	Commencing 2022–23
Continue contracts with non-government organisations providing valued hospice services and support them to identify own source revenue for ongoing sustainable service provision.	2022–23 then ongoing
Support palliative care service integration, including through engagement with Primary Health Networks, particularly for residents of residential aged care facilities.	2022–23 then ongoing



Information about care

Actions	Timeframe
Develop and refine advance care planning forms, supporting documents and processes through co-design approaches with multi-disciplinary groups to ensure they provide appropriate and easy to understand information and guidance to clinicians and consumers.	2022–23 then ongoing
Trial the Decision Aid – Care Companion for people living with a life-limiting illness and their families to support decision-making for end-of-life care.	2022–23 and 2023–24
Deliver a contemporary social media marketing and engagement campaign to increase public awareness and reduce stigmas about death, dying and palliative care, and share information on advance care planning, Advance Health Directives, Wills and Enduring Powers of Attorney.	2022–23 then ongoing
Deliver education and advocacy for health professionals about their role in advance care planning, palliative care access and choices, and bereavement care, to ensure people living with a life-limiting illness, their families and carers are involved in decision-making and have an opportunity to communicate their preferences for care.	2022–23 then ongoing
Engage with specific populations, including LGBTIQ+ people, people with disability, people in prisons, carers of older people, and older people who live in residential aged care facilities to identify their education and awareness needs for palliative and end-of-life care and the specific issues that these people in our community face when living with a life limiting illness.	2023–24 then ongoing



Individual needs and preferences

Actions	Timeframe
Review guidelines and policies supporting care for deceased persons and integrate appropriate prompts to enable tailored services that respond to cultural needs.	2023–24
Promote the need for, and use of, experienced interpreters for First Nations language speaking communities and culturally and linguistically diverse patients and loved ones for all health services, including palliative and end-of-life care.	2022–23 then ongoing
Co-design translated, easy English and culturally safe palliative and end-of-life care resources for First Nations and culturally and linguistically diverse people, with peak bodies and community to increase awareness of palliative and end-of-life care and knowledge to support informed decision-making.	2022–23 scoping and co-design work 2023–24 implementation
Explore options to support First Nations people with a life-limiting illness to pass away on country or be returned to country after passing.	2023–24
Embed First Nations led culturally safe approaches into palliative care service models, to promote health equity and social and emotional wellbeing of First Nations consumers, their families, and carers.	2023–24 then ongoing



Support for families and carers

Actions	Timeframe
Work with Palliative Care Queensland, other peak bodies and Primary Health Networks to support compassionate communities' initiatives, and community development, engagement and awareness initiatives about palliative and end-of-life care.	Ongoing
Investigate technology that can be used to support people to undertake advance care planning, and cope with dying, death, grief, and bereavement in Queensland.	2023–24 – investigate 2024–25 – implement initiatives
Provide palliative care information and advice to support consumers, carers, and families to access palliative care services and support, before and after the death of a loved one.	2022–23 development of model 2023–24 then ongoing



Skilled workforce

Actions	Timeframe
Continue to provide funding for PallConsult, a 24/7 secondary consultation phone service for palliative care practitioners and supportive educational service.	2023–24 then ongoing
Deliver investment and frontline workforce increases across Hospital and Health Services, informed by population need and service demand.	2023–24 then ongoing – variable across HHSs
Establish dedicated Aboriginal and Torres Strait Islander health workforce position/s for each specialist palliative care service to maximise culturally safe care.	2023–24 then ongoing – variable across HHSs
Build the workforce required to link in and support community-based specialist palliative care services for consumers choosing care in the community.	2023–24 then ongoing – variable across HHSs
Establish dedicated bereavement care coordination and counselling positions and build the capability of the specialist palliative care workforce in bereavement care to increase access for carers and family.	2023–24 – variable across HHSs
Promote targeted information and professional development opportunities for Queensland Health staff about palliative care, including providing compassionate care, to ensure staff are equipped to respond to the spiritual, cultural, age related, and other diverse needs of people with a life-limiting illness.	2022–23 then ongoing
Promote existing resources and informal education and training opportunities to improve understanding of grief and bereavement among health and aged care workers, General Practitioners, nurses, and a variety of other community services, including relevant skills for identifying risk of prolonged grief disorder.	2022–23 then ongoing



Data and research

Actions	Timeframe
Co-design standardised approaches for measuring patient outcomes and experiences.	Ongoing
Monitor and evaluate the implementation of the Strategy and consider lessons learned to improve service delivery and patient outcomes.	Ongoing
Support research and the translation of research into practice to inform models of care, workforce education, and palliative and end-of-life care resources for patients and carers through the Centre for Palliative Care Research and Education.	2022–23 then ongoing



Governance and advocacy

Actions	Timeframe
Support the Queensland Palliative Care Clinical Network and other clinical networks to drive development of quality models of care, innovations and improvement across specialist, generalist (including primary) palliative care service delivery and support system integration.	Ongoing
Advocate for continued Australian Government funding for the Specialist Palliative Care in Aged Care project, delivered under the Comprehensive Palliative Care in Aged Care Measure, ahead of the current agreement's cessation on 30 June 2024.	2022–23 and 2023–24
Advocate to the Australian Government to provide additional investment in primary palliative care services through Medicare Benefits Schedule items to support palliative care and advance care planning consults.	Ongoing
Support Hospital and Health Service planning for palliative care services through regular consultation with Queensland Health executive forums and clinical networks and use of endorsed Queensland Health planning guidelines for palliative care services.	Ongoing
Undertake reporting against the <i>National Palliative Care Strategy 2018 – Implementation Plan</i> as required by the Australian Government.	Ongoing
Establish ongoing governance arrangements within Queensland Health, including but not limited to, consumer and First Nations representation, to provide oversight of implementation, monitoring and reporting for the Strategy.	Ongoing
Continue to support Palliative Care Queensland by providing funding for peak body services and advocacy activities.	Ongoing
Include palliative and end-of-life care needs as part of pandemic and other emergency preparedness, response and recovery planning.	Ongoing

Future areas for reform

During the consultation process, we heard about innovations, initiatives and models of care that could improve the experience of people accessing palliative care, and improvements to support clinicians and the sector to deliver improved services. While not included in the action list, we have identified these further opportunities to explore:



Volunteers and volunteer coordinator roles in Hospital and Health Services to provide additional support to people with a life-limiting illness, their families and carers.



Opportunities of a First Nations Centre of Excellence with the Queensland Palliative Care Clinical Network.



Improved clinical digital systems to support information-sharing across health and care services and service systems, such as between specialist and GP, for streamlined service experiences and better multidisciplinary care. Mobile formats for information need to be explored for improved consumer experiences. Innovation in this area is likely to improve interactions with GPs, care staff, and palliative care specialists when they are involved in a person's care.



Opportunities to increase pathways across different areas responsible for end-of-life care including palliative care, voluntary assisted dying, and other services, to promote equal access to quality bereavement support regardless of how a person dies.

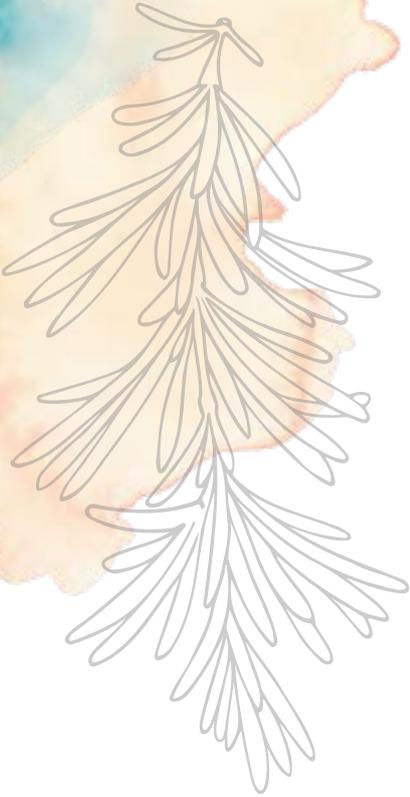
Outcomes and evaluation

Queensland Health is responsible for leading the implementation of the Strategy and driving the reform of palliative care service delivery in Queensland. We will work closely with our partners and stakeholders to deliver the Strategy's actions.

The Strategy will be evaluated to make sure outcomes have been delivered. Undertaking an evaluation will help us to understand the impact of the Strategy and identify areas for future improvement. The high-level outcomes for the Strategy are:

Outcomes

- More Queenslanders with life-limiting illness receive palliative care.
- Improved equity of access to palliative care across health system regions and resident populations.
- Information about palliative and end-of-life care is available and accessed by Queenslanders with life-limiting illness, their families and carers.
- Queenslanders with life-limiting illness receive care in alignment with their preferences.
- Families and carers are supported while providing care for someone with a life-limiting illness and during bereavement.
- A multidisciplinary, skilled workforce provides quality care to people with life-limiting illness.
- Data collection and research inform service development, delivery of care, monitoring and quality improvement.
- Government supports the Strategy through funding, advocacy, coordinated leadership and accountability.



Queensland
Government