



SOUTH AUSTRALIA'S PALLIATIVE CARE STRATEGIC FRAMEWORK

2022 – 2027



Government
of South Australia

SA Health

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Message from the Minister for Health and Wellbeing



The Hon Stephen Wade
Minister for Health and
Wellbeing, South Australia

The State Government is committed to more effectively supporting people in the final stages of their life. Additional investment of \$16 million from 2018-19 to 2021-22 has provided support for a range of initiatives including:

- > Expanded access to metropolitan adult specialist palliative care services after hours, on weekends and for at-risk populations
- > Significantly broader reach across regional South Australia, with specialist palliative care access increased from 19 to over 50 locations
- > Strengthened palliative care in aged care by upskilling staff in aged care facilities to ensure residents have greater opportunity to die in their place of choice
- > An increased breadth of partnerships with the non Government sector, generating unique and innovative ways to improve palliative care for groups in our community
- > Supporting the SA Ambulance Service and upskilling our paramedics to deliver medication for breakthrough pain and reducing the need for transfer to an emergency department
- > Increased medical, nursing and allied health support for paediatric palliative care patients
- > A statewide assessment of palliative care needs
- > Establishment of a statewide clinical network for palliative care.

I am now pleased to present South Australia's Palliative Care Strategic Framework 2022-2027. The Framework is the result of contributions from a large number of individuals and organisations across the South Australian community.

The development of this Framework provides an opportunity for South Australia to undertake further work to improve palliative care in South Australia in alignment with the goals and priorities of the National Palliative Care Strategy 2018 and the vision and goals of the South Australian Health and Wellbeing Strategy 2020-2025.

The Framework outlines a suite of actions that will be undertaken over the next five years. The development of a new Palliative Care Services Plan and Statewide Palliative Care Model of Care for South Australia are key actions that will be prioritised for early completion. These key initiatives will support us to deliver equity of access to high quality, evidence informed palliative care services across South Australia and will support more people with a life-limiting illness to die according to their needs, preferences, values and wishes. The remaining actions in the framework will significantly strengthen our palliative care service system.

The health system is large and complex and achievement of quality, person-centred outcomes for individuals, families and communities requires smooth connections across many people, services and systems. This goes beyond the public health system to include partnerships and collaboration with non-government, not for profit and private health providers and other SA Government services and agencies. This is especially important for people living with life-limiting illness or caring for a person with a life-limiting illness who may have frequent interactions with a range of different health services. In recognition of the complexity and reach of the palliative care service system, we will work collaboratively to undertake the actions in this framework and to support the achievement of the Framework vision:

All South Australians, their families and carers have access to and receive the best possible end of life and palliative care that places the person at the centre of care and supports them to live and die well in accordance with their individual needs, wishes, values and preferences.

Message from the Palliative Care Clinical Network Chairs



Dr David Holden

Chair, Palliative Care
Clinical Network
July 2019 – June 2021

The Statewide Palliative Care Clinical Network recognises palliative care as a person-centred approach for those affected by a life-limiting illness, their carers and the community in which they live, acknowledging that palliative care occurs in all settings and is a shared experience of many living in South Australia. The vision of the Statewide Palliative Care Clinical Network is:

We are committed to consumers, carers, and the community in the delivery of comprehensive best practice palliative care. We will achieve this through supporting inter-disciplinary cross sectors partnership of consumers, services, and health workers.

On behalf of the Statewide Palliative Care Clinical Network we are pleased that this Palliative Care Strategic Framework recognises that all South Australians, their families, and carers, deserve access to, and receive the best possible end of life and palliative care. It has been designed for use by everyone in South Australia to support collaboration, communication, and service delivery across all sectors, to recognise the breadth of palliative care delivery and to assist with the development of service planning and models of care.

It guides collective efforts of palliative care services to support health care users, carers, and the broader community by placing the person affected by life-limiting illness at the centre. It proposes shared priorities and preferred approaches to palliative care, to improve how we collectively support all people to live and die well in accordance with their individual needs, wishes, values and preferences.

The Framework also aligns with the national priorities for palliative care through focusing on:

- > increasing community awareness, understanding and engagement with end of life matters
- > improving access to generalist and specialist palliative care particularly for underserved populations
- > enhancing collaboration and coordination of palliative care
- > improving palliative care data collection, monitoring, and reporting.



Dr Peter Allcroft

Co-chair, Palliative Care
Clinical Network



Kathryn Hourigan

Co-chair, Palliative Care
Clinical Network

Acknowledgements

We acknowledge Aboriginal people as the first Australians, traditional owners of South Australia, and we respect their ongoing living and spiritual relationship with the land and waters. We respect and celebrate the many Aboriginal peoples and their lands across the state of South Australia.

We acknowledge those members of the community who have shared their personal stories and experiences regarding receiving palliative care in South Australia. We also thank the members of the Palliative Care Clinical Network Steering Committee (PCCNSC) and Palliative Care Project Board, who provided significant guidance, content expertise and personal insight to support the development of this Framework.

Executive Summary

South Australia's Palliative Care Strategic Framework 2022-2027 has been developed in recognition of the need for a clear and consistent narrative that identifies our shared priorities and guides our collective efforts to improve palliative care services in South Australia. The Framework aligns our future actions with the available evidence and relevant national and state strategic policy drivers including:

- > The National Palliative Care Strategy 2018
- > The 2018 State Government Palliative Care Election Commitment
- > The South Australian Health and Wellbeing Strategy 2020-2025
- > South Australia's Plan for Ageing Well 2020-2025

Developed by the Department for Health and Wellbeing in partnership with the Statewide Palliative Care Clinical Network and under the guidance of a Project Board, the Framework explores some of the challenges and potential opportunities for improvement for South Australia, identifying:

- > a vision and goals for the palliative care service system in South Australia
- > four priority areas to focus our actions
- > specific actions that we will commit to over the next five years to shape the palliative care system we need so that more people can die well in South Australia
- > potential outcomes that we would like to see

A high-level overview of the Framework is presented on page 6.

FRAMEWORK PURPOSE					
This Framework has been developed in recognition of a need for a clear and consistent narrative that identifies our shared priorities and that guides our collective efforts to improve the palliative care service system in South Australia in alignment with the available evidence and relevant national and state strategic policy drivers.					
VISION					
All South Australians, their families and carers have access to and receive the best possible end of life and palliative care that places the person at the centre of care and supports them to live and die well in accordance with their individual needs, wishes, values and preferences.					
GOALS					
This Framework aligns with the 7 goals identified in the National Palliative Care Strategy 2018 :					
>	Understanding	People understand the benefits of palliative care, know where and how to access services, and are involved in decisions about their own care	>	Collaboration	Everyone works together to create a consistent experience of palliative care across care settings
>	Capability	Knowledge and practice of palliative care is embedded in all care settings	>	Investment	A skilled workforce and systems are in place to deliver palliative care in any setting
>	Access and Choice	People affected by life-limiting illnesses receive care that matches their needs and preferences	>	Data and Evidence	Robust data and a strong research agenda strengthen and improve palliative care
>	Accountability	Governance of the Framework drives action	>	Accountability	Governance of the Framework drives action
PRIORITIES	1. Increase community awareness, understanding and engagement with end of life matters	2. Improve access to generalist and specialist palliative care particularly for underserved populations	3. Enhance collaboration and coordination of palliative care	4. Improve palliative care data collection, monitoring and reporting	
ACTIONS	1. Develop a comprehensive Advance Care Planning program for South Australia	3. Develop a Palliative Care Services Plan for South Australia that delivers equitable access to palliative care and that meet the needs of the population across South Australia into the future	7. Identify and implement community-based service models that enhance and support cross sectoral collaboration and information sharing, seamless transition between care settings and after-hours service provision resources to support:	9. Contribute to the development and implementation of nationally consistent indicators and data collection systems to support capture of data regarding the provision of generalist and specialist palliative care throughout all of the settings where palliative care occurs	
	2. Support and enable Compassionate Communities initiatives that operate alongside clinical care in South Australia	4. Co-design a statewide palliative care model of care that describes an integrated system wide approach to person-centred palliative care service delivery and supports people to die according to their wishes, values, and preferences	8. Co-design patient pathways and supporting resources to support: a. early identification and referral of those who would benefit from palliative care or a palliative approach to care particularly at care transitions and in ED b. seamless coordination, navigation, collaboration and communication regarding palliative care across sectors and settings c. this includes continuing to adapt the existing palliative care HealthPathways to the South Australian context	10. Develop and implement a system wide approach to the collection, monitoring and reporting of data relating to palliative care in South Australia to support evaluation of outcomes and service improvement	
OUTCOMES	> People understand the benefits of palliative care, know where and how to access services, and are involved in decisions about their own care > Knowledge and practice of palliative care is embedded in all care settings	> People affected by life-limiting illnesses receive care that matches their needs and preferences > A skilled workforce and systems are in place to deliver palliative care 24/7 in any setting	> There is a consistent and coordinated experience of palliative care across care settings > People affected by life-limiting illnesses receive care that matches their needs and preferences	> Planning and delivery of palliative care in South Australia is developed and improved through the consistent collection, analysis and reporting of agreed palliative care information and data	

Introduction

Research and anecdote demonstrate all want to die a good death and for most, to die in the presence of trusted carers and loved ones. Whilst an idealistic generalised view of death is unhelpful, it is important to articulate what we as a society aspire to at the end of life.

A good death offers people dignity, choice, and support to address their physical, personal, social, and spiritual needs and provides comfort for the bereaved. To die well has been described as:

- > To know when death is coming, and to understand what can be expected
- > To be able to retain control of what happens
- > To be afforded dignity and privacy
- > To have choice over pain relief and other symptoms
- > To have choice regarding where death occurs (at home or elsewhere)
- > To have access to information and expertise of whatever kind is necessary
- > To have access to any spiritual or emotional support required
- > To have access to palliative care in any location, not only in hospital
- > To have choice regarding who is present and who shares the end
- > To be able to complete advance directives that ensure wishes are known and respected
- > To have time to say goodbye, and choice regarding other aspects of timing
- > To not have life prolonged pointlessly¹.

Despite the appeal of these statements, the institutionalisation of death, increasing levels of social isolation and cultural, social and psychological barriers to open conversations about death and dying mean that even though around 70% of deaths are expected due to a life-limiting illness, many people do not have a 'good death' and may die without reference to their hopes and wishes, beliefs or preferences.

It is also noted that whilst many of these elements of a good death may apply to infants, children, and young adults, the definition of a good death in children and young adults is less clearly defined.

There is a growing recognition amongst clinicians and community members that modern technologies (that can prolong life) do not always maintain or enhance the quality of the life being lived. This can be true for those dying at any age. Many people are now choosing to concentrate on the quality rather than the quantity of the remainder of their lives. Health services must accommodate these realities and identify people at end of life stage and clarify goals of care earlier as it can affect how, and potentially where, people die and the care they receive².

If we are to improve, we need:

- > more public awareness and discussion about the limits of health care at the end of life
- > to plan better to ensure that our values and preferences for the end of life are met
- > services for those dying of chronic illness that focus more on people's wishes to die in the place of their choice, understanding that this place may change according to life circumstances and across the life journey³
- > a skilled and supported generalist palliative care workforce
- > increased awareness among policymakers, health professionals and the public about what palliative care is and the benefits it can offer patients and health systems
- > increased awareness of cultural and social barriers, such as beliefs about death and dying and misconceptions about palliative care, such as that it is only for patients with cancer, or for the last weeks of life⁴
- > improved access to grief and bereavement support when needed, for families and carers.

This Framework responds to a need for a clear and consistent narrative to guide our collective efforts to improve the end of life experience for South Australians with a life-limiting illness. The Framework will align our efforts with:

- > what people with life-limiting illness and their families and carers say matters to them
- > the evidence regarding the need for and best practice approaches to palliative care
- > the vision, goals and priorities of the National Palliative Care Strategy (2018) and Implementation Plan (2020)
- > the vision and aims of the South Australian Palliative Care Clinical Network
- > the vision of South Australia's Plan for Ageing Well 2020-2025.

Importantly, the Framework identifies the significant effort already underway to achieve these things across the community and articulates the gaps and what remains to be done to bring this work together so that more people can die well.



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5.2 FRAMEWORK SCOPE

The scope of this Framework is inclusive of palliative care, end of life care, terminal care and bereavement care for children and adults with a life-limiting illness and their families, carers, and substitute decision makers.

The Framework applies across all of the settings where palliative care is provided and offers direction and advice for everyone working in the palliative care service system regardless of profession, or level of expertise or whether work is paid or unpaid. This includes those working in public or private health care settings, non-government organisations, aged care settings, other community settings, and other government departments who also support individuals who are approaching and reaching the end of life, their families and carers⁵.

5.3 FRAMEWORK DEVELOPMENT

This Framework was developed by SA Health in collaboration with the Palliative Care Clinical Network Steering Committee and a range of other palliative care stakeholders as part of a project completed between September 2020 and September 2021. The Framework is supported by a range of evidence. A summary of this evidence is provided in Appendix 1.

The voices of the wider community have been drawn from a Statewide Palliative Care workshop held in 2019 and a Palliative Care survey conducted in 2020. In addition, feedback on the framework was sought from the wider South Australian Community through the SA Government YourSAy platform and through targeted requests for feedback from key stakeholders. Membership of the Palliative Care Steering Committee and the Project Board can be found at Appendix 2.

5.4 TERMINOLOGY

In recognition of the range of different definitions available and to support a shared understanding, the intended use of a range of terminology is provided in the Glossary on page 22.

South Australia's Palliative Care Strategic Framework 2022-2027

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Framework Vision

All South Australians, their families and carers have access to and receive the best possible end of life and palliative care that places the person at the centre of care and supports them to live and die well in accordance with their individual needs, wishes, values and preferences.

7

Framework Goals

This Framework aligns with the goals identified in the National Palliative Care Strategy 2018:

- > **Investment** A skilled workforce and systems are in place to deliver palliative care in any setting
- > **Understanding** People understand the benefits of palliative care, know where and how to access services, and are involved in decisions about their own care
- > **Capability** Knowledge and practice of palliative care is embedded in all care settings
- > **Access and Choice** People affected by life-limiting illnesses receive care that matches their needs and preferences
- > **Collaboration** Everyone works together to create a consistent experience of palliative care across care settings
- > **Data and Evidence** Robust data and a strong research agenda strengthen and improve palliative care
- > **Accountability** Governance of the Framework drives action

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Framework Alignment

This framework is informed by and supports initiatives that align with the principles, evidence, values, and recommendations provided in the following key documents:

National

- > [KPMG Investing to save report – The economics of increased investment in palliative care in Australia 2020](#)
- > [Introducing Competition and Informed User Choice into Human Services: Reforms to Human Services, Productivity Commission Inquiry Report 2017](#)
- > [National Palliative Care Strategy 2018](#) and [Implementation Plan 2020](#)
- > [National Palliative Care Standards 5th edition \(2018\)](#)
- > [Palliative Care Services Development Guidelines and Paediatric Addendum \(2018\)](#)
- > [The National Consensus Statement: essential elements for safe and high-quality end of life care \(2015\)](#)
- > [National Consensus Statement; Essential elements for safe and high-quality paediatric end of life care 2016](#)
- > [National Framework for Advance Care Planning Documents Terminology, 2021](#)
- > [Exploratory Analysis of barriers to palliative care Summary Policy Paper 2019](#)
- > AIHW National Palliative Care and End of Life Care Information Priorities
- > [Final Report – Royal Commission into Aged Care Quality and Safety 2021](#)
- > [Commonwealth Aged Care Quality Standards 2020](#)

South Australia

- > [South Australian Health and Wellbeing Strategy 2020-2025](#)
- > [South Australia's Plan for Ageing Well 2020-2025](#)
- > [Vision and Aims of the Palliative Care Clinical Network Steering Committee](#)
- > [Palliative Care Needs in South Australia Report 2019](#)
- > [Carers Recognition Act 2005](#)

Framework Priorities

This framework identifies four priority areas that will help us to align our collective efforts with the goals of the National Palliative Care Strategy 2018 over the next 5 years. Under each of the priority areas the following information is presented:

- > statements from service users in our community to illustrate the need for action in this area
- > examples of some of the work that is already occurring to address this priority
- > a statement regarding our commitment to the actions we will take to address this priority drawing on the opportunities for improvement that have been outlined.

9.1 PRIORITY AREA 1

Increase community awareness, understanding and engagement with end of life matters

What we have heard from our community

"I don't think there is enough public education about what supports there are, I was astounded at how much assistance was available to help support mum in her home."

"I believe some staff need education, on the needs of not only the patient but also the family and what is palliative care."

"At the end we found the nursing staff seemed afraid to discuss the dying process with us; we forced the conversation in the end which allowed us to make choices about staying with him over his final few days."

"I wish we had asked for palliative care earlier; I think the term palliative care scared mum she saw this as the end rather than providing Dad with care for however long he had left."

"Education about what the term palliative care means may encourage others to take up the services available sooner."

"I want appropriate support for me and my loved ones when difficult conversations are being had and difficult decisions are being made."

"I want to be able to say what I want and have my decisions respected."

"I want to be able to choose where I spend my last days."

"I don't want to be transferred to hospital unnecessarily."

"Do people truly understand what palliative care is or do they think it's just some morphine in the last days?"

Some examples of what is currently happening in South Australia to increase community awareness, understanding and engagement with end of life matters:

- > An Advance Care Planning Oversight Group has been established to oversee the implementation of the Government's response to the Review of the Advance Care Directives Act 2013 (SA) by Professor Wendy Lacey.
- > The Department for Health and Wellbeing is partnering with the University of Adelaide/UniSA on an NHMRC project considering the barriers to Advance Care Directives particularly in vulnerable populations.
- > The My Life Decisions form is being piloted as an alternative to an ACD for those people who are unable to make an advance care directive due to lack of testamentary capacity. This provides supported decision making for people to indicate their wishes for care and at the end of life who otherwise would not be able to fill out an Advance Care Directive.
- > Compassionate Communities ideas are emerging in a number of areas in South Australia. Conversations to build grief and death literacy as well as galvanise community supports are being trialled in McLaren Vale and the City of Tea Tree Gully and with LGBTI+ communities.
- > Death Cafés are being held across SA in a number of local communities including Walkerville, Willunga, Barossa Valley, Regis Aged Care and Parafield Gardens. These Cafés are part of a global volunteer led movement where people are invited to gather in a café environment to discuss death. The objective is to increase awareness of death so that people can make the most of their finite lives. A Death Café is a group directed discussion with no agenda, objectives, or themes.
- > The Office for Ageing Well and Health Services Programs, is partnering with a range of local governments to develop sustainable peer-led models to support people complete Advance Care Directives.
- > The Paediatric Palliative Care Service is utilising the 'Voicing my Choices' Advance Care Planning guide to assist adolescents and young adults with expressing their end of life choices.
- > A range of current initiatives including the Primary Health Networks Enabling Choice for South Australians project, and the Comprehensive Palliative Care in Aged Care (CPCiAC) project include strategies aimed at increasing the number of people living in aged care facilities who have an Advance Care Directive.
- > The Adelaide Primary Health Network are implementing a project under the Greater Choice for At Home Palliative Care 2021-2025 measure which aims to improve palliative care coordination and improve access to the best palliative care at home.
- > There is increasing awareness and uptake of palliative care 'Needs Rounds' in residential aged care. Needs Rounds are monthly meetings where resident's palliative care needs are discussed. Residents with high symptom burden and greatest risk of dying without a plan in place are prioritised. Evidence shows that regular Needs Rounds result in better quality of death and dying for residents including reduced hospital admissions and less time in hospital and increased confidence and capability of staff to recognise and care for people who are dying⁶.

Our commitment

Learning from and building on the work that is already underway to increase community awareness, understanding and engagement with end of life matters, we will work collaboratively to:

1. Develop a comprehensive Advance Care Planning Program for South Australia that:
 - > clearly defines Advance Care Planning including consistent use of terms across government, health and aged care sectors that is consistent with the National Framework for Advance Care Planning Documents 2021⁷
 - > increases awareness and education across the broader system (health and community) regarding the benefits of Advance Care Planning
 - > improves timely uptake and cross sector sharing of completed advance care planning documents
 - > puts systems in place to identify whether a person has an advance care directive and substitute decision-maker and whether current documents are valid
 - > broadens access for supported decision making and end of life care planning especially in Residential Aged Care Facilities
 - > invests in training, resources, and infrastructure to support the development and uptake of Advance Care Planning tools and processes, with a focus on underserved populations and recognising the opportunity to utilise existing high-quality advance care planning resources
 - > identifies mechanisms for recording, monitoring, and reporting on the use advance care planning in South Australia including information about advance care directives and appointment of substitute decision-makers
 - > promotes the utilisation of existing platforms such as the Electronic Medical Record and My Health Record for sharing Advance Care Planning documentation
 - > identifies underpinning policy related to Advance Care Planning.

2. Support and enable Compassionate Communities initiatives that recognises diverse social and cultural expectations, values and needs and that operate alongside clinical care in South Australia to build and foster:

- > death, grief, and bereavement literacy
- > community capacity to provide culturally appropriate support for those who are dying and their family, carers, and substitute decision makers.

Expected outcomes

- > People in South Australia affected by life-limiting illness receive care in accordance with their physical, social, cultural, and spiritual needs, values, and preferences.
- > People understand the benefits of palliative care, know where and how to access services, and are involved in decisions about their own care at the end of life.
- > Knowledge and practice of palliative care is embedded in all care settings.
- > Increased preparedness for the death of a loved one arising from improved engagement with advance care planning.

9.2 PRIORITY AREA 2

Improve access to generalist and specialist palliative care particularly for underserved populations

What we have heard from our community

"I want services to match and anticipate my care needs."

"I want staff to be aware of and observe different cultural death and dying practices."

"I want my symptoms to be adequately managed, particularly pain."

"I want access to pastoral and spiritual care and other cultural practices."

"I want my general practitioner to be trained appropriately to provide end of life care."

"I want doctors not to offer or order futile, burdensome unwanted treatments, test and procedures."

"I want to have someone to call for advice and support 24 hours a day 7 days a week."

"I want to access services on the weekend to avoid the need for ambulance transfer to hospital."

"I want support to extend to my carers and other family members."

"There are not enough hospice beds, my mother died in a hospital bed and it was traumatic."

"General nurses and general practitioners can provide absolutely awesome general palliative care."

"I feel extremely positive about the benefits of community palliative care for both the recipient and all of the family members. It allowed him to die at home as he wished which has been a huge emotional benefit to those left behind."

"I felt the staff were very alone when it came to their decision-making regarding pain relief. There appeared to be no clinical person they could turn to for advice."

"We have no specialist palliative doctors in the region which sometimes means sub optimal care at the end of life."

Some examples of what is currently happening in South Australia to improve access to generalist and specialist palliative care particularly for underserved populations

- > A 'Palliative Care Needs in South Australia' report was completed by DHW in 2019, the report identifies the potential need for palliative care in South Australia across a range of population groups and illness trajectories.
- > Beginning in late 2019, Local Health Networks and SA Ambulance Service delivered a number of grant funded pilot projects to expand palliative care in the community. Projects included exploring innovative models of palliative care for underserved populations.
- > The Palliative Care Clinical Network is establishing an Aboriginal Advisory subgroup to advise on, and support initiatives aimed at improving access to culturally appropriate palliative care for Aboriginal and Torres Strait Islander people in South Australia.
- > South Australia is partnering with the Commonwealth to fund and deliver the Comprehensive Palliative Care in Aged Care project to improve palliative and end of life care for older people living in residential aged care. This work involves several current projects that will trial an innovative approach to delivering:

- > Hospice in aged care for state funded regional aged care facilities and multipurpose services with palliative care needs in the regional Local Health Networks
- > Hospice in Residential Aged Care Facilities for non-government aged care providers in metropolitan and regional areas
- > General Practitioner Palliative Care Shared Care in Aged Care program in the regional LHN's

Our commitment

Learning from and building on the significant work that is already underway to improve access to generalist and specialist palliative care for all South Australians, we will work collaboratively to:

- > Undertake Palliative Care Services Planning for South Australia that supports us to:
 - > meet the needs of our population both now and in the future
 - > realign health service delivery with changing patterns of need to make the most effective use of available resources
 - > address inequities in service provision so that all South Australians have access to generalist and specialist multidisciplinary care when required.
 - > consider alternative approaches to palliative care funding and service models that improve access to palliative care, equipment, and minor home modifications
 - > address palliative care workforce requirements across South Australia
 - > provide support for innovation, research and teaching
 - > align service delivery with the latest evidence
- > Co-design a statewide palliative care model of care that describes an integrated system wide approach to person-centred palliative care service delivery and supports us to:
 - > align service delivery with latest evidence
 - > introduce and offer culturally appropriate palliative care and supports to health care users and family/ carers early in diagnosis across the different illness trajectories so that they can make informed decisions about treatment options



- > deliver generalist and specialist palliative care in the community and support people to die in their place of choice
- > improve navigation of the palliative care system by ensuring seamless 24-hour support across SA for health care users, carers, and primary care providers
- > enhance palliative care services for alone and isolated people without support or social connections
- > provide appropriate, proactive, and timely information, education and support for family, carers and substitute decision-makers including training on practical aspects of home-based care
- > Develop and implement a system wide strategy for developing both the capacity, capability and sustainability of the workforce to deliver person-centred palliative care across South Australia and that supports the workforce to:
 - > understand and engage with end of life
 - > provide a palliative approach to care
 - > partner with specialist palliative care
 - > support people to die in their location of choice
- > Develop a comprehensive approach to grief and bereavement support provided as part of palliative care in South Australia.

Expected outcomes

- > An appropriately skilled, resourced, and distributed generalist and specialist palliative care workforce with the capability and capacity to deliver the advance care planning and palliative care services required by South Australians.
- > People in South Australia affected by life-limiting illnesses receive care that matches their physical, social, cultural, spiritual needs, values, and preferences.
- > Early identification and referral improve experience and outcomes for the bereaved.



9.3 PRIORITY AREA 3

Enhance collaboration and coordination

What we have heard from our community

"I recently looked after my 97-year-old mother in my home for 18 months until she died. It was a good death and the one she wanted but it took an extraordinary amount of research and work on my part, to access appropriate palliative care. In the end, it was a combination of resources and help from the GP, hospital and the support of family and a retired nurse friend that got my Mum across the line comfortably and peacefully. We are probably a good example of how you want palliative care to look ...but it does need to be so much easier for the main carer. We had all the Advanced Care Directive business in order but my goodness ... it took an extraordinary effort on my part to make it happen."

"There needs to be a lot more cooperation between services, the process needs streamlining."

"I don't want to have to repeat 'my story' multiple times."

"I want services to 'make my life better/easier'; not to be a source of stress."

"I want timely referrals to be made, and services to be coordinated."

"I want continuity of care including services to be provided by a minimum number of people."

"If I am dying, I want systems that 'kick into action' quickly to maximise my opportunity to go home or be cared for on an appropriate hospital ward/room (less clinical environment)."

"I don't want services to be interrupted because of the limitations of packages of care."

"If ongoing contact with palliative care through phone and some visits could have been maintained would have made us and her more informed and secure."

"Handover from hospital to home care was abysmal and traumatising for all involved."

"Following my wife's passing, Palliative Care were still supportive – they arranged for a grief counsellor to visit me and the 1.5 hours she spent with me was better than any other chat I have had with anyone."

"I want support available for carers, so they feel safe and prepared to take on care."

Some examples of what is currently happening in South Australia to enhance collaboration and coordination

- > Specialist palliative care services in the metropolitan area work to co-ordinate the care of palliative care patients with general practitioners, and SA community care providers.
- > Care co-ordination in rural areas is achieved through collaboration between community and specialist palliative care nurses, emergency departments, general practitioners, SAAS, local pharmacists, and allied health teams with support from metropolitan specialist palliative care teams. A range of effective locally developed procedures and pathways have been developed to support this including referral and triage processes and pathways for last days of life.

- > Discharge planners in private hospitals co-ordinate care of Palliative Care patients with Specialist Metropolitan Palliative Care Services and the Metropolitan Referral Unit (MRU) to help facilitate care at home on discharge from hospital.
- > The Paediatric Palliative Care Service has been developing a Statewide Perinatal Palliative Care Pathway that will foster a collaborative interdisciplinary approach between the primary specialities involved and will improve communications and standardise perinatal palliative care.
- > The SA Community Care provider panel delivers a range of end of life nursing care services in the community that aim to:
 - > support people to be cared for, and die, in their place of residence (home or residential aged care facility), if this is their wish, and enable their family/carer(s) to participate as they are able
 - > prevent avoidable hospital admissions; and
 - > enable early supported discharge where clinically safe to do so.
- > SA Ambulance Service provides care to patients who want to be treated with a palliative approach. All registered clinicians can commence treatment in line with articulated plans in a shared decision-making framework. Extended care and community paramedics can provide more comprehensive treatment in the home where this is the wishes of the patient and the family.
- > The Department for Health and Wellbeing is partnering with Palliative Care SA, GriefLink and Flinders University to further understand the scope and requirements of a comprehensive grief and bereavement approach for South Australia.
- > Wellbeing SA and the Primary Health Networks are currently localising a range of Palliative Care Health Pathways to support local clinicians to make the right decisions, together with patients, at the point of care including making requests to services in the local health system.
- > A number of lessons have been learned from the Northern Adelaide Local Health Network (NALHN) grant funded Palliative Care Pharmacist in Aged Care project that involved liaison between specialist palliative care pharmacists in NALHN and palliative

care pharmacists embedded in regional RACFs. This enabled dissemination of appropriate information and support to prepare for patients transitioning between care settings.

Our commitment

Learning from and building on the work that is already underway to enhance collaboration and coordination of palliative care service delivery, we will work collaboratively to:

- > Identify and implement community-based service models that:
 - > are informed by the latest evidence
 - > support seamless transition and information sharing between settings and for after-hours service provision
 - > address funding barriers that inhibit cross sectoral collaboration
 - > build the capacity of service providers to deliver care with support from specialist palliative care
 - > include interagency approaches to reduce the impact of social determinants on access to palliative care
 - > document agreed standards for community based palliative care service delivery.
- > Co-design patient pathways and resources to support:
 - > early identification and referral of those who would benefit from palliative care or a palliative approach to care particularly at care transitions and in ED
 - > seamless coordination, navigation, collaboration and communication of palliative care across sectors and settings
 - > this includes continuing to adapt the existing palliative care HealthPathways to the South Australian context.

Expected outcomes

- > There is a consistent and coordinated experience of palliative care across care settings.
- > People receive safe high-quality palliative care that is consistent with their values, preferences, needs and expectations.

9.4 PRIORITY AREA 4

Improve data collection, measurement, and reporting

Examples of what is currently happening in South Australia to improve data collection, measurement, and reporting

- > Preliminary mapping with adult specialist palliative care, general practice (including rural), SAAS and health care users has identified end-of life-pathways for four key diagnostic cohorts (cancer, solid organ failure, chronic neurological and dementia). These pathways identify broad end of life healthcare transitions in the last 12 months of life and provide a framework to guide future data collection.
- > The COVID-19 palliative care consumer, carer and clinician experience survey ran between September to December 2020 and explored the complexity of receiving and delivering palliative care during the year. Results of the survey have informed the development of this framework.
- > The Paediatric Specialist Palliative Care Service is working with a collaborative within Australia and New Zealand (PapCANZ) to develop the most appropriate framework to guide data collection for paediatric palliative care services throughout Australia and New Zealand.
- > The Registry of Senior Australians (ROSA) research partnership has conducted an evaluation informed by the National Palliative Care Information Priorities that examined factors around the uptake of palliative care in SA and Victoria. This report will provide valuable data about hospitalisation and ED presentations for people aged 65 years and over in the last 3 months of life, along with transitions between home, residential aged care ED, hospital, inpatient or specialist palliative care.
- > Participation in the Palliative Care Outcomes Collaboration (PCOC) by 17 community and 9 inpatient palliative care services to support improved patient and carer outcomes.

Our commitment

Learning from and building on the work that is already underway to improve data collection, measurement, and reporting, we will work collaboratively to:

- > Contribute to the development and implementation of nationally consistent indicators and data collection systems to support capture of data regarding the provision of generalist and specialist palliative care throughout all of the settings where palliative care occurs
- > Develop and implement a system wide approach to the collection, monitoring and reporting of data relating to palliative care in South Australia to support evaluation of outcomes and service improvement.

Expected outcomes

Planning and delivery of palliative care in South Australia is consistently developed and improved through the consistent collection, analysis and reporting of agreed palliative care information and data.

Next Steps and Action Plan

Responsibility for implementation of the actions identified in the Framework sits across a range of areas. The following table identifies responsibility and suggested timeframes for completion for each of the 10 actions recognising that achievement of each action will require a collaborative approach involving a range of partners within and outside of the health system.

Framework Actions	Responsible	Timeframes
1. Implement a comprehensive Advance Care Planning program for South Australia	Department for Health and Wellbeing (Health Services Programs)	Throughout the life of the Framework
2. Support and enable Compassionate Communities initiatives that can operate alongside clinical care in South Australia	Department for Health and Wellbeing (Office for Ageing Well, Health Services Programs) Statewide Palliative Care Clinical Network	Throughout the life of the Framework
3. Develop and implement a Palliative Care Services Plan for South Australia that delivers equitable access to palliative care and that meet the needs of the population across South Australia into the future	Department for Health and Wellbeing (System Design and Planning, Commissioning) Palliative Care Service Providers	Short-term
4. Co-design and implement a statewide palliative care model of care that describes an integrated system wide approach to person-centred palliative care service delivery and supports people to die according to their wishes, values, and preferences	Statewide Palliative Care Clinical Network Department for Health and Wellbeing (System Design and Planning, Commissioning) Palliative Care Service Providers	Short-term
5. Develop and implement a system wide strategy for developing the capacity, capability and sustainability of the workforce to deliver person-centred palliative care across South Australia and supports the workforce to: > understand and engage with end of life matters > provide a palliative approach to care > partner with specialist palliative care > support people to die in their location of choice	Department for Health and Wellbeing Statewide Palliative Care Clinical Network Palliative care service providers	Medium-term

6. Develop and implement a comprehensive approach to grief and bereavement support provided as part of palliative care in South Australia	Statewide Palliative Care Clinical Network Department for Health and Wellbeing Palliative care service providers	Medium-term
7. Identify and implement community-based palliative and end of life care service models that enhance and support cross sectoral collaboration and information sharing, seamless transition between care settings and after-hours service provision	Department for Health Wellbeing (Health Services Programs) Wellbeing SA Palliative care service providers	Throughout the life of the Framework
8. Co-design patient pathways and resources to support: > early identification and referral of those who would benefit from palliative care or a palliative approach to care particularly at care transitions and in ED > seamless coordination, navigation, collaboration and communication of palliative care across sectors and settings > This includes continuing to adapt the existing Palliative Care HealthPathways to the South Australian context	Statewide Palliative Care Clinical Network Department for Health and Wellbeing (Health Services Programs) Wellbeing SA	Medium term
9. Contribute to the development and implementation of nationally consistent indicators and data collection systems to support capture of data regarding the provision of generalist and specialist palliative care throughout all of the settings where palliative care occurs	Statewide Palliative Care Clinical Network	Throughout life of the Framework
10. Develop and implement a system wide approach to the collection, monitoring and reporting of data relating to palliative care in South Australia to support research, evaluation of outcomes and service improvement	Department for Health and Wellbeing (Data and Reporting Services and Health Services Programs, System Design and Planning) Statewide Palliative Care Clinical Network Palliative care service providers	Long-term

Short term: 12-18 months

Medium term: 18 months – 3 years

Long term: 3-5 years

Glossary

The following definitions are provided to guide the reader recognising that there are a range of other definitions available.

Advance Care Planning

A process of planning for future health and personal care whereby the person's values, beliefs and preferences are made known to guide decision-making at a future time when that person cannot make or communicate their decisions. Registered and non-registered health practitioners have a role in advance care planning and require capability to facilitate these conversations effectively.

The National Quality Standards for aged care, general practice and health services all promote advance care planning. Individuals can also choose to engage in advance care planning with other non-health practitioners, such as friends or family⁸.

Advance care plan

Documents that capture an individual's beliefs, values and preferences in relation to future care decisions, but may not meet the requirements for statutory or common law recognition due to the person's lack of competency, insufficient decision-making capacity or lack of formalities (such as inadequate person identification, signature and date).

An Advance Care Plan for a non-competent person is often very helpful in providing information for substitute decision-makers and health practitioners and may guide care decisions but are not legally binding. An Advance Care Plan may be oral or written, with written being preferred. A substitute decision-maker named in an Advance Care Plan is not a statutory appointment⁹.

Advance Care Directives

Advance Care Directives are voluntary, person-led documents completed and signed by a competent person that focus on an individual's values and preferences for future care decisions, including their preferred outcomes and care and can include binding refusals of healthcare. Advance Care Directives are recognised by specific legislation (statutory) or under common law (non-statutory). They come into effect when an individual loses decision-making capacity.

Advance Care Directives can also appoint substitute decision-makers who can make decisions about healthcare, living arrangements and other personal matters on the individual's behalf. Advance Care Directives are focused on the future care of a person, not on the management of his or her assets. Common law (non-statutory) Advance Care Directive: a structured document that is completed and signed by a competent adult and that is not a legislated statutory document. This includes:

- > a document completed and signed by a competent person in a jurisdiction that does not have legislation authorising an Advance Care Directive regarding preferences for care (that is, New South Wales and Tasmania)
- > an instruction or directive completed and signed by a competent person, in a jurisdiction with advance care planning legislation, but where the document does not comply with the requirements set out in this legislation and is recognised instead by common law¹⁰.

A Statutory Advance Care Directive is a signed document that complies with the requirements set out by a jurisdiction's legislation.

Bereavement

Bereavement refers to the event of death of a person with whom there has been an enduring relationship and often includes a period of grief or mourning, especially during and after the death of a loved one.

Carer

In this document, the term 'carer' refers to people who provide unpaid care and support to family members and friends who have a terminal illness. Caring may include help and support with any of the daily activities of living of the person being cared for. It may include physical and personal care such as dressing, lifting, showering, toileting, feeding or providing transport. In addition, carers can be responsible for the management of medications, and also provide emotional and social support.

Caring may also involve help with organising and attending appointments, banking, and dealing with emergencies and, when authorised to do so, being a substitute decision-maker.

Carers are an integral part of Australia's health system and are the foundation of our aged, disability, palliative and community care systems¹¹.

End of life care

Includes physical, spiritual, and psychosocial assessment, and care and treatment for people with a life-limiting illness 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.

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 events¹².

Family

Includes people identified by the person as family and may include people who are biologically related and people who joined the family through marriage or other relationships, as well as family of choice and friends¹³.

Generalist Palliative Care

Clinical management and care coordination including assessment, triage, and referral, using a palliative approach to manage symptoms associated with a life-limiting illness and/or end of life care.

Generalist Palliative Care services should have formal links with a Specialist Palliative Care providers for purposes of referral, consultation, and access to specialist care as necessary.

Generalist Palliative Care may be provided by all health care workers including but not limited to general medical practitioners, nurse practitioners, registered nurses, generalist community nurses, aboriginal health workers, allied health staff and medical specialists from other disciplines¹⁴.

Integrated care

Integrated care entails provision of seamless, effective, and efficient care. The care given reflects the whole of a person's health needs from prevention through to end of life care; across both physical and mental health; and in partnership with the individual, their family, and carers. Integrated care requires greater focus on a person's needs; better communication and connectivity between healthcare providers in primary care, community, and hospital settings; and better access to community-based services close to home¹⁵.

Life-limiting illness

A person with life-limiting illness may die prematurely. This term is often used for people living with a chronic condition that may seem life-threatening but can continue for many years or even decades¹⁶.

Palliative Care

Palliative care is a person-centred approach that places those affected by life-limiting illness at the heart of their care surrounded by their community and support services¹⁷. The World Health Organisation¹⁸ describes palliative care as an approach that improves the quality of life of patients (adults and children) and their families who are facing the problems associated with life-threatening 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.

- > 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.¹⁹

Whilst often described as distinct or separate periods, end of life care, terminal care and grief and bereavement care are all terms used to describe the palliative care journey which may occur over a period of days, months, or years. For the purposes of this framework and to reinforce the continuum of care, these terms will be included under the umbrella term 'palliative care' throughout this document.

Person-centred care

An approach to the planning, delivery and evaluation of health care that is founded in mutually beneficial partnerships among clinicians and people receiving care. Person-centred care is respectful of, and responsive to, the preferences, needs and values of the care recipient and health care users.²⁰

Specialist palliative care

Services provided by clinicians who have advanced training in palliative care. The role of specialist palliative care services includes providing direct care to patients with complex palliative care needs, and providing consultation services to support, advise and educate non-specialist clinicians who are providing palliative care.²¹

Substitute decision-maker

A collective term for a person appointed or identified by law to make substitute decision(s) on behalf of a person whose decision-making is impaired. A substitute decision-maker may be appointed by the person, appointed for (on behalf of) the person, or identified as the default decision-maker within legislation. Substitute decision-makers listed in Advance Care Directives are statutory appointments. Substitute decision makers must carry out their role in accordance with the Advance Care Directives Guidelines for substitute decision-makers.²²



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Appendices

APPENDIX 1.

Background information to support the development of the Palliative Care Strategic Framework

Who palliative care is for

Palliative care is for people of any age that have a life-limiting illness that cannot be cured regardless of the length of time until death. Palliative care assists people with life-limiting illnesses to manage symptoms and improve quality of life. For some people, palliative care may be beneficial from the time of diagnosis of a life-limiting illness and palliative care can be given alongside treatments given by other doctors.²³

Palliative care is most effective when considered early in the course of a life-limiting illness and can be delivered wherever a person chooses. Early palliative care not only improves quality of life for patients but also reduces unnecessary hospitalisations and use of health-care services.²⁴

Throughout this document the terms people, person, patient, client or resident may be used interchangeably when referring to those who are or may be living with a life-limiting illness.

Where palliative care occurs

Palliative care is delivered in almost all settings where health care is provided. This includes:

- > At home
- > In hospital
- > In a hospice
- > In residential and community aged care
- > In other community settings
- > In general practices²⁵

People who are involved in palliative care

The National Palliative Care Strategy 2018 acknowledges that ‘everyone has a role to play in palliative care’. Palliative care is provided by unpaid carers such as family, friends and neighbours, volunteers from community support groups or spiritual and cultural groups. Palliative care is also provided by workers in residential aged care and community-based services as well as by a range of health professionals. These are discussed in further detail below:

Families and carers

Family and other carers provide an essential component of palliative care, often provide the majority of care for a person whose life is limited by illness and can be both providers and recipients of care. In response to their significant contribution, it is vital to provide services that actively support the role of families and carers²⁶. The use of the terms family and carer in this Framework are defined in the Glossary on page 22.

The South Australian *Carers Recognition Act 2005* acknowledges the valuable role of carers in supporting those they care for within the community and requires the state government to be aware of carers’ needs and provide services that reflect the Act and principles of the Carers Charter.

Palliative Care Australia outlines a series of expectations regarding the type and range of services required to support family and carers of people living with life-limiting illness that should be included in palliative care service planning and delivery:

- > Information, education and support for families and carers including training on practical aspects of home-based care
- > After-hours access to support
- > Equipment and medical supplies for home-based care
- > Respite care
- > Grief and bereavement support²⁷

Generalist Palliative Care

The medical management and coordination of care for people living with a life-limiting illness may be undertaken by a wide range of health professionals including general practitioners, geriatricians, general physicians, oncologists, paediatricians, renal specialists, cardiologists, endocrinologists and other specialists across a range of healthcare settings. Other essential team members will include nurses, allied health professionals and pharmacists.

These health professionals are ‘generalists’ with respect to palliative care, notwithstanding that many of them may be specialists in their own discipline. Whilst not all ‘generalists’ see palliative care as their business, all health professionals who provide care to people living with a life-limiting illness, their families and carers should have minimum core competencies in the provision of palliative care.²⁸

Specialist Palliative Care

People with more complex needs should be able to access care provided by specialist palliative care services comprising multidisciplinary teams with specialised skills, competencies, experience, and training in palliative care. This type of care is referred to as ‘specialist palliative care’.²⁹

Specialist palliative services can provide vital consultation liaison services to support, advise and educate non-specialist teams to provide palliative care to people with more complex needs and should be integrated into acute, sub-acute, primary health care, community and home-based care.³⁰ Specialist palliative care support should be available 24 hours per day 7 days per week to enable family, carers and generalist palliative care staff to deliver safe and high quality palliative care.

Framework drivers

Australian Government Productivity Commission Report 2017

A 2017 report by the Australian Government Productivity Commission³¹ found that tens of thousands of the people who die each year in Australia have a medical condition that would be amenable to palliative care, would prefer to die at home and have family and friends who are able to provide the considerable support needed to remain in their homes as they approach the end of life.

Despite this clear preference, they cannot access the community-based palliative care that would enable them to be cared for and to die in their preferred place. The report found that more community-based palliative care services are needed to enable more people who wish to die at home to do so and to increase the availability of community-based palliative care recommended that State and Territory Governments:

- > assess the need for additional community-based palliative care services,
- > design services to address identified gaps in service provision,
- > establish standards for community-based palliative care services; and
- > fund the provision of those services for people who wish to and are able to die at home.

2018 State Government palliative care election commitment

The South Australian State Government is committed to improving and diversifying palliative care options and increasing access to services across South Australia for those who need it most. In 2018 an election commitment was made to deliver renewed palliative care services through the establishment of a statewide clinical network for palliative care; funding to extend community outreach palliative care services from the current weekday service to provide a 24-hour service, 7 days a week; undertake an audit of unmet need for palliative care services as well as the co-design and delivery of a new Palliative Care Services Plan involving:

- > Health care users and carers
- > Health professionals
- > Peak bodies such as Palliative Care SA
- > Local Health Network Boards

National Palliative Care Strategy 2018 and Implementation Plan 2020

Australia's current National Palliative Care Strategy lays out a clear vision for palliative care in Australia that is intended to be used by all Australian Governments to guide the improvement of palliative care across Australia so that people affected by life-limiting illnesses get the care they need to live, die and grieve well. This Framework provides a roadmap for the delivery of palliative care in South Australia that aligns with the shared direction of the National Palliative Care Strategy 2018.

Royal Commission into Aged Care Quality and Safety

Around half of all deaths of Australians aged 70 and over occur in residential aged care.³² People residing in residential aged care should receive specialist palliative care services where required however this is currently not universally available. The Royal Commission into Aged Care Quality and Safety's Final Report has highlighted deficiencies in palliative care in aged care and has made a number of findings and recommendations in relation to Palliative Care that should have positive implications for people with life-limiting illnesses living in aged care settings and implications for other palliative care providers. These include:

- > review of the Aged Care Quality Standards to require residential aged care providers to deliver high quality palliative care in residential aged care, including staff capacity (number, skill, and type), processes and clinical governance for recognising deterioration and dying
- > funding models that address both the staff / resident ratios and the complexity of care and support required so that adequately trained staff can support palliative and end of life care
- > a trained workforce in dementia care and palliative care by 1 July 2022
- > improved access to aged care services for Aboriginal people, CALD communities and people living in rural and remote South Australia
- > improved access to Specialist Palliative Care and generalist health care to support older Australians to die in their chosen place
- > a greater focus upon home care.

This framework recognises that changes to national aged care policy and funding have an impact on palliative care service delivery for older people who access aged care services or require palliative care services in residential facilities and in the home.

SA Health and Wellbeing Strategy 2020-2025

The SA Health and Wellbeing Strategy recognised the need to assist individuals and families to adapt to changes in their health and wellbeing overtime, including at the end of life. Expanding and enhancing specialist palliative care and end of life service as part of an integrated ambulatory model of care is identified as a strategy deliverable. This document provides the framework for suitable models of care to be developed in alignment with current evidence and policy.

South Australia's Plan for Ageing Well 2020-2025

South Australia's Plan for Ageing Well sets out the Government and community's vision for ageing well in South Australia, and was informed by the needs, wants and aspirations of a diverse range of older South Australians and stakeholders. Importantly it sets out a vision where: *South Australia is a healthy, connected equitable and sustainable community, which takes a whole of life approach that fosters many years of living well, and supports us to die with dignity in line with our wishes.* The Plan states that we need to support people to have a death in line with their wishes, open up conversations about end of life choices, the limits of health care, what we want for our end of life and how to plan better is needed.

SA Health Palliative Care Services Plan 2009-2016

South Australia's Palliative Care Services Plan expired in 2016. In 2018 the Health Performance Council (HPC) conducted a revisit review of the Plan, in addition a statistical addendum to the review was completed in 2019 to provide additional information regarding long term trends and outcomes in public hospital utilisation in the months before a person death in South Australia.

These two reports provide a range of findings and detailed advice that offer evidence and analysis that the HPC suggests will be useful in ensuring future strategies lead to initiatives with measurable, evidence-based health and wellbeing outcomes for South Australians across the state. In summary recommendations made in the 2018 revisit review are as follows:

- > Develop a strategic and statewide model of care
- > Embed person-centred care into the model of care
- > Ensure equal access to care for all South Australians
- > Improve health and wellbeing outcomes
- > Expand care in the community
- > Support paediatric palliative care
- > Ensure high-quality and consistent care
- > Develop a workforce that is expert, responsive and culturally mature
- > Establish effective governance and accountability mechanisms
- > Develop and implement policy that is evidence-based.²³

Palliative care needs in South Australia

In response to the 2018 State Government Palliative Care election commitment, the Department for Health and Wellbeing (DHW) developed a [Palliative Care Needs in South Australia 2019](#) report to provide an overview of the needs for palliative care across a range of populations and illness trajectories in South Australia. The report notes that there are approximately 14,500 deaths annually in South Australia and it has been estimated that the percentage of deaths that could benefit from some form of palliative care service ranges from 41 to 72% or 5,851 to 10,452 people respectively.

Whilst palliative care is not just for older people and palliative care is different for diverse age groups, 70% of those in need of palliative care are aged over 60 years of age.³⁴ We know that our population is ageing and the number of older Australians (over 65) is expected to continue to grow to 20% by 2037 from 15% in 2017.³⁵ An ageing population means more people living with life-limiting illness for longer with significant implications for investment in and planning of palliative care service delivery.

The majority of adults in need of palliative care have chronic diseases such as cardiovascular diseases (38.5%), cancer (34%), chronic respiratory diseases (10.3%) and diabetes (4.6%). Many other conditions may require palliative care including dementia, kidney failure, chronic liver disease, rheumatoid arthritis, progressive neurological diseases, and congenital anomalies.³⁶

The number of children in South Australia requiring palliative care is estimated to be between 860 to 1,310 with around a third of those having more complex needs.³⁷ Palliative care for children differs from palliative care for adults across the dimensions of diagnosis, symptoms, age range, the inherent burden of care and impact on families and communities of a child's death. More than 70% of the 50 new referrals per year to the SA paediatric palliative care service are for a range of rare, non-cancer life-limiting conditions that can be broadly grouped into metabolic conditions, neurological disease, and congenital conditions (including cardiac disease).



Different illness trajectories and levels of complexity

Historically, palliative care was provided in the last few weeks or days of life and was often associated with cancer. It is increasingly recognised however that the way we deliver palliative care needs to adapt to a range of different and less easily defined illness trajectories.

In order to overcome the ‘one size fits all model; an attempt has been made to categorise the population potentially in need of palliative care into three “end of life trajectories”.³⁹ These trajectories (see Figure 1 and Table 1 below) show that people following different trajectories benefit from specific clinical approaches at the end of life, in different time frames, provided through different health-care services or professionals.³⁹

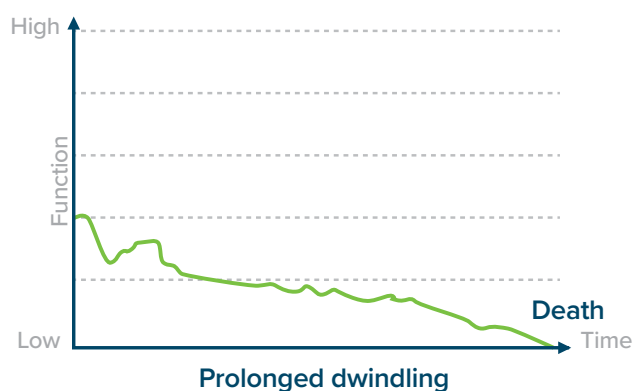
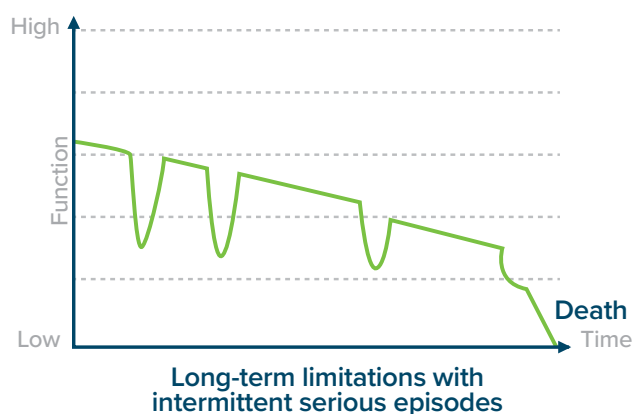
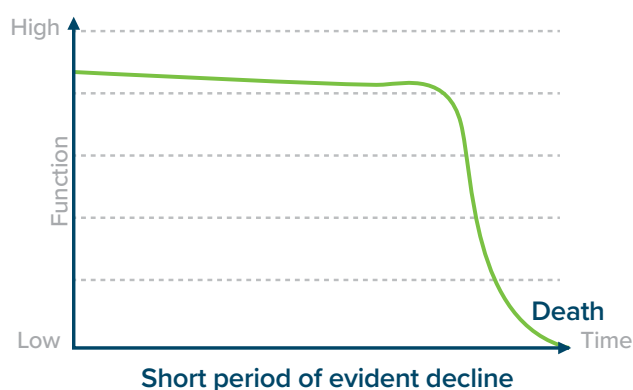


Figure 1 Illness trajectories and palliative care (adapted from¹⁷)

Trajectory 1 – 27% of all deaths (3,895 people)

Short period of evident decline characterised by a long maintenance of good body functions but with a steady progression and rapid decline leading to the clear terminal phase.

Includes: most cancer diagnoses

Trajectory 2 – 28% of all deaths (4,039 people)

Long term limitations with intermittent serious episodes characterised by a gradual decline but broken up by acute episodes of illness and with an unexpected timing of death.

Includes: Cardiovascular diseases, diabetes, Chronic Obstructive Pulmonary Disease (COPD), kidney failure, cirrhosis of the liver, HIV/AIDS, rheumatoid arthritis, and drug-resistant tuberculosis

Trajectory 3 – 13% of all deaths (1,875 people)

Prolonged dwindling characterised by long-term, prolonged, and progressive decline.

Includes: Dementias and Alzheimer’s disease, Parkinson’s disease, and multiple sclerosis.

Table 1 Illness trajectories and palliative care (adapted from¹⁷)

Of the 14,426 deaths registered in SA for 2017, an estimated 9,809 deaths (68%) were predictable and would have aligned to one of these trajectories and thus would have benefited from generalist or specialist palliative care services (Table 1)⁴⁰.

Based on the three illness trajectories outlined above, Palliative Care Australia⁴¹ has developed a model that conceptualises the population of people living with a life-limiting illness as falling within three broad groups based on the complexity of their needs for palliative care which can vary over time increasing or decreasing in complexity.

Suitable models of care should be developed to meet the needs of people based on these different illness trajectories and different complexities of need for palliative care.

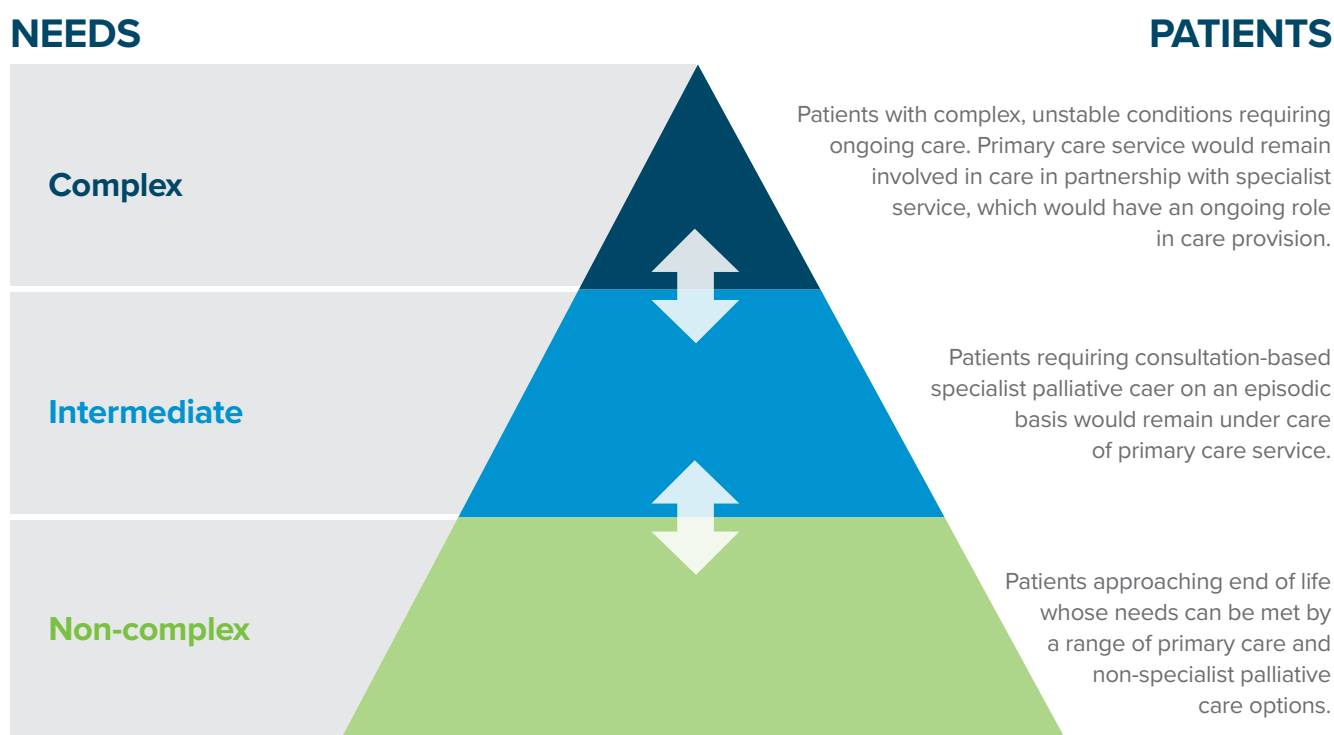


Figure 2 Different levels of complexity require a different service response (NSW ACI)

Current challenges and opportunities

There is a need to improve community understanding, awareness, and engagement with end of life matters

Much planning and discussion occurs prior to life's important events and significant transitions. Events such as births, birthdays, weddings, graduations, funerals and moving to a new house require and receive significant and careful thought and collective effort to ensure that they reflect our unique personal, family, and cultural wishes and expectations.

For a range of reasons, dying, one of the most significant life events, is often poorly planned or not planned for at all. When we fail to plan for death, significant distress, anxiety, and grief can be caused as people with a life-limiting illness and their families and carers don't know or understand their options and their wishes are not discussed or recorded.

In order to prepare and plan for one's own or another person's death a level of 'death literacy' is required. Death literacy is the knowledge and practical skills that allow someone to make choices around end of life options.

People, and communities, with high levels of death literacy have context-specific knowledge about death and dying processes and the ability to put that knowledge into practice.⁴² The act of end of life caregiving provides a deeply personal connection to death and dying and is a catalyst to developing 'death literacy'.

For our community to develop its capacity to support the caring of those at end of life, it needs knowledge, experiences of death and dying, a sense of empowerment and supportive social structures⁴³ that recognise that caring for those who are dying is a shared responsibility. Greater community 'death literacy' can lead to more thought being given to end of life matters.

Opportunities to build death literacy and increase engagement with end of life matters include the Compassionate Communities approach and education, promotion, and support for Advance Care Planning:

The Compassionate Community

Compassionate Communities is a grounds-up approach that recognises the important role of the community in the long and complex task of providing quality healthcare and psychosocial support at the end of life. Compassionate Communities are led by the communities themselves, whether they be cities, local council areas, workplaces, church groups, schools, or other types of social networks.

The Compassionate Communities approach provides an opportunity for groups within the community to provide wrap around support to someone who is dying even though they may not require much clinical care. Research indicates that there are many potential benefits associated with Compassionate Communities including benefits for people at end of life, their families and carers, communities, health and social care professionals, businesses and health and social care systems.

The capacity of Compassionate Communities can be enhanced through various community development initiatives such as:

- > Development and dissemination of resources and information regarding examples of successful compassionate communities' programs and activities.
- > Community forums such as conferences, workshops, or public meetings to support dissemination of information and provide opportunities for community planning.
- > Establishing compassionate communities' linkages with other community development programs.
- > Promotion of the compassionate community through traditional and online media forums ranging from city wide programs through to local acts of practical support and kindness.
- > Formalising Compassionate Communities networks between local government areas to harness available resources
- > Fostering of death literacy widely across the community as well as by providing communities with leadership, coordination, and resources.

Advance Care Planning

Advance Care Planning is a process of planning for future health and personal care whereby a person's values, beliefs and preferences are made known to guide decision-making at a future time when that person cannot make or communicate their decisions.⁴⁴

It is generally agreed that Advance Care Planning, as with the completion of a Will and enduring power of attorney can be done at any time, but should be offered early in a person's life-limiting illness as it provides an opportunity for people to think about, discuss and document their preferences and values with respect to future healthcare and lifestyle and appoint a substitute decision-maker, if they choose. Advance Care Planning benefits everyone including the person, their family, carers, substitute decision-makers and health professionals and can help to:

- > ensure people receive the care they actually want
- > improve ongoing and end of life care, along with personal and family satisfaction
- > reduce anxiety, depression, stress and increase satisfaction with care
- > reduce unnecessary transfers to acute care and unwanted treatment
- > identify and appoint a substitute decision-maker to make medical treatment decisions on the person's behalf that would reflect the person's values and preferences in the event the person loses decision-making capacity.

Advance Care Planning for people with Dementia

Advance Care Planning is of particular importance for the growing numbers of older people with dementia who face significant challenges planning for future care and who may receive limited access to palliative care services, inappropriate use of antipsychotic medications and potentially futile treatments including hospitalisation, intravenous therapy, and other invasive measures in the absence of clearly documented values and preferences for medical treatment and care.

Ideally Advance Care Planning conversations begin before a diagnosis of dementia or as early as possible to ensure that people with dementia can be meaningfully involved and supported in decision making. Advance Care Planning has been associated with significant reduction in rates of hospitalisation, increased use of hospice services as well as reducing stress anxiety and depression in family members.⁴⁶

Supported decision making

People with a disability have a right to make decisions about their lives and what healthcare they receive and to be supported to make their own decisions. In South Australia, the My Life Decisions form is being piloted as an alternative to an Advance Care Directive for those people who are unable to make an advance care directive due to lack of testamentary capacity. This provides a process for supported decision making regarding wishes for care at the end of life for people who otherwise would not be able to fill out an Advance Care Directive.

Advance Care Planning for People who are under Guardianship

People with impaired decision-making capacity may have a guardian appointed by the South Australian Civil and Administrative Tribunal (SACAT). A guardian has legal authority to make substitute decisions for people who have been assessed and found to be impaired decision-making capacity. A guardian will make decisions around consent to medical treatment, accommodation, and decisions about provision of support services.

To ensure that people with impaired decision making can play an active part in considering or influencing their transition to palliative care and how services will be provided once they are nearing end of life, Office for the Public Advocate recommends that decision making at the time of end of life planning for people under guardianship should incorporate the following:

- > Effective communication between medical teams, disability/aged care providers and guardians
- > Clear and consistent understanding and recording or reasons for change of care or transition to palliative care
- > Decisions are guided by client wishes and guardians are consulted to ensure that this occurs
- > Quality of life is considered unique to a person and decisions should not be based on assumptions related to disability diagnosis

Prevalence of Advance Care Planning

There is limited data on uptake of Advance Care Planning across the community however a 2019 study⁴⁸ by Advance Care Planning Australia into prevalence of Advance Care Planning in Australia for over 65's found that in South Australia around 40% of those surveyed (n=402) had an advance care directive compared to 25% nationally with almost 50% of those in residential aged care having an Advance Care Directive in place compared to 38% nationally. Whilst these results are promising there is much to be done to increase the number of people engaging in Advance Care Planning.

Barriers to Advance Care Planning

A significant barrier to Advance Care Planning is lack of clinician and community awareness, skills, support, or comfort in initiating and engaging in conversations about Advance Care Planning. Whilst standards of care across our system are high, family, carers and healthcare workers need awareness, training, and support to engage in and facilitate culturally safe conversations about the goals of treatment for a person with a life-limiting illness.

The National Palliative Care Strategy Implementation Plan 2020, identifies the following priorities to support us to increase awareness of and uptake of Advance Care Planning:

- > Raising awareness of the need and mechanisms for Advance Care Planning
- > Investing in training resources and infrastructure to support the development and uptake of Advance Care Planning tools and processes with a focus on underserved populations
- > Developing and implementing mechanisms for recording, monitoring, and reporting on the use of advance care plans.

Existing service orientation and arrangements can mean that access to quality palliative care for some populations is limited.

The Palliative Care Needs in South Australia 2019 report, identified that access to palliative care services is inadequate and inequitable across South Australia.⁴⁹ Some populations have limited or no access to services and where available, services may be inappropriate to their physical, social, cultural and spiritual needs. These populations include:

- > Aboriginal and Torres Strait Islander people
- > people living with disability
- > people living in rural and remote areas
- > people living in residential aged care facilities
- > people living in supported accommodation
- > people from culturally and linguistically diverse communities
- > refugees
- > people living with a mental illness
- > people living with dementia
- > people experiencing homelessness
- > people who live in prison
- > children with life-limiting conditions
- > people who identify as LGBTQI+
- > care leavers and people affected by forced adoption
- > veterans

A recent study supported by Australian Government Department of Health¹⁴ exploring barriers to palliative care for people from underserved populations has provided useful insight into the particular barriers faced by each of these groups. Statements collected from a range of people during this study are illustrative:

“If you have only seen negative experiences, you may be frightened of palliative care’ (person with disability).”⁵⁰

“I’m not good at communicating so I haven’t spoken about my wishes’ (person with disability).”²⁴

“If we talk about [death], someone will think “you want me to die!”” (Vietnamese community member).”⁵¹

“Indians, and especially women, are very reserved and hesitate to talk about sensitive topics even within the family, let alone in public within the community or more broadly. They are very sensitive to issues that have stigma attached to them or the potential to bring shame to family’ (Indian community member).”²⁵

“Our spiritual and cultural values are important in all respects: the care we receive, the food, music, our sense of community. If these aren’t available, that’s a barrier’ (Indian community member).”²⁵

“How do you say ‘Parkinson’s’ in Portuguese? The words don’t necessarily translate’ (Portuguese community member).”²⁵

“It’s very difficult to talk about or be around people who are dying. I’ve seen that much death’ (Aboriginal community member).”⁵²

“It is too small to have more than one family member stay in, but often six to eight kin would wish to be with the dying person’ (Aboriginal community member).”²⁶

“Many people going into aged care go back into the closet, for fear of how they’ll be treated’ (LGBTI community member).”⁵³

“It is a big issue that family of choice is not recognised’ (LGBTI community member).”²⁷

“Show people respect and they show it back to you; it’s important to have respect at end of life’ (person experiencing homelessness).”²⁸

The study identified a number of common barriers relevant to all under-served population groups and went on to identify the key facilitators and underlying enablers of quality palliative care for these groups. These are presented in figures 3 and 4.

In addition, the National Palliative Care Strategy Implementation Plan 2020 identifies the following priorities to support us to improve access to palliative care particularly for underserved populations:

- > Promoting consistent messaging to build patient, family and care provider understanding of the benefits and need for palliative care
- > Understanding the unmet need and gaps in service provision and likely demand for palliative care in the future
- > Identifying workforce development initiatives such as staff attraction and retention strategies and ongoing education and training for the generalist and specialist palliative care workforce
- > Identifying and implementing service models that improve access to palliative care including utilisation of technology
- > Implementing strategies for increasing access to palliative care for underserved populations
- > Increasing support for carers from diagnosis through to death and into bereavement
- > Inclusion of people affected by life-limiting illness in the planning delivery and evaluation of services.

Universal and common barriers to quality palliative care for people from under-served populations

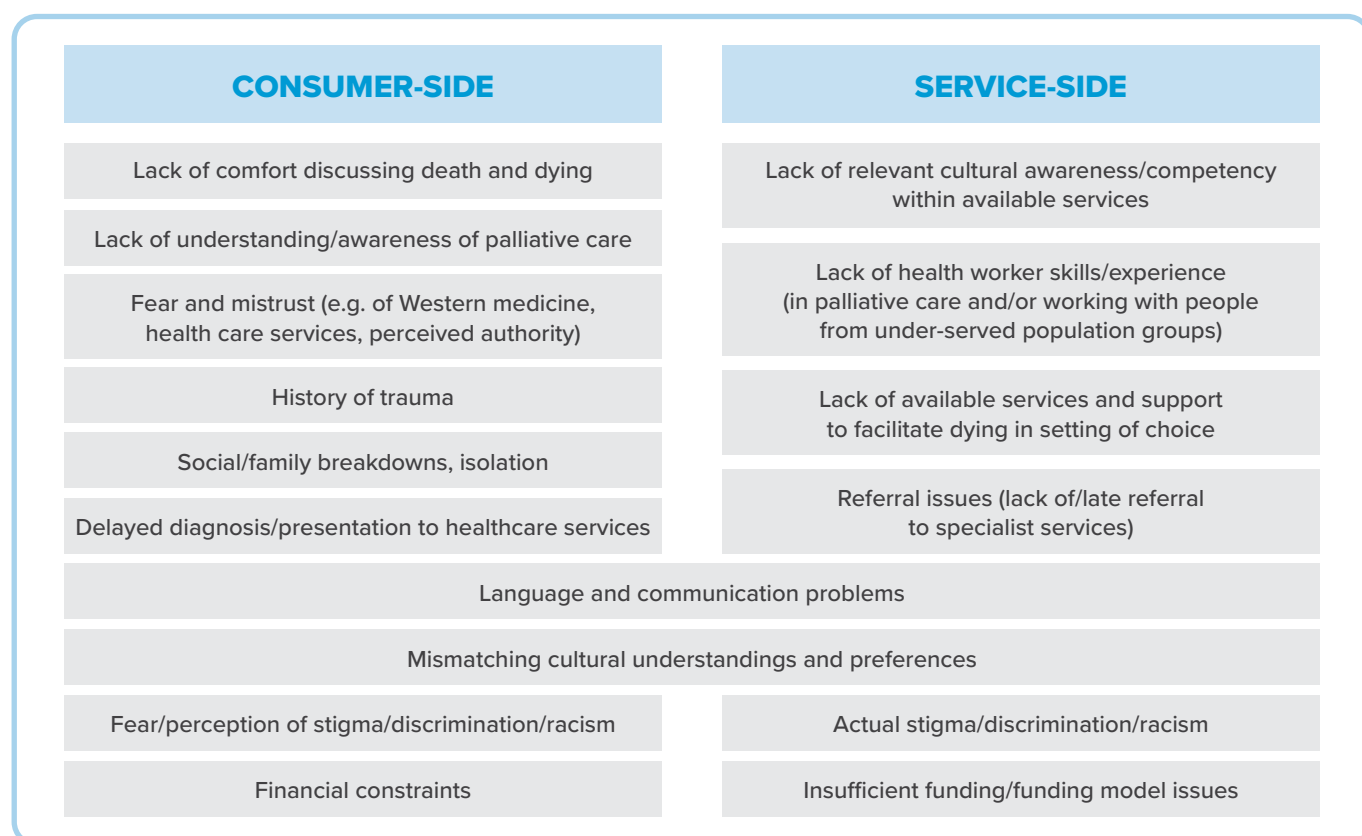


Figure 3 Barriers to palliative care for underserved populations²⁶

Facilitators and underpinning enablers of quality palliative care

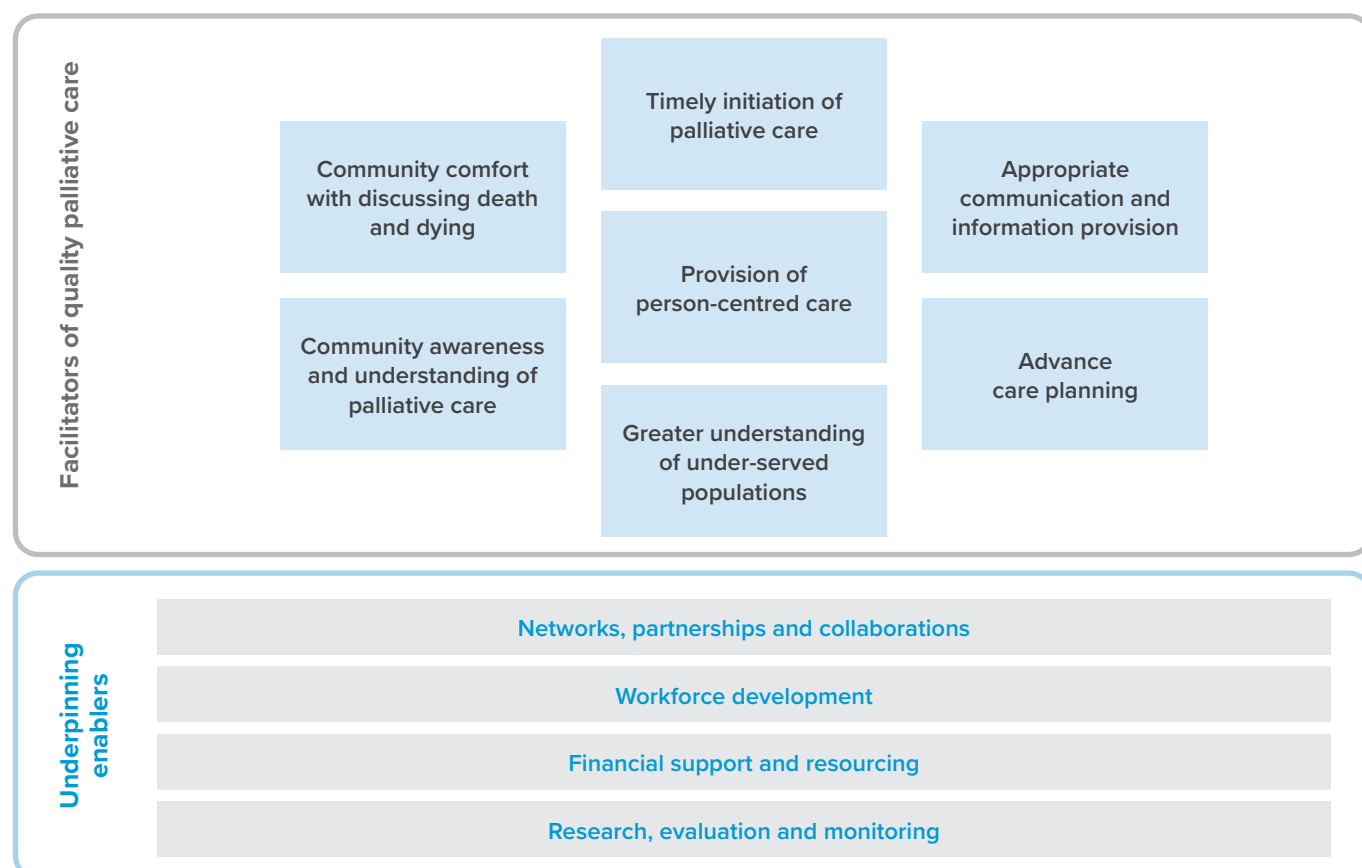


Figure 4 Facilitators and enablers of quality palliative care²⁶

Transition between different care settings is not always well coordinated

When patients receiving palliative care are transferred between care settings, adequate collaboration and information exchange between health care professionals is necessary to ensure continuity, efficiency and safety of care.⁵⁴ Continuity of care and care coordination have significant impact on satisfaction and quality of life as well as reducing the number of acute care re-admissions.⁵⁵

There is evidence however, that current care and transition between settings is not always seamless. A person with a life-limiting illness may need to transition from hospital to residential aged care facilities or community palliative care services, and vice versa, and at times may be cared for by a combination of public and private healthcare providers.

Without sufficient communication to ensure continuity of care these transition points can be a high risk for errors like adverse medication events, including missed doses of medications and disrupted supply when patients are transferred to another setting. This can place people with complex health needs at risk of serious complications, lack of symptom relief and re-hospitalisation.

There are a range of possible reasons for lack of collaboration and coordination including funding barriers, different service models across regions, varying levels of community and clinician awareness of palliative care, poor visibility of information and data regarding patients receiving palliative care and clinical and professional silos.³¹

In addition, there is a degree of inconsistency in the use of palliative and end of life care terminology. If we are to have seamless transitions in care, it is important that everyone has a shared understanding and that language is used consistently across settings.⁵⁶

The health and community service system needs to be organised to promote continuity and coordination of care as people's needs change and they transition between different types and settings of care.⁵⁷

The National Palliative Care Strategy Implementation Plan 2020, identifies the following actions to support us to improve the collaboration and coordination of palliative care:

- > Identification of service models that improve collaboration and coordination
- > Building the capacity of service providers to provide care with support from specialist palliative care
- > Improving the sharing of patient data
- > Addressing interface issues including funding barriers that inhibit cross sectoral collaboration

We need to improve how we collect and use data about palliative care

The development, collection and reporting of accurate, relevant, and timely data about palliative care is central to making informed, evidence-based decisions that improve care.

The purpose of collection and reporting is not limited to monitoring the activities of the system as traditional performance reporting does. Rather, the purpose of collection, measurement and reporting in this context is to measure and evaluate outcomes through using data to identify the impact of actions that have been taken towards achieving South Australia's palliative and end of life care priorities.

A key finding of the 2018 Health Performance Council Revisit Review of South Australia's Palliative Care Services Plan 2009-2016 was that many of the plan's 32 initiatives could not be evaluated due to a lack of available data.

Although there have been some advances in the collection of palliative care data, such as The Palliative Care Outcomes Collaboration (PCOC) which routinely reports on state and national clinical outcomes for adults receiving specialist palliative care, there is limited consistent, national data with full coverage of jurisdictions and care settings.

For South Australia, whilst data is available regarding hospital based admitted specialist palliative care and other admitted care, there is limited visibility of data from non-specialist setting such as general practice, residential aged care, community, inpatient non-specialist palliative care, outpatients and emergency services.

In addition, data collection should extend to quantifying the existence of advance care planning documents, the percentage of documents that satisfy their legal requirements and the percentage of advance care directives as a proportion of total number of advance care planning documents. Targets for the collection of this information should be set and individual health and care settings should be encouraged to assess and monitor service performance against these targets.

The National Palliative Care Strategy Implementation Plan 2020 identifies the following actions to support data collection, measurement, and reporting:

- > Scoping and agreeing on a data collection mechanism
- > Consulting with appropriate national committees
- > Implementing and investing in nationally consistent data collection throughout community, specialist palliative care and acute service settings
- > Reporting collected data

Workforce capacity and capability

When people receive palliative care, they want it to be available as close to home as possible. They and the health system also expect it to be provided by an appropriately trained, skilled, and supported generalist and specialist palliative care workforce.

One of the major challenges to equitable access to palliative care services is the poor distribution of health professionals, particularly in rural and remote regions.⁵⁸ This is particularly relevant in South Australia where almost 30% of the population currently live in rural and regional areas. Specific incentives and alternate models are required to match the service challenges in regional, rural, and remote locations.

A systematic strategy for developing both the capacity and capability of the workforce to deliver culturally responsive palliative care will be integral to the provision of high quality and sustainable services for people who are dying.

Such a strategy should consider:

- > How best to attract and retain health professionals where needed such as through provision of long-term employment contracts, better access to leave arrangements, inter professional and clinical support and other lifestyle and professional considerations³⁶

- > Support for non-specialist palliative care clinicians to build understanding and skills in palliative care through programs such as the Program of Experience in the Palliative Approach (PEPA) and Commonwealth Government funded palliative care education programs
- > Provision of education, training, and support for the generalist palliative care workforce to confidently care for people who wish to die at home and to provide appropriate care during the active dying process
- > Strengthening the role of general practitioners in palliative care provision in the community
- > Partnerships between specialist palliative care services and universities to support delivery of both undergraduate and postgraduate training in palliative care across all health disciplines
- > Embedding education into specialist palliative care services with time and resourcing allocated to teaching and training and capacity building for the generalist palliative care workforce.

Regardless of location, health professionals must be appropriately prepared and remunerated for providing palliative care. This should include adequate remuneration to support clinicians to visit palliative care patients in their homes or in the community and to ensure that clinicians can deliver care that is consistent with national palliative care standards and reflects the complexity and time required to provide palliative care outside of consulting rooms. The nature and scope of such preparation and remuneration will vary between primary and specialist settings, and between disciplines, but must enable health professionals to:

- > recognise and respond appropriately to people with life-limiting illness
- > meet a level of competence necessary for their scope of practice
- > deliver the required standard of care both in the home and out of hours where needed.

Other important considerations

Spiritual care

Spirituality is the way we seek and express meaning and purpose and is a fundamental element of human experience. Spirituality encompasses an individual's search for meaning and purpose in life as well as the way we experience our connection to the moment, self, others, our world and the transcendent. For some people spirituality can be largely faith based, for others it may be their relationship with nature or the profound connections they have with other people. Spiritual care focuses on the needs of the whole person and their family.^{59,60}

Spiritual care is recognised as an integral part of palliative care and a palliative approach includes spiritual assessment, and the involvement of appropriately trained staff. It has been identified that there are gaps in understanding about spirituality and spiritual care across the community and that in order to provide access to spiritual care across care settings including at home, further education and specific funding is needed, for spiritual care practitioners to function as part of the team in the palliative approach.⁶¹

Voluntary Assisted Dying Legislation

On 24 June 2021, the Voluntary Assisted Dying Bill 2021 was passed by the South Australian Parliament. Implementation of the new *Voluntary Assisted Dying Act 2021* is likely to span 18 to 24 months.

The State Government will support the introduction of a safe, accessible voluntary assisted dying scheme that gives eligible South Australians with a terminal illness more choice at the end of life and ensures the integrity of the safeguards embedded in the legislation.

Voluntary assisted dying means administering a medication for the purpose of causing death in accordance with the steps and process set out in the legislation. Voluntary assisted dying must be voluntary and initiated by the person themselves and is usually self-administered. Only those who are already dying from an incurable, advanced and progressive disease, illness, or medical condition are able to access voluntary assisted dying.

The *Voluntary Assisted Dying Act 2021* makes it explicitly clear that the administration of a voluntary assisted dying substance to a person in accordance with *Voluntary Assisted Dying Act 2021* (once commenced) will be taken not to constitute palliative care of the person.

Whilst voluntary assisted dying is not part of palliative care practice, those delivering palliative care will need to work alongside those requesting and providing voluntary assisted dying to ensure non-abandonment of patients, and to ensure that access and equity issues do not drive requests for voluntary assisted dying. A number of organisations have developed position statements and guidance regarding palliative care and voluntary assisted dying to ensure appropriate care is provided to a person living with a life-limiting illness at all times; and to maintain appropriate, respectful and cooperative relationships between health and care professionals.

COVID-19

COVID-19 presents a range of challenges and opportunities and has highlighted a lack of surge capacity for specialist palliative care services not only relating to staffing but access to medications. On a positive note, COVID-19 provided the opportunity to improve timely access to palliative care for patients with COVID-19 and importantly, for anyone with a terminal illness. This was achieved through the completion of several pieces of work which have system wide ongoing benefits. The learnings and successes including telehealth, solo practitioner home visitation and the 24/7 palliative care support line will continue to be evaluated, with feedback to the Palliative Care Clinical Network Steering Committee.

In addition, the Commission on Excellence, and Innovation in Health (CEIH) has conducted a survey for both clinicians and health care users and the community in identifying the impact of COVID-19 on the provision of palliative care. Results of the survey have informed the development of this Framework.

APPENDIX 2.

Palliative Care Project Board and Clinical Network Steering Group Membership

Project Board membership	Role
Ken Lang, Executive Director, System Design and Planning, DHW	Chair
Dr David Holden, Clinical Lead, Palliative Care Clinical Network (July 2019 – June 2021)	Member
Penny Thyer, Director, Health Services Programs, DHW	Member
Mark Waters, Executive Director, Palliative Care SA	Member
Jeanette Walters, Executive Director Integrated Care Systems, Wellbeing SA	Member
Tara Worby, Community Nursing & Palliative Care, YNLHN	Member
Kerri Grant, Aged Care, Rehabilitation & Palliative Care, NALHN	Member
Cathy Wright, Operations Manager, Clinical Performance and Patient Safety, SAAS	Member
Amanda Coldwell, Psychosocial Lead Palliative Care, CALHN	Member
Dr Michael Briffa, Medical Consultant, Paediatric Palliative Care Service, WCHN	Member
Heather Thomson, Regional subacute and restorative care team leader, Out of Hospital Program, BHFLHN	Member
Rebecca Whittaker, Nurse Consultant Palliative Care, LCLHN	Member
Dr Timothy To, Palliative Medicine Specialist, Division of Rehabilitation, Aged Care and Palliative Care, SALHN	Member
David Militz, CEO Carers SA	Member
Jane Mussared, Chief Executive, COTA SA	Member
Rosetta Rosa, State National Liaison Manager at Leading Age Services Australia (LASA)	Member
Dr Russell Shute, GP Blackwood Clinic, and GP adviser for the GP Partners Palliative Shared Care program	Member
Dr Sonia Schutz, Rural GP Clinical Lead, Palliative Care, Rural Support Service	Member
Anji Hill, Project Manager, System Design and Planning	Project Manager

Palliative Care Clinical Network Steering Group membership	Role
Dr David Holden, Clinical Lead, Palliative Care Clinical Network (July 2019 – June 2021)	Chair
Dr Peter Allcroft, Staff Specialist, Southern Adelaide Palliative Services and Co-chair, Palliative Care Clinical Network	Member
Kathryn Hourigan, Co-chair, Palliative Care Clinical Network	Member
Caroline Amato, Director Clinical Operations, Specialist Programs RDNS	Member
Alan Bevan, Consumer Representative	Member
Alice Every, Advanced Nurse Unit Manager, Northern Adelaide Palliative Care Service	Member
Dr Stephen Byrne, General Practitioner, Goolwa Medical Centre	Member
Liz Fallas, Nurse Practitioner, Palliative Care, Limestone Coast Health Service	Member
Sara Fleming, Clinical lead, Paediatric Palliative Care, Limestone Coast Health Service	Member
Dr Linda, Foreman Palliative Care Consultant, Central Adelaide Palliative Care Services	Member
Dr Charlotte Griffiths, Palliative Care Consultant, Mary Potter Hospice, Calvary North Adelaide Hospital	Member
Peter Jenkin, Nurse Practitioner, Palliative Care, Resthaven Inc.	Member
Lesley King, Regional, Rural and Remote Project Officer, Aged and Community Services SA/NT	Member
Jane Marshall, Consumer Representative	Member
Dr Deidre Morgan, Lecturer, Palliative and Supportive Services, Flinders University	Member
Helen Stone, State and Territory Manager SA/NT, Pharmaceutical Society of Australia	Member
Kate Swetenham, Nursing Director, Palliative Care Projects, Department for Health and Wellbeing	Member
Mark Waters, Executive Director, Palliative Care SA	Member
Dr Sonia Schutz, Rural GP Clinical Lead, Palliative Care	Member
Dr Timothy To, Palliative Medicine Specialist, Division of Rehabilitation, Aged Care and Palliative Care, SALHN	Member

APPENDIX 3.

Framework feedback received to support actions

No.	Feedback
1.	There is little to no consideration for the support of palliative care patients during the active dying process phase historically this is not performed well and even with dedicated specialist teams and extended care paramedics, there is a significant shortage across the state that could be filled with community-based clinicians including the Paramedic workforce with additional training in cultural awareness and practices, and the legal process surrounding expected death.
2.	In summary: > Stop outsourcing basic practical palliative care to outside organisations > Palliative care services should be one-stop shops - I shouldn't have to deal with multiple organisations for this care in the home - provide them with the money to be able to have one organisation do this > Stop making the patient and carer ask for help and - know what the patient and family need before they knew themselves - fund the palliative care professionals to do this including grief and bereavement care > Continue to fund the wellbeing services and increase these services to staff and encourage staff to use them as well as families and patients > People only get to die once.
3.	ACPA agrees that the workforce capability is instrumental to the delivery of high-quality palliative care. ACPA does endorse the use of in-service opportunities but suggests that the Framework also considers the range of Commonwealth Government funded palliative care education programs and how they can be used to upskill the workforce. For instance, Advance Care Planning Australia has a learning hub that contains several modules for health professionals to complete, which are freely available: https://learning.advancecareplanning.org.au The modules can be completed by a range of different health professionals across different skill levels. The modules can be utilised as an introduction to the concepts by novice persons, upskilling those familiar with the concepts and acting as refresher or means of continuing professional development for the health professionals more experienced in the area. The SA Government should also support the use of train the trainer programs to support workforce capacity and capability and the use of palliative care and advance care planning champions in the workforce. Advance Care Planning Australia offers train the trainer training.
4.	Hopefully the co-design will embrace a wide range of stakeholders, including service users and carers (former and current), representing cultural diversity of SA society.
5.	There is great potential of reaching out to community leaders, spiritual/religious leaders and encouraging ongoing partnerships to develop and support champions/ambassadors knowledgeable to be conduits of information, advocate for ideas and issues, promote the initiatives, strategies and available services/programmes/support and encourage to share feedback to improve into the future.
6.	In the CALD-specific Aged Care area, data collection can be linked to the CHSP, Home Care packages and GP reporting tools to acknowledge country of origin, the preferred language, the ancestry, language spoken at home, need for interpreters during medical appointments/navigating the system, limited knowledge and understanding of the existing system, eligibility criteria, other culturally-specific issues limiting use of available/existing support measures.

No.	Feedback
7.	There are many community awareness strategies - all small - if there is ever going to be a change in SA community awareness about death and dying - SA needs a coordinated, PUBLIC HEALTH CAMPAIGN about death literacy - media/buses/electronic /TV
8.	Top down - i.e. hospitals to community won't improve access - we see that now - access improvement HAS to be from General Practice - nothing will change unless GPs are salaried to be a part of a coordinated team or the ITEM numbers change to reflect the true input required to coordinate and manage palliative care/end of life care and death at home if that is the patients (and their family's) choice.
9.	As a member of the Riverland Palliative Care Team, I am proud to say that the feedback from clients is positive. The area that we are failing our clients appears to be in the unavailability of a contact person (PC Nurse) after hours and weekends for our clients, particularly those in the Terminal Phase. An on-call PC Nurse is mostly needed for families caring for a loved one in the Terminal Phase wanting advice / emotional support. By not having an available PC Nurse after hours or weekends creates the inability to commence a Niki infusion after Friday afternoon, until the Monday or Tuesday when Public Holidays occur. Families are required to call an ambulance if their GP is also unavailable if problems arise over the weekend. Our clients that have a Niki pump prior to Friday each week will have the syringe changed by an RN doing the Community Health Role, these staff members do not work in Palliative Care and are not trained in providing advice on symptom management, emotional support and making changes to the care over the weekend. The Community Health Nurse is not "on call" for the person in the Terminal phase and will visit only on a Saturday to change the Niki Syringe (set for 48 hrs) to prevent a Sunday visit. Obviously, the funding to provide this is an issue. Another area for improvement would be to have an appropriate number of staff providing palliative care to the Community. We currently have 91 active clients and 3 PC Nurses working part time. One of these has just started this week again the funding to provide adequate staff will prevent staff fatigue and burn out and ultimately a better service to our clients and will prevent admissions to Hospital.
10.	The commitment to a 'comprehensive approach to Grief and Bereavement for SA' extends well beyond deaths within palliative care settings. Although a statewide approach is clearly important and something that palliative care services can contribute to - I think there also needs to be a commitment about grief and bereavement services provided by palliative care services to the families/carers known to our services. As per National Palliative Care Standards 2018 – this should include: > multiple opportunities to provide information and resources about loss and grief and bereavement services before and after the death to families/carers, > bereavement clinicians as part of the palliative care team that have appropriate education/training/ supervision to > undertake structured assessment of bereavement that addresses emotional, behavioural, social, spiritual, and physical domains during the illness and after the death, and > to meet the loss, grief and bereavement needs of the family and carers.

No. Feedback

11. Data collection, measurement and reporting currently through PCOC does not currently include Bereavement (Phase 5).
- > how does this reflect on how palliative bereavement services are viewed/valued by individual services?
 - > without PCOC (or an alternative data benchmarking system) how are palliative care services currently demonstrating the quality/effectiveness of their bereavement support activities, and/or the extent to which bereavement services are meeting the national pall care standards for grief support?
 - > when one aspect of a service is 'invisible' in terms of data collection, what impact does this have on how a service prioritises resource allocation?
- A significant amount of work has also gone into (and is currently being progressed) in adapting pall care bereavement processes so that bereavement activity can be captured within Sunrise EMR – including:
- > registration of the bereaved person on Sunrise, separate to the patient's EMR
 - > development and building of a Bereavement Note as part of the Palliative Care carousel
 - > ongoing discussions with the Sunrise team about how to capture the 'once off' bereavement screening/assessment contacts against the deceased patient EMR (i.e. for bereaved people that decline further bereavement support)
-
12. Currently across metro Adelaide palliative care bereavement services there is huge variation/inequity in the way and extent to which pre and post death bereavement services are delivered/able to be accessed – differences include:
- > dedicated bereavement coordinator FTE
 - > dedicated bereavement counselling FTE
 - > extent to which 1:1 support or bereavement groups are provided
 - > access to flexible service delivery (home visits vs on site appointments vs phone support)
- in my view this does not meet any priorities/goals/statements within this SA Palliative Care Strategic Framework about:
- > increased support for families/carers during the illness and after the death
 - > improving workforce capacity and capability (to meet the loss, grief and bereavement needs of families/carers)
-
13. There needs to be significant thought put into enhancing access and knowledge of services for people and their family and referrers. e.g. There is limited ability to find phone numbers of palliative care services
- Even increasing access in phone service information centres, uniform service contact details in PCSA, SA Health, PHN websites would help particularly if all badged similarly and interactive. Embedding referral information and contact details into GP and Patient Management Systems would be one possibility. Single 1800 phone number needs to be smart enough to work for people in one area looking for support in another so interactive online but also remembering non-literate or non-IT communities there needs to be paper material and funded opportunities to interface with communities, service clubs, local council organisations as well as health services and referrers.
-
14. Compassionate communities are only one aspect of building community awareness and capacity and caring. All these community activities need significant funding and suggest needs discussion about resourcing some of this within clinical palliative care teams who bring credibility and local connection into their communities. Not one size will fit all areas, or regions.
-

No.	Feedback
15.	Community awareness needs to include education in other institutions, schools, universities, workplaces Health workforce training fails to mention undergraduate health professional teaching. Need partnerships with universities to positively embed clinical academics into teaching streams. I.e., clinicians with current credibility enhance the connection and quality and breadth of teaching and role modelling of future careers in all health disciplines by this sort of initiative.
16.	re Specialist Pall Care Omission of the need for consultation into acute and subacute hospitals both metropolitan and rural/remote and specific strategies to facilitate this i.e., specialist nursing and medical input as well as psychosocial access i.e., technologies, face to face visits, resources locally, “pop up” models and strong funded partnerships. Consultation liaison within acute hospitals is a vital function of SPCS provision and needs to be resourced properly. Currently might be considered “unfunded” in some jurisdictions.
17.	No acknowledgement of “Palliative Care Units” – i.e. may be within acute hospitals but must be articulated separately for data collection. Function and resourcing needs to be seen separately from acute hospital data and service provision. The semantics of Hospice and Palliative Care Unit is important for some and for others not an issue. See St Christopher’s website. The first and origin of the modern hospice movement now calls itself “St Christopher’s – More than a Hospice” and their model of inpatient care does not sound significantly different from the fairly acute palliative care inpatient units resourced within public health in SA but the breadth of other services is to be coveted. There is online education, online psychosocial options as well as many psychosocial inputs that are not available in SA. There is no detail about length of stay which might add further “colour” to the service provision model but many more community-facing aspects of the service.
18.	Priority 2 need greater emphasis on funding. Need comparison of SA with other jurisdictions and be able to report on dollars spent per expected death in SA
19.	Priority 3 There are well researched and effective models particularly for non-cancer support that should be funded and barriers to implementation addressed – not more pilot studies without sustainability. Greater emphasis on need for resourced services for non-cancer including embedded palliative care clinicians and even funding of senior positions such as Pall med specialist doctors, Nurse Practitioners employed with protected FTE within respiratory, cardiology, neurology, renal teams and not just in community locations. Greater thought about with challenge of co-locating chronic team consultations with specialist palliative care teams rather than separating acute hospital and community palliative care. Even there is a challenge to find OPD rooms for such synergies. Much better to co-locate the consultations and not put extra travel barriers.
20.	Need to be careful not to blame current clinicians for whole of system difficulty with maldistribution of health professionals. Acknowledge that current models for private medical and health systems including GPs, private palliative medicine specialists funding are frequently not viable and no ability for “loss leader”. Acknowledgement of current strength of metro SPCS integrated services with IP, CL, community model is needed. Less transitions, easier information sharing and continuity of clinicians and administrative systems. This is the envy of many other jurisdictions and should be strengthened and not pulled apart. Opportunities might be to embed community nursing rather than the current convoluted contracted arm’s length approach. Needs proper resourcing. MRU meant to be resource provider. At times obstructive and limits access
21.	PEPA placements and informal networking with Specialist Palliative Care Services have been invaluable to ECH in providing end of life care for clients wishing to die at home however additional formal training opportunities for Community Aged Care staff such as Care Workers would be welcomed.

No. Feedback

22. Alternative approaches to funding including recognition of palliative care in Commonwealth Home Care Package funding (as an adjunct to state health funding) would significantly improve the ability to provide end of life care in the community for older South Australians
23. Consideration should be given to employing salaried GPs to support generalist palliative care
24. Consideration should be given to alternative ways for accessing palliative care pharmacy and out of hours medication supplies in the community
25. Normalising Dying

The 2018 National Palliative Care Strategy notes that it is important that the end of life is recognised as an inevitable part of living so we can ensure that our health and social systems provide the support that individuals, carers and families need as life ends, and in bereavement. While 8.1 recognises death literacy, it limits the work to compassionate communities and to advance care planning. There is a broader need to help build community awareness and to understand individual and societal perceptions and attitudes around death and dying. In an era where there is rapid media cycling and a reliance on social media, ensuring that there is appropriate language, clear messaging, and positive approaches to community discussion around death and life is an essential underpinning for all work in palliative care.

Similarly, advance care planning is predicated on the assumption that people are willing and able to have conversations about death and their future care. The National Framework for Advance Care Planning Documents (2021) reminds us that health and illness are not a linear process and advance care planning should not be reserved only for the end of life period. Rather, individuals can think about their future health and personal care decisions and begin the advance care planning process at any time. Building a life course approach to normalising dying will support the priority given to compassionate communities and advance care planning.

Within this context the importance of readily accessible and trustworthy information for patients, carers, families, and the broader community is critical and should be explicitly noted in the framework.



No. Feedback

26. The role and the potential of 'digital technology and information' in the context of quality palliative care planning and provision is growing. The use of technology in identifying and implementing palliative care service models is acknowledged in p18 of the draft strategic framework. However, given the vast amount of clinical and care data that is collected in the health and care setting, and the virtual nature of many care interaction in the COVID era, it may be useful to have a greater emphasis on identifying the need and the value of technology to contribute to the palliative care. This is particularly important given that palliative care is provided over time and across settings where information, communication and digital resources could enhance awareness and care provision. It should be regarded as a facilitator/enabler of quality palliative care and addressed in priority actions.

The Technology Roadmap for Aged Care, commissioned by the Aged Care Industry Information Technology Council (ACIITC) describes the ways in which technology can enable more effective and efficient care for and by older Australians:

- I. Technology-enabled operational, business and communication systems.
- II. Technology-enhanced care and support for older people.
- III. Technology-enhanced information and access to care.
- IV. Technology-enhanced assessment of eligibility and changing need.
- V. A technology-literate and enabled workforce.

This roadmap can be used as a guide to develop strategies for technology enhanced information, assessment, care, and support in palliative care. The RePaDD research team has extensive experience in the area of digital technology and palliative care.

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27. Community based models of palliative care

To enhance person-centred palliative care, in addition to generalist and specialised palliative care provided that are provided by professional care workers (Priority 2), it is recommended to add 'access to community-based care and the use of community-based care works in the strategic framework. The role and contribution of existing and emerging models of community-based such as aged care navigators, death doulas, and Aboriginal Health Workers is already being discussed in the literature. This cadre of care workers can be included in Action 5 to develop workforce strategy for example the recruitment, training, and ongoing support of community-based workers. This is particularly important to identify and address local needs particularly amongst under-served population groups. This will also align with Action 2 'supporting a compassionate community approach' to improve death literacy and community awareness about end of life matters and provision of palliative care services that meet social, cultural, and spiritual needs.

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28. Equity in access to and social determinants of palliative care

Equity in access to palliative care is emphasised in the National Palliative Care Strategy 2018 and reflected in the SA strategic framework. There is strong evidence on the importance of social determinants of health in general and palliative care in particular which goes beyond just improved access to palliative care services. Some determinants such as stigma and discrimination and social exclusion are acknowledged in the draft document. Other social determinants include socio-economic conditions, housing, education, transport, and employment. It is recommended that the importance of and actions on social determinants of palliative care including inter-sectoral collaboration are explicitly acknowledged and noted in the SA strategic framework (Priority 3). Collecting data on social determinants of health and their association to access and utilisation of palliative care services (e.g., through Geographic Information System mapping methodologies) may be included in Priority 4 and related Actions.

No. Feedback

29. Translational palliative care research and evaluation

RePaDD welcomes the framework Action 13 'support palliative care research and translation of research into practice'. Some important works have been undertaken around barriers to equitable access to high quality palliative care and evaluation of existing programs of palliative care. Little is known about models of care in palliative care that are appropriate for older people. Better education and planning, recognition that people may prefer to die at home, and involvement of family in end-of-the-life care were issues raised in the Royal Commission's hearings. There are also knowledge gaps in relation to the costs associated with palliative care and cost-effectiveness of the current models of care. <https://www.palliaged.com.au/tabid/4345/Default.aspx> Finally mechanisms by which we facilitate change and improvement within our community, services and care providers is still an evolving area of research which will underpin the effectiveness of proposals for change.

30. The discussion covers CALD communities' lack of awareness, trust and understanding of services. This is then not followed through in the commitments section to change things for the future. Culturally safe strategies have to be applied to effectively engage communities in these sensitive conversations. The commitments need to include the training (including the PEPA program) of both generalist and specialist workers, particularly in cultural safety. b). Access requires a greater emphasis upon funding. PCSA would like to see an outcome on p28 that includes a funding comparison on palliative care across Australian jurisdictions in order that we can report upon the resources spent per expected death in SA. A written document of wishes may not be the cultural norm (or even possible). PCSA doesn't want to see ACP as a very middle-class literate process that reinforces barriers through legislation and implementation.

31. how to refer is critical - there needs to be resources allocated to promote pathways and navigation to palliative care services so that people can find their local SPCS. Greater information provision is required.

32. There needs to be greater emphasis on need for resourced services for non-cancer including embedded palliative care clinicians in other specialist teams such as respiratory, cardiology, neurology, renal teams as well as in community locations.

33. The interface with My Aged Care, NDIS is a real issue and barrier to access – this extends to equipment provision, duplication of allied health assessments etc

34. Priority 3 – I'd like to see greater emphasis on commitment from the Level 6 pall care services (in metro) to provision of specialist pall care support for regional SA...rather than reg LHNs needing to pay for specialist services (per negotiated MoUs). Whole of state approach required to provide pall care/end of life care for all in their place of residence (home, RACF)..local regional teams, GPs supported by pall care specialists as per affiliations between metro and reg LHNs for pall care services.

No. Feedback

35. Locally in Mount Gambier it was made obvious in 2019, when a Community Palliative Care Forum was held, (standing room only) that the community felt strongly about:

The need for extended Palliative care options including 24/7 care and support within the community

- > Reinstatement of palliative care volunteers
- > Designated Hospital inpatient Palliative/End of life suites with areas for family and friends
- > Pastoral or bereavement care in the hospital – (ceased between 2012 – 15)
- > No resident Palliative care specialists
- > Increased information about Palliative Care and supporting services

It is apparent that the above needs expressed are due to lack of funding and resources.

How do we ensure, within an allocated timeframe, that End of life care and palliative care strategies and services ensure that every South Australian – no matter where they live, or what illness they have – has access to the highest quality care to allow them to live and die well. With the option of dying in the setting of their choice whether that be in their home or in a hospital setting.

Regional communities can be empowered to enable people to live and die well, but funding and support must be provided.

I totally believe this can happen.

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36. SHPA commends the South Australian government on the development of the draft Palliative Care Strategic Framework and welcomes the opportunity to provide feedback on this strategic framework. Whilst access to palliative care is essential, SHPA believes that access to palliative care pharmacy services must be included as a priority, to ensure safe and quality access and use of medications for people with a life-limiting illness.

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37. Palliative care pharmacists are crucial to ensuring the safe and quality care of palliative care patients across all care settings, especially with respect to management of their medicines. Patients with a life-limiting illness may be transitioning from hospitals to residential aged care facilities or community palliative care services, and vice versa, and at times may be cared for by a combination of public and private healthcare providers without sufficient communication to ensure continuity of care. These transition points are known to be a high risk for adverse medication events, including missed doses of medications and disrupted supply when patients are transferred to another setting. This population group have complex health needs and medication regimens, so missed doses and incorrect medicines place them at risk of serious complications, lack of symptom relief and re-hospitalisation. Hence, access to palliative care pharmacy services is essential to addressing Priority 3 of the draft Palliative Care Strategic Framework, enhancing collaboration and coordination of safe and appropriate palliative care.

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38. Palliative care pharmacists are an integral part of an interdisciplinary team and optimise the outcome of symptom management through evidence-based, patient-centred medication therapy. Palliative care pharmacists educate patients, carers and fellow health professionals on the use of medications, maintain patient medication stock, follow up on patients after discharge and transitions of care, provide prescribing advice to general practitioners and create guidelines for medication use in palliative care settings.

During provision of care there is a lot a responsibility and challenges faced by carers especially when considering complex and frequently changing medication regimens and the fragmentation of care, leading carers to be the single coordinators for their loved ones. SHPA member feedback indicates that carers are more educated and confident about managing the patient's medicines after a comprehensive counselling session with palliative care pharmacists. These counselling sessions cover what the patient's medication regimen is, the dosage and frequency of each medication, whether they are regular or as-required medications, the side effects of each medication, and medical referral points for each medication.

No. Feedback

39. SHPA's Standards of Practice for the Provision of Palliative Care Pharmacy Services further describe activities consistent with good practice for the provision of pharmacy services to a palliative care unit, service, specialist clinic or hospice. They also encompass services provided to palliative care patients in general wards or being cared for on an outpatient basis or at home. Therefore, the co-design and implantation of integrated, ambulatory models of care noted in Framework Action 4, must include access to palliative care pharmacy services.
40. Current pharmacy services provided to palliative care patients in South Australia are mainly provided on a part-time basis and involve clinical, administrative, educational and medication supply functions. SHPA believes that palliative care pharmacists should be embedded across all settings where palliative care is provided including hospital, hospice, ambulatory, residential aged care, within the community and for both rural and remote settings.
41. Hospital pharmacists play a crucial role in supporting palliative care patients across Australia each day, and frequently inform SHPA of the workforce shortages in this space. They have highlighted the need to prioritise medication management in palliative care, by improving the pharmacy workforce capacity and increasing access to clinical pharmacy services for this patient population to ensure high quality care is provided at a level that meets community expectation. The SHPA Standards of Practice for Clinical Pharmacy Service¹ recommends FTE clinical pharmacist:25 beds (or 30 longer stay admission) based on clinical pharmacy services delivered during normal business hours. SHPA recommends that South Australia's Palliative Care Strategic Framework supports achievement of these ratios to ensure safe and effective medication management for Australians in this population group.
42. The draft Palliative Care Strategic Framework notes some small points in regard to Aboriginal consumers. My concern is the lack of services provided to Aboriginal consumers before End of life care is required. These consumers often die in an hospital bed or worse off home alone with no other supports put into place. These consumers and their families need to be engaged with Palliative care sooner e.g. when disease progression has reached an uncontrolled situation. Family support and education needs to be a priority for cultural support and safety from providers going into the consumers' homes. Dying in the home needs a Liaison officer to support families in these times and this needs more education from palliative care. Having a hospice centre for aboriginal consumers would help for those who do not want to stay in hospital. It is noted that an Aboriginal Advisory Subgroup to be established, has this been done and what are the outcomes because in this Strategic Framework nothing has been identified. Supporting family with grief support during consumers illness and looking at all aspects of the consumers life not just a small area.

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