South Australia's Palliative Care Strategic Framework 2021-2026

Draft for consultation

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Government of South Australia

SA Health

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1. Message from the Palliative Care Clinical Network Clinical Lead

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 sector partnership of consumers, services and health workers.

On behalf of the Statewide Palliative Care Clinical Network, I am pleased that this draft 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 the development of service planning and models of care.

It guides collective efforts of palliative care services to support consumers, 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.

David Holden
Clinical Lead
Statewide Palliative Care
Clinical Network

2. 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 sea. We respect and celebrate the many Aboriginal peoples and 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.

3. Executive Summary

South Australia's Palliative Care Strategic Framework 2021-2026 has been developed in recognition of a 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

Developed in partnership with the Statewide Palliative Care Clinical Network and under the guidance of the 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 5 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 5.

Implementation of the Framework will occur under the direction of an appropriate governance group who will prioritise development of a plan for implementation of the 13 actions identified under the four priority areas. The implementation plan will clearly identify roles and responsibilities for each action, expected timeframes for completion and how progress will be monitored and reported to palliative care stakeholders across SA.

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
- **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
- **Investment** A skilled workforce and systems are in place to deliver palliative care in any setting
- **Data and Evidence** Robust data and a strong research agenda strengthen and improve palliative care
- **Accountability** Governance of the Framework drives action

	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
PRIORITIES				
ACTIONS	1. Develop a comprehensive advance care planning framework for South Australia 2. Develop and support a Compassionate Communities approach to operate alongside clinical care in South Australia	3. Develop a Palliative Care Services Plan to drive commissioning of palliative care based on population health needs 4. Co-design and implement integrated, ambulatory models of care that meet the needs of different population groups and different illness trajectories and complexities 5. Develop a Palliative Care workforce strategy that addresses workforce capacity, development, attraction and retention requirements 6. Develop a comprehensive approach to grief and bereavement for South Australia	7. Implement service models that address interface barriers such as funding and information sharing 8. Promote the use of existing platforms such as the Electronic Medical Record and My Health Record for sharing advance care planning documentation 9. Improve identification of those who will benefit from palliative care or a palliative approach to care across all settings (particularly in ED and at care transitions) 10. Co-design patient pathways and supporting resources to support seamless identification, collaboration, communication and coordination of palliative care across sectors and settings	11. Contribute to the development and implementation of nationally consistent data collection mechanisms throughout community, specialist palliative care and acute settings 12. Develop a system wide approach to the reporting and evaluation of palliative care data including identification of resourcing to support capability 13. Continue to support palliative care research and translation of research into practice
OUTCOMES	> People in South Australia affected by life limiting illness receive care in accordance with their physical, social, cultural and spiritual needs and preferences. > People are involved in decisions about their own care at the end of life	> An appropriately skilled, resourced and distributed palliative care generalist and specialist palliative care workforce with the capability and capacity to deliver the palliative care services required by people in South Australia. > Knowledge and practice of palliative care is embedded in all care settings > People in South Australia affected by life limiting illnesses receive care that matches their physical, social, cultural, spiritual needs and preferences.	> People in South Australia affected by life limiting illness have a consistent and coordinated experience of palliative care across care settings	> 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.
ENABLERS	**Networks, partnerships and collaboration**	**Research Evaluation and Monitoring**	**Financial support and resourcing**	**Workforce development**

4. Introduction

Research and anecdote demonstrate that we 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 control over pain relief and other symptom control
- to have choice and control over 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 control over who is present and who shares the end
- to be able to issue advance directives which ensure wishes are respected
- to have time to say goodbye, and control over other aspects of timing
- to not have life prolonged pointlessly[1]

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. Health services must 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 receive[2].

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 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 journey[3]
- a skilled and supported generalist palliative care workforce
- increased awareness among policy-makers, health professionals and the public about what palliative care is and the benefitsw 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 life[4]
- Increased support for those who are caring for a dying person including bereavement.

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 National Palliative Care Standards and Service Development Guidelines 2018; and
- the vision and aims of the South Australian Palliative Care Clinical Network.

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.

5. About palliative care

5.1 Definitions

In recognition of the importance of shared understanding and to support the reader to engage with this document, the following definitions are provided:

Palliative care

The World Health Organisation[5] 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;

Palliative care:

- provides relief from pain and other distressing symptoms;
- affirms life and regards dying as a normal process;
- intends neither to hasten or postpone death;
- integrates the psychological and spiritual aspects of patient care;
- offers a support system to help patients live as actively as possible until death;
- offers a support system to help the family cope during the patients' 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.

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 and are outlined in the glossary on page 33.

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

5.2 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.[6]

Palliative care is most effective when considered early in the course of a life limiting illness. Early palliative care not only improves quality of life for patients but also reduces unnecessary hospitalisations and use of health-care services.[7]

5.3 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 Practices[8]

5.4 People who are involved in palliative care

Palliative care is a person centered approach that places those affected by life-limiting illness at the heart of their care surrounded by their community and support services[9]. Each person's situation is unique. Palliative care may be provided by family, friends and neighbours, volunteers from community support groups, spiritual and cultural groups, community based support providers, general practitioners and other primary health care providers, hospital and health workers from all disciplines and workers in aged and other community care settings.

Generalist palliative care

Generalist Palliative care is provided by people who have not received specialised training in palliative care is called 'generalist palliative care' and almost every health professional will encounter clients at, or approaching end of life and their families. For those patients requiring palliative care whose symptoms become difficult to manage or where the situation is complex, support from a 'specialist palliative care' team may be required.

Specialist palliative care

Specialist palliative care comprises multidisciplinary teams and individuals with specialised skills, competencies, experience and training to deliver care to people where the palliative needs are complex and persistent.[10] Specialist palliative care may also provide consultation services to support, advise and educate non-specialist teams to provide palliative care to people with more complex needs and should be integrated into primary health care, community and home-based care.[11]

Additional terminology is provided in the Glossary at the end of this document.

6. Background to the development of the Framework

6.1 Framework drivers

Australian Government Productivity Commission Report 2017

A 2017 report by the Australian Government Productivity Commission[12] 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 state-wide 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:

- Consumers 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 first 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.

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.

6.2 Purpose and scope

South Australia has an ageing population and a subsequent increase in the number of people living with chronic disease and life limiting illness. This means the need for palliative care is increasing.

This Framework has been developed in recognition of a need for a clear and consistent narrative that identifies how we will plan to meet this need, what our shared priorities and preferred approaches are and that guides our collective efforts in alignment with the available evidence and relevant national and state strategic policy drivers.

The Framework applies across all of the settings where palliative care is provided and provides 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 carers.[13]

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 and their families and carers.

6.3 How the Framework was developed

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 December 2020 and June 2021. 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 1.

7. Palliative care needs in South Australia

In response to the 2018 State Government Palliative Care election commitment, the Department for Health 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 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 the elderly and palliative care is different for different age groups, 70% of those in need of palliative care are aged over 60 years of age . 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.[15] 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.[16]

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[17]. 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". 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.

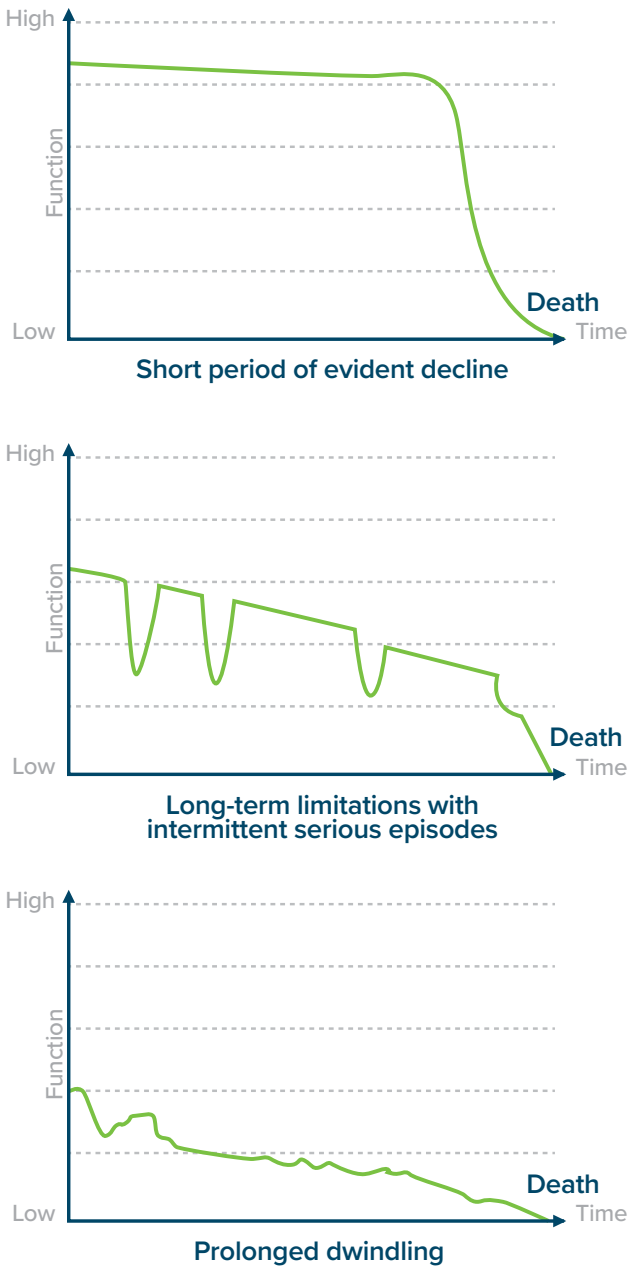

Figure 1 Illness trajectories and palliative care (adapted from[19])

Trajectory 1 – 27% of all SA 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 from[17])

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).

Based on the three illness trajectories outlined above, Palliative Care Australia 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.

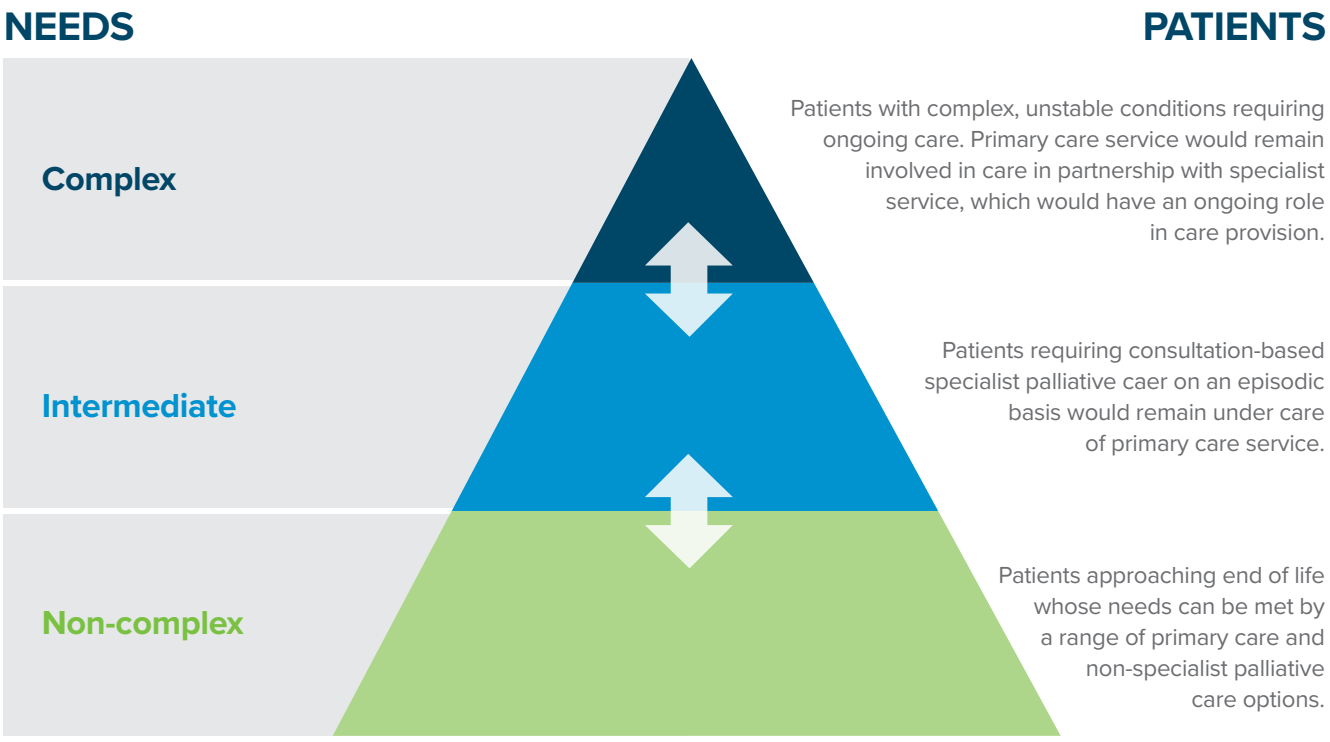

Figure 2 Different levels of complexity require a different service response (NSW ACI)

8. Current challenges and opportunities

8.1 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 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 when 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.[22] 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 structures[23] 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 regarding advance care planning:

The Compassionate Community

The National Palliative Care Strategy 2018 acknowledges that 'everyone has a role to play in palliative care'.

The community has an important role as an equal partner in the long and complex task of providing quality healthcare at the end of life. The 'Compassionate Community' role is enhanced by the fostering of death literacy widely across the community as well as by providing communities with leadership, coordination and resources.

This grounds-up approach provides an opportunity for a series of 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, and health and social care systems.

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 capacity of these 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.

Advance Care Planning

Advance care planning is an umbrella term used to describe the process of documenting preferences for future health care. It is generally agreed that advance care planning, as with the completion of a will 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 for the type of care and the outcomes they consider acceptable. Advance care planning benefits everyone including the person, their family, carers 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
- identify a nominated decision maker to speak for and act in a dying person's stead if they lose the capacity to do so
- reduce anxiety, depression, stress and increase satisfaction with care
- reduce unnecessary transfers to acute care and unwanted treatment[24]

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 wishes for 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.[25]

There is limited data on uptake of advance care planning across the community however a 2019 study 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 (ACD) 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 advanced 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, workers need awareness, training and support to engage in and facilitate 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.

8.2 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. 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 Commonwealth funded aged care facilities
- people living in supported accommodation
- people from culturally and linguistically diverse backgrounds
- Refugees
- people living with a mental health issue
- people with dementia
- people experiencing homelessness
- people who are incarcerated
- care leavers and people affected by forced adoption
- children with a life limiting illness
- people who identify as LGBTQI+
- veterans

A recent study supported by Australian Government Department of Health[14] 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)[27]

"I'm not good at communicating so I haven't spoken about my wishes." (person with disability)[24]

"Yes, I've made an advance care directive. I wanted a legal document as I didn't want to be resuscitated and end up as a vegetable for 13 years like my mother. My family and friends weren't very willing to discuss end-of-life though. People don't like the word 'death'." (person with disability)[24]

"If we talk about [death], someone will think 'you want me to die!'" (Vietnamese community member)[28]

"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]

"Indian children are very sensitive to being judged by the community as having abandoned their parents, "letting them die", which is what people think when they hear the term 'palliative care'." (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)[29]

"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)[30]

"As a trans woman I have a fear of going into any palliative or aged care. At the focus group they were talking about euthanasia and I would definitely consider that." (Trans community member)[27]

"Your friends are your family—[this is a] big element for LGBTI communities, as your biological family may have abandoned you." (LGBTI community member)[27]

"It is a big issue that family of choice is not recognised." (LGBTI community member)[27]

"Access to meaningful palliative care without housing is impossible." (General practitioner)[28]

"Show people respect and they show it back to you; it's important to have respect at end-of-life." (person experiencing homelessness)[28]

"Some people don't have phones, so the best way to get the message out is face-to-face information— word of mouth. People let each other know." (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 and these are presented in figures 3 and 4 below.

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 understanding of the benefits and need for palliative care, including with care providers
- Understanding the unmet need and gaps in service provision including likely future demand for palliative care
- 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, including in bereavement
- Including people affected by life-limiting illnesses in the planning delivery and evaluation of services.

Consideration of these factors along with technological solutions, innovative practices, improving workforce capacity and capability and co-design of new and integrated models of care will be necessary to improve palliative care access for these populations.[32]

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

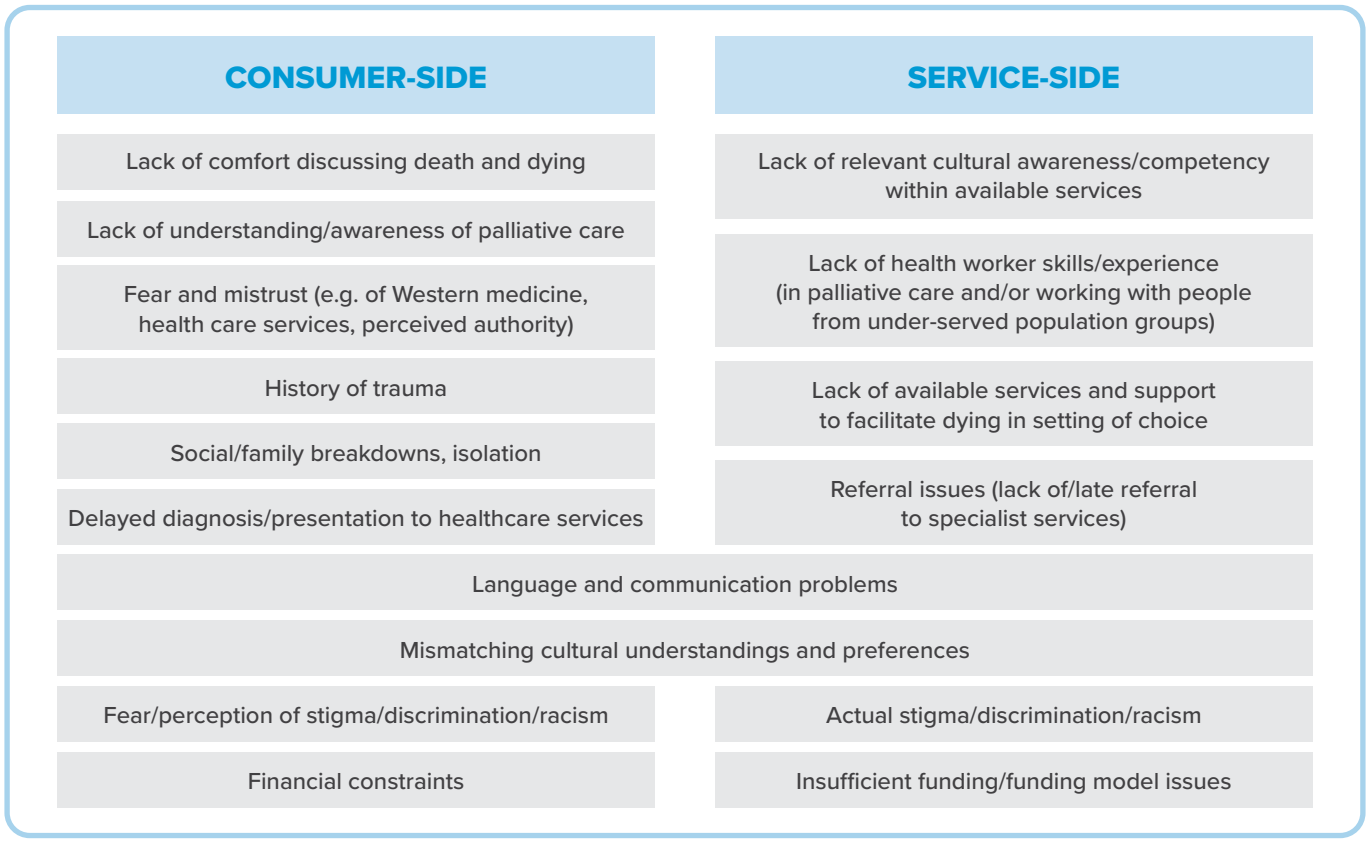

Figure 3 Barriers to palliative care for underserved populations (adapted from [26])

Facilitators and underpinning enablers of quality palliative care

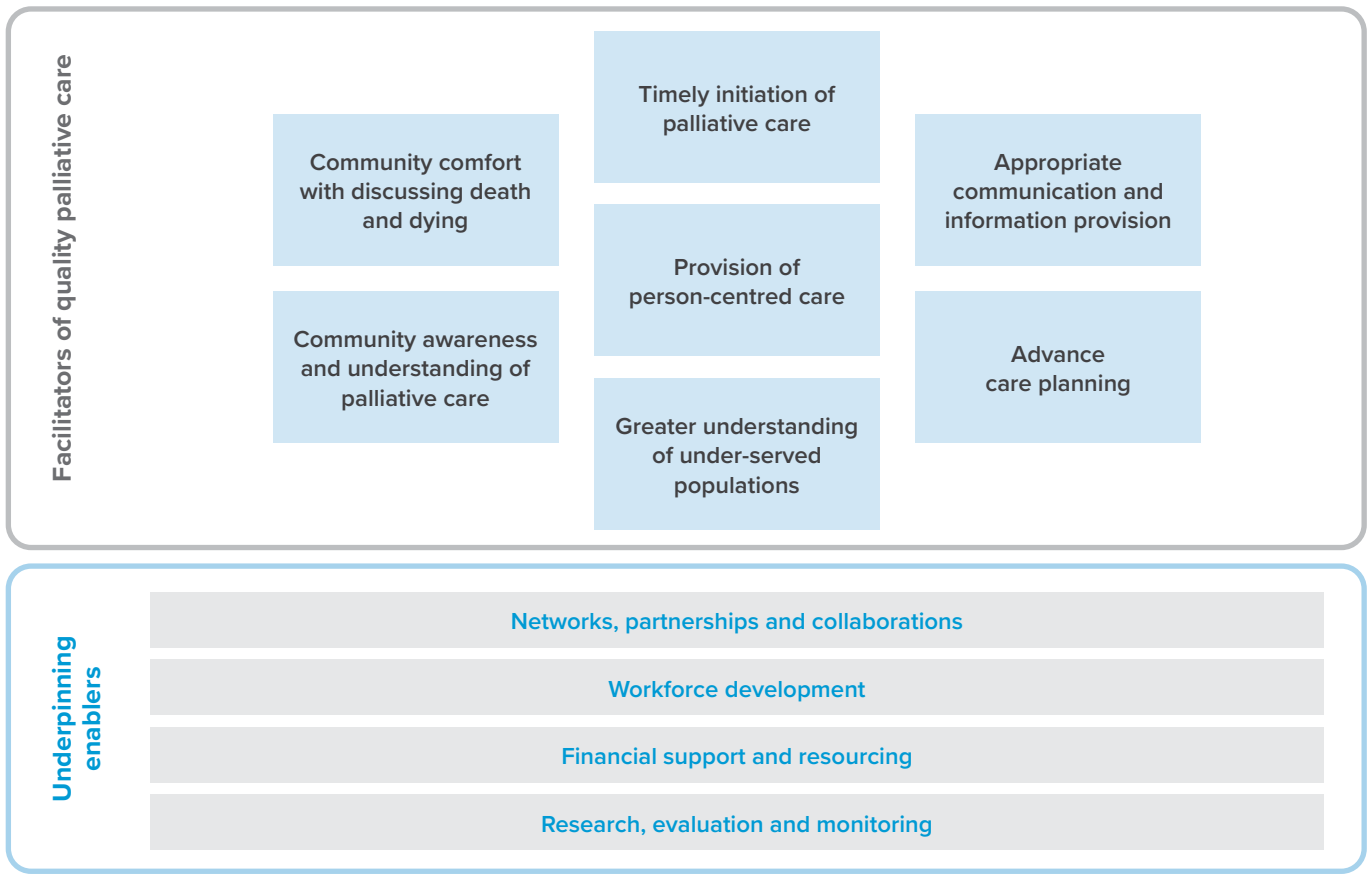

Figure 4 Facilitators and enablers of quality palliative care (adapted from [26])

8.3 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. Continuity refers to the exchange of knowledge between carers, the person and health professionals while care coordination is the alignment of care across providers and settings. 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.[34]

There is evidence however, that current care and transition between settings is not always seamless. There are a range of possible reasons for this 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.[35]

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.[36]

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

8.4 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 however, 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.

Although there have been some advances in the collection of palliative care data, there is limited consistent, national data with full coverage of jurisdictions and care settings.

There have been a range of significant achievements in this area such as The Palliative Care Outcomes Collaboration (PCOC) which routinely reports on state and national clinical outcomes for adults receiving specialist palliative care however there remain substantial gaps.

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. There is work to be done to obtain and link both quantitative and qualitative data across settings to support service planning and improvement.

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

8.5 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 and skilled workforce both at generalist, primary health care and specialist levels.

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 . 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 capabilities in palliative care for the whole health workforce and integrating learning at all levels of cultural competence and culturally safe practice will be integral to the provision of high quality and sustainable services for people who are dying.

Such a strategy should give consideration to how best to attract and retain health professionals where needed such as through provision of long term employment, better access to leave arrangements, inter professional and clinical support and other lifestyle and professional considerations.[36] These considerations need to be taken into both undergraduate and post-graduate training as well as providing suitable in-service opportunities through programs such as the Program of Experience in the Palliative Approach (PEPA).

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.

8.6 Other important considerations

Royal Commission into Aged Care

Around half of all deaths of Australians aged 70 and over occur in residential aged care. The Royal Commission into Aged Care Quality and Safety's Final Report 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 provide 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 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 advice to support older Australians to die in their chosen place
- a greater focus upon home care.

COVID 19

COVID-19 presented a range of challenges and opportunities, highlighting 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 consumers 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.

Voluntary Assisted Dying (VAD) Legislation

There is evidence of significant and sustained community support for access to VAD across Australia. The South Australia Voluntary Assisted Dying Bill 2020 was tabled in both houses of parliament in December 2020, had its second reading March 2021, passed the Legislative Council on May 5, 2021 and is now being debated in the Lower House of parliament.

Whilst VAD is not part of palliative care practice, those delivering palliative care will need to work alongside those requesting and providing VAD to ensure non-abandonment of patients, and to ensure that access and equity issues do not drive requests for VAD. A number of organisations have developed position statements and guidance regarding palliative care and VAD 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.

9. 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.

10. 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

11. 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:

- 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
- Commonwealth Aged Care Quality Standards 2020
- Palliative Care Needs in South Australia Report 2019
- Vision and Aims of the Palliative Care Clinical Network Steering Committee
- Final Report – Royal Commission into Aged Care Quality and Safety 2021
- Exploratory Analysis of barriers to palliative care Summary Policy Paper 2019
- AIHW National Palliative Care Information Priorities (currently in draft)

12. 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

PRIORITY 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."

"My mum died slowly in a ward in a hospital. They refused to transfer her to palliative care even though we asked. We were told she could go back to the nursing home or stay where she was. It was an awful experience"

"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."

"How much care should we expect to be given to someone who is dying?"

"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 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 the McLaren Vale and the City of Tea Tree Gully.
- 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 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.
- There is increasing awareness and uptake of palliative care 'needs rounds' in residential aged care. Needs rounds are monthly meetings where residents palliative care needs are discussed based. 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 dying.[39]

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 framework for South Australia that:

- clearly defines advance care planning including consistent use of terms across government, health and aged care sectors
- 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 plans
- 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
- identifies mechanisms for recording, monitoring and reporting on the use of non-statutory advance care plans in South Australia
- identifies underpinning policy related to advance care planning.

2. Develop and promote a Compassionate Communities approach to build and foster death literacy and community capacity to provide support for those who are dying that operates alongside clinical care in South Australia

Outcomes we could see

- People in South Australia affected by life limiting illness receive care in accordance with their physical, social, cultural and spiritual needs and preferences.
- People are involved in decisions about their own care at the end of life.

PRIORITY 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 timely access to equipment."

"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."

"I want support around relinquishing care and that sense of losing control."

"I want staff who are interested and committed to providing excellent care."

"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."

"The quality of the nursing is the backbone of 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."

"Rural GPs provide the majority of palliative care in rural and remote Australia. This needs to be recognised and harnessed within the rural generalist training pathway."

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 delivery of 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 sub group 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:

1. Undertake Palliative Care Services Planning for South Australia that supports us to:
- Meet future population health needs and addresses 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
- Align service delivery with latest evidence and the National Palliative Care Standards (5th Edition – 2018).

2. Co-design integrated models of care that ensure that we provide the right care in the right place at the right time regardless of location or type of residence and that supports us to:
- Introduce and offer palliative care to consumers and families 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 consumers, carers and primary care providers
- Enhance palliative care services for alone and isolated consumers without support or social connections
- Provide appropriate and timely support for family and carers.

3. Develop a state-wide workforce strategy that identifies and addresses palliative care workforce development, attraction and retention requirements across our system with a particular focus on rural and remote areas.
4. Develop a comprehensive approach to Grief and Bereavement for South Australia that improves access to bereavement support for family and carers.

Outcomes we could see

- An appropriately skilled, resourced and distributed palliative care generalist and specialist palliative care workforce with the capability and capacity to deliver the palliative care services required by people in South Australia
- Knowledge and practice of palliative care is embedded in all care settings
- People in South Australia affected by life limiting illnesses receive care that matches their physical, social, cultural, spiritual needs and preferences.

PRIORITY 3

Enhance collaboration and coordination

What we have heard from our community:

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

"I want to be able to access the expertise of palliative care clinicians in residential aged care."

"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."

"I want my general practitioner and carer(s) to be kept informed."

"I want seamless coordination with the funeral director."

"I want a team approach to my care – to know that there will be a group of clinicians."

"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 want funding to shift so extra care can be provided in the community (or at the place of my choosing)."

"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."

"It is unclear when you transition to palliative and when and how you can access the hospice."

"Lack of communication between clinicians and my family."

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

"Earlier referral of appropriate patients so initiation of contact can occur earlier, and patients better supported during deterioration."

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 Extended Care Paramedics attend palliative care callouts to support care in the home and reduce emergency department presentations.
- 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 HealthPathways 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 models that address interface issues such as information sharing and funding barriers, to improve collaboration and coordination of care, seamless transition between settings and afterhours service provision
- promote the utilisation of existing platforms such as the Electronic Medical Record and My Health Record for sharing advance care planning documentation and to better coordinate care, especially for people with chronic and complex conditions, leading to better treatment decisions and reduced hospital admissions
- improve identification and support for those presenting at the Emergency Departments who will benefit from palliative care
- co-design patient pathways and supporting resources to support seamless identification, collaboration, communication and coordination across sectors and settings. This will include continuing to localise the existing suite of Palliative Care HealthPathways to the South Australian context.

Outcomes we could see

People in South Australia affected by life limiting illness have a consistent and coordinated experience of palliative care across care settings.

PRIORITY 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 consumers 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 provides 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 in South Australia 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:

- Develop and implement nationally consistent data collection mechanisms throughout community, specialist palliative care and acute service settings for both adult and paediatric palliative care
- Develop a system wide approach to the reporting and evaluation of palliative care data to support:
  - greater understanding of population trends, needs and service delivery outcomes
  - ongoing quality improvement
- Continue to support palliative care research and translation of research into practice
- Identify and resource the necessary capability to undertake data analysis and reporting on palliative care service delivery and outcomes in South Australia

Outcomes we could see

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.

13. Next Steps

The DHW will identify suitable governance to oversee the implementation of the 13 actions that have been identified in this Framework, this will include development of an implementation plan that identifies:

> roles and responsibilities for implementation;

> expected timeframes for completion over the life of the Framework;

> how the outcomes identified in the framework will be monitored and reported.

FRAMEWORK ACTIONS

1. Develop a comprehensive advance care planning framework for South Australia
2. Develop and support a Compassionate Communities approach to operate alongside clinical care in South Australia
3. Develop a Palliative Care Services Plan to drive commissioning of palliative care based on population health needs
4. Co-design and implement integrated, ambulatory models of care that meet the needs of different groups and different illness trajectories and complexities
5. Develop a Palliative Care workforce strategy that addresses workforce capacity, development, attraction and retention requirements
6. Develop a comprehensive approach to grief and bereavement for South Australia
7. Implement service models that address interface barriers such as funding and information sharing
8. Promote the use of existing platforms such as the Electronic Medical Record My Health Record for sharing advance care planning documentation
9. Improve identification of those who will benefit from palliative care or a palliative approach to care across all settings (particularly in ED and at care transitions)
10. Co-design patient pathways and supporting resources to support seamless identification, collaboration, communication and coordination of palliative care across sectors and settings
11. Contribute to the development and implementation of nationally consistent data collection mechanisms throughout community, specialist palliative care and acute settings
12. Develop a system wide approach to the reporting and evaluation of palliative care data including identification of resourcing to support this capability
13. Continue to support palliative care research and translation of research into practice

14. Glossary

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

Advance care planning

Advance care planning is a process of planning for health and personal care whereby the person's values, beliefs and preferences are made known so they can guide decision-making at a time when that person cannot make or communicate his or her decisions.

Advance care plan

An Advance Care Plan states a person's preferences about health and personal care and preferred health outcomes. They may be made by, with, or on the person's behalf, and are prepared from the person's perspective to guide decisions about care.[40]

Advance Care Directive

An Advance Care Directive is a legal document that allows a person to make their future healthcare preferences known if they were to lose their capacity to make decisions. It will only operate when a person no longer has decision-making capacity. The law and forms for Advance Care Directives are different in each state and territory and the terminology used may vary as well.[41]

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 systems.[42]

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 events.[43]

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 disciplines.[44]

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 carers and family. 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 home.[45]

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 decades."[46]

Palliative Care

An approach that improves the quality of life of patients and their families facing the problems associated with life-limiting illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.

"Palliative care:

- provides relief from pain and other distressing symptoms
- affirms life and regards dying as a normal process
- intends neither to hasten or postpone death
- integrates the psychological and spiritual aspects of patient care
- offers a support system to help patients live as actively as possible until death
- offers a support system to help the family cope during the patient's illness and in their own bereavement
- uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated
- will enhance quality of life, and may also positively influence the course of illness
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications."[47]

Person centered 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 consumers.[48]

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.[49]

15. Appendices

Appendix 1. 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	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, 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
Rebecca Aisbett, Business Solutionist, Commission on Excellence and Innovation in Health	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	Chair
Dr Peter Allcroft, Staff Specialist, Southern Adelaide Palliative Services	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, Divisional Rehabilitation, Aged Care & Palliative Care, Rehabilitation and Palliative Care, Flinders Medical Centre	Member

16. References

[1] Smith R. (2000). A Good Death. *An Important Aim for Health Services and for Us All. BMJ (Clinical research ed.)*, 320(7228), 129–130. https://doi.org/10.1136/bmj.320.7228.129

[2] SA Health. (2019). *Palliative Care Needs in South Australia October 2019.* Government of South Australia viewed online: https://www.sahealth.sa.gov.au/wps/wcm/connect/d34993a8-ea4f-4207-9ded-42d8709b010a/Palliative+Care+Needs+in+South+Australia+October+2019.pdf?MOD=AJPERES&CACHEID=ROOTWORKSPACE-d34993a8-ea4f-4207-9ded-42d8709b010a-nwKb9.N

[3] Swerissen H & Duckett S. (2014). *Dying Well.* Grattan Institute viewed at: https://grattan.edu.au/wp-content/uploads/2014/09/815-dying-well.pdf

[4] World Health Organization. (2020). *Palliative Care.* WHO. viewed at: https://www.who.int/news-room/fact-sheets/detail/palliative-care

[5] WHO (World Health Organization) 2014. *Global Atlas of Palliative Care at the End of Life* viewed online at: file://dhgsf01/users$/ahill07/Downloads/WHPCA_Global_Atlas_DIGITAL_Compress.pdf

[6] Palliative Care Australia. (n.d.). *What is Palliative Care.* https://palliativecare.org.au/what-is-palliative-care

[7] World Health Organization. (2020). *Palliative Care, Key Facts.* WHO. https://www.who.int/news-room/fact-sheets/detail/palliative-care

[8] Australian Institute of Health and Welfare. (2020). *Palliative Care Services in Australia Web Report.* Australian Government viewed at: https://www.aihw.gov.au/reports/palliative-care-services/palliative-care-services-in-australia/contents/overview

[9] Australian Government Department of Health. (2020). *National Palliative Care Strategy 2018*, viewed at: https://www.health.gov.au/sites/default/files/the-national-palliative-care-strategy-2018-national-palliative-care-strategy-2018.pdf

[10] Palliative Care Australia. (2018). *Palliative Care Service Development Guidelines January 2018.* Viewed at: https://palliativecare.org.au/wp-content/uploads/dlm_uploads/2018/02/PalliativeCare-Service-Delivery-2018_web-1.pdf

[11] World Health Organization. (2020). *Palliative Care, Key Facts.* WHO.viewed at: https://www.who.int/news-room/fact-sheets/detail/palliative-care

[12] Productivity Commission. (2017). *Introducing Competition and Informed User Choice into Human Services: Reforms to Human Services.* Report No. 85. Canberra.viewed at: https://www.pc.gov.au/inquiries/completed/human-services/reforms/report/human-services-reforms.pdf

[13] NSW Ministry of Health. (2019). *End-of-life and Palliative Care Framework 2019-2024.* NSW Government. https://www.health.nsw.gov.au/palliativecare/Publications/eol-pc-framework.pdf

[14] Worldwide Palliative Care Alliance. (2014). *Global Atlas of Palliative Care at the End-of-life.* World Health Organization. https://www.who.int/nmh/Global_Atlas_of_Palliative_Care.pdf

[15] Australian Institute for Health and Welfare, 2018, *Older Australia at a glance*, web report viewed online at: https://www.aihw.gov.au/reports/web/194/older-australia-at-a-glance/contents/demographics-of-older-australians/australias-changing-age-gender-profile

[16] World Health Organization. (2020). *Palliative Care, Key Facts.* WHO. https://www.who.int/news-room/fact-sheets/detail/palliative-care

[17] SA Health. (2019). *Palliative Care Needs in South Australia October 2019*. Government of South Australia. https://www.sahealth.sa.gov.au/wps/wcm/connect/d34993a8-ea4f-4207-9ded-42d8709b010a/Palliative+Care+Needs+in+South+Australia+October+2019.pdf?MOD=AJPERES&CACHEID=ROOTWORKSPACE-d34993a8-ea4f-4207-9ded-42d8709b010a-nwKb9.N

[18] Morin L, Aubry R, Frova L, MacLeod R, Wilson DM, Loucka M, Csikos A, Ruiz-Ramos M, Cardenas-Turanzas M, Rhee Y, Teno J, Öhlén J, Deliens L, Houttekier D & Cohen J. (2019). *Estimating The Need for Palliative Care at The Population Level: A Cross-National Study in 12 Countries. Palliative Med, 31(6)*, 526-536. https://doi.org/10.1177/0269216316671280

[19] Palliative Care Australia, 2018 *Palliative Care Service Development Guidelines January 2018* p.10 Figure 2. Typical Illness trajectories adapted from: Murray, SA, Kendall M, Boyd K et al. 2013 *'Illness trajectories and palliative care'* British Medical Journal, 330 (7498) 1007-11

[20] SA Health. (2019). *Palliative Care Needs in South Australia October 2019*. Government of South Australia. Viewed online at: https://www.sahealth.sa.gov.au/wps/wcm/connect/d34993a8-ea4f-4207-9ded-42d8709b010a/Palliative+Care+Needs+in+South+Australia+October+2019.pdf?MOD=AJPERES&CACHEID=ROOTWORKSPACE-d34993a8-ea4f-4207-9ded-42d8709b010a-nwKb9.N

[21] Palliative Care Australia, *2018 Palliative Care Service Development Guidelines*, viewed at: https://palliativecare.org.au/wp-content/uploads/dlm_uploads/2018/02/PalliativeCare-Service-Delivery-2018_web2.pdf

[22] Noonan K, Horsfall D, Leonard R & Rosenberg J. (2016). *Developing Death Literacy. Progress in Palliative Care*, 24(1), 31-35. https://doi.org/10.1080/09699260.2015.1103498

[23] Noonan K, Horsfall D & Kelly M. (2018). *Beyond Taboos? Australians' Capacity to Care for Each Other Through Death, Dying and Loss.* Research Report. The GroundSwell Project. Sydney. Viewed online: https://static1.squarespace.com/static/5f27363644ecfc2277942c88/t/5fd1a575ce71ee580fa7b883/1607574912249/Beyond+Taboos_The+GroundSwell+Project.pdf

[24] Advance Care Planning Australia. (2020). *Advance Care Planning Explained*. Austin Health. Viewed onlne at: https://www.advancecareplanning.org.au/understand-advance-care-planning/advance-care-planning-explained

[25] Advance Care Planning Australia, 2021 viewed online at: https://www.advancecareplanning.org.au/understand-advance-care-planning/advance-care-planning-in-specific-health-settings/advance-care-planning-and-dementia

[26] SA Health. (2019). *Palliative Care Needs in South Australia October 2019*. Government of South Australia viewed online at: https://www.sahealth.sa.gov.au/wps/wcm/connect/d34993a8-ea4f-4207-9ded-42d8709b010a/Palliative+Care+Needs+in+South+Australia+October+2019.pdf?MOD=AJPERES&CACHEID=ROOTWORKSPACE-d34993a8-ea4f-4207-9ded-42d8709b010a-nwKb9.N

[27] Australian Government Department of Health, *2020 Exploratory Analysis of Barriers to Palliative Care – Issues Report on people with disabilities*, viewed online at: https://www.health.gov.au/resources/publications/exploratory-analysis-of-barriers-to-palliative-care-issues-report-on-people-with-disabilities

[28] Australian Government Department of Health, 2020 *Exploratory Analysis of Barriers to Palliative Care – Issues Report on people from culturally and linguistically diverse backgrounds*, viewed online at: https://www.health.gov.au/sites/default/files/documents/2020/01/exploratory-analysis-of-barriers-to-palliative-care-issues-report-on-people-from-culturally-and-linguistically-diverse-backgrounds-issues-report-on-people-from-culturally-and-linguistically-diverse-backgrounds.pdf

[29] Australian Government Department of Health, 2020 *Exploratory Analysis of Barriers to Palliative Care – Issues Report on Aboriginal and Torres Strait Islander Peoples* viewed online at: https://www.health.gov.au/resources/publications/exploratory-analysis-of-barriers-to-palliative-care-issues-report-on-aboriginal-and-torres-strait-islander-peoples

[30] Australian Government Department of Health 2020, *Exploratory Analysis of barriers to palliative care issues report on people who identify as lesbian, gay, bisexual, transgender or intersex*, viewed online at: https://www.health.gov.au/sites/default/files/documents/2020/01/exploratory-analysis-of-barriers-to-palliative-care-issues-report-on-people-who-identify-as-lesbian-gay-bisexual-transgender-or-intersex.pdf

[31] Australian Government Department of Health, 2020 *Exploratory Analysis of Barriers to Palliative Care – Issues Report on people experiencing homelessness*, viewed online at: https://www.health.gov.au/sites/default/files/documents/2020/01/exploratory-analysis-of-barriers-to-palliative-care-issues-report-on-people-experiencing-homelessness.pdf

[32] SA Health. (2019). *Palliative Care Needs in South Australia October 2019*. Government of South Australia. Viewed online: https://www.sahealth.sa.gov.au/wps/wcm/connect/d34993a8-ea4f-4207-9ded-42d8709b010a/Palliative+Care+Needs+in+South+Australia+October+2019.pdf?MOD=AJPERES&CACHEID=ROOTWORKSPACE-d34993a8-ea4f-4207-9ded-42d8709b010a-nwKb9.N

[33] Khalili H, Hall J & DeLuca S. (2014). *Historical Analysis of Professionalism in Western, Societies: Implications for Inter-professional Education and Collaborative Practice. J Interprof Care, 28*(2), 92-7. Viewed at: https://doi.org/10.3109/13561820.2013.869197

[34] palliAGED. (2020). *Care Coordination.* CareSearch, Flinders University. Viewed at: https://www.palliaged.com.au/tabid/4452/Default.aspx

[35] Palliative Care Australia, 2020, *Palliative Care Australia Members' Forum, Discussion Summary*, 17 November 2020

[36] Palliative Care Australia. (2018). *Background Report to the Palliative Care Service Development Guidelines*, prepared by Aspex Consulting, Melbourne. viewed at: https://palliativecare.org.au/wp-content/uploads/dlm_uploads/2018/02/PalliativeCare-Background-to-Service-Delivery-2018_v3.pdf

[37] Palliative Care Australia. (n.d.). *Workforce for Quality Care at End-of-life, Position Statement.* Viewed at: https://palliativecare.org.au/wp-content/uploads/2015/08/PCA-Workforce-position-statement.pdf

[38] Howe, A *Aged care, death and taxes after the royal commission*, The Conversation, 2021, viewed at: https://theconversation.com/aged-care-death-and-taxes-after-the-royal-commission-145297

[39] Little Company of Mary Healthcare Limited and University of Stirling 2020, *Palliative Care Needs Rounds: The Implementation Guide*, viewed at: https://www.calvarycare.org.au/wp-content/uploads/2020/08/Calvary-Palliative-Care-Needs-Rounds-Implementation-Manual.pdf

[40] Australian Government Department of Health 2018 *National Palliative Care Strategy*, 2018 viewed at: https://www.health.gov.au/resources/publications/the-national-palliative-care-strategy-2018

[41] Palliative Care Australia, 2018 *National Palliative Care Standards 5th Edn*, viewed at: https://palliativecare.org.au/wp-content/uploads/dlm_uploads/2018/02/PalliativeCare-National-Standards-2018_web-3.pdf

[42] Carers Australia, *Who is a Carer*, viewed at: https://www.carersaustralia.com.au/about-carers/who-is-a-carer/

[43] Australian Commission on Safety and Quality in Healthcare, *National Consensus Statement: essential elements for safe and high-quality end of life care* 2015, viewed at: https://www.safetyandquality.gov.au/publications-and-resources/resource-library/national-consensus-statement-essential-elements-safe-and-high-quality-end-life-care

[44] Palliative Care Australia, *National Standards Assessment Program Fact Sheet, Defining your Specialist Palliative Care Service*, viewed at: https://palliativecare.org.au/wp-content/uploads/dlm_uploads/2018/05/NSAP-Defining-your-Specialist-PC-Service-new.pdf

[45] NSW Ministry of Health. *NSW Integrated Care Strategy* 2016 viewed at: www.health.nsw.gov.au/integratedcare/Pages/integrated-care-strategy.aspx

[46] Australian Government Department of Health 2018 National Palliative Care Strategy, 2018 viewed at: https://www.health.gov.au/resources/publications/the-national-palliative-care-strategy-2018

[47] World Health Organization, 2017b. WHO *Definition of Palliative Care*. Viewed on line at: http://www.who.int/cancer/palliative/definition/en/

[48] Australian Government Department of Health 2018 National Palliative Care Strategy, 2018 viewed at: https://www.health.gov.au/resources/publications/the-national-palliative-care-strategy-2018

[49] Australian Commission on Safety and Quality in Healthcare 2015

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