

Victoria's end of life and palliative care framework

A guide for high-quality end of life care for all Victorians

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Authorised and published by the Victorian Government, 1 Treasury Place, Melbourne.

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Except where otherwise indicated, the images in this document show models and illustrative settings only, and do not necessarily depict actual services, facilities or recipients of services. This document may contain images of deceased Aboriginal and Torres Strait Islander peoples.

In this document, 'Aboriginal' refers to both Aboriginal and Torres Strait Islander people. 'Indigenous' or 'Koori/Koorie' is retained when part of the title of a report, program or quotation.

ISBN 978-0-7311-6979-5 (online/PDF)

Available at the department's website <[hyyps://www2.health.vic.gov.au/palliative-care](http://www2.health.vic.gov.au/palliative-care)>
(1605025)

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Acknowledgements

The Department of Health (the department) would like to respectfully acknowledge the traditional owners throughout Victoria and acknowledge their ancestors and Elders both past and present.

The department would like to acknowledge and thank the many individuals, families, carers, and representatives of Aboriginal and Torres Strait Islander communities and culturally and linguistically diverse groups who voluntarily shared their perspectives and experiences of end of life care at the 28 community consultation sessions.

Victoria's end of life and palliative care framework has been developed following extensive consultation with community members, consumers, carers and service providers. Their collective experience and expertise are acknowledged and appreciated.

The views of many Victorians were also received through the <www.betterendoflife.vic.gov.au> website in the form of written submissions, web conversations and tweets. Their participation has facilitated public discussions around important end of life issues which are reflected within the framework.

Finally, this framework has benefited from the expert advice and guidance provided by members of the End of Life and Palliative Care Advisory Group, whose contribution is gratefully acknowledged:

- Professor Robert Thomas, Chief Advisor Cancer, Department of Health & Human Services
- Associate Professor Mark Boughey, Chairperson, Palliative Care Clinical Network
- Ms Fran Gore, non-government organisation representative, Mercy Health
- Dr Peter Hunter, Geriatrician, Alfred Health
- Dr Juli Moran, Palliative medicine consultant, Austin Health
- Ms Irene Murphy, Palliative care nurse practitioner, Gippsland Region Palliative Care Consortium
- Mr Danny Vadasz, Health Issues Centre

The department acknowledges the use of the artwork *Supporting Our Journey* by artist Kahli Luttrell.

Victoria's end of life and palliative care framework

All Victorians are entitled to high-quality end of life care that relieves pain, distress and suffering and provides support to their family, friends and carers.

It is no longer possible to leave end of life care to palliative care providers. Current end of life and palliative care models are unsustainable and will not meet future demand without significant redesign.

This end of life and palliative care framework requires the healthcare, human services, social and community sectors to connect and work together to develop innovative new strategies to deliver care. Importantly, the framework redefines end of life care and guides providers across all sectors to take responsibility for delivering high-quality end of life care.

Some people in Victoria are less likely to receive end of life care that meet their needs. Aboriginal and Torres Strait Islanders, people in rural areas, LGBTI (lesbian, gay, bisexual, transgender or intersex) people, people from culturally and linguistically diverse communities, Forgotten Australians, people with conditions other than cancer and those with a disability, a mental health condition or who are homeless are experiencing inequitable end of life care. This cannot continue.

The framework emphasises a person-centred approach for delivering care according to people's preferences and goals. It focuses on understanding what matters to people who are dying and their families. It outlines plans to redesign our services to be effective, with a focus on delivering care being everybody's responsibility in the healthcare system as part of an integrated service.

Organisations and services have an obligation to equip staff and ensure their organisational culture supports staff in the delivery of high-quality end of life and palliative care, including bereavement support and staff well-being programs.

Priorities

To achieve this, the framework will deliver actions on five priorities:

- delivering person-centred services
- engaging communities, embracing diversity
- coordinating and integrating services
- making quality end of life and palliative care everyone's responsibility
- strengthening specialist palliative care.

By focusing on these priorities, Victorians will be able to receive high-quality care that is consistent everywhere, including in their homes and in local communities. The framework aims to deliver care where and when people require it and ensure people from all walks of life can determine what happens to them at the end of their life.

The framework maximises the expertise of palliative care specialists as a core component of service redesign and sets clear expectations about the delivery of end of life care across the healthcare system. This includes encouraging and facilitating people to have conversations about what matters to them to live well, to die well and to put plans in place for the future.

This framework sets out a foundation for end of life and palliative care by:

- providing clear expectations about how end of life and palliative care will be delivered

- guiding healthcare, human services, social and community sector practices
- identifying actions to ensure end of life and palliative care services are sustainable
- ensuring Victorians are provided with safe and effective end of life care.

By broadening the mandate and redefining end of life care, the framework articulates clear expectations, enabling a broader range of staff to respond to people's end of life care needs in our diverse community.

Who is the framework for?

The audiences for the framework include the following groups.

People

The framework highlights how you can take more control of what happens at the end of your life. It provides information to help you better understand the healthcare system, the challenges we face and suggestions on how to contribute to redesigning and improving care in Victoria.

Communities

The framework provides direction and advice for communities and groups that may not previously have had the necessary information, awareness or access to services. This includes local government agencies, clubs and organisations, all of which play a role in providing people with access to services and enhancing end of life awareness.

Clinicians and Service providers

The framework sets direction for people working in the healthcare, human services, social and community sectors. It outlines innovative opportunities for services and agencies to connect and work together in ways that best fit your locality or region.

The framework asks everyone working in the healthcare, human services, social and community sectors to take responsibility and perform a role in delivering end of life care. Palliative care services alone cannot meet the growing demand that our society will require for care in the final stage of life.

Recognising that a person is dying is an essential requirement for all health professionals working in the healthcare, human services, social and community sectors. The framework provides direction and advice for all staff and workers regardless of profession, discipline or level of expertise.

Have the conversation

Talking about death can be difficult and confronting but is a conversation we all need to have – as individuals, families, communities and as a society. Community consultations conducted for the framework revealed that people want more information about what can happen in the time leading up to death; many have expressed interest in wanting opportunities to talk about death and to document their values in an advance care plan.

The existing legal framework in Victoria for future health decision making is complex. Some people's values remain unknown, sometimes placing feelings of guilt or uncertainty on loved ones.

Documenting preferences and values and having them legally recognised using advance care planning plays an important role in giving people assurance that their preferences and values will be respected.

This means supporting people to have conversations about what matters to them to live well and to die well and to plan for the future in advance.

Why we need to change

Approximately 39,000 people die in Victoria each year.¹ Palliative and end of life care is available across the state, with specialist palliative care providing bed-based, home-based and consultancy services in regional Victoria and metropolitan Melbourne.

Regional consultancy services play an important role in supporting small rural health services and general practitioners in providing end of life care for their local communities. Statewide services include the Victorian Paediatric Palliative Care Service, services for motor neurone disease, Very Special Kids and a statewide specialist bereavement service.

Recommendations were advised by the 2015 Victorian Auditor-General's report into palliative care² and this framework aims to align with the *National Consensus Statement: essential elements for safe and high-quality end of life care* (2015).³ This statement is very relevant for those working in hospital settings.

In addition, demand for end of life and palliative care in Victoria is increasing at an average annual rate of four per cent.⁴ Current service models are unsustainable and will not be able to meet future demand, expectations or needs. These factors led the Victorian Government to a statewide public consultation process in 2015–16.

Public consultation

The consultation process engaged community, consumers, carers and providers about their views and ideas about end of life and palliative care. Their views have informed this framework.

- Close to 700 people participated in 28 public consultations in 18 locations across Victoria.
- Close to 40 organisations and more than 40 community members provided written submissions.
- Fifty website and more than 200 tweet submissions were received.

A wide range of people, including community members, carers and service providers, attended the public consultations. Service providers represented specialist palliative care, aged care, disability services, district nursing, general practice and primary healthcare.

Many of Victoria's health peak bodies and consumers participated, and targeted consultations were held with representatives of Aboriginal and Torres Strait Islander communities, culturally and linguistically diverse groups and current and recent users of end of life and palliative care services.

We conducted extensive analysis on all feedback and submissions to identify themes, ideas and areas of concern. We considered people's ideas, suggestions, concerns and proposals. These have informed the development of the framework and its vision, goals, principles, priority areas and aims.

What we have learned

It is clear that the needs of people who are dying and their families are changing. Community expectations about end of life and palliative care have shifted, and we can no longer rely on traditional approaches to palliative care to meet these needs and expectations. These changes include:

- People want to receive care in their homes and local communities as much as possible.
- People want information that supports them to be partners in decisions about their care.

- People need end of life and palliative care that responds to an ageing population.
- People are sicker and require palliative care that can be provided alongside other treatments that respond to their complex care needs.
- Many people with chronic or life-limiting illnesses (including some cancers) are living for much longer, requiring a different response from end of life and healthcare services.
- Some groups in our community do not access services for end of life care, or get the care they need.
- The healthcare, human services and community workforce needs to adapt with new skills to better identify and support the end of life needs of people, their families and carers.
- All services need to operate more efficiently in order to deliver care that is sustainable.
- Community expectations have increased, with growing interest in discussing death and dying and planning for end of life with a method such as advance care planning.

Defining end of life and palliative care

The terms 'end of life care' and 'palliative care' have different meanings to many people. This framework uses these terms to help focus how interventions are provided by services to people, where and when they need them most.

End of life care

In this framework, 'end of life care' describes the care needed for people who are likely to die in the next 12 months due to progressive, advanced or incurable illness, frailty or old age.⁵ This period is important to recognise because people may experience rapid changes and fluctuations in their condition and often have multiple contacts with a range of health services.

Understanding that a person is entering the last months or year of life can be difficult to determine. Nevertheless, being able to recognise that a person may be dying is an essential requirement for clinicians. A focus on the 12 months before death allows for optimal planning of care. It allows time to engage in purposeful conversations with people and their families to discuss their preferences and what matters to them. It focuses on approaches to meet people's needs in the last year, months, weeks and days of life.

Palliative care

The term 'palliative care' describes an approach to care that improves the quality of life of people and their families who are facing the problems associated with a progressive illness. It does this by preventing and relieving suffering through early identification and assessment, by treating pain and other physical, psychosocial and spiritual problems and by addressing practical issues.⁶

Palliative care is based on people's needs rather than diagnosis or possible time to death and is delivered by a range of health and community providers. Palliative care can be provided at the same time as other treatment intended to reverse or resolve particular conditions.

Specialist palliative care

'Specialist palliative care' refers to clinicians who have specialist qualifications in palliative care and the designated specialist palliative care sector funded to provide care for those with the most complex end of life and palliative care needs.

Often the most valuable role palliative care specialists play is supporting other healthcare teams and professionals through consultation, advice and support to provide end of life care to their patients.

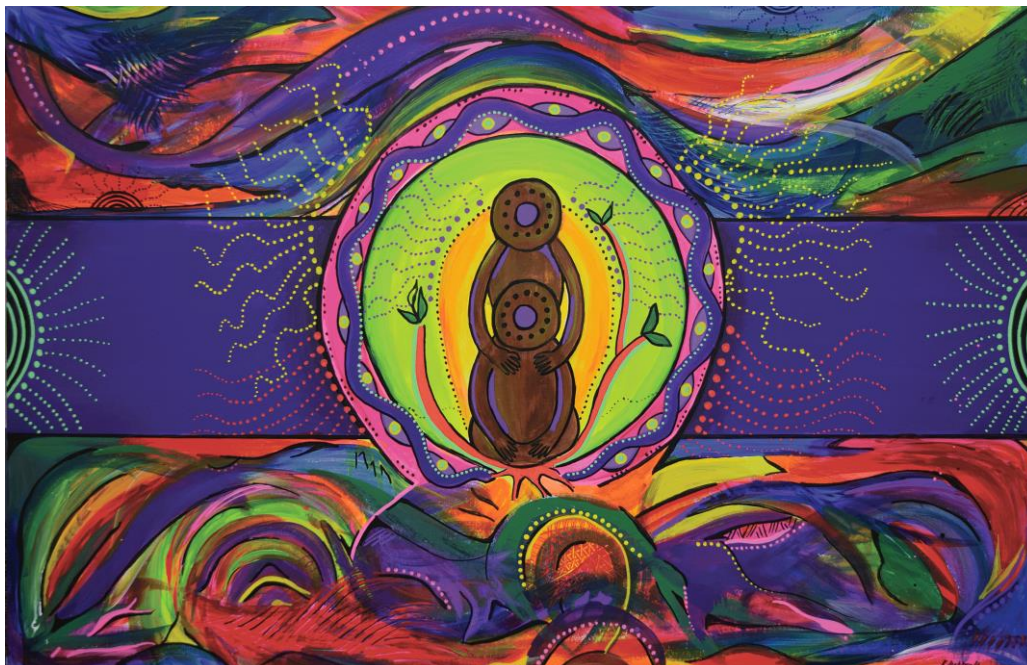
Differing needs and care co-exist

People require varying levels of end of life and palliative care. Some people may need little care, dying unexpectedly, quickly or quietly at home. Others may have conditions with a poor prognosis resulting in early or sudden death in which palliative care may be necessary for only a few weeks.

However, some people may require end of life and palliative care for months or many years. This represents one of the biggest challenges for our health, human services, social and community sectors.

The needs of people with chronic or life-limiting conditions can fluctuate, often over a long period. People with these conditions (mostly those other than cancer) may have exacerbations of their illness, requiring acute treatment to stabilise their condition. One of these episodes could potentially lead to the end of their life. Palliative care can assist by delivering quality-of-life interventions at the same time as other curative-type treatments, contributing to relieving suffering in accordance with a person's preferences.⁷

Supporting our journey



The artwork titled *Supporting our journey* 'symbolises the strong support given by family and community, helping us through our journey that we are travelling. The lines symbolise our path as well as the journey of others. The dots represent the many people who help us or who are on the same path.'

Kahli Luttrell, Yorta Yorta descendent and artist.

Principles guiding this framework

Through consultation for the framework, people and organisations contributed their thoughts and ideas to the principles. This helped establish seven guiding principles that subsequently informed the vision, goals, priority areas and aims.

Dying is part of life

Dying is a normal part of life and being human, not just a biological or medical event.⁸

The person is central to care

A person's care is tailored and holistic; their rights, values and preferences are respected and they determine their own care whenever possible.

Carers are important

Carers receive recognition, support and are valued throughout their caring experience and after a person's death.

All people have information they discuss openly

People, their carers and families have information they understand about genuine choices that they can discuss authentically with their doctor and service providers.

Decision making is legalised and respected

People's decisions that may involve substitute decision-makers, health providers, families and carers are recognised and respected in accordance with relevant legislation.

Services are high-quality and coordinated

Individuals, their carers and families receive coordinated, integrated care from skilful staff.

Care and services are monitored

Underpinning end of life care are best practice evidence, effective monitoring, evaluation of patient-centred outcomes and supporting innovation.

These principles have informed a vision for Victoria and goals to achieve it as outlined below.

Our Vision

The Victorian Government is committed to improving end of life care for all Victorians. The vision for the framework is:

'All Victorians and their families receive the best possible end of life care that places them at the centre where preferences, values, dignity and comfort are respected and quality of life matters most.'

Goals of the framework

To achieve this vision, the government has developed the following goals in consultation with community and expert representatives.

Goals

- People experience optimal end of life care.
- People's pain and symptoms are managed using quality interventions.
- People's preferences and values are recognised and respected in their end of life care.
- Better support for carers.
- People are cared for in their place of choice.
- Where possible, people can choose to die in their place of choice.

These goals inform the development of system measures used to monitor our progress and improvement towards the vision for end of life and palliative care.

Priority areas

Following on from consultation with community and expert representatives, the government identified five priority areas to address for improvement. The priority areas guide investment in end of life and palliative care. Each priority area has specific aims for which actions will be implemented.

The following summary outlines the priority areas and aims for each, in order to deliver the right care at the right time and in the right place, to respond to the needs of people and their families.

Priority 1: Person-centred services

- A person's care is individualised.
- Families and carers are supported and valued.
- People have information that supports decision making.
- People have opportunities to develop their advance care plan.

Priority 2: Engaging communities, embracing diversity

- All communities and groups have access to end of life care and planning.
- Improved engagement with community leaders to enable them to connect their communities to end of life care.
- Communities understand the services available for end of life care and bereavement support.

Priority 3: People receive services that are coordinated and integrated

- People experience services that are coordinated and designed locally.
- The primary, hospital, palliative and aged care sectors connect effectively to respond to care needs.
- Early discussion, referral, planning and coordination occurs.

Priority 4: Quality end of life and palliative care is everyone's responsibility

- Knowledge is increased across the healthcare sector to provide safe, quality care.
- End of life care is consistent across the healthcare system.
- Healthcare staff are equipped to communicate and deliver the benefits of palliative care.
- Organisations actively support their staff in the delivery of quality end of life care.

Priority 5: Specialist palliative care is strengthened

- Models of home-based care are effective and efficient.
- The specialist workforce is used effectively.
- Specialist palliative care is accessible locally.

What we plan to do

'Health services look at the way they provide end of life care to see whether this care is safe and of high quality.'

(National Consensus Statement: Essential elements for safe and high-quality end of life, 2015)

In order to deliver on the priority areas for end of life and palliative care, the Victorian Government will:

- acknowledge people's preferences by introducing statutory recognition of advance care directives for existing and future conditions
- ensure people's preferences are discussed, documented, actioned and reviewed by implementing advance care planning
- provide people with coordinated integrated care by testing new models of care
- ensure people receive the right care in the right place by developing new models of home-based palliative care
- ensure people receive consistent care everywhere by standardising community palliative care, including referral and assessment criteria
- enable volunteers to access programs with training, support and mentorship
- ensure equity of access for all communities and groups and provide for diverse care needs in redesigned models of care.

We recognise the role of the Australian Government in primary care and residential aged care delivery. We will advocate for improvements in end of life and palliative care to maximise the delivery of quality care in those settings.

The Department of Health will work with communities and services to deliver the right care at the right time and in the right place by:

- focusing on people and outcomes
- enabling local solutions
- equipping the service system to deliver earlier and more connected support
- ensuring safety, quality assurance and innovation
- using data and evidence for service development and monitoring.

Measurement and accountability

We will streamline performance measurement and accountability to monitor progress towards achieving the framework goals across all relevant services. Monitoring is important to ensure people and their families and carers receive high-quality care.

The service system will be equipped to deliver care by continuing to identify and reduce barriers and create new opportunities. Improving data integrity will assist health services to better plan for the care they provide. This will be implemented progressively according to the capability of services.

We need to ensure interventions are evidence-based, reduce low-value and futile care, and commit to ongoing and rapid translation of new evidence into service delivery. Greater transparency about

system performance and accountability of all health service providers for the outcomes they deliver will drive system improvement and improvements in care.⁹

How will we know we are improving?

The following chart outlines how data from information systems will be used to measure our progress across all priority areas in achieving the framework goals.

Goals	Measures
People experience optimal end of life care	Client and carer experience survey data
People's pain and symptoms are managed with quality interventions	Benchmarked patient outcomes
People express and record their values and preferences for end of life care	Documented evidence of advance care plans in patient records
Carers are supported	Client and carer experience survey data
People are cared for in their place of choice	Care delivered in the person's place of choice
Where possible, people die in their place of choice	The person dies in their place of choice

Priority 1: Person-centred services

'Person-centred approaches reduce anxiety and improve quality of life.'

(Conversations – Creating choice in end of life care, Australian Centre for Health Research, 2016)¹⁰

Priority 1 aims

- A person's care is individualised.
- Families and carers are supported and valued.
- People have information that supports decision making.
- People have opportunities to develop their advance care plan.

What Victorians said

Victorians said they want:

- responsive care for their life-limiting or chronic condition
- end of life care centred on themselves, their family and carer
- care individually designed for them, empowering them to live and die well according to their own choices
- to have more control over their own care and more involvement in decision making with their treatment team
- choice about their care and about where they will eventually die
- more opportunities to talk about and plan for death – both with their doctor or trusted health professional and collectively in community groups or clubs
- choices discussed early, documented and reviewed regularly, for example, in an advance care plan
- confidence that clinicians will acknowledge and respect their values
- assurance their choices will be actioned when the time comes and they no longer have the capacity to make their own decisions.

'Ask me and my wife what I value and what's important to me – let's talk openly using simple language.'

Graham, aged 67, living with cancer

What families and carers said

Victorian families and carers said they want:

- more information, support and advice about end of life care
- reassurance or help with a loved one's care at any hour – day or night, seven days a week
- support for dealing with grief and bereavement before, during and after their loved one's death
- carers require specific and considerable assistance to perform their caring role. They also want recognition as part of the treatment team.
- options available for appropriate respite.

What the evidence tells us

Person-centred care

There is a high degree of consensus that person-centred care respects a person's values, preferences and expressed needs, includes an awareness of quality-of-life issues and involves information, communication and education.¹¹ Person-centred care is grounded in mutually beneficial partnerships between people, their families, significant others such as close friends, and healthcare providers.¹²

We need to deliver a more person-centred approach, respecting people and their preferences, taking into account the whole person and what they value as important.¹³ People should be educated about the essential role they play in their care and clinicians, in turn, need to relinquish their role as a single authority and learn to ask the person, "What matters to you?"¹⁴

There is clear evidence that when people are involved in their own health decisions, their experience and quality of care improves.¹⁵ Satisfaction with their care improves as well as clinical outcomes.¹⁶ People's wishes for care and where they die are achieved and unwanted hospital admissions are avoided.¹⁷

Authentic person-centred care requires easily accessible and easily understood information.¹⁸ To achieve the best outcomes, people and families must be actively engaged in decisions and have enhanced access to information and support.¹⁹ An advance care plan records values, beliefs and preferences to provide clarity for health professionals who provide treatment and services.²⁰ People are more likely to receive care consistent with their choices if it has been discussed.²¹ Failure to talk about and plan for death is one of the most significant obstacles to improving the quality of dying, particularly if discussion is insufficient or delayed.²²

Better support for carers

Carers provide the backbone of care to many spending time at home at the end of life, regardless of where death actually occurs.²³ They experience stress due to uncertainty of their loved ones condition, a perceived lack of support²⁴ and questions about how to provide care. This places carers at increased risk of anxiety, burnout and other issues with their own health.²⁵

Access to good quality information as a central coping resource is essential for carers, supports them in caring for people at end of life and helps them better manage their caring role.^{26,27} Two studies found that carers were empowered to take on their often complex caring role when they had adequate information and knowledge they can understand.²⁸

Telephone support or a nurse visit is associated with easing anxiety and improving family support overall.^{29,30} Even if not used often, telephone support makes carers feel that someone is there for them.³¹ By connecting carers to experienced staff by telephone when problems emerge, they can often avoid emergency department visits.^{32,33}

Evidence shows that people who experience complicated grief are more likely to have poor health and psychological and social outcomes.³⁴ For people who have been assessed as experiencing complicated grief, specialist interventions have been demonstrated to be of value.³⁵

What we plan to do

The Victorian Government plans to introduce statutory recognition through legislation of advance care directives. Victorians who have the capacity will be able to document treatment and care preferences for existing and future conditions.

We will implement advance care planning that will help ensure people's preferences for end of life care are discussed, documented and reviewed. These preferences provide guidance for clinicians, families and carers when making medical decisions on their behalf.

We will improve access to information and resource material, enabling greater awareness of end of life and bereavement support. By responding to the need for information and knowledge, local communities will be supported to gain greater understanding of end of life care and issues.

What can you do

'I found all the info I need to do an advance care plan at the [Better Health website](http://www.betterhealth.vic.gov.au) <www.betterhealth.vic.gov.au>.'

'At our hospital we talk more to patients about their values and what is important to them for their future care.'

Priority 2: Engaging communities, embracing diversity

'Developing and sustaining end of life knowledge enables communities to act more effectively when someone in their community is dying.'

(End of life at home: co-creating an ecology of care, Western Sydney University, 2015)³⁶

Priority 2 aims

- All communities and groups have access to end of life care and planning.
- Improve engagement with community leaders to enable them to connect their community's end of life care.
- Communities understand the services available for end of life care and bereavement support.

What Victorians said

- Groups needing greater support include Aboriginal and Torres Strait Islander communities, people living in rural and remote areas, people living in aged and disability residential care, adolescent and younger adults, children, LGBTI people, Forgotten Australians, people from culturally and linguistically diverse communities and those with conditions other than cancer or with mental health conditions or people who are homeless.
- Some communities and groups recognise that they have not accessed end of life services and may not have had the relevant information to do so. They suggest their strength as a community could be used to greater advantage to build their own capacity and connect with end of life services.
- Groups and communities identified key community members or Elders as being direct channels of communication, influence and leadership.
- Rural communities highlighted the inequity of access to end of life care compared with their metropolitan counterparts.
- Many said spiritual preferences and cultural traditions and customs need consideration. Some cultural customs about death were often incompatible with certain hospital or legal regulations.
- Centralised culturally appropriate information in multiple formats and languages is required. Some end of life concepts can be confronting and confusing for other cultures. Understanding the nuances of their culture or group is needed to provide appropriate translations.
- Adolescent and young adults felt that early involvement to establish trust, normalisation and appropriate inpatient facilities were deemed important.

'It would be really good to have someone from my own culture given enough help so they can look after me.'

Shiromi, aged 23, living with lymphoma

What the evidence tells us

Culture is the internal and external manifestation of a person's values, norms and beliefs that is learnt throughout life. Cultural awareness is the ability to acknowledge differences.³⁷ Despite Australia's cultural diversity, ethnic minority groups continue to have less access to healthcare including palliative and end of life care.^{38,39}

We need to overcome disparities in access and outcomes for individuals and communities across the state.⁴⁰ Ensuring equity of access can be achieved through improvements in provider processes and strengthening engagement and community connectedness.⁴¹ Meaningful community engagement and information sharing contributes to improved health outcomes and culturally appropriate care.⁴²

People needing end of life care spend most of their time with family, friends, acquaintances and colleagues, not healthcare workers. These networks help families and carers cope, particularly for people dying at home.⁴³ While formal providers are supportive, they do little to establish or maintain these networks despite much scope to do so.⁴⁴

People with disabilities can often be in situations of rapid deterioration leading to end of life and palliative care needs. They need appropriate and timely access to care.

Preparing communities to help their own people at end of life may include building social capital or creating an 'ecology of care' relevant to their local culture. Carers find caring difficult when their communities do not support them. Informal networks, attachment to place, environment and protective networks for carers enable greater support.⁴⁵

Education with a specific focus for Aboriginal health practitioners has resulted in greater engagement with Indigenous communities to improve end of life care.⁴⁶ A flexible, clinical learning experience supports skill development in providing culturally appropriate palliative care for Indigenous Australians.⁴⁷

Cultural competence is an amalgam of skills, abilities, capabilities and competencies necessary for the establishment of respectful and culturally appropriate relationships.⁴⁸ Taking the time to understand a person's unique cultural needs, values and beliefs is the most respectful way of delivering palliative care and facilitating a dignified death. An interpreter may be required to achieve this.⁴⁹ For younger people in particular, a challenge to overcome can be the desire to provide hope through treatment, whilst also discussing the possibility of dying.⁵⁰

What we plan to do

We will provide greater access to end of life and palliative care programs that are culturally relevant for specific communities, enabling all people to receive the benefits of end of life and palliative care.

We will empower communities and groups through targeted engagement to ensure people and those services providing culturally appropriate care, understand and receive the right services at the right time to meet their needs.

We will improve access to training opportunities and resources that provide communities and groups with information they can understand, and support that is culturally appropriate.

What you can do

'We're giving feedback and helping with translation concepts in our language.'

'I'm talking with other agencies about a better understanding of the cultures in our area.'

Priority 3: People receive services that are coordinated and integrated

The system has many individual services – public and private – we need to get better at ensuring that the patient experiences this as one system.

(Victorian Health Reform Summit, 2015)

Priority 3 aims

- People experience services that are coordinated and designed locally.
- The primary, hospital, palliative and aged care sectors connect effectively to respond to care needs.
- Early discussion, referral, planning and coordination occurs.

What Victorians said

- People expect healthcare services to work together to address their needs. Providers' approaches may differ, but people want to experience healthcare as one system.
- A strong theme emerged from both health service providers and consumers that integrated and responsive services were desired. People talked about the distress associated with repeatedly conveying what is often a difficult story. The preferred end state was a flexible system where smooth service transitions create a seamless experience and care 'just happens'.
- The desire for a designated care coordinator was strong. The discipline of the coordinator was not important, but rapport and emotional investment was. Many participants received conflicting advice, often interpreted as a lack of coordination and poor communication.
- Victorians want care available nearby and expect primary care to assist them to live optimally at home. General practice was viewed as a major gateway to services for local communities.
- Inadequate transfer of information within hospital services, between metropolitan and regional services and coordination in rural and regional areas was a frustration for many.
- Consumers expressed that good coordination should continue after death, not only to support families and carers, but to avoid inappropriate mishaps that increase distress (such as delivery of equipment after a person has died).
- Early discussion, referral and intervention of care for aged care residents, children and young people were strong themes. Introducing end of life care early for children and young people was seen as especially important to build familiarity, trust and to normalise their situation.
- Service providers want people referred earlier. Services genuinely want to support people flexibly and reduce the burden on families.

'I know services are working well when I don't have to repeat my story 20 times.'

Jane, aged 45, living with motor neurone disease

What the evidence tells us

Redesigning and integrating systems across teams and care episodes with optimised resources can achieve successfully integrated care.⁵¹ People experience fragmentation, duplication, gaps and delays in the care when integration is poor.⁵²

Effective care for end of life is best met by multiple services working together. An effective responsive system is one in which care responds to changing needs; clinicians work across professional boundaries and care packages are organised so people receive services when and where they need them.⁵³

There is evidence that people whose deaths are expected use inpatient and emergency department services extensively in the last year of life.⁵⁴ Coordination, communication and clarity of care goals between providers can optimise resources and reduce unnecessary hospital visits.⁵⁵ This includes understanding local patterns of response and service gaps.⁵⁶

Primary care, hospital services and palliative care need a strong culture of collaboration and teamwork, with clear systems of connection. Models of care created locally or regionally by services to achieve speedier and effective coordination may include pilot or test versions with new governance structures. Some services may need guidance to operate in a more sophisticated way and to reduce fragmentation. Clinicians need to work together as a team to enable the best possible care.⁵⁷ Without a coordinator role taking overall responsibility, care can be poor and information discordant or delayed.⁵⁸

Different funding approaches can support improvement in coordination and integration across organisations and services.⁵⁹ Formal partnerships, an interdisciplinary approach and strong leadership with experienced providers could facilitate new alliances that reduce agencies working in isolation.⁶⁰

Early referral to palliative care significantly improves people's quality of life, their mood and improves their survival time.⁶¹ Models of care focused on partnerships and effective sharing of information are a priority.⁶² We need to reduce barriers to information sharing and make better use of new technologies.⁶³

What we plan to do

We will enable coordinated integrated services by testing new models of care to deliver flexible care to people and their families, with local solutions tailored for metropolitan and rural settings.

We will support sectors with relevant resources to connect effectively. This will ensure services operate as one integrated system in delivering people's care at the right time in the right place.

We will enable people to engage in earlier discussion about their end of life wishes and advance care planning and enable improvements for earlier referral, planning and care.

What you can do

'I'm giving feedback on the new care system in our town.'

'At our agency we're forming an alliance with two other providers so we can provide better care.'

Priority 4: Quality end of life and palliative care is everyone's responsibility

Dealing with death and dying can be difficult. Health services ensure that there are processes for clinicians and others to be provided with support and training.

(National Consensus Statement: Essential elements for safe and high-quality end of life, 2015)

Priority 4 aims

- Knowledge is increased across the healthcare sector to provide safe, quality care.
- End of life care is consistent across the healthcare system.
- Healthcare staff are equipped to communicate and deliver the benefits of palliative care.
- Organisations actively support their staff in the delivery of quality end of life care.

What Victorians said

- People expect health professionals to have core skills appropriate to their position. They want increased end of life care knowledge and skills for those working in the health, human services, community and social sectors.
- Core skills identified for care providers were empathy and a level of comfort in having difficult end of life conversations, particularly in primary care settings.
- People raised concerns about insufficient training for direct care workers, particularly those in residential aged care facilities. Care providers acknowledged this, noting the need for specialist palliative care support for complex end of life cases.
- Employers and direct care workers frequently raised the need to include basic competency in end of life care in undergraduate degree and aged care courses.
- Palliative care services being delivered differently was often mentioned. Many acknowledged that services would appear different in regional and remote areas, particularly near jurisdictional borders. Consistency of quality and access was more pronounced in relation to after-hours services.
- Supporting and evolving volunteer programs was raised by both community members and service providers. Many expressed the view that volunteers deserve greater recognition and that they represent an area of untapped potential. Strategies to recruit, develop and retain volunteers was seen as important.
- Service providers require greater clarity about the triggers for referral to a palliative care specialist.

'Palliative care specialists need to be there to support and advise us, but we are delivering most of the end of life care, so need skills too.'

Sam, Assistant in Aged Care

What the evidence tells us

Clinicians routinely work with people nearing death; in many cases health professionals know when a person is highly likely to die in a year or less.⁶⁴

Failure to talk about and plan for death is one of the most significant obstacles to improving the quality of dying.⁶⁵ Although some staff find it challenging to talk about death and dying, the rapport between care providers and those nearing death provides opportunities to have useful conversations about the best possible quality of life for as long as possible.⁶⁶

Advance care planning provides clarity for health professionals.⁶⁷ Clinicians have wide access to validated advance care planning resources and training but this is not enough to ensure that the wishes of dying people are met.⁶⁸ Further measures are needed to ensure that plans are implemented.⁶⁹

All clinicians, regardless of practice setting, need to work collaboratively using an interdisciplinary approach with those requiring end of life or palliative care – in general practice, community and hospital services, and residential aged care.⁷⁰ Palliative care is 'core business' for any aged care system.⁷¹

Many clinicians, patients and their families see adopting a concurrent 'palliative approach' or a referral to palliative care even for 'shared care' as an 'admission of defeat'. Instead, end of life care advice should be seen as a way to ensure that the "best care possible" is being delivered. In other words – the right care, in the right place, at the right time.⁷²

Cooperation is required with the Australian Government as the key provider of primary and aged care services. Issues of care substitution and shifting of costs require management to ensure services are responsive and do not create gaps or duplication.

Hospital and health service executives have a responsibility to ensure staff are upskilled, enabling consistent delivery of end of life care. Evidence shows that services increase their capacity to provide palliative care when training in the palliative approach to care is implemented.⁷³ All clinicians should be able to have easy access to regular, ongoing up-skilling in "best practice" end of life care management.⁷⁴ Understanding each person's cultural needs and preferences is essential to provide palliative care and includes the special communication skills best learnt through formal teaching programs.⁷⁵

There is evidence that implementing clinical guidelines, protocols and tools improves care and reduces emergency department admissions.^{76,77} There is significant evidence that introducing standard pain assessment and measurement tools can improve people's experience of pain.⁷⁸

Volunteers play an important role. New evidence suggests that if volunteer programs are optimally designed, they could simultaneously enhance society, along with the health and quality of those volunteers.⁷⁹

In all client settings, staff should ask themselves:

'Would I be surprised if this person died in the next 12 months?'

If the answer is no, service providers need the skills to have appropriate conversations with people and understand how to initiate care and support for the person, their family and caregiver.

What we plan to do

We will support training opportunities in the healthcare, human services, social and community sectors, ensuring staff are equipped to communicate and deliver the benefits of palliative care.

We will enable development of protocols and processes that ensure people receive consistent care everywhere across Victoria.

We will support the healthcare, human services, social and community sectors to develop organisational volunteer strategies, enabling people and their families to receive relevant care and support from well-trained volunteers.

What you can do

'We promoted the communication training course at our hospital so people don't fear these conversations so much.'

'Our service has a strategy for our volunteer program.'

Priority 5: Specialist palliative care is strengthened

'If you are distressed in any way, you receive rapid assistance from clinicians who can reduce your suffering.'

(National Consensus Statement: Essential elements for safe and high-quality end of life, 2015)

Priority 5 aims

- Models of home-based care are effective and efficient.
- The specialist workforce is used effectively.
- Specialist palliative care is accessible locally.

What Victorians said

- Particularly at end of life, people want suffering and anxiety reduced. For many this means being at home, surrounded by family and friends. People want professional care accessible nearby so they can experience quality of life as they progress towards death in their place of choice.
- People may need specialised medication out of hours or advice for a complex need that may require the involvement of a palliative care specialist.
- People were concerned about the inequity of services in some regions, such as after-hours specialist advice.
- Aged care providers expressed concerns about the lack of access to specialist palliative care support, acknowledging that they require this support to care for people with complex needs.
- Victorians expressed a need for increased access to specialist palliative care services, both direct service provision and to support other end of life providers. They suggested better use of nursing specialists including nurse practitioners and nurse consultants.
- Greater flexibility in the delivery of care was required, as dying often does not follow a defined path.
- It was suggested that specialist palliative care be promoted more fully as an attractive career pathway and that workforce development should be strategic.

'Getting access to medication in our town after hours would be easier with the right staff available.'

Bill, aged 78, carer

What the evidence tells us

A growing body of literature shows that involvement of palliative care can facilitate meeting people's wishes to die at home or in a more home like environment.⁸⁰ Access to palliative and end of life care can minimise investigations, treatments and procedures that offer no improvement in quality of life.⁸¹

Community based palliative care can significantly increase the proportion of people who are able to die at home when good end of life services are available.⁸² People are more satisfied with care, and are less likely to be admitted to hospital or visit emergency departments. Increased home and community care for those who are dying is likely to reduce demand on hospital and on residential aged care services. The burden on carers can also be reduced.⁸³ People receiving care in the community have lower overall healthcare costs.⁸⁴

Specialist palliative care services are associated with more family centred outcome, attending to emotional and spiritual needs and giving people greater confidence in their own ability.^{85,86} This is particularly relevant for children and young people where assessment of prognosis can be difficult.⁸⁷

Involvement of palliative care consultancy services has been demonstrated to identify previously undiagnosed problems, improve physical and psychological symptoms, reduce intensive care and hospital admissions, lower care costs and improve documentation of people's goals.^{88,89}

The use of principles and processes of health-promoting palliative care have demonstrated that care practices and culture can be transformed.⁹⁰ These concepts provide a template for developing new models of care that uses specialist skills and knowledge more effectively. It does this by promoting relationship building to create social networks that enable a connected model to deliver quality care.⁹¹

What we plan to do

We will support services to provide community- and home-based care through effective innovative models to ensure people receive care at home or according to their preferences.

We will strengthen regional palliative care consultancy services through improved coordination and models of care, ensuring people can receive specialised care locally.

We will enable development of models of care that use the specialist palliative care workforce effectively, to ensure people receive the care they require in a timely manner.

What you can do

'We're planning a model in collaboration with the specialist palliative care staff at our regional hospital to make our agency work more streamlined.'

'We're placing more importance on our existing networks and improving coordination.'

Glossary

Advance care planning

Advance care planning is the process of planning for future health and personal care. A person makes their values, beliefs and preferences known so they can guide clinical decision making when and if they are unable to make or communicate their decisions themselves. Advance care planning can be verbal or written. Both verbal and written advance care plans can result in the appointment of a substitute decision-maker.⁹²

Advance care directive

An advance care directive, or advance care plan, is a document in which a person may express their preferences and values in relation to future medical treatment. These documents are used in Victoria and are ideally created through a process of advance care planning that includes conversations with family, friends and health practitioners.

Carer

A carer (usually a family member or friend) is someone who is unpaid and provides care to a person (usually at home). The carer may or may not live with the person, and the carer may be aged or have their own health issues.

Client

The client is usually the primary recipient of palliative care but may be a family member or carer, for example, if receiving bereavement care after the death of a loved one.

End of life

Two areas of definition exist. One is the period of time a person lives with an advanced progressive illness. The other refers to the end stage of weeks or days prior to death.

End of life care

This describes the care delivered to people with progressive, incurable illness to live as well as possible until they die. It allows the supportive and palliative care needs of both the patient and their family to be identified and met using the palliative approach to care for approximately the last 12 months of life.

Family

This refers to all types of families including those that include pets, single parents, same-sex parents, nuclear, extended and blended families.

Forgotten Australians

This refers to orphaned child migrants who arrived in Australia the 1920s–1960s. The Prime Minister offered a formal apology to this group in 2009, and they have become known as 'Forgotten Australians'.

Generalist palliative care

The term 'generalist' was historically used to describe palliative care provided by non-specialist palliative care clinicians or teams. The term preferred now is 'end of life care'.

It is now recognised that end of life and palliative care are an integral part of the standard clinical practice of most health professionals who are not part of specialist palliative care teams; almost every health professional will encounter clients at or approaching end of life, clients with progressive or symptomatic illness and bereaved families.

LGBTI

This refers to people who identify as lesbian, gay, bisexual, transgender or intersex; often referred to collectively as the LGBTI community.

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.

Life-threatening illness

This refers to a person with life-limiting illness who is likely to die prematurely. Often used when referring to children or adults who have an illness with a poor prognosis and their life span may be considerably shortened.

Palliative approach

The palliative approach is based on the tenets of palliative care. It aims to improve the quality of life for individuals with life-limiting illness and their families through early identification, assessment and management of pain and other physical, psychological, social, cultural and spiritual needs. The palliative approach tailors care to the needs and priorities of individuals and their families.

Palliative care

Palliative care is defined as care that improves the quality of life of patients and their families facing the problems associated with life-threatening or 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.⁹³

Palliative care consultancy

Working with the client's treating team, palliative care consultancy provides specialist insight, advice and support for both clients and families, and other healthcare providers.

Person-centred care

Person-centred care means that the client is involved in all planning and decision making and care is aligned with their priorities.

Specialist palliative care

Specialist palliative care is provided by medical, nursing or allied health professionals, as individuals or part of a specialist team. They have specialist palliative care qualifications and accreditation and work substantively, if not exclusively, in expert interdisciplinary teams of palliative care health professionals. Specialist palliative care clinicians look after clients and families with complex symptoms and/or complex spiritual, psychological, cultural or bereavement needs. Specialist palliative care clinicians also provide education and support to other clinicians and usually undertake or collaborate in research.⁹⁴

Appendix

End of life care and palliative care across service sectors

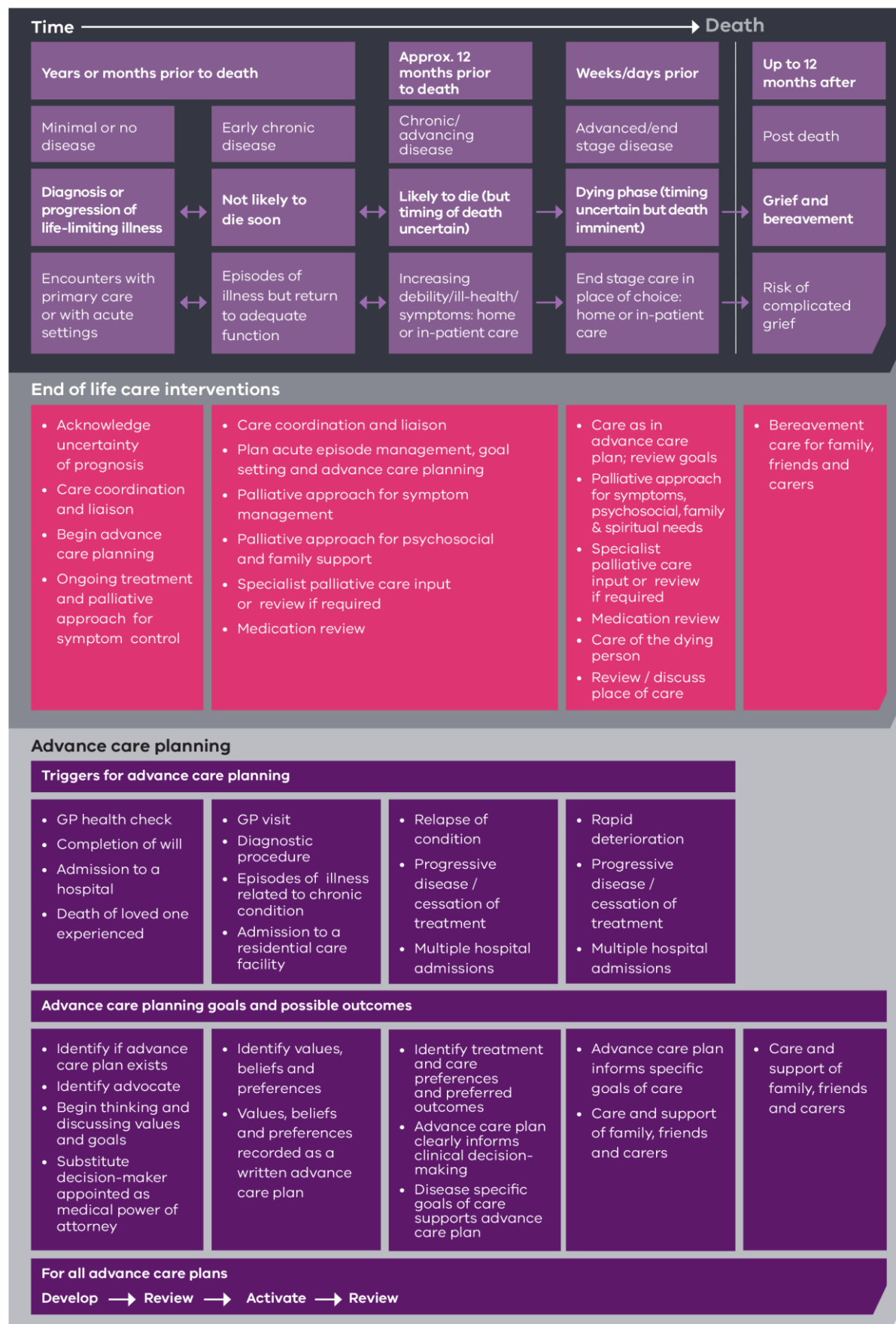


Resources in Victoria

End of life and palliative care information at [better health website](http://www.betterhealth.vic.gov.au): <www.betterhealth.vic.gov.au>

Disease spectrum

The stages of care and triggers at points of time are illustrated in the disease spectrum⁹⁵



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