Advance care planning implementation
Greater say for dying patients

June 2015 Update

Contents

The Victorian government believes that all Victorians are entitled to quality end of life care which relieves pain and suffering and provides empowerment to patients and their family, friends and carers. People using our health services should be supported to have informed discussions about their future preferences – including end of life care - with their health professionals, substitute decision maker, families and carers. Advance care planning is a central part of ensuring Victorian's have opportunities to have a greater say in their future health and personal care so that their values, beliefs and preferences are made known and can guide future decision making.

Successful advance care planning depends on services having an organisation-wide commitment to delivering person-centred care – creating an environment where treatment is guided by what matters most to a person. Advance care planning is for everyone, however it is particularly important for those with early cognitive impairment, a life limiting illness, who are frail, vulnerable, isolated, with comorbidities, or needing end of life care.

This update provides the latest information on those projects that support and progress the implementation of advance care planning. Future work will include consultation about the development of a broad end of life care framework - stay tuned!

Department of Health & Human Services
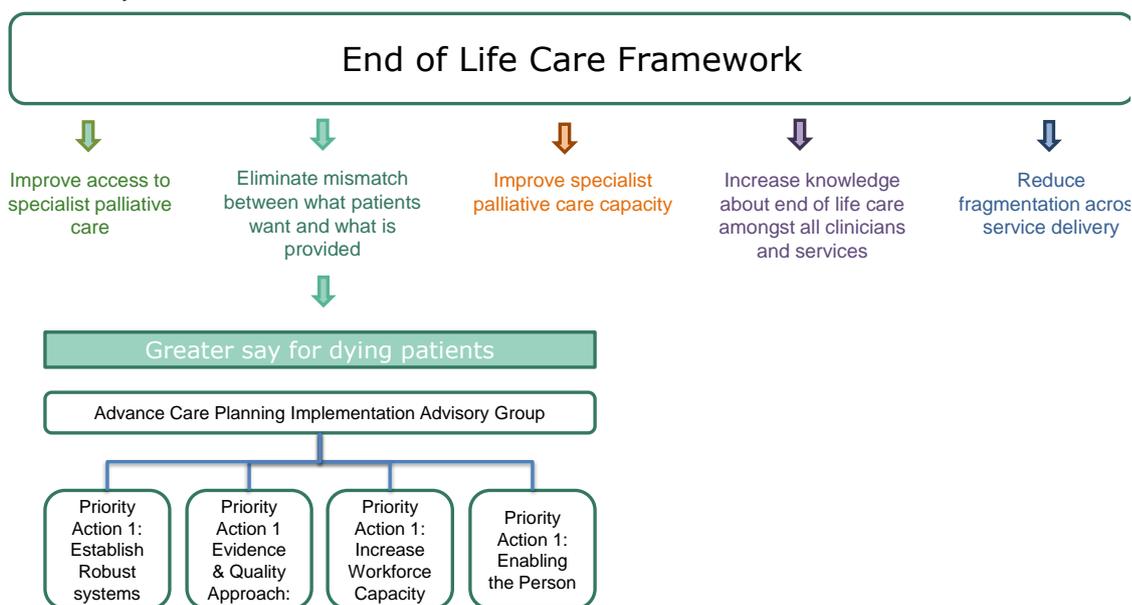
Key contact Person

Are you the advance care planning (ACP) contact person for your health service or organisation? Please ensure that the information is disseminated to the relevant people within your organisation.

Advisory Group

The Department of Health and Human Services (the Department) has established an Advance Care Planning Implementation Advisory Group. This group provides advice and support to the Department, and other relevant stakeholders, on issues relating to the implementation and sustainability of the strategy. The meetings are chaired by Colleen Pearce (Victorian Public Advocate) and convened quarterly.

Members of the group are
- Colleen Pearce (Office of the Public Advocate)
- Bill Barger (Ambulance Vic)
- Anthony Bartone (AMA)
- Sam Brean (Eastern Health and ACP program manager representative)
- John Chesterman (Office of the Public Advocate)
- Charlie Corke (Barwon Health)
- Barbara Hayes (Northern Health)
- Sue Hendy (COTA)
- Juli Moran (Austin Health)
- Lisa Pearson (Goulburn Valley Health and rural representative)
- John Rasa (Networking Health Victoria)
- William Silvester (Respecting Patient Choices - national perspective representative)
- Danny Vadasz (Health Issues Centre)

In the June meeting, the Advisory Group resolved that along with commencing to meet Year 2 measures, the Department and health services needed to focus on the following year 1 measures:

1. Prioritise having **executive and clinical leaders** respond to **quality** audits (Priority Action 1: Establish robust systems),

2. Prioritise establishing **mentoring** to support training (Priority Action 3: Increase the workforce capacity)

3. Allow the position description and orientation program requirements (Priority Action 3: Increase the workforce capacity) to be met if the broader topic of providing a person-centred care approach is covered. Therefore advance care planning does not need to be mentioned specifically, but rather an emphasis on treatment and care being aligned with a person's preferences is required.

Update on projects to support implementation

The Department has funded a number of projects to support implementation. Many of these projects are looking at advance care planning from a different perspective and we are very encouraged with some of the emerging findings.

Scoping Survey

Led by Austin Health

All public health services completed the first advance care planning scoping survey. Thank you to everyone who took the time to do this.

The scoping survey provided useful information to help the Department understand how health services were progressing with implementing the advance care planning strategy. As a result, initiatives to overcome barriers and gaps identified by the survey have commenced.

Importantly:
- health services have or are putting in place systems to deliver advance care planning across the organisation
- executive leadership is predominately strong
- comments suggests that while implementing advance care planning can be challenging, clinicians understand the benefits and have strong commitment to successful implementation.

> *Initially I thought this would be a big onerous task however the enthusiasm from our nursing and allied health staff has made my task easier.*
>
> Operations Manager

Areas for health service improvement included:
- providing staff with mentoring to support consolidation of advance care planning skills
- working with consumers at risk of cognitive decline
- expanding advance care planning beyond palliative care and residential aged care facilities
- And finally there is only one **'d'** in advance care planning.

The next scoping survey will focus on advance care planning in specific programs; ie Health Independence Programs and Transition Care Programs.

Outcome: Benchmarking and identification of gaps, barriers and strengths to guide implementation presented to Advisory Group, December 2014.

System Wide Advance Care Planning

Led by Networking Health Victoria

Hume, Inner North West and Barwon Medicare Locals were the successful consortiums who are being supported to improve the uptake, scalability, transferability and perception that advance care planning is part of "usual care" within their local areas.

These three consortiums represent a rural, regional and metro location, with Hume having the additional challenge of working across New South Wales and Victoria.

Outcome: Tools and techniques for implementing available to other regions by December 2016.

Transferability Options Paper

Led by Austin Health

The scoping survey and the System Wide Advance Care Planning project illuminated the need to improve transferability of advance care plans.

Austin Health is undertaking an investigation to explore the options available to Victoria in terms of improving transferability of advance care plans across organisations.

This is important if clinicians are going to be able to build upon a previous advance care planning conversation and if the advance care plan is going to be found at the time it needs to be activated.

Austin Health will be contacting a wide range of stakeholders to better understand the systems their organisation uses and to better understand barriers and requirements.

Outcome: List of recommendations to address issue of transferability of advance care plans presented to Advisory Group by October 2015

Resources to support health professionals

Led by the Australian Medical Association (AMA)

The AMA has reviewed resources available for doctors around advance care planning and developed an education tool that has been tested through a consultation process. Feedback from those who have previewed the resource has been very enthusiastic. It has the potential to be broadened as a useful resource for allied health and nursing clinicians.

Outcome: Print version available July 2015, interactive online format available by June 2016.

Having difficult conversations factsheet

Led by Northern Health

To complement the work being undertaken by AMA, Northern Health is working to develop a simple 'cheat' sheet, which can support junior doctors when having difficult conversations.

Outcome: Difficult conversations 'cheat' sheet available in print version July 2015.

Guidelines to support conversations when caring for very sick children

Led by Royal Children's Hospital

Following a comprehensive literature review and evaluation of current practice, Royal Children's Hospital have developed a guideline and tool which they are currently trialling.

Outcome: Guidelines will include, tool, list of recommended clinical triggers for ACP and examples of useful phrases to use with families available July 2015.

Understanding decision-making doctor, consumer and substitute decision-makers

Led by Alfred Health

Read the report summary (here) from Alfred Health suggests that the form used is not the most important element. It is the conversations that are key.

Outcome: Provides evidence around consumer, doctor and substitute decision-maker decision making.

Diverse cultural groups and ACP

Led by Northern Health

Dr Barbara Hayes has led a research project that has conducted 39 interviews with interpreters, representing 20 language groups. Interpreters provide a unique perspective as they represent not only their own views, but the experiences of communicating with people from their language groups.

Initial results suggest:
- family is a big driver
- widespread superstition about talking about death
- many cultural groups with little experience of planning in general.
- health literacy levels are a barrier to ACP

Outcome: Provides new evidence about the barriers and opportunities for engaging with people from non-English speaking backgrounds available June 2015.

Developing resources for consumers

Led by Health Issues Centre

Having just completed 8 focus groups, the Health Issues Centre have started compiling results.

Preliminary results suggest that
- There is resistance to documenting decisions in advance of knowing the specific circumstances
- Substitute decision makers go into the role naively and report significant unmet support needs; they want guidance and support from professionals
- Past experience, family dynamics and relationships play a significant role in approaches to ACP
- There is confusion regarding the definition of advance care planning and its components

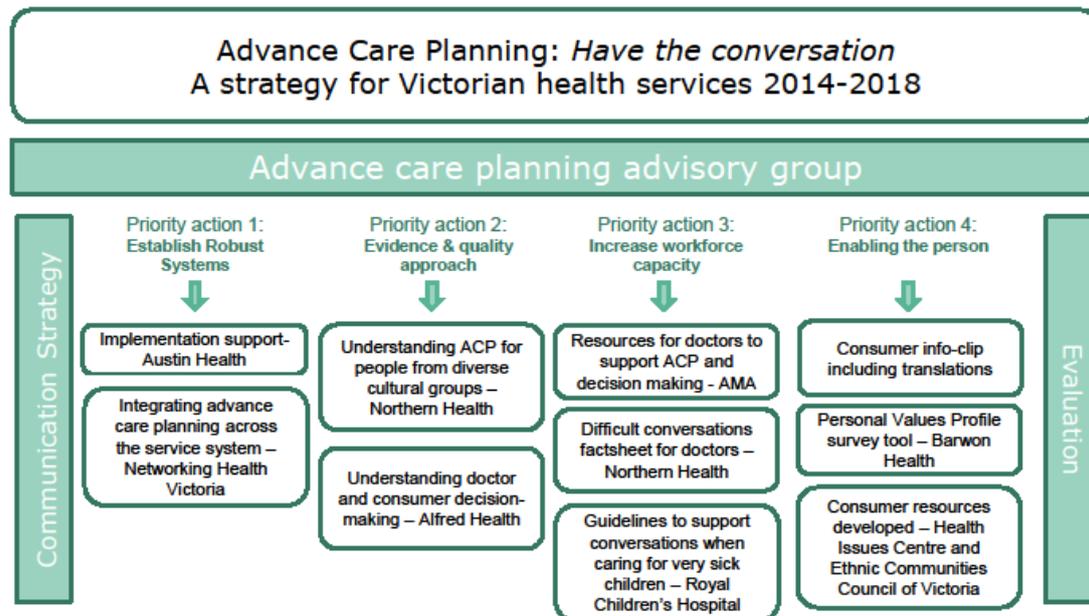Outcome: Provides new evidence and recommendations about engaging with consumers available by July 2015.

Developing resources for consumers from different cultural groups

Led by Ethnic Communities' Council of Victoria

Work with Filipino, Macedonian, Serbian and Turkish groups is being undertaken to better understand how advance are planning can be best undertaken with people from these cultural groups.

Outcome: Provides new evidence and recommendations about engaging with consumers from four culturally diverse groups available July 2015.

Department of Health and Human Services
Strategy Implementation

Advance Care Planning: *Have the conversation*
A strategy for Victorian health services 2014-2018

Advance care planning advisory group

Priority action 1:
Establish Robust Systems

- Implementation support- Austin Health
- Integrating advance care planning across the service system – Networking Health Victoria

Priority action 2:
Evidence & quality approach

- Understanding ACP for people from diverse cultural groups – Northern Health
- Understanding doctor and consumer decision-making – Alfred Health

Priority action 3:
Increase workforce capacity

- Resources for doctors to support ACP and decision making - AMA
- Difficult conversations factsheet for doctors – Northern Health
- Guidelines to support conversations when caring for very sick children – Royal Children's Hospital

Priority action 4:
Enabling the person

- Consumer info-clip including translations
- Personal Values Profile survey tool – Barwon Health
- Consumer resources developed – Health Issues Centre and Ethnic Communities Council of Victoria

Communication Strategy

Evaluation

The above diagram illustrates the structure for the implementation of the advance care planning strategy

Consistent language

Many enquiries to the Department are from consumers confused about terminology.

Advance care planning can be made simpler for clinicians and consumers alike if we are consistent with our language.

Try to make your communication consistent with the strategy. Check websites, emails, brochures, forms and policies and look out for the following...

- only one **'d'** in advance care planning (not advance**d**)

and try to use these terms
- advance care plan (rather than *advance care directive* or *statement of choice*)
- substitute decision maker
- enduring power of attorney (medical treatment)
- advance care planning (rather than a brand name)

Statement of Priorities

Many health services have made agreements to implement advance care planning systems as part of the 2014-2015 Statement of Priorities. Health services have developed specific goals under the broad objective of:

Implement formal advance care planning structures and processes, including putting into place a system for preparing and/or receiving, and documenting advance care plans in partnership with patients, carers and substitute decision makers.

Policy & Funding Guidelines

Policy and Funding Guidelines

Advance care planning funding arrangements and obligations for health services can be found on page 26 (section 1.6.7.6 of Part 1: Overview) and page 236 (section 3.2.1.7 of Part 3: Conditions of funding) in the 2014-15 Policy and Funding Guidelines.

VAED

In 2015-2016 advance care planning will be included in the Victorian Admitted Episode Dataset (VAED).

VAED changes for 2015-2016

The definition will be: *An alert, flag or similar present in the medical record or patient management system that indicates an advance care plan and/or substitute decision maker has been recorded.* The 4 codes are:

1 No advance care plan alert
2 Presence of an advance care plan alert
3 Presence of a substitute decision maker alert
4 Presence of both an advance care plan alert and a substitute decision maker alert

VINAH

There has been some confusion about what constitutes an 'advance care plan documented date' in the Victorian Integrated Non-Admitted Health (VINAH) minimum dataset. The reporting guide can be found on page 70-71 at the following link:

VINAH minimum dataset

Of fundamental importance is that:

1. An advance care plan comprises any of the following:
• a record of a discussion about future wishes
• a discussion with significant family members and/or friends that communicates a person's future wishes
• formal written wishes that are witnessed and signed
• informal written wishes that are neither witnessed nor signed
• a completed enduring power of attorney (medical treatment)
• the appointment in writing of a substitute decision maker
• a completed Refusal of Treatment Certificate

2. In whatever form the documentation takes, it must have the potential to assist in some way with future decision making about health and personal care. This is by either appointing a substitute decision maker or recording the person's wishes.

3. An 'ACP documented date' should not be recorded if the topic of ACP is introduced but no information to guide future decision making is gained.

Factsheets

Are being added to the www.health.vic.gov.au/acp website and will cover:

- Stand alone clinics

- Powers of Attorney Act 2014

- Ambulance Victoria – coming soon

- MBS items – coming soon

Resources to assist

Is your health service 'conversation ready'?

Take the short *Conversation ready* quiz.

The Conversation Project provides valuable insight into developing an organisation wide approach to advance care planning.

This blog interviews Dr Lauge Sokol-Hessner about implementing *The Conversation Project.* Much of what is discussed resonates with the experience of implementing advance care planning in Victoria.

Forms

Some services have requested a prototype advance care plan to assist with implementation. The Department has created this advance care plan form with input from a number of health services. Your health service is welcome to use this form. Please provide feedback of ways it can be improved. This is by no means the single form to be adopted by the state, but rather an option for health services.

The form is available here

Making advance care planning scalable

Bob Arnold wrote *Mastering Communication with Seriously Ill Patients*. More recently he and his team have written about the need to make advance care planning scalable and suggests two crucial tools to make advance care planning more accessible.

- Conversations
- Technology

See link here

This article supports the approaches taken by My Values and My Directives in terms of accessibility and scalability. These resources are important additions to the options that are available to people.

My Values – www.myvalues.org.au

My Directives – www.mydirectives.org

What we are reading

- *Dying for a chat* by Ranjana Srivastava (Oncologist at Monash Health)
- *Being mortal* by Atul Gawande
- *Dear Life; Quarterly Essay* Karen Hitchcock

These books are captivating and provide great insight into the role of informed consent and the value of communication in providing good medical care.

> ### Atul Gawande suggests there are 4 questions to ask in understanding a person's hopes and fears:
>
> 1. Do you understand your prognosis?
> 2. What are your fears about what is to come?
> 3. What are your goals as time runs out?
> 4. What trade-offs are you willing to make?

What we are watching

Being Mortal - This documentary brings Atul Gawande's book, *Being Mortal* to life. It captures doctors reflecting on their communication techniques with clients facing life limiting conditions.

It is supported by a number of resources including Facing Mortality a resource to help people talk to their doctor.

The article asks...

- But how do you or a loved one talk to your doctor when one of you have fallen seriously ill?
- How do you prepare yourself?
- How do you figure out what to say?

Contact us for more information

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