Voluntary Assisted Dying Implementation Conference

Community and Consumer Information

Mary Draper AM

Voluntary Assisted Dying Implementation Taskforce, May 2019
The Challenge of Implementation

The Voluntary Assisted Dying legislation is complex.

It seeks to balance access to voluntary assisted dying with clear conditions on who is eligible to access it.

It surrounds a clinical practice with significant legally prescribed steps and procedures.

Access to voluntary assisted dying is balanced with a number of safeguards to allay community concerns.

This has consequences for those seeking voluntary assisted dying as well as doctors and other health practitioners who are involved.

Ref White, B., Wilmott, L., Close, E
The challenge of complexity

‘System design is the key so that complexity is “inwardly facing” and not experienced by people seeking voluntary assisted dying and doctors assisting them’

Ref White, B., Wilmott, L., Close, E
Where community and consumer information matters

- Every human life has equal value.
- A person’s autonomy should be respected.
- Informed decision making.
- Quality care that minimises suffering and maximises quality of life.
- Therapeutic relationships be supported and maintained.
- Open discussions about death and dying.
- Conversations about treatment and care preferences.
- Genuine choice balanced with safeguards.
- All people have the right to be shown respect for their culture, beliefs, values and personal characteristics.
Resources for consumers and the community

Informed decision making is a key guiding principle, so access to relevant consumer oriented information is vital.

Many people who ask for voluntary assisted dying will have done a great deal of information seeking online.

The information provides support for people as they need to navigate a fairly complicated process at a late stage of their illness.

The consumer information supports people in having conversations with their doctors about end of life and voluntary assisted dying.
Access to information

The community and consumer information is intended to provide people with an independent source of access to accurate and up-to-date information about voluntary assisted dying.

It also provides an information referral source for health professionals wanted to refer people for authorised information about voluntary assisted dying.
Mary Draper AM (Chair)
Julian Gardner AM (Chair of Taskforce)
Tricia Malowney OAM
Associate Professor Peter Hunter
Jo Cockwill (Cancer consumer and community representative)
Andrew Greaves (Safer Care Victoria)

Rod Harris, MND Vic
Danny Vadasz, CEO, Health Issues Centre
Representatives of the Better Health Channel
Nikolaus Rittinghausen, ECCV
(Molly Carlile AM and Dale Fisher Peter Mac contributed to early meetings)
Credible and accurate information about voluntary assisted dying is developed for the community and individuals who may be considering accessing voluntary assisted dying.

Dissemination strategy developed that ensures the information is accessible to the Victorian community.

Community information and consumer guidelines are available prior to the commencement of the Act.

A review process to ensure information and guidelines remain up-to-date is in place.
Target groups for community and consumer information

Information for the community so that they have accurate information about the legislation, clarity about who is and isn’t eligible, and safeguards in the process.

Information for members of the community who are considering or seeking voluntary assisted dying to assist them in thinking about voluntary assisted dying and support them through the processes of seeking access to voluntary assisted dying.
Development of the resources

• The Department contracted with Dr Bronwen Merner and A/Prof Sophie Hill from the Centre for Health Communication and Participation at La Trobe University to develop and user test the community and consumer information.

• The Centre worked with the Working Group to develop the information through a process of iterative development and finely tuned detail.

• The challenge was to translate legislatively precise concepts into accessible community language without losing accuracy. The input of consumers into this process was an enormous help in doing this.

• Bronwen Merner will comment further on this and now outline the process of developing the community and consumer information.
Summary of community and consumer information
Community and consumer information

Suite of community and consumer information has been prepared and user-tested with community organisations, health practitioners and consumers.

General community information presented as FAQs e.g.

- Can someone with dementia access the voluntary assisted dying medication?
- Who can help a person access the voluntary assisted dying medication?
- Can someone be pressured into asking for voluntary assisted dying?

FAQs are being translated into the top 10 community languages in Victoria.

Material available in Easy English and additional 7 languages.
Community and consumer information

Detailed consumer guidance is provided in *Voluntary assisted dying: Information for people considering voluntary assisted dying*

**This resource covers:**

- Considering end of life care
- The voluntary assisted dying process
- The dying process
- Getting support
Considering end-of-life care

Making decisions about end-of-life care

Do I meet the conditions for voluntary assisted dying?

Getting information from your doctor about voluntary assisted dying

Talking to your doctor about voluntary assisted dying
The voluntary assisted dying process

What process do my doctor and I need to follow?

Voluntary assisted dying process checklist

What if my doctor is unwilling to help me?
The dying process

Preparing for and taking the voluntary assisted dying medication

After death occurs
Support

Getting support

Talking about your end-of-life preferences

Supporting your family member or friend through the voluntary assisted dying process
The information is available at:

Dissemination

Key community organisations that expected to be points of contact will refer members of the community to the DHHS website.
Health services don’t need to ‘re-invent the wheel’ because there is an authoritative source of information that has been developed specifically for consumers and user tested.

Insight into what the process looks like from the consumer perspective and how to manage the complexity in an ‘inward facing’ way.

Health services can develop supplementary information about their local processes.
Governance

DHHS will be responsible for governance, receiving feedback and updating of community and consumer information