Developing the voluntary assisted dying community and consumer information

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Objective

To work with the Community and Consumer Information working group to:

Develop **accurate** and **appropriate** information about voluntary assisted dying **targeted to consumers** to ensure the Victorian community has access to **credible** and **reliable** information and guidance about voluntary assisted dying.
Principles

- comprehensive
- accessible and user friendly
- clear and simple
- evidence-informed
- person-centred

- neutral
- diversity and equity lens applied
- subject to consultation and evaluated
- subject to regular review and up to date
Original brief – 3 levels of information

Level 1. General community information

Level 2. Information for people considering voluntary assisted dying

Level 3. Consumer guidelines for those wishing to request voluntary assisted dying
Environment scan – international context

- End of Life Washington
- Death with Dignity Oregon
- Alberta Health Services
- Relevant research articles
Environment scan – local context

• *Guide to producing and sourcing quality health information* (Centre for Health Communication and Participation, 2019)

• Voluntary Assisted Dying Act 2017

• Relevant Ministerial and Parliamentary Committee reports

• Guidance provided by the working group
Community and Consumer Information working group

- Included people with community, consumer or carer expertise
- Contributed significantly to which topics should be covered in each level
- Health information guidance states that health information should start with what people want to know
Stages of development

- Project commenced (May 2018)
- Level 1 draft and revisions
- Input from Working Group
- Preliminary Level 1 published (Aug 2018)
- Level 2 and 3 draft and revisions
- Input from Working Group
- Evaluation of the information (Oct 2018)
- Implement evaluation feedback
- Input from Working Group
- All information completed and uploaded (March 2019)
Brief overview of the information
Community and consumer information about voluntary assisted dying

Community information about voluntary assisted dying
(general audience)

Consumer information about voluntary assisted dying
(for people considering or going through the process of voluntary assisted dying)
Community information about voluntary assisted dying (Level 1)

- Introduction
- FAQs
Voluntary assisted dying – Information for people considering voluntary assisted dying (Level 2 and 3 combined)

• Divided into the following topic headings:
  • Considering end-of-life care
  • The voluntary assisted dying process
  • The dying process
  • Support
  • Additional information
Where to find the information

- Department of Health and Human Services

- Better Health Channel
DHHS website (all the information)

Community information about voluntary assisted dying (Level 1)

Voluntary assisted dying – Information for people considering voluntary assisted dying (Levels 2/3)
Better Health Channel (community information only)

Link to DHHS website with all of the information (Levels 1, 2/3)

Community information about voluntary assisted dying (Level 1)
Evaluation of the information
### Who read what?

<table>
<thead>
<tr>
<th>Level of information</th>
<th>1</th>
<th>2</th>
<th>3</th>
</tr>
</thead>
<tbody>
<tr>
<td>Community organisations and advisory bodies</td>
<td>✓</td>
<td>x</td>
<td>x</td>
</tr>
<tr>
<td>Consumers</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Health practitioners</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
</tbody>
</table>
Level 1 only:

- Peter MacCallum Cancer Centre
- Victorian Comprehensive Cancer Centre
- Cancer Council
- Dying with Dignity Victoria
- Go Gentle Australia

- Ethnic Communities Council of Victoria
- Carers Victoria
- Council of the Ageing Victoria
- Women with Disabilities Victoria
- Victorian Disability Advisory Council
- Communication Rights Australia
Levels 1, 2 and 3: Consumers and health practitioners

- Feedback received from 14 people including consumers, carers and health practitioners
Summary of main feedback – Level 1

- Confusing terms substituted when possible e.g. “continuing” was changed to “consistent”
- Question added about the difference between voluntary assisted dying and euthanasia
- Further emphasis on the need for two doctors to assess a person is eligible for voluntary assisted dying
Summary of feedback – Levels 2 and 3

- Large volume of feedback – people engaged with the subject matter and the resources
- Major change based on solution from consumers of working party: Levels 2 and 3 combined - and information now grouped by topic
- ‘Talking with your Doctor’ resource developed and added
- Inclusion of decision trees to reduce the complexity of the process
- More information added about voluntary assisted dying care navigators
- “Feedback and complaints” section added
- A “Terms you may need to know” section added
Talking with your Doctor

Located in ‘Voluntary assisted dying: Information for people considering voluntary assisted dying’ pp. 13-16

What you can do before the appointment

- Think about the reasons why you are considering voluntary assisted dying.
- Think about any symptoms you are experiencing (for example, pain, fatigue, delirium or difficulty breathing).
- Think about your fears about your disease and how your life will end, so that you can ask what supports are available.
- Consider taking a trusted person with you to the appointment.
- Let the doctor or receptionist know if you need an interpreter or speech pathologist at the appointment.
- Think about any questions you want to ask your doctor or anything else you think they should know.
Some questions you may want to ask your doctor about your disease

• What happens to people like me with this disease?
• What are the ways my disease can be treated?
• How will things change as my disease gets worse?
• What symptoms am I likely to experience as my disease gets worse?
• What support will I be able to get while I am dying?
• What usually happens to people with my disease in the last weeks or days of life?
At the appointment

Your doctor can only talk to you about voluntary assisted dying after you have asked them about it first. If you have a trusted person with you at the appointment, they cannot ask for you. Only you can start the conversation.

When asking about it, you do not need to use the term ‘voluntary assisted dying’ but it will help to be really clear with your doctor about what you are asking. If you feel more comfortable with terms like ‘euthanasia’ or ‘dying with dignity’ you can use those instead.
Examples of ways to start the discussion

- I feel like I can’t go on like this; would voluntary assisted dying be an option for me?
- I don’t see the point of another couple of months slowly dying. Can you give me a drug to speed things up?
- Can you tell me about the voluntary assisted dying laws?
- Can you tell me how I can get the medicine to end my life?
- I want to know how you can help me to die.
- How do I get that medicine to end it all when it gets too much?
What to expect from your doctor

Once you ask about voluntary assisted dying – or if your doctor is unsure whether you are talking about voluntary assisted dying - they may ask you some questions to help find out what you want.

For example, if you ask a more general question like ‘I wish my life was over, can you help me?’ the doctor may ask you for more information to check what you are asking about.
Some questions your doctor may ask

• How long have you been feeling like this?
• What are your main concerns?
• What do you know about your disease and how it is progressing?
• What do you know about your treatment options? How do you feel about these options?
• What help with your symptoms would make your life more comfortable?
• What practical help would make your life more comfortable?
• Have you heard of palliative care? How do you feel about getting palliative care support?
What if your doctor cannot or will not help you?

- Doctors, and other health practitioners, have the right not to give you information about voluntary assisted dying.

- Your doctor may not want to give you information because:
  - they do not agree with voluntary assisted dying
  - they work in a health service that does not offer voluntary assisted dying
  - they are not qualified to give you the information you need.
What if your doctor cannot or will not help you? (continued)

In these cases, your doctor or health practitioner may refer you to someone who can help. If they do not, you can contact a voluntary assisted dying care navigator who can link you with the right person.
If you make the decision to go through the voluntary assisted dying process

If you feel you have enough information, and decide you want to go through the process to seek voluntary assisted dying, and access the medication, you will need to make your first request.

You can make your first request at this appointment or you can wait and make another appointment and then make your first request if you choose. Your first request should be clear, so the doctor understands exactly what you are asking.

Even after you have started the process for voluntary assisted dying, you can change your mind at any time, up until the time when you take the medication.
Where to get more information

You can get more information about voluntary assisted dying from:

• your doctor or health practitioner
• a voluntary assisted dying care navigator.
Strengths of the information

• Sound, comprehensive foundation for consumer information about voluntary assisted dying (it will change over time)

• Robust process of development and evaluation – input integrated from working group, DHHS, community organisations, consumers and health practitioners

• Successful model for developing health information
Challenges

• A complex human experience can be described using many different words and in many ways

• And so we received many views on how to communicate this information and had to navigate through with discussion and consensus processes
  • We gave primacy to the feedback received during the evaluation phase
  • We had to ensure that words were simple but also accurate

• We were writing information for a health care process that no one has used locally and so continuing to refine and improve this information from people’s experiences and perspectives will be important in the future
Where to find all of the community and consumer information

Thank you

latrobe.edu.au