This is where most Australians die
Sadly, the majority of Australians (74%) want their life and end-of-life to be different.\(^1\)
Many Victorians still do not receive End of Life Care which meets their individual needs and preferences.

In Victoria, as in the rest of Australia, the experience of dying often involves:

- fragmented care
- invasive and intensive interventions
- inadequate treatment of distressing symptoms
- numerous hospitalisations
- frequent transitions among care settings
- poorly coordinated programs
- onerous for responsibilities for families
For patients and their loved ones, no care decisions are more profound than those made at the end of life...

But they are not sharing them...
8 in 10 Australians do not have an advance care plan in place.

7 in 10 Australians have not even discussed health goals or end of life choices with their loved ones.

35% of advance care plans cannot be found when needed.
Good End of Life Care enables people to live in as much comfort as possible until they pass away, and to make choices about their care.
Challenges to achieve choice

- Increasing demand
- Changing demographics
- Changing disease patterns
- Rising expectations and patient preferences
- Groups with diverse needs
- Palliative care in Residential Aged Care Facilities
- Rocketing health expenditure and capacity challenges
10 pre-conditions underpin choice driven end of life care

- Person, carer and family centred care
- Needs based care
- Integrated coordinated care
- Advance care planning
- Equitable 24/7 access
- Ensuring everyone matters
- Collaborative case managed services
- Shared records
- Education and training
- Research and evidence
Critical difference
CONVERSATION
CONVERSATION makes a difference

- greater alignment between patient preferences and the care they receive
- higher patient quality of life
- improved patient satisfaction
- less use of aggressive or non-beneficial life-sustaining treatments
- greater use of hospice care
- increased likelihood that people will die at home or in a comfortable setting
- reduced family distress, anxiety and depression
- reduced stress among doctors, nurses and other caregivers
- improved resource use and costs efficiencies
Comparison of patients who received End of Life Care counselling and those who don’t

<table>
<thead>
<tr>
<th>Preferences and planning</th>
<th>Had counseling</th>
<th>No counseling</th>
</tr>
</thead>
<tbody>
<tr>
<td>Accepts illness is terminal</td>
<td>53%</td>
<td>29%</td>
</tr>
<tr>
<td>Wants to know life expectancy</td>
<td>84</td>
<td>67</td>
</tr>
<tr>
<td>Values comfort over life extension</td>
<td>85</td>
<td>70</td>
</tr>
<tr>
<td>Against death in intensive-care unit</td>
<td>49</td>
<td>28</td>
</tr>
<tr>
<td>Completed do-not-resuscitate order</td>
<td>63</td>
<td>29</td>
</tr>
<tr>
<td>Completed living will, durable power of attorney or health-care proxy</td>
<td>72</td>
<td>46</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Care received in the last week of life</th>
<th>Had counseling</th>
<th>No counseling</th>
</tr>
</thead>
<tbody>
<tr>
<td>ICU admission</td>
<td>4.1%</td>
<td>12%</td>
</tr>
<tr>
<td>Ventilator use</td>
<td>1.6</td>
<td>11</td>
</tr>
<tr>
<td>Resuscitation</td>
<td>0.8</td>
<td>6.7</td>
</tr>
<tr>
<td>Chemotherapy</td>
<td>4.1</td>
<td>6.7</td>
</tr>
<tr>
<td>Feeding tube</td>
<td>8.9</td>
<td>7.3</td>
</tr>
<tr>
<td>Outpatient hospice used</td>
<td>76</td>
<td>57</td>
</tr>
<tr>
<td>Outpatient hospice of a week or more</td>
<td>66</td>
<td>45</td>
</tr>
</tbody>
</table>

Taking the lead

WHO

that a shared approach is best, patients laying out their preferences and priorities, and doctors help them understand the risks and benefits associated with them

Although most people say they are open to having end of life conversations with loved ones …

< 27% actually do

ADVANCED ILLNESS: STRUCTURAL AND FINANCIAL DISINCENTIVES TO HAVE A CONVERSATION
THE DEFAULT DECISION IS TO TREAT NO MATTER HOW HOPELESS OR PAINFUL
### Timing and triggers matter

**VOLUNTARY PARTICIPATION, UNIVERSAL OPPORTUNITY**
for informed conversation and planning

<table>
<thead>
<tr>
<th>Primary Care</th>
<th>Acute Care</th>
<th>Aged Care</th>
</tr>
</thead>
<tbody>
<tr>
<td>- Flu shot</td>
<td>- Medical clinic patient with a new diagnosis or deterioration of cancer or chronic disease or requiring referral to acute service e.g. renal referral for diabetes</td>
<td>- Making a will</td>
</tr>
<tr>
<td>- &gt;70 years age check up</td>
<td>- Pre-admission clinic for high risk surgery patients</td>
<td>- Requesting a seniors card</td>
</tr>
<tr>
<td>- Electronic Health Record</td>
<td>- Specific in-hospital support team for potential medical futility decision-making</td>
<td>- Commencement of long term organ support e.g. dialysis, home oxygen</td>
</tr>
<tr>
<td>- Taking out a private health insurance plan</td>
<td>- ACD status included in discharge summaries.</td>
<td>- Disability support pension application</td>
</tr>
<tr>
<td>- PBS safety net</td>
<td>- Registering for organ donation</td>
<td>- Commencement of home support services</td>
</tr>
<tr>
<td>- Registering for organ donation</td>
<td>- Turning 75</td>
<td>- Admission to nursing home.</td>
</tr>
<tr>
<td>- Psychiatric patient programs.</td>
<td>- Psychiatric patient programs.</td>
<td></td>
</tr>
</tbody>
</table>
Improving communication and community engagement on End of Life Care has become a central mission for many healthcare institutions, funders and governments globally.

Spectrum of engagement in end-of-life care: developing community capacity

- **Inhibiting factors:**
  - Low level of power sharing by service
  - Work initiated by organisation
  - In response to top-down requirements
  - Organisation leads on work
  - Public as a series of individuals
  - Opportunistic work
  - Low level of community capacity

- **Supporting factors:**
  - High level of power sharing by service
  - Work initiated by community
  - In response to community-identified need
  - Communities lead on work
  - Public as whole communities
  - Proactive work
  - High level of community capacity

- **Stages:**
  - Inform
  - Consult
  - Co-Production
  - Collaborate
  - Empower

- **Outcomes:**
  - Increasing quality of care and health and wellbeing
Social action and cultural change
The Australian Conversation project

let's have dinner and talk about DEATH

Since our launch, 100,000 people have attended “DEATH DINNERS” in over 30 countries.

Featured in


SITE LAUNCH 8-24-13

At the dinners, “There’s laughter, there’s tears, there’s a real kind of facing of what it means and what they want to do about it and making sure that their family knows what they want.”

— Washington Post

Over the past month, hundreds of Americans across the country have organized so-called death dinners, designed to lift the taboo around talking about death in hopes of heading off conflicts over finances and medical care -- and avoiding unnecessary suffering at the end of life.

— Bloomberg

Participants like Laura Sweet, who hosted a dinner party on her apartment building’s roof, are finding that frank conversations about death can be refreshing and enlightening. As she put it, “people hesitated to leave and said they could talk about this for days. I don’t use the word magical much, but this evening was.”

— Huffington Post
The Australian Conversation Project

How we want to die, represents the most important and costly conversation Australia isn’t having.

Death Over Dinner
Difficult Conversations
AUSTRALIA

Requires an MBS item number to remunerate GPs for having advanced care planning conversations with

• 75-year-old assessment
• newly diagnosed dementia
• residing in residential aged care facilities

2016

US Centers for Medicare and Medicaid Services (CMS) will reimburse physicians for engaging patients in advance care planning conversations

Reason:

skilled communication among patients, family members, and clinicians about patients' values and goals is an important way to improve End of Life Care
By talking more openly about dying, death and bereavement and discussing your end of life wishes, and the wishes of those close to you, you can make a difference.

Healthcare is important, but we all have a responsibility to support each other in times of crisis and loss.

We encourage you to initiate timely conversations with honesty and openness.
Australian Centre for Health Research Limited (ACHR)
114 Albert Road | South Melbourne VIC 3205
T +61 3 8682 6747
achr@achr.org.au

www.achr.org.au

Michael Hebb
TED MED
https://www.youtube.com/watch?v=4DT0aMfFtuw