This is where most Australians die

Sadly,

the majority of Australians

(74%)

want their life and
end-of-life to be different.[1]

1. PALLIATIVE CARE AUSTRALIA SURVEY 2013

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

CHANGE

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

- 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

makes a difference

Comparison of patients who received End of Life Care counselling and those who don't

◆ Preferences and planning

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

◆ Care received in the last week of life

	Had counseling	No counseling
ICU admission	4.1%	12%
Ventilator use	1.6	11
Resuscitation	0.8	6.7
Chemotherapy	4.1	6.7
Feeding tube	8.9	7.3
Outpatient hospice used	76	57
Outpatient hospice of a week or more	66	45

Wright AA, et al. JAMA, Oct 8, 2008

Taking the lead

WHO

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

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

< 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

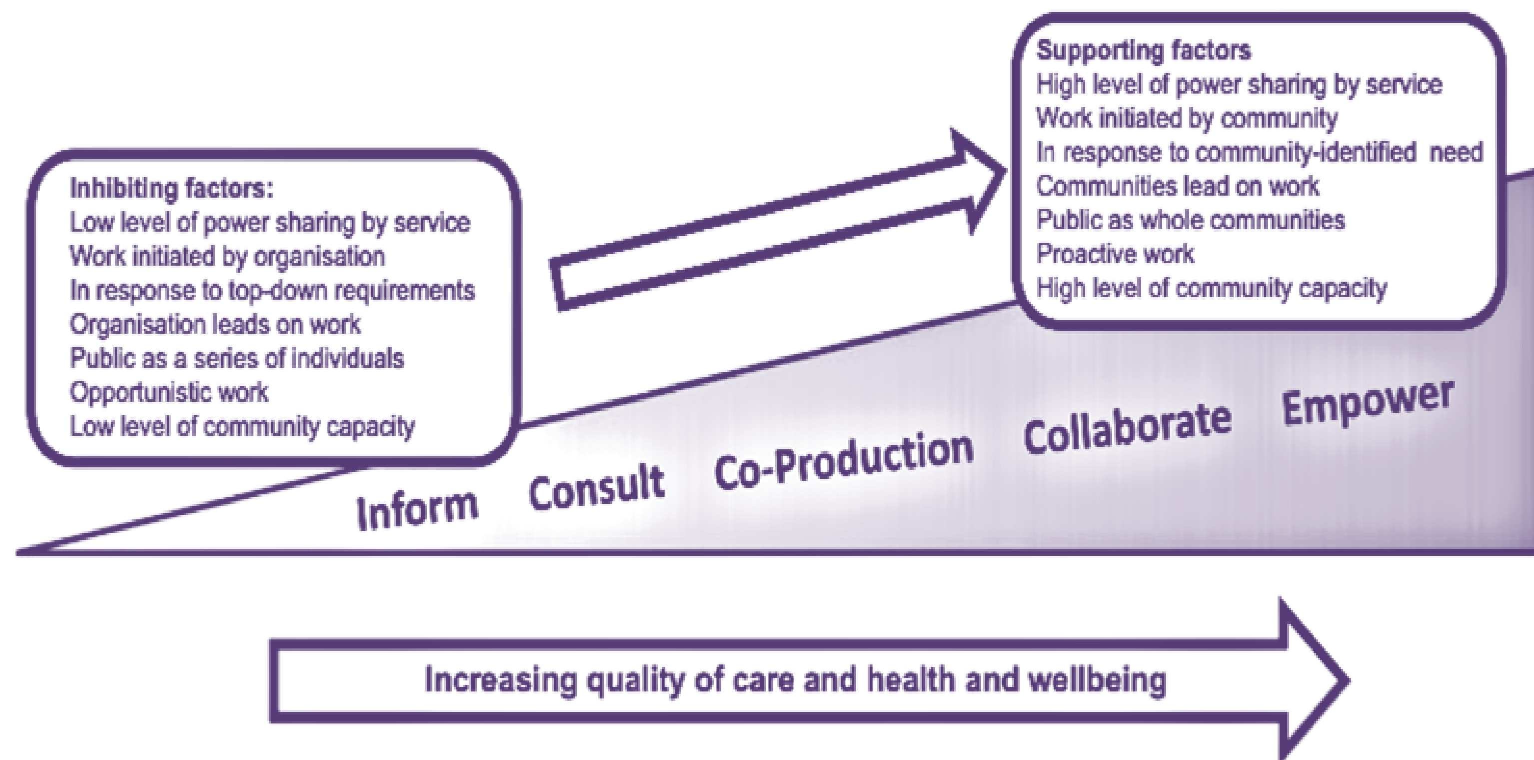
VOLUNTARY PARTICIPATION, UNIVERSAL OPPORTUNITY

for informed conversation and planning

60% are well	30% are chronically ill	10% are near death
Primary Care	**Acute Care**	**Aged Care**
• Flu shot • >70 years age check up • Electronic Health Record • Taking out a private health insurance plan • PBS safety net • Registering for organ donation • Turning 75 • Psychiatric patient programs.	• 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 • Pre-admission clinic for high risk surgery patients • Specific in-hospital support team for potential medical futility decision-making • ACD status included in discharge summaries.	• Making a will • Requesting a seniors card • Commencement of long term organ support e.g. dialysis, home oxygen • Disability support pension application • Commencement of home support services • Admission to nursing home.

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



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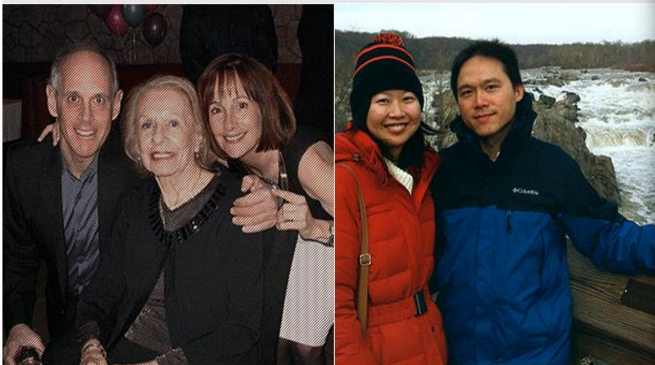
The Conversation Project is dedicated to helping people talk about



When it comes to end-of-life care, one conversation can make all the difference.

Let's Talk.

Begin Your Conversation Today.

starter kit »

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Dying Matters

'Let's talk about it'

Raising awareness of dying, death and bereavement

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Breaking bad news

The way someone learns about the death of someone close can stay with them for a lifetime. Our guidelines will help you get it right.

More

Find Your 1% campaign

Helping GPs deliver quality end of life care

Dying Matters shop

Latest News

Health Minister Mark Drakeford urges people in Wales to talk about death

As part of Dying Matters Awareness Week (18-24 May), people across Wales are being urged to talk more openly about dying,

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SEARCH SAVE RAISE

Since our launch,

100,000 PEOPLE

have attended

"DEATH DINNERS"

in over

30 COUNTRIES.

Featured in

USA TODAY · Los Angeles Times · The Washington Post · The New York Times · The Wall Street Journal · The Huffington Post · the Atlantic · npr · Forbes · Bloomberg

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

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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.

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