

Beyond Taboos?

Australians' capacity to care for each other through **death, dying** and **loss**

How are we doing with death in Australia?

It's time to lift the lid and go deeper.

We wanted to move beyond the known problems with dying and understand more about the experiences of dying, caring and grief in the Australian community.

We wondered about what people learned from their experiences and what they did with that learning. The more we know about the experiences of everyday people, the greater progress we can make toward transforming the experience of caring, death and grief in Australia.

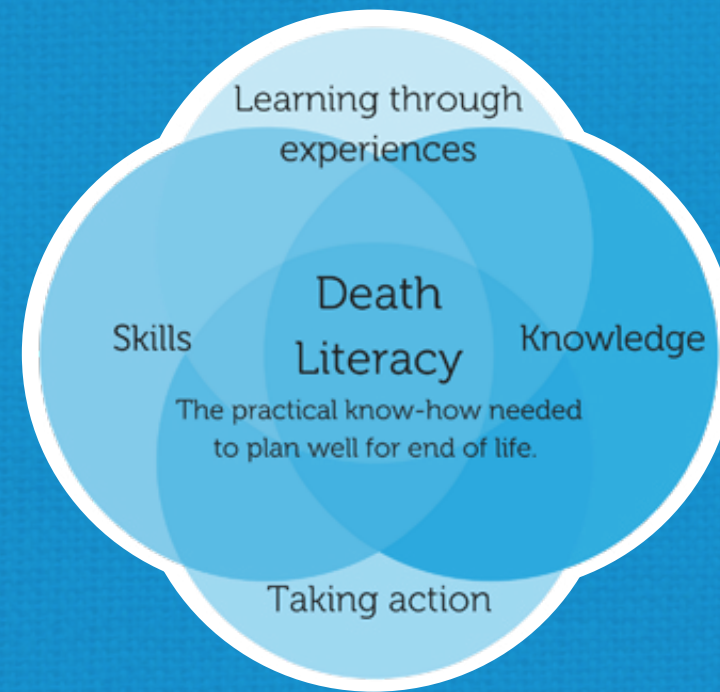
It's time we recognised the existing know-how in our communities.

So then we can start to build a different way of doing death.

We invite you to draw on this report to open new conversations.

This research is being developed in partnership between The GroundSwell Project and The Caring at End of Life research team, led by Prof Debbie Horsfall, at Western Sydney University. Over a decade of collaborative, community informed, social research about end of life care and the public health approach to end of life forms the bedrock of this national survey. A major outcome of this work will be the Death Literacy Index which will enable us to both measure and understand social changes around caring, death, dying and bereavement at local, national and international levels. **This research is funded by The J.O. & J.R. Wicking Trust.**

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What is death literacy?

Knowledge about, and understanding of, the death system. The resulting skills strengthen individual and community capacity to take action and care for one another at times of dying, death, loss and grief.

It is part of the new public health framework in which citizens are central to decision-making about, and access to, end of life and death care options.

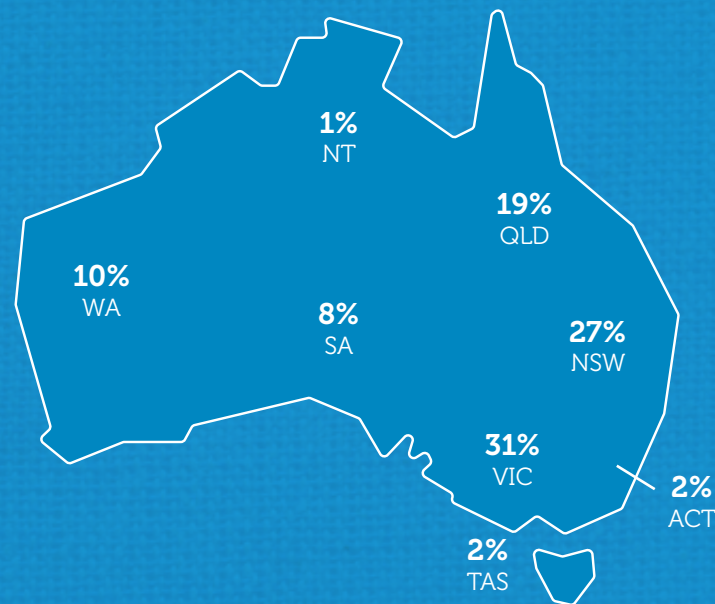
Death literacy has four components; skills, knowledge, experiential learning and social action and all provide a framework for behavioural and systemic change (Noonan, Horsfall, Leonard and Rosenberg, 2016).

Who did we speak to?

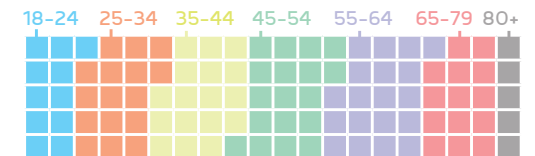
AUSTRALIANS ARE A CARING BUNCH ...



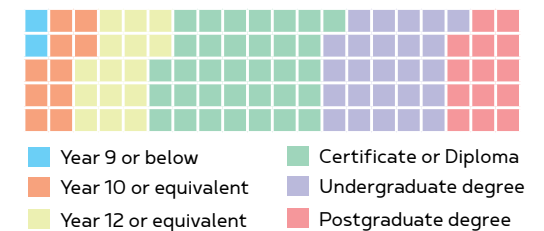
In early 2018 we surveyed a representative sample of 1330 people (53% female, 47% male) from across Australia about their experiences with death, dying and grief.



Age



Level of education



- ♦ **13%** have worked or volunteered with people at end of life.
- ♦ **11%** have worked in bereavement support.
- ♦ **9%** have attended training on how to help people who are dying or bereaved.

What have we done?



Many of us have offered support when someone is dying. We provide hands on care, emotional support and bereavement support

- ♦ **52%** send a condolence card after a death.
- ♦ **47%** of us have provided emotional support to a person who was dying.
- ♦ **46%** of us have been involved in caring for someone who is dying in hospitals (**15%**) private homes (**15%**) and aged care facilities (**10%**).
- ♦ **29%** have contributed to 'hands on' care of a person dying. **18%** have given medications to a person who is dying.



Supporting Carers

54% knew carers of people dying, **90%** had provided emotional support, **78%** bereavement support, and **63%** had sat with the dying person. **88%** of us have made contact when someone is dying.

What can we do?

- ♦ **45%** are able to offer support to people with a dying family member.
- ♦ **45%** can support feeding a person dying.
- ♦ **43%** can support a dying person's grief.
- ♦ **42%** feel able to sit with a person who is suffering pain when dying.
- ♦ **31%** are willing to put into practice what they have learnt about death and dying.
- ♦ **28%** feel able to advocate for a dying person about medical intervention.
- ♦ **26%** are willing to be rostered to sit with someone dying.
- ♦ **19%** are able to care for body after death.



People can and are involved in end of life care. Many people help with emotional support and are able to be physically present when someone is dying.



Learning about death ...



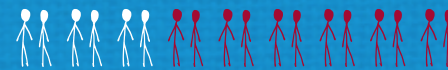
We are learning about death from our personal experiences.

Very few had key learning experiences in our schools or through community activities.

Key Learning experiences are found through:



56% say personal experience



33% see family as important



20% say faith, community or practices



7% say school contributed.



9% say community activities.

Learning from grief and loss...



More than half of us feel
changed by our experiences
with grief and loss.

40%+ of us believe we are
more equipped to help others
and feel more confident to
face similar challenges.

- ♦ **59%** feel more compassionate towards others because of their experiences with grief and loss.
- ♦ **51%** reported their experience increased their wisdom and understanding.
- ♦ **42%** felt more equipped to deal with grief and loss again.
- ♦ **40%** felt their emotional strength to help other people with death and dying was improved.
- ♦ **41%** had increased confidence to face similar challenges themselves.



When it comes to talking about death...



There are many more
Australians talking about death
than not. This challenges some
of the beliefs we have about
death being a taboo topic.

- ♦ **27%** of Australians avoid the topic of death and dying.
- ♦ **26%** of people say that they avoid conversations about death because they feel uncomfortable.

- ♦ **36%** of people are discussing death and dying with their family.
- ♦ **37%** of Australians have had a conversation with a dying person about their death.
- ♦ **18%** had helped another person make their end of life plans such as with an ACD or funeral.
- ♦ **51%** have a will.





Talking to adults about death is perceived as easier than talking to children about it.

24% of people feel able to talk about death, dying or loss with a child.

43% of people have experienced the death of someone close to them under the age of 16.

53% feel able to talk to another family member.



Navigating the system



We tend to know more about navigating the funeral industry than we do for end of life or aged care.

We're not too bad at finding information though, with 45% of us knowing how to get information about palliative care. Fewer of us know how to get information about carer and bereavement support.

This is important when you consider that half of us would like to access palliative care and also have support from our GP.

- ♦ **20%** of people know how to navigate the health system to support a dying person to receive care.
- ♦ **19%** knew how to navigate the aged care system to advocate for a person's EOL wishes.
- ♦ **33%** know how to navigate the funeral industry.
- ♦ **40%** know where to get information about dying.
- ♦ **45%** know where to get information about palliative care, but only **22%** know how to access palliative care in their area.
- ♦ **35%** know where to get information about bereavement support.
- ♦ **36%** know where to get information about carer support.
- ♦ **52%** reported they would use palliative care services and **56%** would use the services of their local doctor if they were dying.



Death is an active part of life



- ♦ **63%** have sat with someone dying.
- ♦ **44%** have spent time with a person after their death.
- ♦ **40%** regularly participate in rituals to remember someone who has died.
- ♦ **39%** have witnessed the death of another person.
- ♦ **20%** keep ashes or care for a grave.
- ♦ **14%** have helped care for a dead body.
- ♦ **54%** of us know someone who has been an end of life carer.
- ♦ **59%** have heard about someone dying at home in their community.



At times of death, loss and bereavement many of us are still involved in caring and supporting one another in homes and around our community.



How can we build
on the strengths
that already exist in
our communities?

Building on the connections we already have

Who are the people we connect with and call upon in times of need?

- ♦ **84%** of us have someone to contact if they need help.
- ♦ **34%** of us talk to our neighbours.
- ♦ **17%** of us feel that our experience of grief or loss made us feel more connected to our community.
- ♦ **19%** of Australians report they are living in communities that are discussing death and dying.

Sharing our stories and learning from each other.

There is a lot of experience and knowledge in our communities. What if we shared that more readily with each other?

- ♦ Currently just over a quarter (**27%**) of us avoid the topic of death and dying.

Improving our knowledge about dying and death

How can we get access to 'expert' knowledge about death and dying when we need to?

- ♦ Only **24%** feel able to identify the signs that death is close when a person is dying.
- ♦ Only **9%** of people know what an end of life doula does
- ♦ Less than **20%** of people say they know about the laws regarding disposal of a dead body, funeral requirements, dying at home and carer/bereavement leave.

Rituals

What are our shared rituals? How might we develop these?

- ♦ **46%** aren't aware of special days in their culture to remember people who have died.
- ♦ **13%** have helped organise rituals to support a person who is dying.

How can we build on the the existing capacity in our nation and our communities?

Despite the growing interest in public health approaches to palliative care, there is limited research demonstrating the impact of these initiatives. We are still learning how end-of-life knowledge and information is transmitted through community development programs and how these initiatives contribute to transforming current, service dominant approaches to health care. From our previous research what we do know is that people have the ability to 'do it their way' and step outside of institutionalised dying. The act of end-of-life caregiving provides a deeply personal connection to death and dying and is a catalyst to developing 'death literacy'.

Having death literacy helps EVERYONE. In keeping with new public health approaches, death literacy draws on a community development framework which suggests that if a community is to develop its capacity to support the caring of those at end of life, it needs knowledge and experience, a sense of empowerment and supportive social structures. This is distinctly at odds with the current trend toward carer training and formal death education programs for people facing end of life. Because death education programs are typically not designed to mobilise networks or create social action, they may actually promote compliance with the dominant medical approach by reinforcing the primacy of professional knowledge. The concept of 'death literacy' appears to capture, in an accessible and useful way, the social change outcomes of public health and palliative care. What is now

needed is a useable and comprehensive way of measuring both this concept and interventions claiming to further death literacy development.

It is our hope that the Death Literacy Index will provide a population based measure of death literacy which will enable us to a) determine current levels of death literacy at a whole of population and local level and b) measure the impact of local and wide-scale initiatives. This research has the potential to make a significant contribution to understanding the impact of interventions designed to increase the death literacy of communities, organisations and even whole nations thus contributing to scholarly, policy, practice and public knowledge of and debate on successful strategies and interventions in the end of life field. We anticipate that the index will be generalisable internationally and will enable evidence based decision making regarding best practice in increasing death literacy in a whole of community approach.

The new public health palliative care movement calls for a move away from an individualised model of death, dying and loss caregiving to a whole of community approach. There is then a very real need to understand environments and relationships which support collective community caregiving at end of life.

We hope this report is a powerful step towards a collective effort to build on the capacity and indeed the desire from Australians, to **do death differently**.



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Our research team



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THE GROUND SWELL PROJECT

The GroundSwell Project is working to develop death literacy through community engagement and action in communities around death, dying and loss. In 2016 The GroundSwell Project received funding from the Wicking Trust to support the development of the compassionate communities practice in Australia, including working with Western Sydney University to develop The Death Literacy Index, which once developed, could provide an annual snapshot of death literacy in our community.