Death Literacy in Australia: The GroundSwell Project

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Vision

A world where everyone knows what to do when someone is dying, caring or grieving
Our purpose…

is to create a more death literate society, one where people and communities have the practical know-how needed to plan well for end of life. This means shifting focus from 'talking about it' to transforming this 'difficult' conversation into one of deep community engagement, social action and empowerment.
Death Literacy is the practical know-how needed to plan well for end of life.
Death literacy

- Knowledge
- Skills
- Experiential learning
- Social action

... about the death system (not just end of life planning or care)

Death literacy is 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.
Figure 2  Focus Group 5 time 1.
Figure 3  Focus Group 5 time 2.
The Death System...

The social construction of death, dying, and grief is intimately tied to the death system or the “sociophysical network by which we mediate and express our relationship to mortality” (Kastenbaum, 1972, p. 310).

All societies have a death system that organizes how its citizens think, behave, and structure their death experiences. Death systems vary across culture and historical period, but all have common elements (people, places, times, objects, and symbols) and functions (warning and predictions, prevention of death, care for the dying, disposal of the dead, social consolidation, making sense of the death, and socially approved killing).
The Compassionate Community approach recognises that care for one another at times of crisis and loss is not simply a task solely for health and social services but is everyone’s responsibility.
D2KDay bringing to life conversations and community actions around death, dying and bereavement.

- 2018 – 6th year
- 411 events across Australia
- Emphasis on community hosts / events
- Resources that encourage action
- Arts and community events
ComCom Practice forum: developing grassroots practice in Australia

- Support local community to develop Compassionate Communities approaches
- 8 communities in Australia over next 18 months
- CD leader – supports/mentors
- Western Sydney University researching process and outcomes
- Compassionate City Charter?
Death Literacy Index:
Measuring impact

- Western Sydney University, La Trobe and QUT.
- Population based understanding of death literacy (outcome of ComCom)
- Provides a way for us to understand population based changes over time in Australia
The next 3 years…

- Continue to support the development of community development work in the EOL space in Australia.
  - CD worker in Aged Care
  - CD worker in Acute Palliative Care ward
- Publishing findings of aged care, DLI and Practice Forum Research.
- 6th International Public Health Palliative Care Conference in Sydney 2019
Thank you

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