

# Dying2Learn

MOOC ON  
DEATH AND DYING

dying2learn  
*The first ever  
Australian MOOC on  
death and dying*

Christine Sanderson  
Deborah Rawlings  
Deborah Parker  
Lauren Miller-Lewis  
Jennifer Tieman

*NSW Palliative Care Conference  
Broken Hill, 2016*

CARESEARCH<sup>®</sup>  
palliative care knowledge network



# The challenge: death literacy



*Death literacy = the practical know-how needed to plan well for death*

- Ability to think about and discuss death with others
- Realistic understanding of health and health care options
- Knowing what you want and (maybe) how you might be able to get it

# Death literacy and the social media

## Social media creates new opportunities

- Witnessing death and being present with dying people
- A “safe” space for discussing death
- Sharing of experiences, role modelling
- Providing information

# Using social media: the MOOC



***MOOC = massive  
open online course***

- Free
- Open to anyone to enrol, but not public
- Time-limited

# The making of a MOOC: Development

- The course was not designed to teach about or promote palliative care
- Exploring attitudes, beliefs, values
- Encouraging reflection
- Hoping to attract non-clinicians (aka “normal people”)
- Promotional strategies

# The making of a MOOC: Development

## Topics x 4 weeks

Week 1 : How we engage with death and dying

- *Humour, language, memorialisation*

Week 2 : Representations of death and dying

- *In art, film, television*

Week 3 : If death is the problem, is medicine the answer?

- *How we die, medicalisation of death, technology*

Week 4 : Digital dying

- *Our digital footprint, our digital legacy*

# Example ....

Peer Content

Groups

Gallery

Administer Students

Course Setup

## Part 2. The role of medicine in how we die

Take some time now to watch the PBS Frontline film "[Being Mortal](http://www.pbs.org/wgbh/frontline/film/being-mortal/)" which was made by an American surgeon, Dr Atul Gawande. This is a full length documentary (59 minutes) which explores how medicine "does" death - the good and the bad, the upside and the downside. Put the kettle on, put the phone on silent and take the time to watch it. It is highly recommended.

Here is the link to "Being Mortal" <http://www.pbs.org/wgbh/frontline/film/being-mortal/>

You may wish to think about some of the following issues while you watch - these are some of the very real challenges for both doctors and patients in Western health care systems ....

- Can we predict or diagnose dying? When and why might it be difficult? When and why might it be important? Should people always be told?
- Can we 'control' death? What might that mean? Do you think this is an idea that is particular to our modern world? What does it mean for us if medicine can't control death?
- How can doctors and patients decide how much treatment is enough? Think about some of the factors that might make this decision particularly hard.
- Think about the language we use when talking about serious illnesses, like cancer or heart disease. How do you think this language might affect the way people make their personal decisions? When is it helpful, and when isn't it?
- What might be the most important things to do for people who are seriously ill and likely to die in hospital? If you have had any experience of hospital as a patient, or friend or family-member of a patient, what are your thoughts about hospitals as a place where people die?



# The making of a MOOC: Delivery



- Learning about how to run a MOOC by running a MOOC
- “Curating” vs “teaching”
- Four weeks, four “teachers”
- A massive online conversation about death and dying – intense, engaging, personal



# The making of a MOOC: Evaluation

- Participants :  $n = 1156$
- 2/3 Health professionals, 1/3 general public ( $n = 369$ )
- Majority female – 92%
- 9782 comments
- 24 activities
- We will be analysing data beyond the foreseeable future

# The making of a MOOC: Evaluation

Evaluation of the MOOC will explore

- Shifts in attitudes to death and dying across the course
- Content of discussions – eg about advance care planning, prior experiences of death and dying, attitudes to death, discussions about euthanasia, etc
- Differences between participation of health professionals and non-professionals

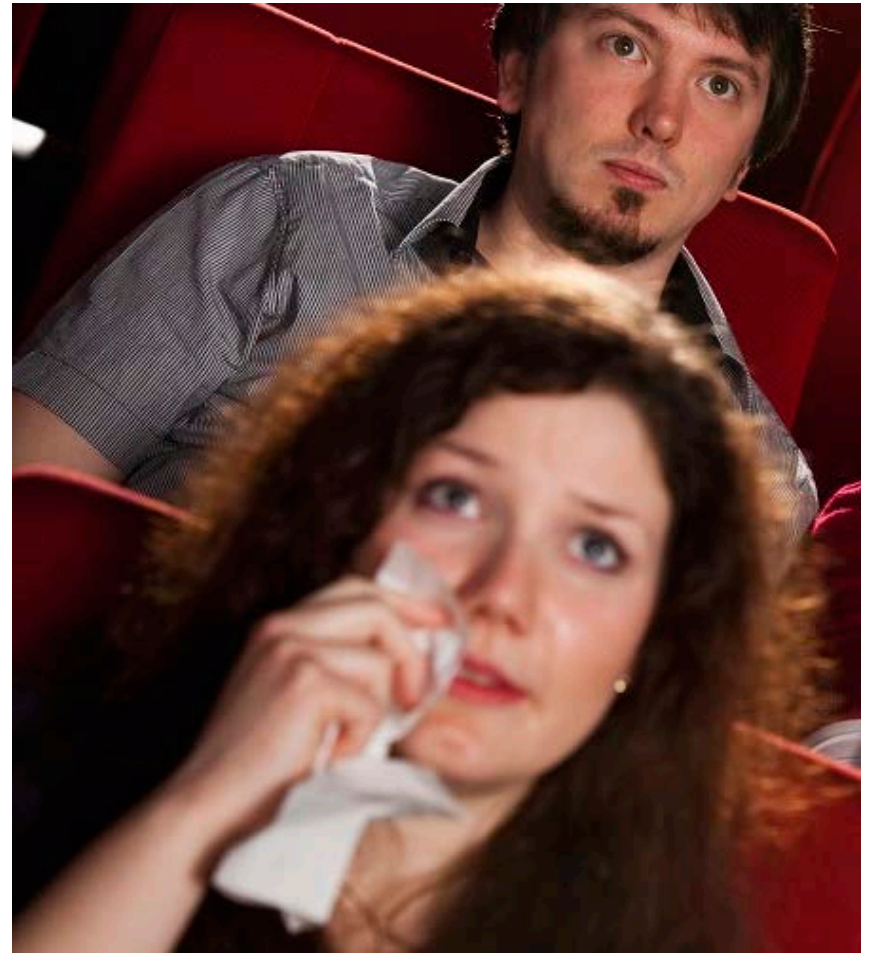
# Learnings for us



Most of the course went well but ....humour is tricky!

# Learnings for us

- There is a *real* eagerness to have some of these conversations
- Health professionals are people too – moving from the professional stance to the personal
- Many participants were reflecting on significant bereavements
- Participants were eager to connect off-line – several groups have been set up



# Some of the “lightbulb moments” for participants



*...I've never been present at a death, so very little to go on to help me write down my wishes. Reading about the dying process and the effects of different interventions or withdrawing interventions has been useful...*

# Some of the “lightbulb moments” for participants



*... I realised how much my feelings/thoughts around death and dying had changed during the course. Some information, some pictures were quite hard and confronting, but I felt good to have faced them.*

*I loved the open-ness of everyone and the sharing of so many different experiences both personal and professional...*

# Some of the “lightbulb moments” for participants



*... “Being Mortal” was powerful and although we talk about how hard those conversations are, to watch the doctors faces and demeanour was a revelation as to HOW hard it actually is. Hats off to them ...*

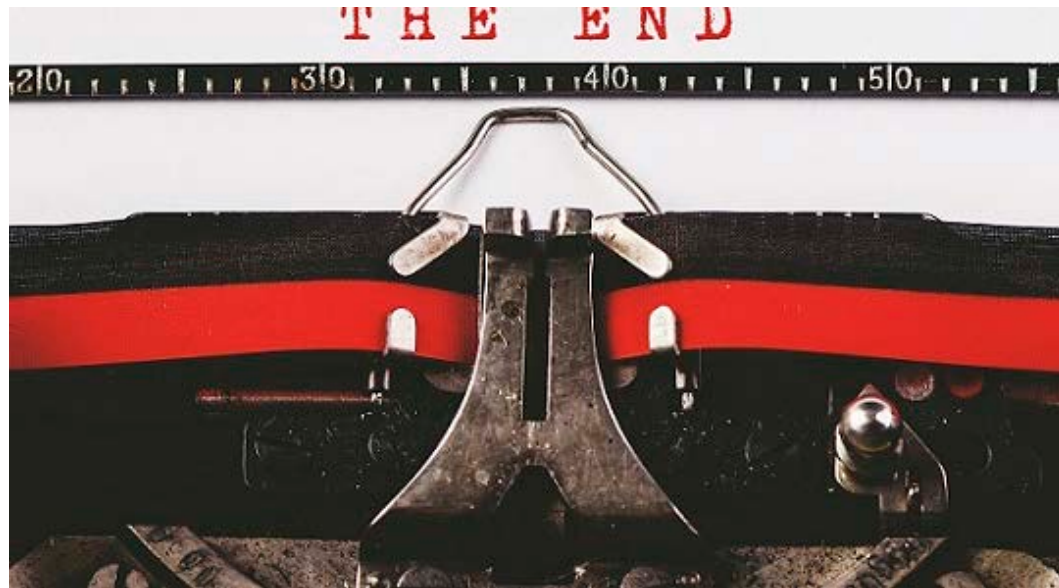
# Our participants were wonderful

*“ It just reinforced for me the incredible strength and bravery required just to live, and then to die. We are all capable of so much. ”*





# Next steps



Actually, this is NOT the end  
We will do it all over again in 2017



Dying2learn was funded by the Commonwealth Department of Health

CareSearch would like to thank the many people who contribute their time and expertise to the project, including members of the National Advisory Group and the Knowledge Network Management Group

The Groundswell Project and the OpenLearning platform both deserve special mention and acknowledgment