

Dying2Learn 2020



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What is Dying2Learn?

CareSearch initiated Dying2Learn as part of its 2015-2017 work program. CareSearch is an online resource of palliative care evidence for use by health professionals, patients, carers, and families. The website is available at www.caresearch.com.au.

We wanted to hold an online conversation with Australians and build community awareness of palliative care and death and dying. MOOCs (or massive open online courses) are short courses open to anyone with internet access and they are generally offered free of charge. They provide an opportunity to engage in socially constructed learning and peer exchange.

We chose Dying2Learn as a name to make it clear what the topic was about and to acknowledge a curiosity and interest in the topic. In 2020, 1,394 people enrolled for the course. They read, answered, commented, questioned, and shared their knowledge, experience, and feelings.

You cannot create something as unique as Dying2Learn without passionate and creative people. The facilitators for 2016 and 2017 were Professor Jennifer Tieman, Professor Deb Parker, Dr Chris Sanderson and Deb Rawlings. Dr Lauren Miller-Lewis joined the team of facilitators in 2018 working with Deb Rawlings.

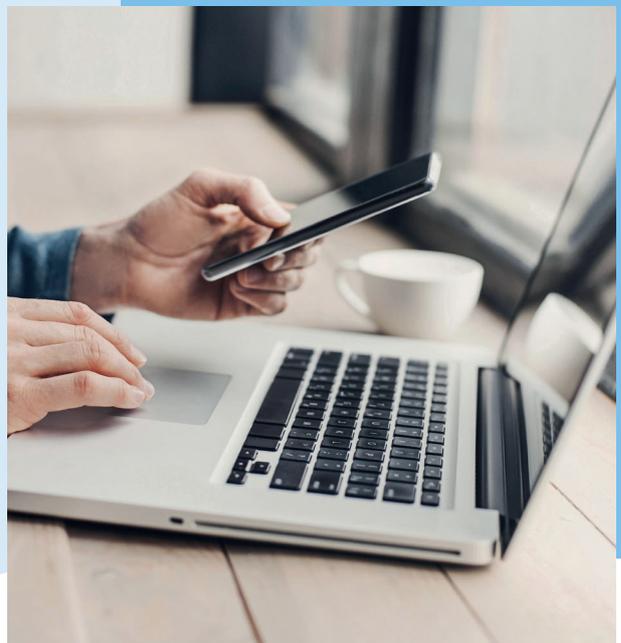
Each facilitator brought a specific and individual passion – Jen was interested in the digital world and how it was changing how we found and shared information around death and dying and how we grieved. Deb P wanted people to reflect on how we represent death and dying in books, art, films, music, and TV and to find out what art forms mattered to the community.

Chris wanted to share her knowledge as a palliative care physician and to challenge people to think about what is the role of medicine in dying. Deb R knew that grief and loss affected individuals and families and wanted to explore how the language we use, and the ways we remember affect us. Lauren brought positive psychology into the picture when she joined focusing on meaning in life and legacy making.



Orientation and Digital Treats

2020 was the year of digital treats. We were keen to create a selection of small interactive activities that allowed people to explore and learn about death and dying. These were some of the special things we built to keep you interested while waiting to start the modules.



During my childhood death was spoken about openly when it came up in conversation. Death and what comes after it is something that I have reflected my whole life. I am curious about how we all view the topic so differently.

I see this course as an opportunity to continue to learn about death and dying...and continue the conversation about good end-of-life care.

This course popped up in my work emails and I thought.... wow this looks interesting!

Match the quote

This one caused some angst. People searched the internet to get the correct matches. We relented and created an answer sheet for Week 5!

Beethoven		"Oh wow."
David Bowie		"Music has been my doorway of perception and the house that I live in."
Marie Antoinette		"Pardon me sir. I meant not to do it."
Winston Churchill		"Friends applaud, the comedy is finished."
Steve Jobs		"It's better to burn out than to fade away."
Frida Kahlo		"I'm bored with it all."
Jane Austen		"I hope the exit is joyful and hope never to return."
Kurt Cobain		"I want nothing but death."
Humphrey Bogart		"I should have never switched from Scotch to Martinis."

I enjoyed matching the quotes. First time, I had few matches. Second time, I googled researched which was a lot of fun. Fascinating.

So interesting how all these cultures and religions relate to the handling of death and burial. What a varied species we humans are.

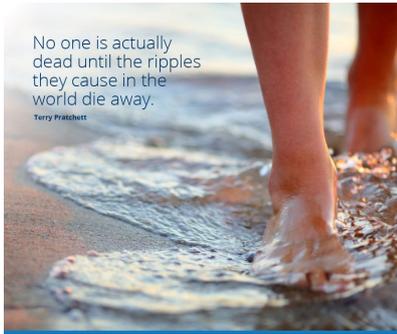
It's fascinating to read about the different practices and rituals around the world, how diverse we all are. Certainly, in the western world we have tried to brush a lot of conversations around death and dying under the carpet.



Death around the world

Previous MOOCs had highlighted the need for more information on other cultures and practices. This year you could travel from Madagascar to Russia and back to Tibet.

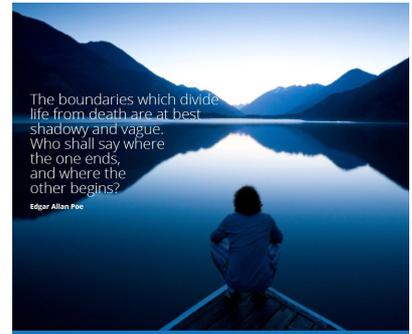
And don't forget our posters



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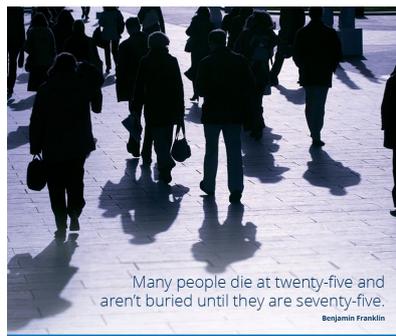
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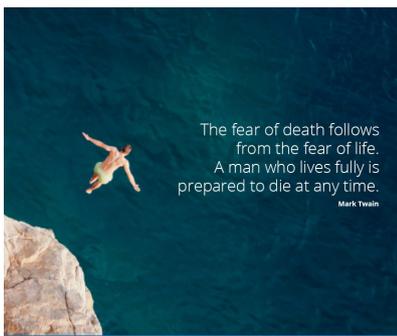
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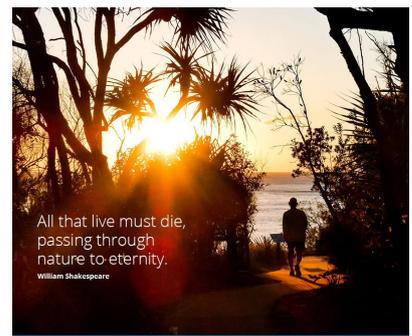
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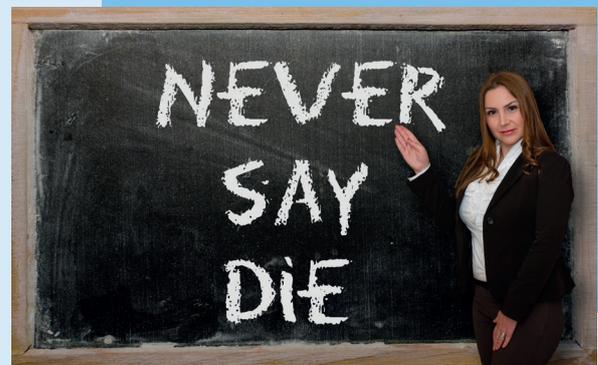
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Week 1: How We Engage with Death and Dying

This first module had three related parts. The first part looked at the use of humour while the second looked at how we engage with death and dying, through the language we use, public mourning, and funerals. The third part explored how we engage with death and dying while we still live.



Module 1A: How We Engage with Death and Dying – Humour

Module 1B: How We Engage with Death and Dying – Language

Module 1C: How We Engage with Death and Dying – Public Mourning

Module 1D: How We Engage with Death and Dying – Funerals

Module 1E: How We Engage with Death and Dying – While We Still Live



CARE & FEEDING of YOUR GRIEVING PERSON



YOU DON'T NEED TO BE PERFECT, JUST PRESENT.

I can't help but think that many of us appreciate the Monty Python 'Dead Parrot' sketch more than we would like to admit - I know I do.

When my grandma passed away she told everyone in the family "Don't spend too much money for my funeral, use that money for having a great meal all together with the family and friends"

I have not given as much thought about my own legacy although I have a desire to leave a legacy. I believe in paying it forward so if I can do something so intrinsic but of such value to others, then that would be the legacy I would like to leave.

Legacy for me is those little bits and pieces of me that shape or influence those I come into contact with. Remembering my name is not important - the actions, values and beliefs are.

What the facilitators said



Lauren: During week 1, we discussed the use of humour about death, and heard a variety of perspectives about how it can be a useful tension-reliever, but its appropriateness depends on who instigates the humour and the personalities of those involved - 'reading the room' is important. We also shared the meanings that funerals, memorials, and mourning have for us, their cultural significance, and how these rituals can influence the grieving process.

We saw great diversity in plans for what we would like to do before we die, and spent a moment imagining what this might be if we only had eight weeks to live. And when it comes to thinking about living with our legacy in mind, it seemed that legacy has various meanings for people, whether it be something tangible that we leave behind, or simply our thoughts about how we hope to be remembered by our loved ones after we die. Sometimes legacy was about how it would make the legacy-leaver feel as they face the end of life, but also important is how legacies left by loved-ones can give comfort to legacy-recipients. Our loved-ones can live on in our memories.



Deb: We noted that many of you had been bereaved, and for some quite recently too. It was important to acknowledge this and for everyone to know that we appreciate that you were sharing in a time of sadness. It was lovely to hear you mention your friends, work colleagues, relatives and loved ones who had died, and to hear something about them. For some of you, there had not been the opportunity to grieve properly nor to attend a funeral and that was clearly hard.

So, I wanted to highlight something that I found on Twitter. This image is from Ripon Cathedral in England and are of 11,000 origami angels, made by volunteers and school children, each one a dedication to the tireless workers throughout the COVID-19 pandemic and to the people who have died. I felt that it was such an uplifting sight and one that I thought would resonate with everyone in Dying2Learn. I suggest that you revisit the images and take a minute to reflect and remember. Also please continue to take care of yourselves, all of you.



Week 2: Representations of Death and Dying

This module examined how death and dying are portrayed across a variety of medium. In this week we firstly delved back into history to see how death and dying have been portrayed in art and literature. This provided a backdrop

for a more contemporary view of how death and dying has been represented in different media such as film, music, podcasts and TV.

Module 2A: Death and Dying via Art and History

Module 2B: Death and Dying in Film

Module 2C: Death and Dying through Television

Module 2D: Death and Dying in Other Mediums

I don't think there is enough shows that portrays in reality.

It is curious that although there are many TV dramas and films that have significant content about death and dying that still many people are not at all ready to accept that it is something natural and will happen to us all.

Amazing collection of paintings, that really speak to you. I have lately been thinking a lot about death and want to be prepared.

I think it is songs that you may have shared with the person that evokes a memory of a time with that person.



What the facilitator said



Deb: Well so many delved into the content for Week 2 – Representations of Death and Dying. We had a special activity through facilitated access to art works from the Art Gallery of NSW.

While we are not collating the top 10 art works there is no doubt the front runner for popularity was Briton Rivière - *Requiescat*. It was terrific also to see from the Pause art sets how so many of you would be able to use these images to open conversations with people.

We also voted on the Top 10 Books and Movies. Number 1 book was *Tuesdays with Morrie* by Mitch Albom and the movie was *The Notebook*. We even created a *Dying2Learn* Spotify playlist, a truly eclectic mix. It has been inspiring reading your stories and insights throughout the course. You have given me new lists of books, movies, songs, and podcasts to consider.

Acknowledgment of death and dying within society through published texts and art meant that death and dying were embraced as part of life. In contrast, today you may hear the phrase death denying. That is, our society no longer embraces death as part of living but has instead hidden or sanitised death and dying.

Favourite film about death:
The Bucket List

Reflection on film: I really like this movie because if I had the choice I would like to know that I am dying and put my affairs in order and complete as much as I could off my bucket list. It is a movie that makes you think about what is really important to you in your life.

Favourite film about death:
Four weddings and a funeral.
Reflection on film: Irreverent comedy has a great place in normalising tragedy and this film does it brilliantly.

And the winner is!

We asked the 2020 cohort for their favourite books and movies. And the results are in!

We also asked them about songs and created a Spotify list.

What else did the 2020 cohort love?

Dylan Thomas's prose, Rage Rage against the Dying Light

In the Arms of an Angel by Sarah McLaughlin

With the End in Mind by Kathryn Mannix

Man's Search for Meaning by Viktor E. Frankl

Dying Well by Ira Byock

Stop all the Clocks by Auden

Andre Bocelli, Time to Say Goodbye

Bette Midler singing Wind Beneath My Wings

This House of Grief - Helen Garner

Supermarket Flowers by Ed Sheeran

Bob Dylan – Knockin' on Heavens Door

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Top 10 books and movies voted on by the 2020 Dying2Learn participants

Top 10 Books

- 1 Tuesdays with Morrie by Mitch Albom
- 2 The Book Thief by Markus Zusak
- 3 The Lovely Bones by Alice Sebold
- 4 Dying to Know: Bringing Death to Life by Andrew Anastasio
- 5 Being Mortal by Atul Gawande
- 6 The Prophet by Kahlil Gibran
- 7 When Breath Becomes Air by Paul Kalanithi
- 8 Top Five Regrets of the Dying by Bronnie Ware
- 9 Smoke Gets in Your Eyes by Caitlin Doughty
- 10 Die Wise: A Manifesto for Sanity and Soul by Stephen Jenkinson

Top 10 Movies

- 1 The Notebook
- 2 The Bucket List
- 3 Ghost
- 4 Beaches
- 5 Death at a Funeral
- 6 Up
- 7 Me Before You
- 8 My Sister's Keeper
- 9 The Fault in Our Stars
- 10 Love Story



Week 3: If Death is the Problem... Is Medicine the Answer?

The mortality rate, despite all the achievements of modern medicine, continues to be 100%. This module looks at the role of medicine in supporting people at the end of life. In this week we looked at how we die and what we die of. The group then went on to consider how we treat seriously ill people at different ages and lastly, we explored the idea of choices about dying.



Module 3A: What Will We Die Of?

Module 3B: Dying Old, Dying Young... Let's Talk About Ageism

Module 3C: Choices, Choices, Choices – What Choices Do We Have About Dying?

What the facilitator said



Chris: When I was a medical student I realised that everyone dies, eventually – but as I went through my training I also became aware that we are pretty bad at dealing with that reality. That started me on the path I have been following ever since - looking after patients when they are dying, as a palliative care doctor.

Doing this work gives me a “through the looking-glass” perspective on what medicine is for, what it can do, and what it can’t do. In our discussions, the theme of tragic versus normal dying elicited some profound reflections. Tragic deaths seem to haunt us because of the sense of missed chances, things left unsaid, or being unprepared (both the person who has died, and those who are left behind). Suddenness is a common theme, as is suffering / pain / distress – the death that is not peaceful.

Another big theme is the deaths of children, but also the effect of a premature death of family members on children who are left behind, and who may never fully recover from that loss. Many people talked about the incredibly complicated feelings related to those who commit suicide – these range from compassion, to confusion and shock, through to anger. Often all at once. There were beautiful stories shared of memories of people whose deaths, though many years ago, have never been forgotten, and poignant stories of the impacts those deaths have had on people’s lives.

What will we die of?

Good question. And the answer is, it depends - on how old you are, your gender, your background, or where you live.

Basically, you'll probably die older and of a disease rather than something external like a car crash.

But when asked about age of dying and unexpectedness, people saw dying young as more tragic and unfair.

And regardless of what you hope, you are probably not going to live forever. At least not in the foreseeable future.



Are we ageist? Whose life is more important? Who gets to choose?

There was a lot of discussion about COVID-19 and about aged care and older people. And you had lots to say about equity, medical futility, ethics choices, understanding options, costs, selfishness.

So many views and opinions were put forward. It was a genuine discussion of complex issues.

This is incredibly difficult to answer. Do you save a life that will only last a few more weeks or one that may or may not live years? What are the variables, the patient's wishes?

This is such a grey area, but for me equality is everything, in life and in healthcare. But I know such decisions can often be made, and I do not envy the person that has to make such decisions.

I have definitely seen people regret having treatment and in my experience doctors are much more likely to offer treatment than have a realistic conversation around risks/benefits/outcomes of doing nothing, and have especially seen this with older people who never "bounced back" from said treatment.

Beautiful stories, we need to be human, love, care and respect each other till the very end.

I work in the Aged Care Industry and each time a customer dies it makes me realise how precious life is. ...Every person has a contribution to make to life.

Yep life is short. We can be here today and gone tomorrow. Life is precious. Treat yourself and others right.

Week 4: Digital Technology

Week 4 was an exploration of how the digital world and digital technology is changing perspectives around health and around death and dying as well. The internet is no longer just about finding information, it is about connecting and interacting.

By the end of this module we should have an increased understanding of the range of online materials relating to death, dying, and palliative care and be able to recognise that the digital environment is shaping interactions, attitudes, and perspectives about death and dying.



Module 4A: The web is big

Module 4B: Digital access, equity, and use

Module 4C: Digital opportunities

Module 4D: Dying is personal. Dying is public

Module 4E: Digital legacy

What the facilitator said



Jennifer: It is always intimidating having the last week of Dying2Learn because there has already been so much content in the first three modules. As facilitators, it is remarkable to be able to use a digital platform to build ideas into shareable modules and to use functions that enable us to listen to songs, to see pictures and videos, and post ideas and views.

Each time we have run Dying2Learn, I have been the one looking at digital death and dying. Week 4 races online, into the web and addresses everything digital. So, it is fitting and poignant that the last MOOC is being held in 2020, a year where our understanding of death has changed and a year where lockdowns have changed our relationship with the digital world.

For many participants, Week 4 content was a challenge with concepts around after death avatars, social media mourning, and thinking about what to do with their own digital footprint. There was also genuine amazement at what was available on the web. But what was also clear to me was that even with all this technology, the week remained a very human exercise where people told stories, provided resources, and supported each other.

Many people in the West think that medicine can cure anything and some doctors struggle to tell patients that they are out of treatment options.

This is a interesting module! It has pulled me up in my tracks as I have unconsciously journeyed into this space. Is it appropriate? What is the best that I can endorse and develop from the internet? What are the things I need to let go that are not helpful, ethical or lacking respect? Still thinking!!!!!!!!!!!!

Dealing with death online

These are good things in both the physical world and the digital world but things are changing. More people are now sharing their diagnoses treatments and dying online.

People are looking at how they can continue to interact after their death with avatars, holograms, messages from beyond the grave.

This year has seen a new dimension arising in digital mourning. We have recognised grief across the world with COVID-19 as it affected not only individuals but also communities and countries. We have learned to grieve virtually as we could not be together. What changes will social media use make to the way people grieve?

We live in a digital, online world nowadays - of course, we will mourn on-line now. And with current covid restrictions, we will attend funerals and memorials online too. We need to be respectful, compassionate, and authentic in our online presence.

Sharing resources

By now, the digital doorway was unclosed. There was a flurry of activity as people downloaded online resources and shared websites, and saved links to blogs, videos, TedTalks, articles, and twitter handles. It also raised the issue around how to judge whether something you find is trustworthy and what is fake news and misinformation.



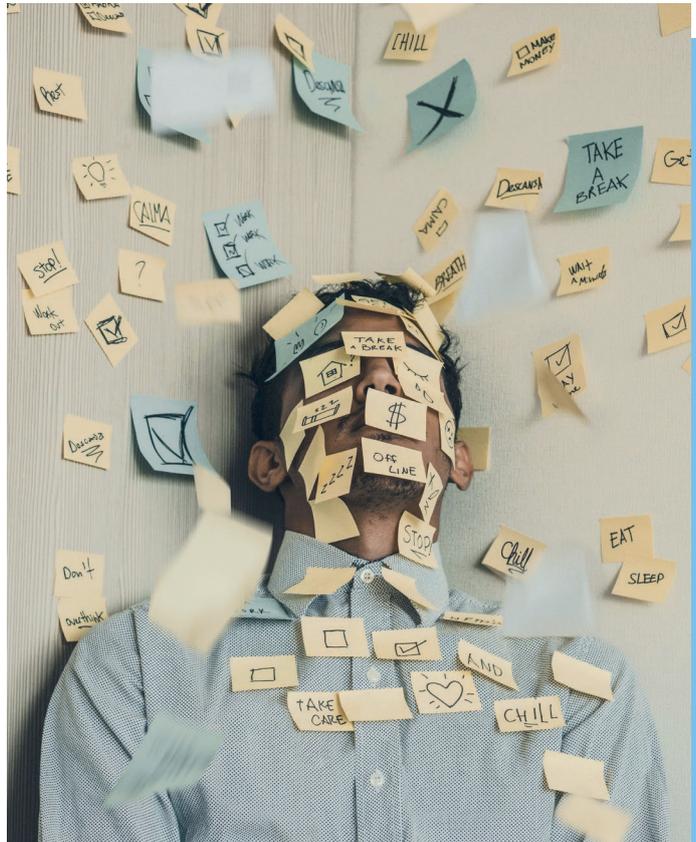
If you can still post to a person's social media pages after they have died, does that complicate the process of understanding they have gone? Can it be helpful to some? So many questions!

Very eye-opening information and content to process - as an older person with a fairly limited digital footprint I hadn't contemplated the implications of our digital lives after we die.

Card sorting

And then we finished by asking participants to make sense of all the content by sorting ideas and topics to make a new organisation for the course. Forty two ideas and the freedom to arrange them as you saw fit.

Many commented that it made them realise how many different aspects there were when thinking about death and dying.



It made me pause to reflect on the many topics we have covered over the past few weeks. It is a way of reaffirming that there is no right or wrong way to deal with death.

It was a fun task to complete and made you think of how and why you are grouping certain tasks into certain groups.

Week 5: Reflections

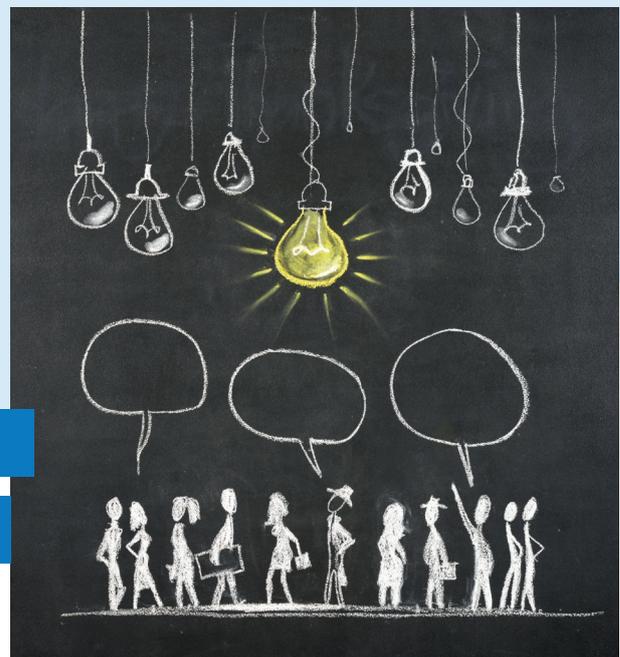
So Week 5 was a time for us all to get together, to reflect on what had been covered in four intense weeks, and to sort out all the bits and pieces associated with finishing up a course. There were four specific activities.

Activity 5.1: Making Death and Dying a Part of Life

Activity 5.2: Three Words about Death and Dying

Activity 5.3: Time to Reflect

Activity 5.4: The Last, Last post!



What a strange time to be alive in to go through a global pandemic, but with the level of information/ media connectedness that we now have...we don't even know what the full ramifications are or will be yet...

Dying2Learn

