

LET'S TALK ABOUT DEATH!

Thanatophobia is a fear of death. I'm yet to find a word that describes a fear of saying Death, but there should be because it's a real thing!

Over the years I have heard many euphemisms used in place of Death or Dying. Passed, left, gone, lost, and expired. I was unaware that patients expire like perishable food products. What concerns me more is that it's not just the community, but also amongst the medical profession. Using such words can leave room for misinterpretation. "I'm sorry your mum has gone" - gone? gone where?

A majority of health care professionals enter into health because they want to help people and make them better, so it's not surprising that many are uncomfortable discussing death with their patients, and their families. However when that discomfort prevents these conversations happening, it's a problem. Death becomes the elephant in the room.

I was recently at a family meeting where the doctor avoided using the word dying so much that the family had little understanding of what the prognosis was. In fact, the word was replaced with "unhappy" to describe an acute ischemic bowel. The family were told that the bowel would continue to become "more unhappy" and that would not be good for the patient. Not once in a one hour meeting was the "D" word mentioned by the treating team. Now I don't mean to be all glum but the word is Dying.

We have to be mindful that not everyone is medically literate, in fact the average literacy level in Victoria is of level three. This means not everybody can read between the lines, so simple clear terminology needs to be used otherwise we risk miscommunicating with patients and families. This in turn can cause increased stress, unpreparedness and even trauma thus continuing this fear of Death in the community.

As medicine continues to improve, new cures, and better surgical procedures evolve, we need to accept that medicine will always have limitations. Death is a normal process of life. The human mortality rate continues to hold steady at 100%.

Starting the conversation by asking patients what's important to them at this point in their life, and how do they feel things are going, followed by silence can give you a lot of insight into what a person already knows, and what matters most to them. When we don't talk about what matters it can lead to increased feelings of isolation, loneliness and distress.

Communication workshops are run by various organisations, including Cancer Council Victoria and GRPCT, and can be a very useful first step in improving your communication skills and comfort, when having difficult conversations around death and dying. After all, these conversations will not become easier if we continue to avoid them.

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DYING TO KNOW DAY

On the 8th of August the Grampians Regional Palliative Care Team, Ballarat Health Services and Ballarat Cemeteries held a Dying To Know Café and Bar, with the aim of encouraging people to get together and talk about death and dying.

The Dying To Know Café provided people with a safe/non judgmental space to discuss death over a coffee and cake. Patrons were encouraged to explore issues surrounding death, a topic that is often considered unmentionable/taboo in western society. The conversation doesn't have to be bleak or depressing, death is a fact of life that we all have to face as mortals.

The concept was established in 2010 in the United Kingdom, and has spread across Europe and North America. To date over 8964 meetings have been held across 65 countries.

The conversations were guided by facilitators who were there to participate and listen to the views of those partaking. Too many people are dying in ways not consistent with their own values or wishes because we are reluctant to have these conversations with our loved ones, for fear of upsetting them. End of life planning can, or even should, occur at any age regardless of our age or health status.

By encouraging community led conversations about end of life care, we can plan ahead and communicate what we do or do not want at the end, by increasing our death literacy. Having knowledge helps people make informed decisions about their end of life care, and being able to use that information can be empowering. What is an advanced care plan, and how is it used? What are the palliative care services in my area and how do I access them? Are some examples of information that can be shared in these discussions.

The day was attended by members of the community ranging in age and backgrounds, with many laughs, and some tears, as people reflected on their own personal experiences around the death/s of their loved ones. It is an honour to be part of these conversations that leave an important message to our loved ones about our values and preferences at end of life. In a difficult time in our lives, what a gift it is to have had these important conversations.

THE DAY OF THE DEAD OCTOBER 31 - NOVEMBER 2

The Day of the Dead or Dia de Muertos is a Mexican holiday that involves family and friends gathering to pray and remember those who have died, helping them on their spiritual journey. In Mexico death is viewed as a natural part of the human cycle. Celebrations often start on the 31st of October. The 1st of November is known as "The Day of Innocents" and this day is dedicated to honour infants and children who have died. The 2nd of November is the day where deceased adults are honoured. On this multi-day holiday, death is not viewed as sadness but as a celebration, where their loved ones spirits awake.

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