End of life through a culturally and linguistically diverse lens

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I lost my husband recently and that experience made me live and think about end of life practices more deeply.

Throughout the years we talked about life and about the life that we wanted. We wrote some indications in our Advance Personal Plans (APP)on what we did not want. This requirement, to provide instructions about choices we would wish if we became unable to express them, was something we were not aware of when we first moved to Australia from Italy. I do not believe many countries have anything similar. Once we realised the importance of having an APP, in particular appointing Alternative Decision Makers, we wrote down some things, especially around health matters.

What we never wrote down was anything about our funeral preferences. We were in agreement on cremation, but what to do with the ashes was never resolved. My husband travelled a lot, exploring and writing mostly about the Indian subcontinent. At some point he imagined friends and family travelling to India together to disperse his ashes in one of the places he loved. Later, as he grew older, he changed his view. I remember the last time we talked about it, not many years ago, when he simply said: 'you and my daughter will do as you please.' That response did not help, or perhaps it did.

Deciding on one's own wake, funeral arrangements and music to be played can bring comfort to both the person and their family. It allows them to have a say and to know that they will be remembered in a certain way. This too was something we never spoke about. Our experiences of funeral arranging had always been similar. One chose a funeral home and talked to the parish priest to book a day and decide on a burial place. There was not much time between the passing and the date of the funeral, sometimes only a couple of days. Everything else followed a well rehearsed routine and the involvement of families could be, and mostly was, minimal.

Here in Darwin, everything was different. The hospice was supportive and accommodating. There was no need for me to leave the room. I could take the time I needed and call family, friends and a minister. In hindsight this was critical, because when I left the room at the hospice after almost five hours, I was ready. I was surrounded by our closest friends and family, and thanks to video calling even those who could not come in person were part of those moments.

The funeral arrangements that followed were partly routine, such as deciding on the date, the location, the coffin or urn and the type of funeral. The date came as a surprise though, as the first available spot was ten days later. What at first seemed a long wait turned into a gift,

because it gave us time to think and to prepare. Other aspects became deeply personal. With guidance I was able to organise the final goodbye in a way that would have made my husband smile, and that allowed everyone else to feel part of it because the choices were meaningful.

Finally there was the eulogy. Since my husband had spent most of his life overseas, it had to be meaningful not only for those attending the funeral in Darwin, but also for friends and family following online.

Organising, choosing, liaising with people, talking to family and friends and celebrants, all contributed to making the farewell less traumatic and helped me take the first steps into the next stage of my life.

For many older people who move into residential care, not necessarily because of dementia, but often to receive more support, the staff and carers who look after them often become the ones they turn to for help in recording their stories and wishes. Even when an Advance Personal Plan is in place, people may change their minds.

Different cultures have different rites, yet they all share the same role. They offer comfort and solace and they ease the transition to the next phase.

For aged care service providers who need to provide the most appropriate and



person-centred care, it is important to be aware of the cultural and spiritual practices of the people they support. Good practice means asking, listening to personal stories, understanding personal preferences and adjusting services so that rites, traditions and personal wishes are acknowledged. In this way, families feel respected and older people are honoured in ways that are meaningful to them.

Useful resources

- <u>Dying to Talk Discussion</u> <u>Starters</u> Palliative Care Aus
- Proveda.com.au
- The Awkward Conversation
 We're All Avoiding (But Really
 Shouldn't)
- Your Emotional Will

On the COTA NT website,

- Advance Personal Plans
- <u>Advance Personal Plans in Languages</u>

If you need resources translated, please contact me on 8941 1004 or email.