

## THE HUMANITY OF CARING

In September 2019, I attended the Oceanic Palliative Care Conference in Perth. The theme Universal Access: Oceans of Opportunities explored palliative care as a human right. The conference aimed to highlight what can be done to ensure people from underserved populations have access to palliative care and have their pain and other symptoms managed at end of life.

The conference highlighted the relative luxury of palliative care in Australia, compared with other nations in our oceanic region. Whilst specialist palliative care provision in rural and regional Australia can be difficult to access, the basic general principles of palliative care are embedded across our health care systems, ensuring patients have access to generalist palliative care at a minimum.

Dr Christian Ntuzimira, a Palliative Care Physician in Rwanda delivered the key note address, speaking on the Humanity of Caring. Dr Ntuzimira stated that in Rwanda they have a saying – “When you are well, you belong to yourself, but when you are sick you belong to your family”. He explored Ubuntu philosophy, defining a “soul” as humanness, caring, sharing, respect and compassion. They talk about life until the end, but do not ignore the elephant in the room – death.

There has been a historical shift in the meaning of death itself, influencing the patient’s end of life perception. Historically death was viewed as an achievement because:

- It was considered as part of normal life, a natural phenomenon
- It was viewed as a natural reprieve, a reward after a well lived and fulfilled life, and it was a reward to be a “spirit”, an ancestor, a high level presence in the family.

This perception of dying is not isolated to Rwandan culture. Yongey Mingyur Rinpoche, a Tibetan teacher and master of the Karma Kagyu and Nyingma lineages of Tibetan Buddhism, describes the custom of turning over their cup before going to sleep, signifying not just the end of the day, but the end of one’s life. In the morning they turn the cup right side up: their new life begins, and they are ready to receive.

Dr Ntuzimira argued that the concept of heaven and hell stemmed from western cultures and Christianity, and this has led to the fear of death as sanction, and argues death is more frightening today in some cultures as a result of this concept.

In many cultures the focus of caring is on the person, and lesser on the medical or clinical focus of the illness. In Rwanda a family member with a terminal diagnosis is cared for by the family. Dr Ntuzimira explored the concept of western cultures having a level of disconnection from caring, with a greater emphasis on institutional care, rather than family based care.

Dr Ntuzimira’s keynote address highlighted the importance of respecting the cultural and spiritual aspects of caring for a person who is dying, and ensuring that the humanity of caring is not lost. It is easy to be caught up in the clinical focus of caring for someone, treating the disease and fighting death, rather than ensuring the individual needs of people are met in a compassionate and flexible model of care. This can be achieved more by listening to the person, their extended family and their wider community, and ensuring their preferences and values for end of life care are heard, and documented.

In a multicultural country like Australia, we must develop community awareness that death is a natural part of life, and work to change the inability to have these discussions earlier for fear of upsetting the patient. As a Palliative Care Nurse Practitioner I feel honoured to be a part of these conversations with patients, ensuring their values and preferences for end of life care are communicated with their families, and health care teams. Across our region I have witnessed the incredible displays of compassion and humanity when people come together to ensure someone’s dying wishes are honored.

In Australia caring within the community is achievable, but more emphasis must be placed on adequate provision of support for patients and carers, with the focus shifting away from institutional care to a primary care model. Our role as palliative care clinicians is to support patients and families to have these conversations, recognize that they are valued in our community, and allow them to play a key role in the decision making of where their end of life care is delivered.

**Regina Kendall**  
Nurse Practitioner, GRPCT

## DAY OF THE DEAD BBQ

The Day of the Dead (el Día de los Muertos), is a Mexican holiday where families welcome back the souls of their deceased relatives for a brief reunion that includes food, drink and celebration. A blend of Mesoamerican ritual, European religion and Spanish culture, the holiday is celebrated each year from October 31- November 2. According to tradition, the gates of heaven are opened at midnight on October 31 and the spirits of children can rejoin their families for 24 hours. The spirits of adults can do the same on November 2. During this brief period, the souls of the dead awaken and return to the living world to feast, drink, dance and play music with their loved ones. Altars are usually decorated with flowers, candles, ceramic skulls, and most importantly pictures of loved ones. Food placed on the altar consists of the loved ones favourite dishes and treats. Drinks should be placed in the altar to quench the thirst of the dead after their long journey back home. It's not a gloomy or morbid occasion, rather it is a festive and colourful holiday celebrating the lives of those who have passed on.

The roots of the Day of the Dead go back some 3,000 years, to the rituals honoring the dead in pre-Columbian Mesoamerica. The Aztecs and other Nahua people living in what is now central Mexico held a cyclical view of the universe, and saw death as an integral, ever-present part of life.

GRPCT believe that the topic of death isn't taboo, weird or morbid. It would be great to live in a world where every person, every family and every community knows what to do when someone is dying or grieving. Regardless of age, culture, religion, profession or health status we all benefit from opportunities to participate in meaningful rituals and self-expression about death.

In that spirit we organised the successful Day of the Dead BBQ held on the 31st of October 2019. Many BHS staff from various services attended. We plan on building on that success and offer more opportunities to gather, reflect and talk about death. In the end, we are all concerned. The death rate has and always will be 100%!

**Valerie Armanente**

*Clinical Nurse Consultant, GRPCT*



It is that time of the year when we reflect on the year past. I decided this year I was going focus on gratefulness. Most days it has served me well and I go to sleep with good memories of the day gone. So with is in mind I would like to share my thoughts. What a wonderful year it has been for the GRPCT. We welcomed four new staff members Val, Cate, Stacey and Karen, we also said goodbye to Shelley. We appreciated the short but memorable gift of Buddy to the team while Greg was on sabbatical. We said farewell to many patients some of whom taught us valuable lessons. It was also with a very heavy heart we said goodbye to very precious and very much loved family members. But I am reassured and appreciate what a wonderful team I have the honour and pleasure to work in. So from our team to yours, we wish you a very merry Christmas and a wonderful adventure filled 2020. I am grateful for your support of the GRPCT.

**Jade Odgers**

*Operations Manager, GRPCT*

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