

# Media Release

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## Palliative Care: disability and dying well

Palliative Care is not a comfortable topic for most. Though it is fair to say it's more accepted in an aged care setting where the person has "lived a good life" and death is the next natural step.

But what about children and young people with disabilities? This week is Palliative Care Week, and an important opportunity to raise some questions in this area.

As an organisation that supports people with disabilities and their families, our VMCH community has experienced the heartbreak of losing students from our specialist school, and adults who access our services. Degenerative conditions, compromised health systems which turn into life threatening complications, and general illnesses such as leukaemia are often contributing factors.

So how do you explain to someone with an intellectual disability they will die? How do you support the parents of a child who lives with a disability that will ultimately take their life?

**Maree Gilbert is one of 16 VMCH Pastoral Care Practitioners whose role involves supporting individuals, their families and the VMCH community through the end of life journey. Maree spends much of her time at St Paul's College, our specialist school in Balwyn.**

"The support I provide to a family will depend on their wishes: it could be emails and phone calls of support, visiting hospitals or hospice settings, visiting homes, prayer, grief and loss support," Maree says.

"I have sat with a student in hospital while their parent catches a few minutes of sleep or has a shower. I have read stories to students, arranged for priests to visit if that is what the family wanted. More widely, I provide emotional and spiritual support to staff, prayer opportunities for those who find comfort in that, rituals/stories that can be used with students. And when a student has died, I have helped with prayer services for staff and the community and arranged rituals such as a candle and picture of the student to help other students grieve and understand what has happened."

Maree says the death of a young person is obviously something people find hard to understand or accept.

"We feel that a young person has missed out on more. In reality, they have loved and been loved just as much as an older person. All of us leave our mark on the world."

**One of the greatest challenges faced with palliative care in a disability setting is how we talk about death and dying.**

"I believe it is important to be honest and open. I have experienced the sense of knowing a young person is aware they weren't getting better and that their life was coming to an end. I have watched a peace come across a young person when a prayer is said or they are told it is okay to let go of the struggle. I have also seen students and people with disabilities come to terms with a death of a friend – to be sad that they will not see their friend again, that they are with God."

**Maree says it's important we talk about death, grief and loss. And that perhaps a way of becoming more comfortable with the topic of palliative care is looking at it as a privilege not everyone gets.**

"Sudden and unexpected death does not give us the opportunity to say our goodbyes. I hope that as a Pastoral Care Practitioner I can support the dying and their families to journey through this time with a sense of not being alone."

**If you would like some guidance about how to support someone with intellectual disabilities face confronting situations, please visit: <http://www.breakingbadnews.org/>**

For more information on palliative care support in Australia, visit: <https://palliativecare.org.au/>

## Media enquiries

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## About VMCH

Here at VMCH, our services are as diverse as the people we support.

Our values underpin the work we do. As a Catholic not for profit organisation, compassion, respect and inclusion aren't just words to us, they guide us in everything we do.

While we've been around for over a century, we're always moving forward. Always staying true to who we are by supporting people and families to live their best lives; providing a place to call home and spaces to learn and grow.

Our professional and compassionate teams are with you on your life journey; helping you with a wide range of support from early learning and therapy, specialist education, disability services, affordable homes, residential aged care, retirement living and at-home aged care.

