



## Children's hospice and family support

limiting condition. We have a team of family support practitioners in metro Melbourne and in regional offices based in Ballarat, Geelong, Port Fairy, Bendigo, Shepparton, and Pakenham. My name is Pauline Hammond, and I am the Ballarat based practitioner, supporting families from Bacchus Marsh through to the South Australian border.

I am part of a multidisciplinary team of social workers, psychologists, art therapists, and family counsellors. The work we do, like the children we meet, takes up whatever space and form is required for each family. Sometimes that work looks like pragmatic assistance, in the form of funding applications, advocating, counselling, making referrals, and securing resources. These are the anticipated tasks generally associated with supporting families who are navigating a complex health system.

But sometimes the support is more subtle, taking its time to reveal itself. For example, it might present in the form of an eight-year-old boy who has been diagnosed with a brain tumour and is desperately trying to understand what is happening to him. It's sitting with him cross legged on the floor, reading books, and playing with playdough, gently getting to know each other. It's practicing deep breathing by smelling pretend pizza's and blowing out pretend birthday candles. It's finger painting and allowing his silences to settle into the grooves of the paint. It's coaxing his hopes and dreams into existence, instead of denying them. It's hearing his voice when he didn't realise, he had one. And finally, it's celebrating his hero within, when he discovers a strength that I have been witnessing for months.

I would argue that palliative care is all about the living. We are surrounded by it and reminded of it with each diagnosis that forces families to consider their lives through a totally new lens. Each day becomes a possibility for new experiences and meanings, that will become memorialised forever. Many of those experiences will still be joyful, as life continues despite our distress. Sadness and grief are also present, but they serve to highlight the love that exists, which is never more tangible, than in the palliative care space.

The seven-year-old fairy princess, who wanted her entire family to come together, was surrounded by love and life, when she died. Experiencing her make-a-wish, as a final act of living, meant that her last memories were full of warmth, possibility, and magic. Her extended family were with her on holiday; well supported, fully informed, and spending precious time enjoying each other's company. Bereavement support began for the family whilst they were interstate and continued seamlessly as they made their way home again. Difficult discussions about dying had already taken place, and the family were supported to plan the funeral that they previously imagined for their little girl. The parents drew strength from their daughter's input prior to her death, and truly believed that she orchestrated those last days to be exactly how she wanted them to be.

Children are amazing and my work allows me to be in awe of them every day. When we think of children, they are synonymous with life, energy, wonder, and curiosity. They embrace their space without apology, taking up whatever room they need. They teach us how to live in the moment, laughing at will and relentlessly seeking answers. And this is also true when they are dying.

Paediatric palliative care is seen by many as a contradiction to all that our children represent – but is it? Aren't the elements of life, energy, wonder, and curiosity, even more present when children and families are learning to live with a life limiting condition? They want to know "Why is this happening to us?" "How can we continue to live after a death?" "What does this mean for our family?" "How can we remember them well?" "How will this impact siblings?"

Very Special Kids (VSK) is a charitable state-wide organisation, that supports families of children with a life

Very Special Kids continues to support families and siblings beyond the child's death. This open-ended relationship is an acknowledgement that grief is not something that families "move past" or "get over". It's not linear and it's not tidy. Grief is messy, painful, unpredictable, and generally, hard work.

I agree that talking about death and dying is tough. Talking about death and dying with children, is really tough, but it can also be comforting. The conversation is an opportunity for children to be involved, to express themselves, to be heard, and to identify where to turn for help, when the emotions feel too big. And learning to identify those emotions is important at all ages. Learning that happy has a colour, angry can pop like a balloon, calm is slow, and sad is fat and heavy like a rain cloud. I love to support children to find their own language that will ultimately help them adjust to the changes occurring in their life. An invisible string can help explain the concept of remaining connected after death, and a bag of worries can externalise the cause of anxiety. Encouraging age-appropriate conversations can dissipate the fear often associated with death. It can validate feelings, calm insecurities, and clarify for adults what the children are thinking.

The death and dying conversation is hard but having it will begin a process of understanding and acceptance. A process that will be revisited by surviving siblings many times, as they reach new developmental milestones and have a greater capacity for cognitive consideration.

Children have told me that when we die, they believe we turn into angels, or dust, or protective spirits. One child told me that they think we come back as kittens and puppies. Who am I to argue this theory? We all have our own truth when it comes to death.

My support of families might sometimes be in the form of a coffee morning with other parents, arranging a weekend getaway for the family, or individually matching a volunteer in the family home. Support might also be in the shape of a bereaved parent weekend, a teenage experience in the snow, or an online support group, with people in similar situations, who "just get it". Activities such as these, as well as family fun days, are more than just picnicking at gardens or splashing at a water park. They are a memorial for deceased children, a memory for the living, and an opportunity to meet other families, undaunted by equipment and visible medical needs.

When a child dies, Very Special Kids family support practitioners, are often the only remaining service to stay engaged with the family. We offer a unique, and I think truly valued type of support in the paediatric palliative care space. We accept referrals directly from families or health professionals and an independent medical team verifies the life limiting condition for eligibility. We also accept bereavement referrals of up to twelve months post death, for eligible children. We offer a suite of family support services, and all our services are free to registered families. Our end of life support extends to care in family homes, regional and metro hospitals, or onsite in our hospice, which is currently undergoing a complete rebuild.

My work specifically as a family support practitioner can be difficult to define. My duties are enhanced by flexible boundaries and intuitive responses. Often, it is the simple act of consistently showing up, that is valued the most by the families I support. It's that regular weekly phone call, to touch base and hear how grief is behaving. It's the fortnightly zoom session that offers comfort from my makeshift home office, directly into their lounge rooms. It's the skype call from a grave site, to show me the kangaroo eaten rose bush, that could be distressing but ends up being funny. It's being present to witness the pain and not turn away from it. It's the rescheduling and reimagining, to accommodate the crazy world of covid. It's puzzles, stories, drawings, and creativity shared by children. It's talking, listening, understanding, and then doing it again next time, and the next, and the next. Like the work of all palliative care teams, it can be exhausting, confronting, privileged, and hopeful. And very often, it's all of these things at once.

### **Pauline Hammond**

Very Special Kids

Family Support Practitioner

Barkly Square, 25-39 Barkly Street BALLARAT 3350

Phone: 0457 727 505, Email: [phammond@vsk.org.au](mailto:phammond@vsk.org.au)

For more information about referrals please call 9804 6221 or email [referrals@vsk.org.au](mailto:referrals@vsk.org.au)

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