



31.07.2015

Very Special Kids (VSK) is an organization that works to support families who have a child with a life-threatening condition, from diagnosis, through to adulthood or bereavement. This support is provided through the Family Support Team and our children's hospice - the only children's hospice in Victoria. Support is available to families for the duration of their child's life, death and into the period of bereavement. Our practice is informed by the child's treating specialists and family requests. VSK has an important role to play in the conversations that involve planning for the end of life stage in a child's journey.

The following aspects of end of life care would like to be highlighted for this inquiry:

- There is a need for greater awareness of the value of approaching a palliative discussion earlier with families. Paediatricians and consultants are well placed to begin these discussions in collaboration with the family and palliative care professionals. In order for this to happen effectively referrals to palliative care need to be made in a timely way that allows families the option of considering what is best for their child in the period before the anticipated death.
- Families need to be given clear choices all along the treatment path. To this end it is important that health professionals have a stronger capacity to have conversations about end of life care in the face of impending death. Funding needs to be available for ongoing training for all health care professionals, including doctors, focusing on how to have those difficult conversations and to have them at the right time. There is a significant skill involved in knowing how to manage such conversations. We recommend that training in this area become standard for doctors, nurses and other professionals who work in this field. This would include a discussion of the benefits of any remaining treatment options and any adverse effects of such options. Families rely on their child's consultants and paediatricians and often have a high level of trust in their treating team. When such conversations are missing and treatment continues regardless of any discussion of alternatives, death can be a shock and create great feelings of bitterness and anger. Such a discussion is painful for families to endure but a very helpful one in the longer term. We have found that once families engage in the palliative process with clarity they are able to help their child to live as richly as possible in the remaining time available to them. This engagement with life in the face of death enables families to feel

**Children's hospice and family support**

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more acceptance of the death when they are subsequently grieving the loss of their child.

- The timing of these conversations is extremely important. We have found that these end of treatment conversations happen too late. In this case families do not have time to pay attention to quality of life concerns and therefore miss a vital opportunity to help their child live as richly as possible in the time remaining. We have observed that when this opportunity is given the grief process is less likely to be filled with regrets and more likely to allow for a greater peace for the child and for families at the end of life.
- There is a need for strong plans in place for end of life care, especially around symptom management and access to palliative care services outside of business hours. Informed decisions need to have been made at all stages. This should be a collaborative process with doctors, palliative care staff, family networks and relevant community support. This recommendation applies across the state. Evidence suggests that early intervention with palliative care services and well informed advanced care planning allows for a greater peace for the child and families at end of life.

Submitted by the Service Delivery Team at Very Special Kids