

CHOICES

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Very Special Kids Inc.

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Typically children die in hospital.

Many parents would prefer their child to die at home. Very Special Kids Inc. has provided an alternative place for those parents who don't wish for their child to die in hospital but are unable to care for them at home during their terminal phase.

These children require specialised palliative care, often needing injections and other nursing care. Some are unwilling or simply, not able to learn. Private nurses are an expensive option and public agencies have decreasing funds to provide necessary palliative care. Very Special Kids is able to provide alternative palliative care for the child who is dying.

Very Special Kids Inc. has established the first paediatric hospice in Australia. It has been Very Special Kids' dream to build a facility that provides out-of-home respite and palliative care to complement the already established programs that it offers families. Very Special Kids House provides care for up to eight children each day. It has several programs, including respite, enrichment, palliative care and emergency respite care.

The initiatives provided by Very Special Kids reflect the standards of care that have been established by leading paediatric palliative care facilities in England and Canada.

Very Special Kids Inc. is the Australian leader in paediatric palliative care. It is now used as a resource for other organisations wanting to establish paediatric palliative care and holistic support programs both here and abroad.

BACKGROUND

In Melbourne, in 1984, two families whose children were dying from leukaemia met in hospital. The two families assisted and supported each other through the period of treatment and through their experience of death. At the time, there was no appropriate support for families of children with life threatening illnesses.

Over the next year many more parents came together because they saw the need to offer support to others who were experiencing similar grief and anguish. They also appreciated the complexities involved and that support should not be solely on other parents. Clear and immediate objectives were enunciated and the need for the appointment of a person to train volunteers was identified as a priority. It was agreed that, with a band of trained volunteers, Very Special Kids would be more effective and able to reach out to the large number of existing and potential families who may need assistance.

Early in 1985, the Sydney Meyer Trust gave a grant of \$10,000. This enabled Very Special Kids to be established and a part-time coordinator employed. Sister Margaret Noone was the first employee and is now the Director of Very Special Kids.

In the late eighties Margaret travelled overseas, researching paediatric palliative care facilities in both Canada and England. She returned to Australia with the vision of building the first children's hospice in Australia.

With the assistance of the government of the day and a grant of \$5 million from the estate of the late George Adams, Very Special Kids House was established in 1996 as Australia's first respite and palliative care centre for children with a life threatening illness.

This special place forms an integral part of the ongoing work of Very Special Kids.

THE ROLE OF THE HOSPICE

Very Special Kids is dedicated to the provision of palliative care - a philosophy of care that provides coordinated medical, nursing and allied health services for families of children with life threatening illnesses. This philosophy of care includes physical, psychological, emotional and spiritual support for the child, and the child's family and friends. Palliative care also includes grief and bereavement support for the family and others after the child's death.

Very Special Kids House was designed to be an extension of the child's own home, with flexible help offered to meet needs of each individual child whether it is respite or palliative care. It is a place where the whole family can be together in a warm and loving environment, while being fully supported during some of the most difficult times of the child's illness.

If the family chooses to stay, they are able to remain fully involved in their child's care or may be happy to hand some or all of the responsibility of their child's care over to the hospice staff. Very Special Kids House is also a place where a child can stay on their own, giving parents or carers a real change of scene for a day or more.

ABOUT THE HOSPICE

The hospice has open plan living, dining and recreation areas with accommodation for up to eight children at any one time, in separate bedrooms with shared ensuite facilities. There is accommodation in a separate building for up to four families.

The hospice has a pool table, television room, playroom, computers and a hydrotherapy pool that children and families can use for relaxation. There is a multi-sensory room that has a musical waterbed and lots of colour and light to help the children with relaxation and pain relief. It's also lots of fun.

There is an outside playground and barbecue for children and families to enjoy and the local shops and cafes are within walking distance.

THE HOSPICE TEAM

A House Manager and a team of staff who have extensive experience in caring for children run Very Special Kids House. The staff share a commitment to meeting the individual needs of each child and their family. Trained nurses are on the premises 24 hours a day and doctors on call 24 hours a day. The child's specialist may continue to treat the child whilst staying in the hospice, or liaise with the Very Special Kids medical staff. In addition, staff and volunteers provide creative play for the children that is stimulating and fun.

The Family Support Team provides psychological, emotional and spiritual support as the need arises. Allied health support, such as occupational therapy, is outsourced if not available from the staff within the hospice.

IMPLEMENTATION OF THE MODEL

After a referral is received from the family, the Family Support Team worker visits the child's home to meet the child and family. At this time the worker discusses the family's needs with the parents or carers, ascertains their specific requirements, and begins the process of developing an individual family plan.

A tour of the hospice is organised and the family is introduced to the House Manager. Bookings are arranged for a time that suits the family and details of the child's care plan are discussed:

- * referrals and advice on social welfare and community resource services
- * provision of opportunities to enable sharing with families in similar circumstances
- * inservice education for staff and volunteers
- * newsletters to families, volunteers, members and donors
- * reference library and video camera loan.

'I knew that Haley was safe even when I wasn't there with her. We were lovingly cared for, both before and after Haley died'.

Bookings can be planned in advance, be made on a random basis or last minute in the event of emergency respite being needed. Guidelines for the use of the hospice are explained to the families at this time.

OTHER SERVICES PROVIDED BY VERY SPECIAL KIDS

- * child and family support throughout Victoria
- * hospital visitation program
- * bereavement support and counselling
- * a broad range of holiday and weekend camps
- * social functions and outings for families
- * seminars and briefings on matters of interest for staff, volunteers and families
- * referrals and advice on social welfare and community resource services
- * provision of opportunities to enable sharing with families in similar circumstances
- * inservice education for staff and volunteers
- * newsletter to families, volunteers, member and donors
- * reference library and video camera loan.