

PPCCMN

PEDIATRIC PALLIATIVE CARE
COALITION OF MINNESOTA

A goal of the Pediatric Palliative Care Coalition of Minnesota is to be a unified voice for providers offering pediatric palliative care. We endorse the following attributes of effective pediatric palliative care:

- Every child/young person shall be treated with dignity and respect whatever their physical or intellectual ability.
- Every child/young person will be provided management of their pain and other distressing symptoms.
- Every child/family/caregiver will be provided education on palliative care and pain and symptom management appropriate to age and understanding.
- Parents and identified medical decision makers shall be acknowledged as the primary caregivers and involved as partners in all care and decisions involving their child.
- Every child/young person shall be given the opportunity to participate in decisions affecting his or her care, according to age and understanding.
- An honest and open approach shall be the basis of all communication.
- The family home shall remain the center of caring whenever possible and desired. Care away from home shall be provided in a child-centered environment by staff trained in pediatric palliative care.
- Every family shall have access to a 24-hour interdisciplinary pediatric palliative care team for flexible support in the home. The pediatric palliative care team will work in collaboration with the primary provider.
- Every child and family shall receive emotional, psychological and spiritual support to meet their needs in a culturally sensitive fashion. This shall begin at diagnosis and continue throughout the child's lifetime, death and in bereavement.
- Every family shall be entitled to an identified "key worker", a healthcare professional or community provider who will enable the family to build up and maintain access to an appropriate network of support.
- Every family shall be given the opportunity of regular consultations with a pediatric specialist who has particular knowledge of the child's condition.
- Every family shall have access to suitable flexible short term breaks both in their own home and away from home, with appropriate pediatric nursing and medical support.
- Every child shall have access to education, extended school opportunities and other appropriate childhood activities.
- Transition of care to adult services for adolescents and young adults will be anticipated and coordinated.
- Every family shall have timely access to appropriate social resources, consultations and referrals.

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