

About the Michigan Alliance for Pediatric Palliative Services

The Michigan Alliance for Pediatric Palliative Services (MAPPS) was formed to address the needs of children with chronic illnesses or with conditions that might threaten their lives, along with the needs of their families and caregivers.

In the past, these needs have often gone unmet. The healthcare system has failed to ensure that patients' comfort is attended to and that symptoms of serious illness such as pain or breathlessness are adequately treated.

The system can also fail in responding to the concerns of parents and family when they ask what is best for their sick child. And even when services exist that address these needs and concerns, they can be hard to get access to.

MAPPS draws on the experience of professionals from nursing, medicine and social work, along with hospice and palliative care organizations, insurers, business leaders and community members from across the state of Michigan. The MAPPS working group includes parents and other family members who have supported and cared for a seriously ill child. Their experiences have helped shape this website and make sure it addresses the needs of children and families in a meaningful way.

The mission of MAPPS is to improve palliative care for pediatric patients in Michigan, which means reducing or preventing their physical, emotional and spiritual suffering, and improving quality of life for children and families. To fulfill that mission, MAPPS established the following goals:

- To raise awareness of pediatric palliative services by educating the community of seriously ill children, their extended families and friends.
- To provide education to healthcare professionals who provide such services to pediatric patients and their families.
- To actively encourage and develop improvements in legislation and health care policy so that every eligible child and family can receive quality care.

Guiding Principles

The work of the Michigan Alliance for Pediatric Palliative Services is guided by these core beliefs:

- Families and children living with life-limiting conditions are entitled to education about their disease, information about risks and benefits of treatment, and facts about likely outcomes.
- Families and children living with life-limiting or chronically disabling conditions should be encouraged to become partners with the healthcare team in making decisions and in planning treatments for the child.
- Patients and their extended families are entitled to compassionate and expert medical care, effective control of pain and physical complaints, and emotional and spiritual support.
- Children should know what is happening to them. Whenever possible, even very young children should be involved in discussions about their conditions and have a voice in the decision-making process.

- Actions taken in order to hasten death should not be permitted. Quality of life should be maintained at the highest possible level when death cannot be avoided, and when death does occur, it should be as natural as possible, with an emphasis on peace, comfort and dignity.