

Hospice care is based on a number of important concepts that significantly set it apart from hospital care:

- Family members are usually the principal caregivers and are supported by a team of professional and volunteer staff.
- The priority of care is comfort. The child's physical, psychosocial, and spiritual needs are considered. Pain and symptom control are primary concerns, and no extraordinary efforts are used to attempt a cure or prolong life.
- The family's needs are considered to be as important as those of the patient.
- Hospice is concerned with the family's post-death adjustment, and care may continue for a year or more.

The goal of hospice care is for children to live life to the fullest without pain, with choices and dignity, in the familiar environment of their home, and with the support of their family. Hospice care is covered under state Medicaid programs and by most insurance plans. The service provides home visits from nurses, social workers, chaplains, and, in some cases, physicians. Medications, medical equipment, and any necessary medical supplies are all provided by the hospice organization providing care.

With children, the home has been the more common environment for implementing the hospice concept, and this benefits the family in a variety of ways. Children who are dying are allowed to remain with those they love and with whom they feel secure. Many children who were thought to be in imminent danger of death have gone home and lived longer than expected. Siblings can feel more involved in the care and often have more positive perceptions of the death. Parental adaptation is often more favorable, demonstrated by their perceptions of how the experience at home affected their marriage, social reorientation, religious beliefs, and views on the meaning of life and death.

If the home is chosen for hospice care, the child may or may not die in the home. Reasons for final admission to a hospital vary but may be related to the parents' or siblings' wish to have the child die outside the home, exhaustion on the part of the caregivers, and physical problems such as sudden, acute pain or respiratory distress.