

Pediatric Palliative Care Resources

From diagnosis through end-of-life and bereavement, physicians provide comprehensive care with a family-centered approach including medical, emotional, social and spiritual support services and therapies to enhance quality-of-life.

What is Palliative Care:

Specialized medical care for children with serious life limiting illnesses. It is focused on providing patients with relief from the symptoms, pain, and stress of a serious illness and improves a child's quality of life.

What is Hospice Care:

End of Life care provides an interdisciplinary team of the health care professionals and volunteers, with the goal of care to help people who are dying have peace, comfort and dignity.

What Pediatric Palliative Care/Hospice Care is NOT and common Myths:

- Withdrawal of all support/care
- Painful
- Giving up hope
- Only for Cancer patients

Myth: Once a patient elects hospice, he or she can no longer receive care from the primary care physician.

Reality: Hospice reinforces the patient-primary physician relationship by advocating either office or home visits, according to the physician preference. Hospices work closely with the primary physician and consider the continuation of the patient-physician relationship to be of the highest priority.

Myth: Patients can only receive hospice care for a limited amount of time.

Reality: The Medicare benefit, and most private insurance, pays for hospice care as long as the patient continues to meet the criteria necessary. Patients may come on and off hospice care, and re-enroll in hospice care, as needed.

Myth: A patient needs Medicare or Medicaid to afford hospice services.

Reality: Although insurance coverage for hospice is available through Medicare, most private insurance plans, HMOs, and other managed care organizations include hospice care as a benefit. In addition, through community contributions, memorial donations, and foundation gifts, many hospices are able to provide patients who lack sufficient payment with free services.

Below are resources available in the Valley with information on how to get your patients these services.

Hospice of the Valley

<http://hov.org/>

Whether the child is in the hospital, at home or transitioning in between, Hospice of the Valley can help by providing compassionate care and services. Inpatient homes, Ryan House, are also available when a child requires around-the clock care, or when the family needs extra support.

Patients must have a prognosis of less than 6-12 months to live if the disease is to run its usual course. Care is based on the needs of the families and is provided regardless of financial circumstances. Please call **602-530-6900** to have a patient evaluated.

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Pediatric Palliative Care Home Team:

Patients who do not meet the prognosis criteria for Hospice, but still have a life limiting diagnosis can receive excellent support services for the patient and family. Support services are provided by Hospice of the Valley with social work and nursing visits at home. Please call **602-530-6900** to have a patient evaluated and specify Pediatric Palliative Care Home Team.

Ryan House: Local home for children that provide both Respite and End of Life care. <http://ryanhouse.org/>

Respite:

- Ryan House provides planned and unscheduled respite care designed to give families a much needed break from the round-the-clock needs of their children. Up to 28 days a year of respite care per child will be available to Ryan House families – at no out-of-pocket costs to them.

End of Life:

- Ryan House will provide families with supportive assistance in anticipation of imminent death. Ryan House will provide families with resources for bereavement support in addition to assistance with advanced care planning, care coordination, and referrals for funeral planning.

Who Qualifies:

- Generally speaking, any Arizona child from birth to age 16 diagnosed with a life-limiting or life-threatening condition and who is currently being cared for at home is eligible.
- A physician or the parents can call Ryan House by telephone at **602.200.0767** and provide the following information:
 - child's name
 - date of birth
 - child's diagnosis
 - parents'/guardians' names
 - contact information – telephone number, address, email
 - physicians/health care professionals involved in child's care
 - release of medical records/information

Prehospital Medical Care Directive:

Prehospital Medical Care Directive form (commonly known as the Do Not Resuscitate or DNR form) is authorized by A.R.S. § 36-3251. The DNR form allows an individual and family to indicate that the patient does not want to be resuscitated if he or she suffers cardiac or respiratory arrest. Pediatric Patients can have a Prehospital Medical Care Directive filled out by families and carried with them. Free copies of the DNR form may be requested by calling the Bureau of Emergency Medical Services at (602) 364-3150 or download from <http://www.azdhs.gov/bems/dnr.htm>. It must be printed on **Orange Paper**.

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BEHAVIORAL THERAPIES/SUPPORT:

The New Song Center for Grieving Children.

http://www.hov.org/ns_about_us.aspx

The New Song Center for Grieving Children was founded in 1989 by volunteers. The mission is two-fold: providing nurturing support for grieving children, teens, young adults and their families, and offering comprehensive grief education to volunteers, professionals and the community.

Within age-specific grief support groups, a safe place is created in which children are supported through developmentally appropriate activities including sand trays, expressive play and various art projects at bi-weekly meetings. Adults attend their own support groups, where they learn how to help children and teens process grief in a healthy manner and how to help themselves cope with loss.

Families transition through the grief process together at one of the various valley locations. If you, a family member or a friend need grief support, call 480.951.8985. Referrals to New Song Center also come from school counselors, teachers and social workers, faith groups, hospitals, medical professionals, hospice, police and fire departments and community therapists and counselors.

Other Local Support Options/Organizations:

- Primary Physicians
- School Counselors
- Church Support Groups
- Private Insurance—Magellan or other private therapies.
- [Compassionate Friends](#), 480.361.1877
- [Mothers in Sympathy and Support](#), 623.979.1000
- [Stepping Stones of Hope](#), 602.264.7520