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Special support for seriously-ill children

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Hospice and Palliative Care professionals face an everyday challenge - breaking through the perception that accepting help from this specialty is "giving up" or giving in to death. There can be a fear that privacy will be invaded and life as the patient and family know it will become even more out of control. Families often have preconceived ideas of how they will be treated. Dealing with this perception is ages old with adults, so imagine the challenge with a seriously ill child.

We take for granted the healthy children we see every day. Statistics convey that about 15-18% of children in the United States live with a chronic illness. 53,000 children between the ages of 0 and 19 die in the United States each year. The most common serious ailments in this age group are cardiac, congenital, and malignancy. That's a lot of sick children - and a lot of families affected. As you can imagine, care needs for serious and chronic illness are complex and families need help. Advanced care planning by an interdisciplinary team can ensure that no stone is left unturned to ease the nest of physical, social, emotional, and spiritual issues.

It's important to understand the value of hospice and palliative care services as part of the interdisciplinary team so the choice to offer, accept, or decline this special help is an educated and not short-sighted reactionary one. If patients, families, and professional providers fear even bringing up or hearing the words "hospice" or "palliative care", an important opportunity for help and support can be missed. For that's what hospice and palliative care is - help. Hospice and palliative care helps in a number of special ways to promptly address any physical, social, emotional, and spiritual issues affecting the quality of

life of the child and the family members. Families have a right to know options available. Being open to discussing and hearing about options helps to minimize regret later, as knowledge of options empowers families to take more control of their own unique situation as they navigate the ebb and flow of all the serious illness brings with it.

Families structure their life around a sick child. The Hospice and Palliative Care team's focus of care is on both the child and the family. The entire family needs as much, if not more, attention and care as the child. Working with the child's primary care team 24/7, nurses can help monitor and manage troublesome symptoms. The social worker can address all kinds of personal family concerns (e.g. financial, legal, helpful resources) and often makes fun and nice things happen (e.g. Princess party, art therapy, pet therapy, massages, etc.) by enlisting help from other staff and volunteers as needed. Hospice and palliative care professionals are a perfect sounding board for questions, concerns, and guidance about decisions and quality of life. Care comes to the child and family in the comfort of their own environment and at a time and in a way pleasing to the family.

Another specialty aspect of hospice and palliative care is grief support. Families are known to report isolation when dealing with grief. Hospice and palliative care grief counselors are experts at honing in on ways to help move forward in a healthy way.

Some recent legislative initiatives now benefit seriously ill children and their families. Passage of the Affordable Care Act altered the Medicaid hospice benefit as it applies to children (age 0 - 20) by increasing access to community-based supportive services for children



with life-limiting illnesses. The "Concurrent Care" requirement within this Act enables curative, on-going treatment measures for the illness to continue side-by-side with hospice care.

The "Palliative Care and Hospice Education and Training Act" (H.R. 3119) bill amends the Public Health Service Act to require the Department of Health and Human Services to award grants or contracts for Palliative Care and Hospice Education Centers. These Centers must improve the training of health professionals in palliative care and establish traineeships for individuals preparing for advanced education nursing degrees, social work degrees, or advanced degrees in physician assistant studies in palliative care.

Hospice and palliative care is a specialty to be valued, not feared or avoided. The old-fashioned compassion factor, a tailored approach, along with subject knowledge, are key ways that hospice and palliative care can benefit a difficult situation and make a memorable difference in the lives of families dealing with a seriously ill child.

A northwest Pennsylvania resource guide for families, volunteers and medical professionals caring for children with life-limiting illnesses is available at the Pediatric Palliative Care Coalition website at www.pppc-pa.org.