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Community Outreach Program in Education (COPE) Series



A Case in Point:

The following case illustrates the complex decisions faced by families with a dying child and how important it is to have open communication and to utilize available resources.

Mark and Heather are the parents of three children. Jimmy, their youngest, was 5 years old and was hospitalized after relapsing with leukemia for the second time. An unsuccessful bone marrow transplant 3 months earlier led the health care team to inform Heather that further treatment such as chemotherapy was not likely to provide a cure for Jimmy.

Heather was the sole recipient of this sad news that day at the hospital. Feeling very fearful and overwhelmed, she considered protecting the whole family from this news by keeping it to herself. Soon after receiving this news her 8 yr old daughter, Jessica called begging her to attend her dance recital the following night. Heather hung up from that call and realized she needed help. The load was getting too heavy.

They sought the assistance of their social worker and a child life specialist from the hospital on moving forward. A team of hospice professionals was welcomed into their home. Together Mark and Heather chose not to pursue further aggressive treatment for Jimmy but rather to bring him home, focus on his pain and symptom management and maximize his quality of life. While it wasn't easy, they experienced the benefits of talking with one another in an honest, gentle and compassionate way.

Jimmy enjoyed his time with his family and sleeping in his own bed with his dog, Snickers. He died peacefully at home. Months later Heather shared her gratitude towards Jessica for forcing her to see the importance of honest communication and asking for help.

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Caring for a Child Approaching the End of Life & Keeping the Family Together: Being Aware of the Diverse Needs of the Family Unit



This is the first issue of the new *COPE Series II, Caring for a Child with a Terminal Illness and Keeping the Family Together*. The purpose of this series is to provide parents who are caring for a dying child with some awareness as to the potential challenges that may confront all members of the family. Our hope is that the insights from this series will help maintain the integrity of the family unit.

This issue focuses on cultivating awareness of the broad spectrum of needs for all members of the family. It is a natural response for the focus of the family to be on the child with the terminal illness.

What is most important is that the family not make this their sole focus. Extend the scope of the family focus to parents, siblings and even grandparents, if they are considered a critical element in the circle of support. When family members have sufficient information and vision to make informed choices, the inherent stress of the situation and its impact on the family unit can be minimized.

Inherent Stresses in the Situation - most professionals will agree that caring for a dying child can be the most difficult task parents will ever face during their lifetime. Add to this the need for parents to take care of one another while providing a loving and nurturing environment for the other children of the family and you now have a monumental task. Raising a family is a challenge for most parents as they juggle the necessary day-to-day activities associated with their jobs, getting kids to school, managing finances, doing laundry, buying groceries and supporting siblings in extracurricular activities. The inherent stresses associated with caring for a dying child in parallel with satisfying "normal" family needs often forces principal decision makers in the family, assumed to be the parents for this discussion, to make compromises.

Striving for Normalcy – compromise in making choices on how best to serve the family unit is often a necessity for parents. A key ingredient to making successful compromises is to strive for normalcy on the part of all family members. Minimizing the change in daily routines will go a long way toward maintaining harmony at home and keeping siblings from feeling as though they are being neglected. Achieving this objective without making some changes will be difficult. Parents need to be knowledgeable about outside resources and how they can assist in the achievement of normalcy.

Communications – the topic of communication within the family could be the focus of an entire COPE series so only a few key points will be made here. Perhaps the most important aspect of good communications is to create an environment where all family members can communicate freely. This is especially important between parents and the children. Parents must also keep an open communication channel between themselves and the grandparents, if they are part of the circle of support for the family. Encouraging discussion at the dinner table allows everyone to communicate as a group in a "safe" setting. Having one-on-one discussions with the children as you tuck them into bed provides a means for children to discuss their concerns or fears with you privately.

Lastly, it is important to briefly mention communications with the family and the dying child. While each family will inevitably choose a communication philosophy or style that is comfortable for them, the professional consensus is that honesty and openness are preferred over a protective approach. Terminally ill children often know they are dying, whether we choose to tell them or not. Shielding them from the truth may further isolate them at a time when they most need support.

If kids are normal, not sick, they like to be treated special.
But if kids have a disease, they want to be treated normal.
Anonymous (11 yr old girl)