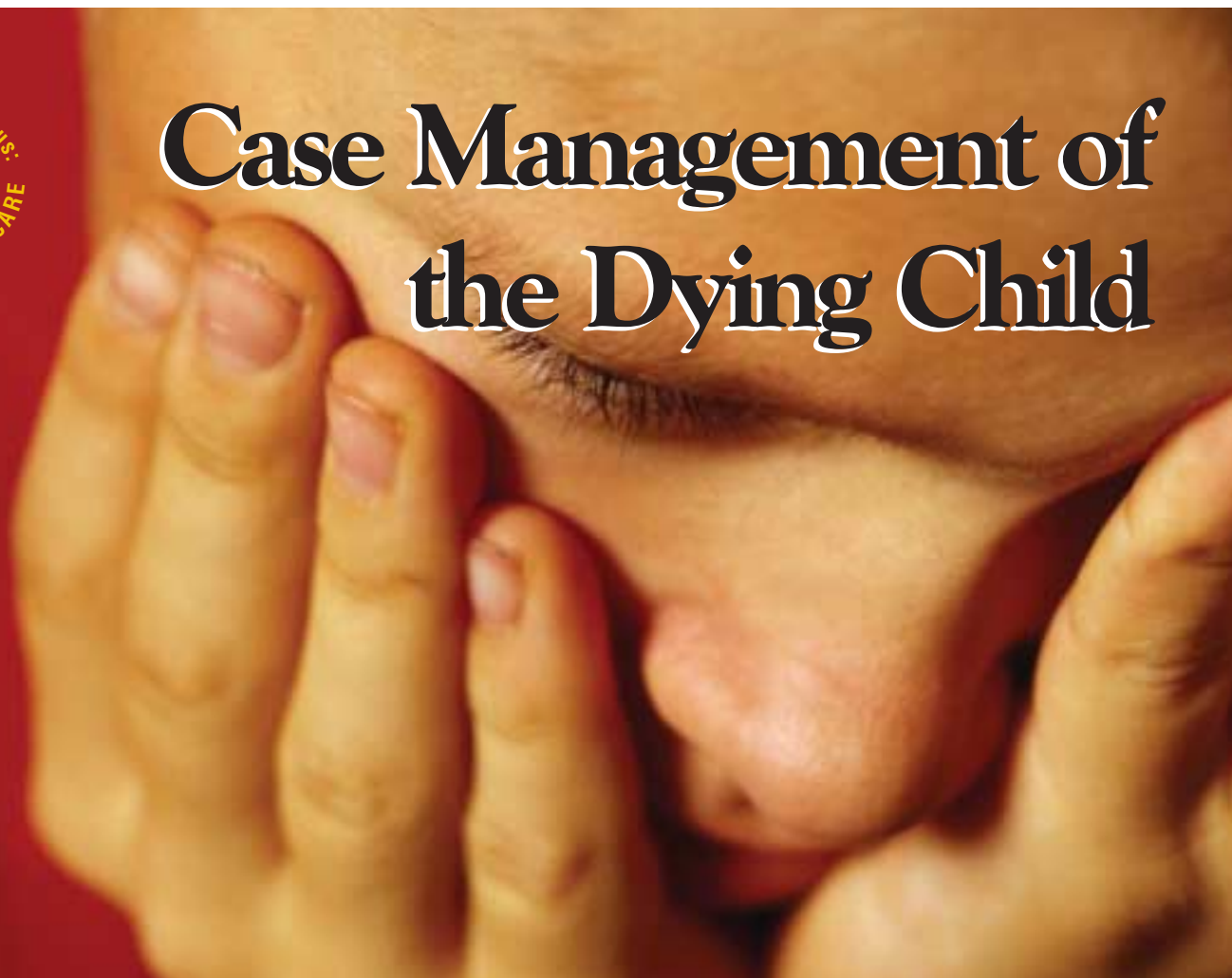




# Case Management of the Dying Child



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**A** *parent should never have to bury a child.*  
One of our cultural beliefs is that someone can suffer no greater loss than a child. This loss interrupts the expected cycle of life, and parents are anguished at the loss of a child who so often has embodied their hopes and dreams for the future.

Because of advances in research, medical care, and technology, our cultural belief and basic supposition that “children don’t die” has been heightened in recent years. This denial makes accepting death as a painful reality that much more difficult for the child, parents, grandparents, siblings, friends, and even professional care providers.

Parents of a child who is dying find themselves facing their worst nightmare. The situation can pull them closer together or tear them apart. Grandparents agonize over not being able to shield their own child from this devastating situation. Siblings often face guilt, fear, and the anxiety of how this will affect them and their place in the family. The unspoken question by siblings that often needs to be addressed is, “Can this happen to me?”

Some people question God’s existence or lack of mercy when such a situation arises. Parents blame the health care system, the environment, even themselves as they struggle (often in anger) to understand the ending of such a young and seemingly incomplete life. The faith that sustained a family in the past may be questioned or even abandoned in anger or despair. In other cases, faith may be the cornerstone of the family’s ability to bear the reality that a child will die.

As case managers, we are best prepared when we know and respect the cultural and faith beliefs and practices of the children and families whose lives we enter on such important levels. As we help them navigate the roller coaster of final treatment attempts, palliative care, and end-of-life (EOL) issues, we do well to understand and support that which they hold dear and which will see them through this ordeal.

It is also quite possible for the dying child and the parents to find themselves isolated from friends and family, both in the hospital and at home. This results from a generalized sense of helplessness by others who want to back away from a situation that feels unbearable. People sometimes feel awkward about having "healthy children" while their friends' child is dying, so they stay away at the very time their presence may be needed most.

I have long remembered a mother who told me that she felt cut off from other people's children and what was going on in her community when others attempted to "protect" her from such everyday information while she cared for her dying teenage daughter at home. In fact, the mother felt so strongly about this experience that, at her daughter's funeral, she asked her daughter's young friends to keep her aware of their lives. She said she wanted to hear of their going to the prom and off to college or getting married so that she would not have to feel she had lost "all the other children in her life as well" when her young daughter succumbed to cancer. In this case, she did not want "survivor guilt" to rob her further of her closeness to the children she knew.

Our personal, professional, and societal discomfort with the notion that children sometimes die as a result of illness or injury is evidenced in the lack of consistent and well-organized care for dying children and their families. Nurses, physicians, social workers, case managers, chaplains/pastoral care providers, and others involved in the care of sick or seriously injured children have less experience in dealing with the deaths of their patients because children do die far less frequently than adults. Families

therefore may find themselves surrounded by a host of well-meaning individuals or even systems of care that are inexperienced in addressing the unique needs involved in a child's process of dying.

Pediatric hospice, respite, home care nursing, and insurance benefits and services in many instances lag behind those for adults for a variety of reasons. At a recent dedication of the first free-standing hospice in New York, I noted that this beautifully decorated and well-appointed facility showed no visible indication of an ability to address pediatric cases, either in its decor or size of beds and equipment. I discussed this with the hospice coordinator, who reminded me that most children who die still do so in the pediatric intensive care units where their acute illness or injury has been treated; they die where parents feel they have received all their care and where caregivers familiar to them will attend to them in the end as well.

However, I was relieved to hear that this hospice staff has had experience with some pediatric hospice (in the children's homes) but does not anticipate that parents will choose a free-standing hospice facility over their home.

Disappointingly, there continues to be a lack of knowledge among insurers and other payers about rare childhood diseases that can result in pediatric death. Consequently, insurers who could provide much-needed case management to their claimants may miss the boat in identifying these cases early enough to make a serious impact on the child and family's journey through this experience. In my current practice setting, such children would be identified when their treatments or hospital admissions are precertified.

Adequate funding for appropriate EOL care for pediatric cases sometimes is poorly addressed in the benefits plan language of small, self-insured employer groups and even by large insurance providers. Such care may include the necessary continuance of physical or speech therapy, even when death is expected. Such therapy can help the

child remain ambulatory and active, being childlike and enjoying the best possible quality of life for as long as possible in this final phase. Unlike adults, terminally ill children sometimes remain actively involved in playing until just hours before death.

For parents facing the most grievous sorrow of their lives, having to deal with insurers and other payment sources to request flexing a benefit for these therapies, home care nursing, or hospice services can be overwhelming and result in the child remaining in the hospital until death occurs, rather than having the opportunity to die at home in familiar and more comforting surroundings. The short-sightedness of this arrangement (given the costs of the continued hospital stay versus home care visits and other hospice and respite care) usually can be rectified by a seasoned case manager who knows the nuances of the benefits plan, the multilayered needs of the child and family, and the community resources available meet the unique needs of this situation.

Because we look at a child as having so much life ahead under normal circumstances, the focus of "doing everything possible" to prolong or save the child's life often continues up until death, despite the clarity of the diagnosis and the exhaustion of all known treatment modes. Although the parents and other caregivers may be able to say, after the death, "We did all we could to keep this child alive," there is all too frequently a lack of guidance for parents or child on how to come to terms with the reality of impending death so that the focus can be on living as fully as possible now and sharing pleasant times that can become important memories to those who will be left behind.

If the death occurs more suddenly or under more intense medical circumstances, the child and family may miss the opportunities for closure, acceptance, and the understanding that all that could or should have been done for the child was done. This sometimes leaves parents and other survivors facing the questions of whether they provided everything the child needed to face the end of life. Parents have been

known to agonize afterward, asking themselves and others if they made the child's experience the best it could be. They can be left wondering whether the child had a good death. A case manager who is well versed in the unique needs of dying children and those who care for them can intervene early and at various points in the dying process to see that these questions are answered positively.

Your own case management practice may find you regularly dealing with a pediatric population facing life-limiting illnesses, or you may only occasionally find yourself faced with these unique challenges. In both instances, having an awareness that the death of a child is vastly different in many ways than the death of an adult is vital to your comprehensive management of these circumstances.

### **A Child Is Not Just a Small Adult**

A case manager working with a dying child must possess the knowledge that children do not simply require smaller dosages of adult medications and mini versions of treatment and equipment. The case manager needs to be aware, for example, that a 6-year-old will not have the same understanding of the irreversibility of death as 12-year-old does. The physical, emotional, and psychological needs of a child also vary, not by age per se, but by developmental level.

In being well prepared to address the needs of dying children across developmental stages, a case manager can best assist the child's parents and other care providers to understand how and when best to present information and what the typical fears and needs of the child are and how to address them.

Societal distaste for the reality of pediatric death leads to avoiding discussions of EOL issues, for far too long in some cases. As case managers, we must work to overcome our own desire to avoid this sad reality. We need to educate ourselves, look deeply at our internal resources for this type of work, and be ready and willing to take a leadership role in helping a child and family to prepare for the end of life. These needs often should be addressed while other

measures are still being taken to prolong the child's life. With certain diagnoses and situations, a case manager can, early in treatment choices, encourage a family to be open to the discussion of hospice or other EOL plan, should all other choices become insufficient. Planting this seed of thought early improves the chance that they may be willing to have this discussion when the time comes. This progression of choices and decisions can promote a feeling of purposeful planning and engagement in care by the child and parents right up until the end of life.

Depending on the child's developmental stage and level of ability, as well as the family's religious and cultural backgrounds, parents may be encouraged to learn what the child's feelings or beliefs are about how he or she would like to spend the remaining time. Supporting a child's reasonable efforts to seek honest and developmentally appropriate answers, express anger, maintain privacy, and make choices about care and treatment, final days, and in some instances, funerals or memorial services is something a case manager can do as a broad-based and more globally accessible member of the support network.

In cases where a child is too young or so developmentally impaired as to be non-verbal or in some other way unable to communicate his or her needs or desires, the case manager can encourage the parents to make sensitive choices for the child's comfort, continue engagement, and facilitate the child's cues for having parents release him or her when death is at hand.

In my own years of pediatric nursing and case management experience, I have found myself in the position of facilitating parents spending final hours with their children. In the neonatal unit, when parents had to say goodbye to a newborn infant unable to overcome the medical complications of severe prematurity or other life-limiting illness, my tasks included recognizing parents' longing for the normal, healthy baby they had expected combined with the sadness of having to let go of the child born to them. Understanding this shock enabled me to address the parents'

needs for reassurance that everything necessary medically was taking place and meeting their own need for private time with their baby to face the last moments of life.

### **Case in Point**

My role with pediatric oncology patients led to my being present for the final days and hours of some of these young patients. It was both agonizing and a blessing to be present with these children and their parents. Faced one night with a young, inexperienced nurse who could not emotionally manage a family in a child's final hours, I was called to coordinate EOL care and sit with the young single mother of a 6-year-old boy who had slipped into a coma. His brave yet devastated mother, who had been his champion and staunch advocate during the management of several years of chemotherapy treatments and a variety of other attempts to conquer his cancer, now sat in a corner, unable to approach his bed and sit with him during these last moments.

Assessing the situation, I came to see that she needed guidance in how to sit and talk with her young son, the light of her life, and give him permission to take his last breath, although it meant leaving her behind. Taking into consideration what I had come to know about her lifestyle, usual style of talking through every aspect of care with her son, and their faith beliefs, I encouraged this mom to share her belief in the transition to a new life where the boy's deceased dad would be waiting for him and how she would go on with her own purpose in this life, where she was well loved, until they met again. As she spoke these words, she came to sit with him and cradle him in her arms. He awakened briefly, and they each accepted the moment of his death. There was a peaceful closure for them both and for their very grateful nurse case manager.

Although my current practice of telephonic nurse case management precludes those types of witness interactions with pediatric patients and their families, I am well aware of the importance of a case manager's expertise in interpreting, negotiating, or flexing pharmaceutical and health care benefits.

These skills often obtain home-based hospice services to allow a child to live in familiar surroundings until death. In some cases, needed services (hospice, adequate home care nursing, respite) are not provided in a health care plan, and no one steps in to gain some flexibility by the insurer or find facilities early enough. Parents often do not know what to expect in the end or how their child can die at home or in a hospice setting where the focus is on living fully and pain free as possible.

### **Pain Management**

Myths surrounding pain medications and their effects on dying children still cause some parents and caregivers to underrequest or underprescribe pain medications for a dying child. Parents and health care providers unfamiliar with medications, treatments, etc., may fear addiction to pain medications or falsely believe that respiratory suppression from morphine will hasten death. Depending on developmental level, a child may deny pain to avoid a feared treatment (i.e., needles), although most pain medications can be provided by less painful routes. Parents often fear pain medications will make a child "too groggy" to interact with others in the final weeks and days of life. On the contrary, when a child's pain is well controlled, he is able to be true to the tasks of development and can remain child-like to the end.

The consequences of this continued misinformation among patients, families, and even health care providers not trained in EOL pain management and palliative care techniques results in needless suffering by the child. Another consequence is parents and other caregivers being haunted by memories of the child in pain. A case manager who stays well informed on EOL care can be a wonderful advocate in pain management, avoiding both physical pain for the dying child and psychic pain for the family. With pain under control, greater communication can be facilitated that leads to greater acceptance of the impending death by the child, parents, and siblings as they come together as a family to face the final stage of dying.

As case managers, we often have to gen-

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tly insinuate ourselves into the normally private relationships between patient and physician, patient and insurer or other payment source, and patient and family members to affect positive change. When the patient is a dying child, we sometimes have to find even more gentle ways to promote acceptance of the dying process by physicians and other healing professionals to allow time for EOL care to begin when the child and family can benefit most from it.

### **Conclusion**

In review, case managers accepting the unique challenges of working with dying children and their families must stay well informed on EOL issues and the resources available, health care and pharmaceutical benefits, and how to work creatively with insurers and other payment sources.

As case managers, we can lend our well-developed expertise in considering all developmental, cultural, financial, medical, and religious needs of the child and family when we join or lead the team in planning and implementing EOL care. Comprehensive and high-quality case management can best be provided by personnel who know that these children and their families can be nurtured and assisted in achieving personal growth and development even in the final stage of life.

This type of case management is not for the faint hearted. However, the personal and professional growth that can be

experienced while working with these brave and wonderful children and families is beyond description and well worth the time, effort, and commitment to meeting the needs of this very special population. □

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