

Coping with Crisis and Handicap

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Preface

For over 20 years I have accepted the challenge and had the privilege of caring for sick children, agonizing with their parents during periods of serious illness, which were sometimes fatal. Because of my particular interest in and concern about birth defects and genetic disease, many of these children had severe disabling handicaps, which were often genetic and included mental retardation. Hence care of these children and their families was often complicated by the presence of serious or profound genetic defects. The initial realization of the nature of the disorder invariably led to emotional difficulties and inevitably later spawned chronic distress. For some children inexorable deterioration led to untimely deaths, while the parents agonized over their handicapped, chronically ill, or defective—but nevertheless loved—children.

The personal pain I experienced in having to communicate diagnoses about irrevocable or fatal disease or handicap soon after birth was surpassed later only by the agony of caring for child and family through to the end of a fatal disorder. While these cumulative sad experiences may have conferred no special abilities in caring for sick and handicapped children or their distraught parents, I soon recognized the critical importance of care by an interdisciplinary team. Most would concur about the importance of a team approach to the care of the dying or handicapped child and agree that we all have much to learn. Conversations with only a few bereaved parents will confirm how inadequate our support systems really are. The majority of parents with dying or seriously handicapped children will also, in my experience, be able to be correctly critical of at least some aspects of the management of their children.

As a consequence of these realizations, we organized a National Symposium on Coping with Crisis and Handicap. This volume consti-

tutes a record of those proceedings. Symposium discussions evolved as a consequence of the multidisciplinary involvement of those concerned about the care of dying and handicapped children. We were fortunate in being able to benefit from the participation of a unique set of individuals, all of whom brought not only acknowledged expertise but also special and often personal insights into these particularly difficult problems.

The first day was devoted to a consideration of coping with death and dying in childhood. Discussion about the management of the dying child in the hospital initiated the proceedings. Ms. Genevieve Foley, who has had extensive experience in the care of dying children, particularly those dying from various malignancies, shared her special insights, gained from long experience at the Massachusetts General Hospital in Boston. Professor Ida Martinson has done some outstanding research studies concerning the management of the child dying at home; she communicated many of the lessons and guiding principles of care observed in her studies. Mrs. Harriet Sarnoff Schiff, who lost her 10-year-old son to congenital heart disease, articulated with singular clarity the parental perspectives that were so instructive in her book on bereavement. The eternal question "Where was God?" was eloquently addressed by Rabbi Harold Kushner, who had also lost a child from a prolonged genetic disorder.

Drawing upon extensive experience in the care of children with chronic fatal genetic disease, I next shared my insights and perspectives on this subject, with special attention to cystic fibrosis and genetic disorders characterized by mental retardation and/or a fatal outcome. Rabbi Earl Grollman discussed the child's perception of death and, for this volume, kindly allowed us to reprint his outstanding paper "Explaining Death to Children." In addition, I am grateful for his paper on "The Clergyman's Role in Grief Counseling." Dr. William Worden outlined his impressive experience, gained at the Massachusetts General Hospital, in the management of individuals who have attempted suicide and their families. Dr. Edwin Cassem, who was unable to attend the meeting, was most gracious in allowing us to reprint a major paper he has written on "Treating the Person Confronting Death." Through his unique involvement with the critically ill and dying at the Massachusetts General Hospital as Chief of the Psychiatric Consultation-Liaison Service, our understanding of the dimensions required for sensitive and superlative care has been broadened.

The first day concluded with a careful examination of the medical ethics involved in the care of the child with terminal illness. This subject

was addressed by Professor Robert Veatch, who has made extensive contributions to the literature on death and dying. Professor George Annas rounded out an emotionally enervating day by considering various legal rights of the dying patient. He is especially well known for his writings on the rights of hospital patients.

The second day focused on the problems concerned with coping with congenital or acquired handicap in childhood. We were especially fortunate to learn from the personal experience and theological insights of Reverend John Carr. His accomplishments and perspectives about living with physical handicap were especially enlightening. Dr. Mary Challela, who has had outstanding experience with the nursing management of mentally retarded children, outlined her detailed approach to helping parents cope with profoundly retarded children. The frequently neglected subject of the siblings of children with handicaps, especially mental retardation, was thoughtfully addressed by Professor Allen Crocker. We were all able to benefit from the lessons of his long experience in the Developmental Evaluation Clinic at the Children's Hospital Medical Center in Boston.

The enormous and stressful problems associated with the management of autistic children were discussed by Dr. Walter Christian. His expertise, gained partly from his experience as Director of an institute for autistic children, added a valuable dimension to the symposium. Dr. Ludwik Szymanski is a child psychiatrist whose special knowledge of retarded children reflects his involvement in the Developmental Evaluation Clinic at the Children's Hospital Medical Center. His subject was the frequently forgotten one of the sexual vulnerability of retarded individuals.

Societal failure to teach children early in life about the acceptance of normal and abnormal human variation is evidenced daily by children's cruelty to their disabled or defective peers. Dr. Alan Brightman, who is recognized as an outstanding educator, skillfully guided us through the approaches necessary to more sensitively educate our children about their handicapped peers. The awesome injuries suffered as a consequence of burns in childhood have required the help of individuals with unusual mettle. At the Shriners Burns Hospital in Boston, Ms. Margaret O'Connor has not only taught many burned children during their long process of recovery but also helped teachers and their pupils to cope with the return of the profoundly burn-disfigured child to the classroom. Her work has also necessitated educating public health agencies about their responsibilities vis à vis the rights of these burned children to return to school. The coping strategies of these children and their fam-

ilies, as observed and analyzed by a most experienced social worker, were discussed by Mrs. Sue Cahners, also of the Shriners Burns Hospital.

Mr. Henry Beyer, in the penultimate address, considered various legal aspects concerned with the care and rights of the handicapped. He has done legal work for years on behalf of the handicapped. The final presentation was made by Professor Gunnar Dybwad, who is internationally recognized for his many decades of work on behalf of retarded citizens. His special societal perspectives, with particular reference to government responsibilities for the mentally handicapped, are a distillate of his distinguished experience and prolific writing.

This book should prove valuable for all those concerned about coping with death, dying, and handicap in childhood, including members of the many professional disciplines that focus their attention or care on such children. The list is endless, and includes nurses, physicians, social workers, psychologists, teachers, theologians, ethicists, lawyers, health educators and administrators, public health department personnel, and staff members in preventive and social medicine departments. This book would be especially meaningful as well to all parents and families faced with the necessity of coping with death, dying, or handicap in childhood.

The gamut of emotions experienced by every parent with a dying or seriously handicapped child includes guilt, despair, chronic grief, and even rage. Unfortunately, coping with such overwhelming emotional burdens is not only very personal but often very lonely. None of us are taught or prepared beforehand to cope with the loss of a child or with having a seriously handicapped one. Moreover, the support systems that we have developed are still invariably inadequate. This book is therefore dedicated to the effort of helping parents cope by focusing on their needs and on those of their children and by increasing the sensitivity, knowledge, and insight of their caretakers.

AUBREY MILUNSKY

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Ms. Foley is the author of several articles and co-editor of *Nursing Care of the Child with Cancer*. She is a charter member and past national president of the Association of Pediatric Oncology Nurses. In 1980 she was named one of Boston's Ten Outstanding Young Leaders by the Boston Jaycees. She is the first nurse so honored by the Boston Jaycees.

The Child Dying in the Hospital

GENEVIEVE V. FOLEY

In *To Live Until We Say Good-Bye*, Elisabeth Kübler-Ross tells the story of Linda and her daughter Jamie, age 5. Jamie is dying of a brain tumor. Linda, a single parent, decides to have Jamie die at home. Kübler-Ross relates how Linda telephoned her and “proudly announced ‘We did it!’ ‘We did it’ referred, naturally, to her own courage and her own pride that she had decided to take Jamie home.”¹ The narrative continues with Kübler-Ross and Linda describing the many positive aspects of the decision. Linda identifies the unique opportunity: “to do all that was left to be done for her [Jamie]—to make her comfortable, to provide her with familiar things, and most important to surround her with the love of her family and friends.”²

Although this episode in the book is concerned with a child dying at home, it says much about the child who dies in the hospital. The idealist may like to think that every dying child could be at home if he/she wished. The pragmatist may know that thought is sentimental and unrealistic. Cancer and other chronic illnesses of childhood give the child and family time. Time to plan. Time to prepare. Time to investigate alternatives. For many, though, time is a luxury. Accidents continue to be the leading cause of death for all age groups except infants. Neonatal difficulties and sudden infant death are problems that claim the lives of many children under one year of age. Some children die from suicide and abuse, others from chronic illness. The emergency room, the operating room, the neonatal or children’s intensive care unit, the inpatient

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units—any of these may be the place in the hospital where the dying child and his/her family will be found.

For some children, then, there will be no alternative. This statement may fill some with dread. The phrase “dying in the hospital” has come to mean, at worst, dying physically or emotionally alone, in a cold-to-alien environment over which the individual has little control. At best, “dying in the hospital” means “it was all we could do and everyone was nice.”

That last statement tells you, “I do not think we have found our best yet.” An editorial in *Cancer Nursing* gives us a clue where to start. The editorial describes a community meeting at which the benefits of hospice care were being related. At the conclusion of the discussion a man in the audience asked, “Why do you have to wait till you are dying to get this kind of care?”³ The man posed the question most in harmony with the lessons concerning life that the dying teach us. I therefore urge you to return to your practice setting and look at how family-centered your pediatric nursing service is. How welcome are families? How much are families included in planning care? Do only the dying have sibling visits? I suggest that the first method to improve care for the child dying in the hospital is to improve care for any hospitalized child and his/her family.

Where to begin the improvements is a difficult question. Allow me to share with you how the Pediatric Nursing Service at Massachusetts General Hospital approached this question. Seven years ago the Pediatric Nursing Practice Committee wrote a statement of philosophy and a set of objectives. These documents pledged the service to family-centered care based on principles of child growth and development and to accountable nursing care through the provision of a primary nurse for each patient. The years have passed and we are still struggling to achieve our goals, but the commitment has been made and the goals set.

Last year the Pediatric Nursing Practice Committee wrote “Standards of Care for the Dying Child.” The committee debated the content of the standards for months, and our implementation is imperfect. The goals are clear, however. The staff in all units know the department’s agreement on the importance of continuity of care, on the need for sibling involvement, and on the advisability of follow-up care after the child dies. The standards also recognize that the staff’s grieving must be worked through if they are to be able to continue to invest themselves emotionally in their patients.

As we professionals work to improve our service to others we will need to do more than make written commitments. I believe we must listen to the families and the children who are experiencing chronic

illness. This is a group that is very knowledgeable about the hospital system and our interventions. If we have the humility to learn from them I believe they can help us change our methods of care delivery. I project that changes will first occur in the inpatient pediatric units, the intensive care areas next, and finally the emergency room.

What are the elements of health care needing change? Let us recall Linda's words: "to do all that was left to be done for her—to make her comfortable, to provide her with familiar things, and most important to surround her with the love of her family and friends." Four areas are identified—participation and control, comfort, personalization of the environment, and provision of a loving atmosphere that invites family and friends.

Before I begin to look specifically at each of these points I should mention that my own interest is in chronic illness. My practice primarily involves children with malignancies. I am based in the inpatient pediatric units as a member of the Pediatric Nursing Service. For the past six and a half years I have also been involved with pediatric ambulatory chemotherapy patients.⁴ I follow families from the day of diagnosis through the good and bad times of their treatment and finally to their triumph over cancer or its triumph over them. I have kept in touch with many of the families of the children who have died. Sharing with these families over a long period of time through the illness–wellness continuum has led me to certain biases. I shall share these with you.

Let us turn to the first area where we need to improve our care. I believe that we are less inclined to make decisions for families if we really know them. The chronically ill child again points the way. From the minute the family learns that a child has a life-threatening illness the family must be helped to become active partners in care. It is the responsibility of nurse and physician to educate the child and family about the disease and treatment plan. A family accustomed to sharing in decisionmaking will have less difficulty in making decisions about how to handle the child's death.

A key concept for all of us is that there is no one right way to die, nor one right place. The acceptance of individual differences is essential. It is not our responsibility to sit in judgment on the family who decides to stay home (notice I did not say who is sent home) while their child dies. It is not our responsibility to condemn the family whose culture demands weeping and wailing. It is our responsibility to prepare the family for the range of responses which we have seen in the months and years after a child's death. It is our responsibility to act as the child's advocate and bring the child's worries and fears to light. It is not our job to decide in isolation how those worries and fears should be met.

It is not necessary that we decide what is the appropriate way for parents to act when confronted with their child's body. It is our task to provide privacy and to facilitate their wishes.

An especially important area where the staff can help parents stay in control concerns the needs of siblings. No matter where a child dies, or at what age, parents need help in telling their other children. Some nurses, particularly in emergency rooms and intensive care areas, have been hesitant to discuss the needs of siblings with recently bereaved parents. I have more often experienced a reduction in parental anxiety after a discussion concerning siblings. The point is that the family may accept or decline the offer. We need to make it.

A second important area involves the decision as to where the child is to die. The hospital nurse must have the knowledge and skill to offer a family the full spectrum of alternatives. Last week a mother and I talked about where her two-and-a-half-year-old was to die. Her questions ranged from the impact of a home death on the child's brother to the laws of her state regarding pronouncement of death. She did indeed decide on a home death on the basis of information provided by someone who knew both her and her sons.

The provision of an environment in which the child feels comforted but which also reflects the child as an individual is a major challenge. Children feel the most comfort in an environment that welcomes their parents. Those of us who care for the chronically ill learn daily that almost all parents can be present for treatments and procedures if adequately prepared and supported. I remember Lisa, a three-year-old dying of central nervous system leukemia. Her father always held her for her spinal taps. His closeness to her at that time added to her comfort enormously. Tommy's mother was different. She did not even want to see the bone marrow needles. For her a chair was placed so that her back was to those performing the test and she was side by side with her son, looking at him, holding his hand, offering encouragement.

Comfort is also concerned with pain relief and physical well-being. Many parents and children who decide that the hospital is the best place to die do so out of concern for pain relief. In reality this is an infrequent problem with proper management of outpatient pain medications. Occasionally an extreme pain control measure is required and hospitalization is necessary. Reliance on medication alone is a mistake, however. Comfort is enhanced by expert physical care, by positioning, by good oral hygiene, and so on. Many comfort activities can be taught parents so that they are the ones bringing physical comfort to the child. At minimum parents can be helped to assist if they wish.

A child's environment is personalized by people and things. The

inclusion of significant others in addition to parents is crucial. Karl was a teenager whose daily bath was given by his favorite brother—even when Karl lapsed into unconsciousness. For Mark a special teacher was needed in his last hours, for Mary a grandmother and favorite uncle.

The child's special toys, pictures of family members, classmates, girl- or boyfriends, the child's own clothes—all of these contribute to personalizing the child's space. This is a very important task for child and parent and should be accomplished no matter what the space limitation. Recently in the intensive care unit I saw a comatose child whose family had taped a religious prayer card, a Red Sox schedule, a family picture, and a Star Wars trading card to the head of his bed. Thus the family communicated some of the child's individuality. No one should die known solely as a motor vehicle accident.

The last issue is caring and involves our making the hospital a more human place not only for patients and families, but for all of us as well. How can dying in the hospital be humanized? On the surface this is a deceptively easy question. The answer involves no money, no equipment, no additional staffing. Death is more human when you and I stop being strangers, when you and I allow ourselves to tear down the boxes labeled "parent," "child," "professional" and treat each other as people united by a common purpose

Humanization of care begins with identifying yourself and by asking the child and parents, "What would you like me to call you?" Humanization continues with a thoughtful assignment of staff as a minimum and the provision of a primary nurse as the optimal. It is our saying no to caring for a different patient every day. You and I know that we do not share ourselves with people who continually run in and out of our lives. Yet we expect parents and children at a vulnerable time in their lives to relate to and take support from the parade of people who interact with them daily. Consistency is essential for the establishment of trust. Consistency of persons should be the goal, consistency of approach the unalterable norm. Utilization of nursing care plans, nursing histories, and patient progress notes are all readily available ways to personalize care.

Again, if all the way along we have tried to know the child and family as people we will not have to worry about an emotionally isolated death. We will have fewer concerns about his/her being surrounded by strangers. We will know the family members and friends in the room.

Dying more humanely in the hospital is possible. The suggestions offered here are not new. They are rooted in common sense, growth and development theory, and the principles of interpersonal relations. Why then are we still fighting the fight? I think it is because we have