End-*of*-Life Care
for Children

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THE PICTURE DEPICTS A SUNSET, REPRESENTING THE END OF LIFE, AND RINGS IN THE WATER, AN INTERPRETATION BY THE ARTIST OF THE RINGS OF LIFE AND THE IDEA THAT CHILDREN LOVE TO SKIP A ROCK EVEN THOUGH THEY KNOW THE ROCK WILL EVENTUALLY SINK. THE SIGNATURE OF THE ARTIST – AN EYE – REPRESENTS THE VISION NEEDED TO CURE THE DISEASE OF PEDIATRIC CANCER.

This book is
dedicated to
Valerie Wheeler,
Tom Robinson
& Connie Long.

All of whom
understood the
importance of
end-of-life care.

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Introduction

Caring for a dying child is one of the most difficult responsibilities a health care professional will ever encounter. In a society and time where health care professionals are trained to cure, the transition to palliative care can be a tremendous burden. The focus on cure can sometimes cloud the realization that death may occur, regardless of the intervention. A significant barrier to quality care for children at the end of life is the ambivalence of physicians, nurses, other health care professionals, and families who believe that choosing supportive terminal care interventions represents failure. Optimal end-of-life care may be overlooked when the health care team is still focused on curing the disease, and the importance of comfort and support may be neglected while attempting to save the child.

Current education of physicians, nurses, and others caring for children does not provide an extensive knowledge base related to end-of-life care. Emphasis on promoting health and curing disease, combined with the constant changes in technology, leaves limited time for learning how to provide necessary comfort and support when caring for dying children. Even less time is spent on helping health care professionals cope with their own fear, sadness, and grief related to the death of a patient.

This booklet, funded by the Texas Cancer Council, was developed to bridge the gap during the transition from aggressive treatment to quality palliative care at the end of life. Developmental considerations are presented to provide a conceptual background for learning how to work with a child who is dying. Understanding the child's perception of death will assist the health care provider in supporting the family as well as the child when end-of-life care must be discussed.

Comfort in talking to families about the end of life grows with preparation and experience. This booklet will guide health care professionals in effective ways to break bad news to parents and to present options of supportive care in a hopeful manner. It also reviews dilemmas related to treatment at the end of life, and emphasizes supporting each family caregiver involved with the child's care. The burden of caring for a child at the end of life is enormous, and guidelines or suggestions on how to provide support and teach the family ways to provide care physically for a dying child are included.

Information presented in the section on the physical care of the child at the end of life provides a resource for medical management related to numerous symptoms that may be experienced during the terminal phases of an illness. Other options for intervention and care are presented in relation to blood product support, hydration and fluid administration, nutritional intervention, and alternative medicines.

Attention to the family is an essential aspect of supportive care when the dying patient is a child. This section of the booklet focuses on helping the family. It addresses spiritual issues and provides insight into religious practices related to end-of-life care. In addition, it discusses the cultural implications of caring for patients of various ethnic backgrounds.

The last section of the booklet provides information regarding the support of professionals caring for dying children. A review of the impact of grief and loss on the provider is discussed. Strategies to provide quality education and training on end-of-life care will assist many health care institutions to improve care in the future. Resources on end-of-life care include written references, web site addresses, and support organizations that can be of great benefit for helping children and their families during this most difficult period.

Caring for terminally ill children is an intensive, multifaceted process that requires focused management of physical, psychosocial, and spiritual issues with a clear goal of increasing child and family comfort and quality of life. Every member of the health care team has an important role in assuring that quality of life continues during the remaining weeks or months of the child's life. It is the goal of this booklet to provide helpful information to physicians, nurses, social workers, clergy or chaplains, other health care professionals, and the family involved in the care of a child facing the final stages of his or her illness.

Making Difficult Decisions · 1

The death of a child is viewed as outside the natural order of life. Children represent hope, energy, and health. A dying child can challenge our understanding of life, faith, and certainty in the future. For health care providers and families of dying children, questions abound. Have all curative options for the child been exhausted? When and how should the child and family be told of the prognosis? How will the pain and distress of dying be managed by the health care team and the family? Who should make the decisions regarding whether to continue treatment or turn solely to end-of-life care? Who should manage the terminal care? Is it ethically appropriate to stop treatment? What will dying be like for the child? For his or her family? For the doctors and nurses providing care?

For children with progressive, life-threatening illness and their families, there often are numerous compromises to be made when balancing between treatment and quality of life. The burden of chronic illness and the care it demands can exhaust a family financially, physically, and emotionally. As the disease progresses, despite efforts at cure or control, the physician must weigh the cost of any proposed treatment with the impact that treatment will have on the child's comfort and quality of life. This information must be presented to the family and child in an empathetic manner.

BREAKING BAD NEWS

Presenting bad news to patients and families is one of the most difficult tasks faced by health care professionals. Physicians and nurses receive limited educational preparation regarding how best to prepare a family for serious information related to a child's illness. If effective patient/family and health professional relationships are to be established, change in disease status must be communicated in a compassionate manner. Buchman and Baile (1998) have published an important resource for clinicians that provides a practical approach to sharing difficult information (Table 1).

When preparing to discuss bad news regarding a child's illness, it is important to decide who should be included in the discussion. Frequently, there are several family members closely involved in the child's care. A general rule is to allow the parents to make the decision as to who should attend the meeting. If there are many relatives at the hospital, ask the parents to choose the closest family members to be present for the initial meeting and offer to be available at a later time to meet with the others. The importance of privacy during these meetings cannot be over emphasized. Health care professionals should sit beside the parents, rather than stand, while discussing sensitive issues. Attention should be focused on the parents during this time, and interruptions such as phone calls and pages should be avoided if at all possible. A calm demeanor and a willingness to listen to the parents are important. If the family is non-English speaking, a professional interpreter should be used. Family members, particularly young siblings, should not be placed in the difficult position of translating painful information.

TABLE 1. BREAKING BAD NEWS TO FAMILIES

Approach	Effective Techniques
Provide a setting conducive to communication	• Ensure privacy; use appropriate body language; make eye contact. • Have parents choose who will attend.
Determine what the parent knows	• Ask questions. ("What have you made of all this?" or "What were you told?") • Listen to the vocabulary and comprehension of the parents. • Recognize denial, but do not acknowledge it at this stage.
Determine what the parent wants to know	• Obtain a clear invitation to share information (if this is what the parent wants). Use questions such as, "Are you the sort of person who likes to know every detail, or just the basic facts?"
Give information (aligning & educating)	• Start at level of parent's comprehension and use the same vocabulary. Give information slowly, concisely, and in simple language. Avoid medical jargon. Check regularly to be certain that content is understood.
Respond to parents' reactions	• Acknowledge all reactions and feelings, particularly using the empathic response technique (identifying emotion, identifying cause of emotion, and responding appropriately). • Expect tears, anger, and other strong emotions.
Close	• Briefly summarize major areas discussed. • Ask parents if they have other important issues to discuss at this time. • Make an appointment for the next meeting.

Adapted from: Buchman R, Baile W: How to Break Bad News to Patients with Cancer: A Practical Protocol for Clinicians, Spring Education Book, p. 205, American Society of Clinical Oncology, 1998 with permission.

Discussions about bad news may be facilitated by first determining what the parents and family already know about the situation. Appropriate questions to ask include: "What have you been told so far?" and "What concerns do you have today?" Give the information slowly and clearly. Pause frequently to determine the family's level of comprehension. Demonstrate empathy by allowing them time to respond. Remember that exhausted parents and family members may release their emotions readily and may not be able to discuss the news in detail when it is first delivered. Often the goal of the initial meeting will be to provide the family with basic information and emotional support. A second meeting can then be scheduled to discuss the situation in more detail. Providing family members with specific details about what will occur next will allow them to focus their thoughts on decisions they will have to make in the near future.

TRANSITION TO PALLIATIVE CARE

Another difficult challenge faced by the team caring for a child with progressive disease is the transition from care aimed at curing a disease to care focused on managing symptoms to promote comfort. Initially, when a child is diagnosed with a chronic, life-threatening condition, the focus is appropriately on curing or controlling the disease to provide the child with the maximal length of life. During this period, the family, child, and treatment team may have a higher tolerance for patient discomfort and side effects.

However, for some children, the disease continues to progress. Families and health care professionals must face a number of ethical dilemmas at this point (Table 2). The physician must understand the family's values and definition of *quality of life* to guide the family through the course of their child's disease and eventual death.

EUTHANASIA, ASSISTED SUICIDE & PALLIATIVE CARE

In recent years there has been much debate professionally and in the media regarding the issues of assisted suicide and euthanasia. Health care professionals need to have a clear understanding of these issues and their own personal beliefs and values.

Euthanasia An act committed by someone other than the patient that is intended to bring about the death of an individual suffering from painful or prolonged illness for reasons of compassion or mercy.

TABLE 2. COMMON ETHICAL DELIMMAS IN CARING FOR TERMINALLY ILL CHILDREN

Rationale in Providing to Patient	Rationale in Withholding from Patient
PAIN CONTROL	
• Comfort is primary goal. • Improved quality of life. • Easier dying process if child is pain free.	• Side effects of opioids. • Decreased level of cognition. • Fear of addiction (unfounded in terminally ill patients).
CHEMOTHERAPY OR EXPERIMENTAL THERAPY	
• Prolonged life span. • Possible increase in quality of life. • Provides sense that family has done everything they can to save the child.	• Decreased blood counts, increased risk of infection, bleeding. • Side effects of treatment may be painful, uncomfortable.
SUPPLEMENTAL NUTRITION AND HYDRATION (INTRAVENOUS, NASOGASTRIC, G-TUBE)	
• Belief that the child is hungry/thirsty. • Child cannot or will not eat. • Fear that child will "starve" to death. • Primary role of parent to feed and nourish child. • Parental guilt.	• Supplemental feedings beyond what child can ingest may actually cause nausea/vomiting. • Increase in tumor growth (feeding the tumor). • Increase in fluid volume may result in congestive heart failure, increased respiratory secretions and/or pulmonary congestion, which leads to questions of whether or not to implement diuretic. • Increased urine output leads to increased risk of skin breakdown if child is incontinent. • Risk of third spacing. • Death is more comfortable and natural. • Complaint of thirst is associated with dying process, not level of hydration (Zerwekh, 1997).
RESUSCITATION	
• Family does not want to give up. • Conflicts with culture or religious beliefs. • Denial that child is actually going to die.	• Allowing nature to take its course. • Family believes child has suffered enough, does not want aggressive intervention. • Relieves family of responsibility to stop interventions that might prolong life.
AUTOPSY	
• Research to help other children. • Ability to check genetic link.	• Religious, cultural belief. • Family feelings. • Desecrates body for funeral viewing (an unfounded fear).

Hockenberry-Eaton M, and others: Essentials of Pediatric Oncology Nursing: A Core Curriculum, Association of Pediatric Oncology Nurses, Glenview, IL, 1998, with permission.

Assisted Suicide The act of providing fatal means to a person who intends to commit suicide because of actual or feared pain and suffering due to prolonged or terminal illness.

Palliative Care Sound medical/nursing assessment and interventions directed at relieving pain and other distressing symptoms of chronic or terminal illness in order to provide the individual with the best quality of life possible.

A significant barrier to good pain and symptom control for terminally ill children is the fear that escalating doses of medications to treat difficult symptoms will result in the child's death. Practitioners with limited experience managing terminally ill children often struggle with the ethical dilemma of alleviating a child's pain and suffering despite the perceived risk of producing the child's death. The principle of double effect provides an ethical framework for health care professionals to consider as they make decisions with regard to interventions aimed at pain and symptom control.

PRINCIPLE OF DOUBLE EFFECT

An action that has one good (intended) and one bad (unintended, but foreseeable) effect is permissible if the following conditions are met:

1. The intervention itself must be good or indifferent. Only the good consequences of the intervention must be sincerely intended.
2. The good effect must not be produced by the bad effect.
3. There must be a compelling or proportionate reason for allowing the bad effect to occur.

When the goal of care is the alleviation of pain and suffering, the interventions used to achieve that end can be viewed as ethically justifiable when the principle of double effect is applied. If there are difficult ethical questions regarding management of a child's terminal illness, it is always appropriate to consult the institution's ethics committee.

SHARED DECISION-MAKING

Shared decision-making implies an open communication between individuals, usually the patient and/or family and doctor, aimed at sharing information and preferences regarding treatment. In a shared decision-making model, the physician is the expert, providing honest, clear information regarding diagnosis, prognosis, treatment options, and risk/benefit assessment. The patient and/or family shares information with the physician regarding values, acceptable levels of discomfort or inconvenience, and the ability to comply with treatment. The physician and patient/family are able to use this shared information to make informed decisions about the best course of treatment (Charles, Gafni, & Whelan, 1997).

The process of shared decision-making between the child, family, and health care team allows for all options to be discussed with regard to their consequent risks and benefits, the prognosis or course of the illness, and the impact on the child and the family's resources. Following are some important points to consider as care options are explored with the child and family:

- Continually assess the impact of the child's illness and treatment on the family.
- Provide honest, accurate information regarding the trajectory of the disease, anticipated complications, and prognostic information.
- Focus discussion on what the family desires for the child in terms of comfort and quality of life.
- Avoid personal opinion or judgment regarding the family's questions and decisions.
- Reassure families that the health care team will continue to support the child and family actively, regardless of their decisions.

There are situations that may require extraordinary consideration, due to legal or procedural implications regarding delivery of care. It is important to follow state regulations and institutional policies when providing care to terminally ill children. Variations in state regulations may affect the way the following situations are handled:

- Do Not Resuscitate (DNR) order.
- Time limitations for DNR order.
- Home death notification. Consider state/county medical examiner laws regarding a child's death at home.
- Nursing pronouncement of death.
- Mandatory autopsy.
- Transportation of bodies.
- Paramedics or school system honoring DNR order.
- Narcotic control.

OPTIONS FOR CARE

Once it has been determined that the goals of care have shifted from attempts at cure or control of the disease to palliation and comfort, it is important to provide the family with all options available to them. The first goal is to determine the location of care that the family feels is best for them and the child, and to provide the necessary support to provide care in that setting. Often, families will move between various settings (hospital, home, hospice) as the child's disease progresses. The location of care may change based on the child's disease status, symptom control, and the family's comfort level in providing care.

Hospital care may provide the child and family with the support and comfort of familiar staff and surroundings at a time when the child is very ill. However, some families may prefer to avoid returning to the hospital. Staff caring for a hospitalized child with a terminal illness must be aware of the goals of care. All efforts should be made to make the child's surroundings comfortable and familiar, and to maintain as consistent staffing as possible. Orders and medications for pain and symptom control should be readily available to avoid delays in providing comfort for the child. Attention to the child and family's emotional and spiritual needs should be assessed consistently and addressed appropriately.

Home care provides the family with the necessary medical equipment and medications, as well as periodic nursing visits, to maintain the child at home. Nursing visits generally are scheduled to conduct a diagnostic test or procedure, and also to provide education for the family regarding care. The frequency of visits often is determined by the family's insurance coverage and can widely vary. Depending on the child's condition and medical coverage, families may qualify for extended in-home nursing care. The home care option can be used in conjunction with hospital care to allow as much time at home as possible for the child and family.

Hospice provides care to children with terminal illnesses. An interdisciplinary team of professionals skilled in caring for terminally ill patients provides support that enables family members to provide care for the child at home. This team includes physicians, nurses, certified nursing assistants, social workers, chaplains, and volunteers. Hospices provide all necessary equipment, supplies, and medications. Nursing visits are available 24 hours a day, seven days a week. Social workers and chaplains also make home visits to assist the family with the difficult emotional and spiritual issues that accompany the death of a child. Many hospice organizations also are able to provide inpatient care or staff caregivers in the home up to 24 hours a day for short periods of time to regulate pain control or symptom management, or to provide care in the final days of life. Respite care is also available in an inpatient setting. Hospice staff members are experts in managing pain and symptoms associated with progressive, terminal disease, and in supporting the emotional and spiritual needs of the terminally ill and their families. Currently, there are limited hospice organizations that have a designated team for children. However, many hospices will accept children and work with the attending pediatrician to manage care. Hospice care is covered by most private insurance plans, as well as by Medicaid in most states.

When the Dying Patient is a Child · 2

DEVELOPMENTAL CONSIDERATIONS

Cognitive development and age form the foundation for a child's understanding of the concept of death. Understanding emerges over time in a sequential pattern, but the process is diverse and varies by child. There are general considerations for caring for children of different ages at the end of life (Rando, 1984).

INFANCY THROUGH TODDLERHOOD (0-2 YEARS)

Normal developmental tasks for infants include developing trust in parents, while achieving a sense of differentiation. Separation from parents is a primary fear. Terminally ill infants have no concept of death, and are most affected by the family's emotional and physical state. Reactions occur in relation to separation from caregivers and alterations in routines or surroundings. To support a child this age, encourage parents to stay with the child as often as possible, and provide physical relief and comfort.

Toddlers' developmental tasks include establishing small amounts of independence from parents, wanting a sense of control over their environment, and learning basic self-care skills. Terminally ill children less than two years of age have limited understanding of the dying process. Because differentiation from others is not complete, children at this early age are influenced by the emotions of others, often reacting as they see their parents react. Hospitalization is extremely stressful.

To be supportive, minimize the child's separation from parents as much as possible. If a parent cannot be available, encourage the parents to find a consistent, reliable adult to stay with the child. Provide opportunities for the child to practice and master age-appropriate skills; when possible, offer a variety of acceptable options for the child. Help the child succeed at the tasks attempted by providing necessary materials. Encourage the family to maintain familiar routines, or explain reasons why the routine must be changed. Encourage regular play activities. Provide maximum physical relief and comfort.

EARLY CHILDHOOD (3-5 YEARS)

Development of a conscience begins during this age, and children enjoy making decisions and expressing themselves. A sense of exploration and wonder propels children forward. Children of this age are becoming increasingly differentiated from parents, and enjoy self-sufficiency. The world is viewed in terms of good or bad, and magical thinking leads children to believe they have a direct impact on the events in their lives.

For the preschooler, the concept of death is limited, and death may be seen as reversible or temporary. Illness and separation from parents may be perceived as punishment for bad thoughts or actions; feelings of guilt and responsibility for causing illness/death may develop. Children may regress behaviorally in an attempt to feel secure.

To be supportive, assure the children that they are not being punished; provide clear, honest explanations of the illness and treatments. Minimize separation from parents and significant others when possible, and keep changes to a minimum. Provide outlets for normal childhood emotions and impulses, as well as an environment that encourages curiosity. Provide maximum physical relief and comfort.

MIDDLE CHILDHOOD (6-9 YEARS)

Peers are important at this age, yet children return to the security of home and family for comfort. Children have the ability to master and learn; constant activity is normal. Feelings of independence, self-confidence, and individuality are emerging. Rules and order are internalized, and every act is thought to have a punishment or reward.

Hospitalization or illness may be seen as a punishment for past wrongs. Children's evolving sense of self may be impacted by the illness, creating feelings of anger and confusion. Parents may be held responsible for the illness.

To be most supportive, provide children with concrete details and truthful, open communication about the illness. Provide opportunities for children to exercise their remaining skills and abilities so they can feel a sense of achievement, mastery, and control. Interaction with friends should be maintained, and separation from parents should be minimized. Allow children to be involved in planning or carrying out treatment procedures, if possible. Provide maximum physical relief and comfort.

LATE CHILDHOOD (10-12 YEARS)

Through socialization with friends and the onset of puberty, children begin to develop a body image, self-esteem, and identity. Peers are critical, and privacy is extremely important. Young adolescents begin to incorporate information to solve problems, and want more independence from parents. Children of this age have a realistic view of death as inevitable, irreversible, and universal. They understand that biological life ends in death.

When terminally ill, young adolescents may struggle between the developmental need to begin separating from parents and the natural tendency to regress due to the illness. Peer groups may feel their own independence threatened and may withdraw, leaving adolescents feeling alienated from parents and rejected by peers. There is a marked concern among adolescents for how the illness will affect their physical appearance.

Allow young adolescents to be involved in the decision-making process, and provide opportunities for them to interact with the medical staff. The 10–12 year-old needs to be allowed or encouraged to share feelings and ask questions so he or she feels some measure of control over the situation. Treat adolescents with respect and dignity, providing clear, honest, and direct communication. Encourage association with friends. Allow children as much control and independence as possible. Provide privacy and maximum physical relief and comfort.

TEENS (13-18 YEARS)

The development of identity, body image, and self-esteem continue; additionally, a sexual identity is being formed. Young people of this age seek to establish emotional and economic independence from parents. An adult view of death exists, yet teens often believe they are infallible and immortal.

Teens with a terminal illness worry that they may not be able to attract a boyfriend or girlfriend, and that peers may reject them. Teens may be more concerned about the physical side effects of treatment than about dying. They are concerned that their independence from parents will be impeded. As the illness has its effect on the body, they feel a loss of control.

In all aspects, treat the teen with respect, providing clear, honest, and direct communication. Provide for privacy, and find ways to recognize and support the teen's unique identity. Offer opportunities to express emotions, and encourage association with friends. Allow teens as much control and independence as possible. Recognize and address issues of sexuality. Provide maximum physical relief and comfort.

TALKING ABOUT DEATH WITH DYING CHILDREN

Although some children, even at the youngest ages, are not isolated from the reality of death, communicating with them about the subject of death remains difficult. Children with life-threatening illness often are more aware of their prognosis than adults are able to acknowledge comfortably; their own bodies give them clues, as do as changes in parents' emotions and behaviors. Talking about death openly and honestly provides children with a sense of trust and confidence through which they can express their feelings and concerns. Open communication relieves their sense of isolation, allays their fears and anxieties, and gives them the opportunity to fulfill any unfinished plans. Awareness of the child's developmental level, realization that effective communication can reduce anxiety, and recognition of the existing communication system within the family are important factors in good communication (Lansdown, 1994). Use the style of communication most comfortable for the child when talking about death.

The context in which death is discussed impacts how the child interprets the discussion. It can either add to his/her fears and anxieties or allay them. Therefore, openness and honesty should be the underlying context of all communication. Children often communicate their needs through questions, interactions, and play. Caregivers must take cues from the child and let the child guide the discussions. Careful observation of the child's affect and thorough assessment help identify the child's actual needs and readiness to talk. Calm, sensitive responses directed at these needs can provide adequate information.

TABLE 3. GUIDELINES FOR COMMUNICATING WITH DYING CHILDREN

Begin on the child's level	• Gear information to the developmental age of the child, remembering that younger children tend to be concrete thinkers, while older children are capable of abstract thought. • Begin with the child's experiences; "You've told us how tired you've been lately."
Let the child's questions guide	• Begin the conversation with basic information, and let the child's questions direct the conversation.
Provide opportunities for the child to express feelings	• Look for clues that child is open to communication. • Be accepting of whatever emotion is expressed.
Encourage feedback	• Ask the child to summarize what has been heard. This provides the opportunity to clarify misunderstandings.
Use other resources	• Books and movies can encourage dialogue. • Ask the child to name the people whom they can discuss problems with.
Use the child's natural expressive means to stimulate dialogue	• Use books, games, art, play, and music to provide a means of expression.

Doka KJ. Living with Life-Threatening Illness: A guide for patients, their families, and caregivers. Lexington Books, Lexington, MA, 1993, with permission.

It is important to provide specific and literal explanations of death that distinguish fact from fantasy, using words with which the child is familiar. Do not be evasive, but modify explanations according to the child's understanding. Make it clear that with death, life stops, and that the dead cannot return. Avoid euphemisms and philosophical interpretations that can easily be misunderstood. Use words like *die* or *dead,* not *going on a long journey* or *pass away.* Additionally, provide ample opportunity to address the child's questions. Table 3 provides guidelines that can assist in communicating with dying children.

In the correct context, the health care provider and family can help validate the completeness of the child's life, freeing him or her to feel a sense of accomplishment and purpose. Open communication gives children strength and courage to cope with the circumstances of their own death and death in general. It allows them to feel, express and come to terms with a wide range of powerful emotions. Health care providers and family caretakers must be able to discuss the following topics openly and honestly with the dying child (Spinetta, 1980):

- Why certain treatment is being discontinued.
- That death is a part of the natural life cycle.
- The family's spiritual belief regarding what happens after death.
- The child will not be alone at the time of death, or after (the child is looking for parental presence and support throughout, both during the dying process and after death).
- The child's life has had an impact on the lives of others.
- It is all right to cry and to feel sad.
- It is all right to feel angry and resentful.
- It is all right not to want to talk to anyone for a while.
- Emotional support will be available when needed.
- When the child experiences pain, the health care team will do everything possible to reduce the pain.
- Death itself will not hurt, and the pain will end.
- The purpose of a funeral is to allow loved ones to say goodbye.

ASSESSING THE FAMILY'S COMMUNICATION SYSTEM

Communication systems within a family influence a child's thinking and affect how caregivers, children, and families relate. They guide health care providers, caregivers, and the child in their interactions, based on who knows what. Hence, there is a delicate balance of behavior and interactions. In an open communication system, the child and all caretakers are aware that the child is dying (Glaser, Barney, Strauss & Anselm, 1965; Lansdown, 1994). They all act on this awareness, communicating openly and honestly. In a mutual pretense system, both the parents and children know death is inevitable but choose to act otherwise. Everyone portrays that they are not concerned because they do not want to worry and upset one another. To discourage this mutual pretense, caregivers can confront parents gently with the suggestion that the parents may be using this approach, and then educate the parents about the importance of open, honest communication. In the suspected awareness system, the child suspects what the others know and attempts to confirm or invalidate the suspicion, often through play and school work. In the avoidance system, the child has not been told of his impending death. This style upholds that the less said by anyone, the better (Glaser and others, 1965; Lansdown, 1994). Parents may benefit from a parent support group or from talking with a counselor for assistance in developing healthy and appropriate communication patterns. It also is important to provide unconditional support and guidance to children, parents, and families.

OTHER METHODS FOR COMMUNICATION

An environment that promotes exploration of the subject of death allows children the space to demonstrate their needs and to express their feelings and thoughts. Expressive styles include nonverbal communication, dramatic play, art, music, puppetry, and dance. The approach one uses to encourage such expression should be suited to and comfortable for the particular child. These alternate creative modalities may provide insight into the child's intuitive and unconscious awareness of death.

THE ROLE OF THE PROFESSIONAL

There is no single approach for talking about death with individuals and families. However, the professional can promote communication that is healthy and helpful for the child and the family, both during the dying process and after the death. Careful examination of one's own attitudes toward death, together with observation and assessment of the family, encourages supportive communication, allows expression of needs and feelings, and satisfies the needs of both the child and family. Following are considerations for professionals communicating with families and children facing end-of-life issues:

- Examine personal beliefs and motivations.
- Validate personal opinions.
- Strengthen the role of family members.
- Remember the importance of nonverbal communication and symbolic language (such as touch and quiet presence).
- Use a variety of means to communicate (e.g. music, writing).
- Consider the choice of words used to discuss death (e.g. lost, sleeping).
- Be aware of the needs of all the children involved with the dying child (siblings, classmates).

Caring for dying children and their families places the professional caregiver in a position of establishing intimacy with the family they care for. Professionals develop relationships with their patients through the care-giving process and, as a result, become privy to their patients' most private moments of love, grief, and suffering. The challenge for the health care professional is to develop the necessary intimacy with the patient and family to be able to guide them through the physical and emotional pain of death, while maintaining boundaries that allow the professional to separate the family's loss from his or her losses.

A DYING CHILD'S GRIEF

A child with a terminal illness is on a journey that most others in his/her support network have not been on. Children look to parents to guide them through this unknown territory, a task that most parents are not prepared (either emotionally or by experience) to do. Additionally, terminal illness sets the child apart from other children, placing the child in a world that is foreign, painful, and time-limited. Facing the end of life can therefore be a frightening, lonely experience for a child. The dying child may experience the following emotions:

- Anger toward the illness and the deprivations it brings.
- Anger toward the parents/caregivers for their inability to make the illness go away.
- Fear of regression, loss of functioning.
- Fear of separation, loneliness, abandonment.
- Fear of bodily mutilation.
- Sadness over current and future losses.
- Guilt for how the illness is impacting the family.

- Shame and embarrassment over the physical changes caused by the illness.
- Fear of the unknown.
- Fear of suffering and pain.

To address these emotional issues, the following approaches are recommended:

- *Be honest* Dying children are more aware of their prognoses than adults often are capable of acknowledging. Attempts to keep the prognosis from the child are ineffective, and result in feelings of isolation, mistrust, and fear for the child. Information about the illness should be communicated in language that the child can understand, and followed by sufficient time to stay with the child to discuss questions and concerns. To be emotionally supportive, listen to and take cues from the child, recognizing that the child may vacillate between acceptance and denial.
- *Minimize separation from parents* Most young children fear separation from their parents, especially in a hospital setting. To address this fear and minimize separation, arrange for accommodations, such as another bed or a sleeper chair. If the parents cannot be available, encourage them to enlist the help of an adult with whom the child has a loving, trusting relationship.
- *Be emotionally available* A dying child needs someone to listen to fears and concerns, and to help in exploring feelings. A child is less anxious when his/her emotions are accurately perceived and responded to appropriately and sensitively.
- *Encourage quality of life* Encourage the parents to allow the child to maintain a normal routine for as long as possible. Activities such as going to school and associating with peers provide a sense of security for the dying child. Encourage day-to-day living as opposed to day-to-day dying. To promote a sense of mastery and control, encourage age-appropriate activities and allow freedom of choice when possible, so the child can exercise remaining skills and abilities.
- *Maintain discipline* Ill children need limits and discipline just as much as healthy children. Boundaries help children feel secure.
- *Sustain hope* Maintaining hope is a critical measure for quality of life. The focus of hope must change from a hope for cure to hope for a meaningful life and peaceful death.
- *Maintain familiar routines, or explain why routines must be changed* Familiar schedules or daily activities provide a sense of security for the child.
- *Provide privacy* Adolescents and teens need to have their privacy respected, and their developing sexuality recognized and addressed.

PROVIDING SUPPORT FOR THE BURDEN OF CARE

Care of the dying child is a complex and emotionally difficult challenge that impacts the well-being of all family caregivers. Providing care and support to meet the needs of the dying child causes grief and distress in caregivers, regardless of their preparation. It is the role of the professional to recognize the individual needs of family members and to help them meet the challenge of caring for the child. Helping family members to fulfill their own expectations of what is significant regarding the impending death of the child can enhance their coping abilities and continuation of life after the death. Competent health care providers who show compassion and human caring contribute to caregiver satisfaction and create a connection that is most supportive for families.

Family caregivers experience a variety of powerful emotions that can threaten their coping abilities. Health care providers cannot eliminate these emotions, but can help redirect them into healthier channels. Anger, guilt, anxiety, and helplessness are emotions parents experience and can project onto other family members and members of the health care team. Guilt can be better tolerated if the parent is encouraged to express it openly and understand that guilt may play a natural role in important relationships. Parental anxieties may be constructively redirected through active participation in their child's care.

The financial burden often is the most stressful aspect of the situation. The burden of a life-threatening illness and end-of-life care leaves families wondering how they will manage financially in the present and long-term. The financial burden drains relationships between family members and weakens this crucial support system. Connecting families to area charity organizations and benefits can ease this strain and provide some relief. Additional stresses of parent caregivers include working a full-time job, managing care of their well children, and maintaining healthy personal relationships. It is not uncommon for parents to seek support outside of their marital relationship and immediate family. To help individuals cope, the health care provider can help them identify a social support system specific to their needs. Hospice staff, family, friends, neighbors, Church contacts, and employers can help to provide respite, regular provision of meals, arrangements for well-child care, and connections to resources for financial, spiritual, and psychosocial needs.

NEEDS OF THE FAMILY CAREGIVERS

EDUCATIONAL

Preparation and education of family members in various aspects of care provides a sense of competence and ease during a frightening transition. Empowering family caregivers with knowledge and guidance gives them some assurance that they can meet the needs of their child. Preparation of caregivers should be tailored to meet their unique needs and concerns. Information should be honest and up-to-date, and should be communicated in a style of learning appropriate to each family member. Education should begin early in the care-giving process for a smooth transition to palliative care. Table 4 identifies some of the needs of family caregivers and offers suggestions on how health care providers can help families meet these needs. Education about physical care is best provided as needed, or just ahead of what you think the child may require. Telling a parent that they will learn to assess their child's need for suctioning, or to provide care during respiratory distress too early can be frightening or overwhelming.

EMOTIONAL

Healthy adaptation for families mourning the death of a child has been linked to the psychological support provided to caregivers prior to and following the death (Foley & Whittam, 1991). Anticipatory grief, guilt, and feelings of inferiority are psychological issues that should be addressed by social workers, support groups, and counselors. Helping family members work through difficult feelings as they occur can ease their minds and refocus them on the present. The stress and trauma of the situation often increase tension and emotional vulnerability, which can weaken or damage relationships between couples and among families. Encouraging individual family members to seek support outside of the family circle can ease this burden and strengthen family members, who then can be more available, emotionally and physically, to one another.

RELIGIOUS AND SPIRITUAL

The religious and spiritual needs of the dying child and the family may not be as easily discernable as the emotional needs, but how well they are met may be a key element in determining how well the family members copes with the situation. It may be necessary to facilitate communication between the child and the family, so they are able to explore their own beliefs and fulfill their individual needs. Resources such as a chaplain, other spiritual leader, or social worker may be of help as the child and the family seeks spiritual comfort. Health care professionals also can offer spiritual support by learning to be comfortable with death, listening to the family, and performing small acts of kindness.

SIBLINGS

Parents often are concerned about how to deal with siblings of the dying child. Siblings' reactions and feelings are influenced by their developmental stage and maturity level (Lansdown & Goldman, 1988). However, more often than not, children of any age feel a sense of isolation and may withdraw or act out. Siblings may feel jealous of the attention the ill child receives. Siblings often experience losses related to changes in interaction with parents, ability to participate in school activities, and their increased responsibilities in the family. Honest communication and participation in the care of their dying sibling often helps to provide a sense of connectedness and importance. It also can provide a clearer understanding of the situation. Helping parents to be attentive to the emotional needs of siblings and to maintain supportive relationships between siblings, the dying child, and themselves can promote the well being of all involved, both before and after the death of the child. Encourage parents to provide siblings with regular time alone with each parent to support and nourish normal development. A normal routine that promotes fun, laughter, and love creates lasting memories and pleasurable experiences that can be shared by the entire family. Parents also should encourage siblings to pursue activities and relationships outside the home. Supportive relationships with health care professionals provide siblings with another outlet for open and honest communication that can lessen their fears and anxieties. If parents are unable to be at home, arrange for consistent care of siblings with adults whom the siblings accept and enjoy.

TABLE 4. PREPARATION AND EDUCATION OF FAMILY CAREGIVERS

Needs of Family Caregivers	Professional Interventions
PRACTICAL NEEDS	
• Is home care, hospice care or care in the hospital appropriate for my child? • How will we pay for end of life care at home, in the hospital, or in hospice? • How will we pay our other bills? • Where do I get equipment and supplies? • How does the equipment work? • Who do I call if equipment malfunctions? • How should we arrange our house to best meet the needs of our child? • Will there be help available to us at home? • Who do I call for medical questions?	• Explore family's preferences for home care or hospice as appropriate. • Evaluate family's funding source and provide resources and assistance as necessary. • Provide family with appropriate telephone numbers and contact people for questions about equipment and medical care. • Plan for availability of caregiver's family (i.e. parents, family, friends, professionals) and help coordinate a schedule for provision of care. • Provide contact person for family to call with concerns or questions.
PERSONAL CARE	
• How do I give my child a bath? • How do I give my child a bed bath? • How do I wash my child's hair in bed? • How do I change linen with my child in bed? • How do I perform skin care? • How do I perform mouth care? • How do I administer medications? • What do I do if my child does not want to eat? • Is there something I can do to get my child to eat? • Are there alternate forms of feeding? • Does my child need supplements or a special diet?	• Instruct all caregivers about providing daily care to the child. • Provide written instructions and reference material for caregivers to review. • Assess the child's nutritional status and parent's view on supplemental nutrition. • Educate family on decreased nutritional needs and potential complications with over-feeding or over-hydration.
PHYSICAL CARE	
• How do I assess my child's pain? • When should I give pain medications? • What do I do when pain management is ineffective? • What should I do when our child is constipated or has diarrhea? • How do I control nausea and vomiting? • What do I do if my child has a fever? • What do I do if my child has seizures? • What do I do if my child has trouble breathing?	• Assess the child's current comfort status and educate family on current interventions. • Educate family about assessing the child's comfort level. • Instruct the family that the child may be uncomfortable for a variety of reasons (i.e., constipation, anxiety, fever, headache, muscle cramp, disease) and educate them about appropriate interventions for particular circumstances. • Provide an accessible supply of medications that can help alleviate discomfort (i.e., laxative, sedative, antipyretic). • Encourage caregiver to telephone contact person for questions or ineffective interventions.
ACTIVITY AND SOCIAL INTERACTIONS	
• Can we safely travel and enjoy family gatherings with our child? • In which activities can we engage our child? • Should friends and family be encouraged to visit? • What interventions can I do to help my child relax and rest comfortably?	• Encourage family to engage in fun and memorable activities with the child. • Encourage visitors when appropriate. • Encourage family to employ relaxation techniques that have previously been beneficial to the child.

TABLE 4. PREPARATION AND EDUCATION OF FAMILY CAREGIVERS (CONTINUED)

FINANCIAL

As the time needed to care for the dying child increases, changes in lifestyle can affect employment status and, ultimately, the financial security of families. Medical bills, transportation costs, meals, and wages lost due to time away from work all contribute to the financial stress experienced by families of seriously ill children. This financial burden, plus out-of-pocket living expenses, costs of medical equipment or medications, and funeral preparation add stress to the situation. An examination of economic resources available to the family, coupled with early planning, can help families manage finances. It may be helpful to direct the family to consider the following potential financial resources (Laizner and others, 1993):

- Insurance policies
- Social Security and Medicare/Medicaid benefits
- Employment benefits (including policies where co-workers can donate time off)
- Federal, state, and local taxes (keep all receipts)
- Banking (checking/savings accounts, trusts, etc.)
- Stocks, bonds
- Charitable organizations
- Family Leave Act

CAREGIVER PERSONAL

Personal care and meeting household needs often are of secondary importance to caregivers but necessary to consider. Self care, housework, laundry, grocery shopping, and well-child care left unattended create unnecessary stress. Encourage caregivers to accept help from family and friends. Encourage caregivers to delegate tasks that can be done by others. Remind them that it is okay to relinquish some responsibilities temporarily, and that guilt is a natural reaction. Extended family members, friends, neighbors, the Church community, and health care providers can provide support, and thereby allow rest, adequate sleep, and maintenance of one's own health. Help the family to define its support network, and to understand that this network can impact the family positively, both practically and emotionally. It is not uncommon for outside help to diminish after the death of the child, which often leaves the family lonely and depressed. It is important to remember that support is needed after the death of the child. A network of friends and family should be established and made available to the family after the death (Harrington, Lachey & Gates, 1996).

RESPITE

Living with the day-to-day care demands of a terminally ill child can be physically and emotionally exhausting. Depending on the circumstances, the caregiver may have to give medications, assist the child with toileting, or comfort the child's fears, leaving little actual time to rest. Often, the professional staff or other family members may expect that the parent (most often the mother) is the person best suited to give medications and provide personal care to the child. These demands, coupled with the stress of managing complex medications and medical interventions, can overwhelm the parent, causing resentment and frustration. These feelings may then leave the caregiver feeling guilty and inadequate. Respite allows the caregiver to attend to her or his own personal needs and activities, spend time with other children in the home, or get a good night's sleep. Professionals can help by exploring possible ways to secure respite for the caregiver. Options might include professional nursing assistance in the home, admission of the child to an inpatient unit (hospital or hospice) to allow the parents rest, or possible alternate caregivers in the family or immediate support system. It also is necessary to reassure the caregiver that they are not a failure or a terrible parent if they leave their child's care to others for a period of time.

Physical Care of the Dying Child · 4

Currently, there is little published research on symptom management in terminally ill children. However, there are several guidelines published regarding the care of the dying child. (McGrath and others, 1998; Goldman, 1994; Faulkner & Armstrong-Dailey, 1997; Frager, 1997). Children can experience a variety of courses as they progress through the dying process, with periods of relatively normal behavior and activity between symptom exacerbations. There may be a gradual decline in activity and alertness, or the child may be fully alert until the final hours. Each child's decline and death will be unique, and management of the dying process must be tailored to the particular child's symptoms.

The most important step to managing symptoms of terminal illness in children is a thorough assessment of the presenting problem. Information regarding the symptoms' onset, severity, and effect on quality of life should be obtained from the child and parents. Unlike pain, there are no assessment tools for symptoms experienced by children with terminal illness. The practitioner must consider the most likely cause of the symptom and determine the best course of intervention. For example, pain with urination may be related to a urinary tract infection and amenable to treatment with antibiotics. Shortness of breath with exertion may be related to progressive disease. Oxygen support and modification of daily activities to conserve energy would likely help to minimize this symptom. However, it will not eliminate the underlying cause. This distinction is important in helping the family to understand the expected outcome of the suggested treatment in relation to the child's overall condition.

Non-pharmacological and medical management are combined to optimize treatment. The route used to administer medication to children must be carefully considered. Generally, the least invasive route should be used to administer pain and symptom management medications. Children present a special challenge in administering medications depending on their age, level of cooperation, and temperament. If taking medication becomes a struggle, children and parents often will under-report severity of pain and symptoms to avoid the trauma of taking or giving the medicine. Most pain and symptom control medications for children can be given orally, sublingually, transdermally, intravenously, or by subcutaneous infusion. Compounding pharmacists can be helpful in creating alternative routes for medications. For more information regarding compounded medications contact your pharmacist or the Professional Compounding Centers of America (PCCA); telephone: 800-331-2498; web site: WWW.THECOMPOUNDERS.COM.

In the rare instance that non-pharmacological and medical interventions do not reduce symptoms, more invasive interventions (i.e. radiation, paracentesis, thoracentesis, etc.) may be necessary to improve patient comfort and quality of life. As the focus of care shifts from cure and control to comfort and palliation, it is vital that the treatment team be aware of the child's and family's wishes regarding the extent of interventions.

The family's view of quality of life, religious and cultural values, and level of acceptance of the terminal process will shape the types of interventions considered as symptoms occur. One family may choose to continue blood product support if the child is otherwise comfortable and active but has fatigue and shortness of breath related to anemia. Another family may choose to forgo transfusions in a similar situation to avoid having to return to the hospital or clinic. Practitioners must respect each family's choice regarding their child's care.

GASTROINTESTINAL SYMPTOMS

Gastrointestinal (GI) symptoms may range from the mildly uncomfortable to the extremely painful and debilitating. Nausea, vomiting, diarrhea, and constipation may occur in the terminal stage of illness. They must be managed appropriately to assure preservation of comfort and dignity.

ANOREXIA

Anorexia, or loss of appetite, occurs in nearly all children with terminal illness. It may be an intermittent problem relieved by various interventions, or may be a persistent, chronic symptom in the final days to weeks of life. Children are not usually bothered by the fact that they are not hungry and do not want to eat, but this condition often causes anxiety for their parents or caretakers.

Anorexia may be caused by a variety of factors including: pain, nausea, vomiting, constipation, medications (e.g., opioids, antibiotics), oral ulcers or candidiasis, extrinsic compression of the stomach or intestines by tumor, depression, altered taste, or release of substances in response to the disease process.

Assessment Interval history and physical examination should be aimed at identifying potentially reversible factors contributing to loss of appetite. Assess the child for sores in the mouth, difficulty or pain

with swallowing, nausea, vomiting, uncontrolled pain, or constipation. Review current medications and assess for possible side effects that may be contributing to the anorexia. During physical examination, pay particular attention to sores, plaques or erythema in the mouth and the oropharynx, presence of abdominal or fecal masses, and decreased bowel sounds.

Management General measures that may help to alleviate anorexia include the following:

- Prepare foods the child chooses.
- Use small plates and keep portions small. Large portions may look overwhelming.
- Have a variety of foods available for ready access and preparation when the child is hungry.
- Give the child foods he/she asks for.
- Give small bites of food or soft foods if the child is having difficulty swallowing solid foods.
- Use a 'toddler-cup' or a straw if swallowing liquids becomes difficult.
- Feed the child slowly to decrease the risk of choking.
- Offer thick liquids, like shakes, smoothies, gelatin, or pudding, that may be easier to swallow.
- Maintain good oral hygiene prior to and after eating.
- Treat reversible conditions that may be causing or contributing to anorexia, nausea, or vomiting.
- *Never force food or fluids if a child does not want them.* This can cause unnecessary distress for both the parent and child.

Pharmacological interventions (Table 5) may be useful in stimulating appetite or alleviating feelings of fullness if the child wants to eat, but does not have a good appetite. It is important to remember that refusal to eat or drink in the last days of life is normal. Intervening in this process may cause increased discomfort for the child. Health care providers should educate family members to be aware of this natural phenomenon without feeling guilty or helpless, and to resist the urge to force the child to eat and drink.

NUTRITIONAL SUPPLEMENTATION

It is natural for children to consume less food and fluids as they progress through the terminal phase of the illness. This is one of the most difficult aspects of the dying process for parents to accept. Many parents fear that their child is starving to death. Parents may ask about high calorie supplements, such as Ensure® or Boost®, and may request the use of nasogastric, g-tube feedings, or hyperalimentation. These options, including the associated risks and benefits, should be discussed with the parent and child. The child's physical condition and the impact of decreased nutritional intake on quality of life should be considered. Supplements with high sugar and milk contents can increase mucous production and lead to increased thick secretions. Hyperalimentation can increase the risk of infection and cause fluid overload. Health care professionals must understand each family's reasoning and the rationale for nutritional supplementation, and attempt to balance this need with maintaining optimal symptom control.

NAUSEA AND VOMITING

Nausea and vomiting may develop due to anorexia, intestinal obstruction, increased intracranial pressure, or as a side effect of opioid therapy. Nausea and vomiting can cause extreme exhaustion and dehydration if not well controlled.

Assessment The etiology of the child's nausea and vomiting must be established. A detailed assessment of the onset and duration, as well as the presence of concomitant symptoms (e.g., headache, visual disturbances) must be obtained. Absence of bowel sounds, constipation, and emesis containing bile are physical signs that indicate an intestinal obstruction. Increased intracranial pressure should be considered if the child is experiencing symptoms such as headache, excessive sleepiness, visual changes (e.g., blurred vision, diplopia), ataxia, and forceful vomiting (typically occurring on arising or suddenly sitting upright). The use of opioids for pain control can cause nausea and vomiting in some children.

Management Medical management of nausea and vomiting is based on the suspected underlying cause. Corticosteriods may be helpful in reducing an intestinal obstruction. Antiemetic medications combined with medications to reduce secretions (e.g., glycopyrrolate) can be helpful in relieving nausea and vomiting related to intestinal obstruction. In cases of severe nausea and vomiting related to obstruction, placement of a nasogastric tube can decompress the stomach and provide comfort. Medications that promote gastric emptying (e.g., metoclopramide) or motility should not be used if obstruction is suspected. Steroids can provide relief from vomiting due to increased intracranial pressure. Nausea and vomiting related to medications or anorexia may be managed by a number of antiemetic medications (Table 6).

In addition to medical management with appropriate pharmacologic agents, there are a number of non-pharmacological interventions that may help to prevent or alleviate nausea or vomiting:

- Avoid potent or noxious odors (e.g., cooking, perfumes, urine/stool).
- Increase intake of clear liquids, as tolerated.
- Maintain good oral hygiene.

TABLE 5. PHARMACOLOGIC INTERVENTIONS FOR ANOREXIA

Dose	Comments
MEGESTROL ACETATE (MEGACE)	
Children and adults: 10 mg/kg PO either as 1 dose or in 2 divided doses (maximum 800 mg/day)	Stimulates appetite to promote weight gain in anorexic or cachexic patients.
DRONABINOL (MARINOL)	
Children and adults: 2.5 mg/m2/dose 3-4 times/day	Increases appetite to promote weight gain in anorexic or cachexic patients.
DEXAMETHASONE	
15 mg/m2/day	Works well for short-term stimulation of appetite. Reassess in 2 weeks for effect; consider tapering.
MULTIVITAMINS	
Infant drops: 1 ml PO qd; children and adults may take 1 chewable or 1 tablet PO qd.	Anecdotal evidence suggests that B vitamins may increase appetite.

TABLE 6. PHARMACOLOGIC MANAGEMENT OF NAUSEA AND VOMITING

Drug	Dose	Comments
NAUSEA AND VOMITING CAUSED BY INCREASED ICP		
• Dexamethasone	1–2 mg/kg IV/PO initially, then 1 to 1.5 mg/kg/day divided q 6h; max: 16 mg/da	• May reduce bowel obstruction, relieving nausea and vomiting. • May need to increase dose periodically as disease worsens. • Side effects include weight gain, edema, and GI irritation.
NAUSEA AND VOMITING CAUSED BY INTESTINAL OBSTRUCTION & OPIOID USE		
• Promethazine	0.5mg/kg IV/PO q 4–6h; max: 25 mg/dose	May cause drowsiness, paradoxical reaction.
NAUSEA AND VOMITING CAUSED BY ANOREXIA & GE REFLUX		
• Metoclopramide	1–2 mg/kd/dose IV q 2–4h; max: 50 mg/dose	May cause paradoxical reaction. Do not use if intestinal obstruction present or if opioids used for pain control.
NAUSEA AND VOMITING CAUSED BY OPIOID USE		
• Droperidol	0.05 to 0.06 mg/kg IV q4–6h	May cause hypotension, sedation.
• Haloperidol	0.2 to 0.6 mg/kg PO/IV/SC	Commonly used in hospice care.
• Ondansetron	0.15 mg/kg/dose IV or 0.2 mg/kg dose PO q 4h; max: 8 mg/dose	Expensive, may not relieve vomiting due to other causes.

- Offer small helpings of food, not large portions.
- Offer ice chips, or small ice cubes made from frozen juice.
- Avoid milk products, greasy or spicy foods.
- Teach distraction techniques (e.g., deep breathing relaxation, reading, listening to music).

HYDRATION & FLUID SUPPORT

If ulcers, candidiasis, or excessive dryness occur in the mouth and oropharynx, the child may not be able to take fluids well. However, if adequate fluid intake is not maintained, the child will become dehydrated and may suffer from poor skin turgor, sunken eyes, dry mucous membranes, chapped lips, and decreased urine output. These symptoms may be very distressing for the child and parent, and contribute to a decreased quality of life.

If dehydration occurs in the absence of severe debilitation, alternate methods of hydration can be used to maintain adequate hydration and promote comfort. This may be particularly indicated for children with good symptom control. If IV access is easily available and non-traumatic, a fluid bolus of 20 mg/kg of normal saline can be administered over one hour as volume replacement. This bolus is followed by up to 1600 ml/m2/day of normal saline and 5% dextrose to maintain hydration. Potassium supplementation of 20 mEq/L is added to the maintenance fluid if urine output is adequate. Optimally, fluids should be given overnight to allow for mobility and freedom from pumps during the day. When the precipitating problem has resolved and the child is again taking oral fluids, the IV infusions can be discontinued. Subcutaneous fluid administration (hypodermoclysis) is an alternative method of providing hydration for patients who do not have intravenous access readily available, or who do not want a peripheral IV or indwelling central venous access device inserted. Fluid volumes of 500 to 1000 ml can be administered via the subcutaneous route in a 24-hour period. Either normal saline or normal saline and 5% dextrose solution should be used as plain dextrose solutions may cause pain and swelling. Potassium supplementation of 20 mEq/L is added as needed if urine output is adequate. Hyaluronidase 500 to 750 units may be added to each liter to promote absorption of fluid from the subcutaneous tissue. When the child is active or has a planned activity, subcutaneous hydration may be given during the night only.

In the last days of life, supplemental or maintenance fluids are unnecessary, and may in fact be detrimental. As the child becomes weaker, his or her ability to absorb fluids and solid food decreases. This can lead to increased secretions, pulmonary edema, nausea/vomiting, and abdominal distension if intravenous volumes are not appropriately adjusted. If the family is uncomfortable withholding fluid in the final days of life, a small volume of subcutaneous fluid (500-1000 ml/day) may be given. Symptoms of overhydration can be managed with furosemide.

CONSTIPATION

Constipation is a frequent problem experienced by patients in the terminal stage of illness. It can occur even in patients who have no oral or enteral intake. Constipation occurs due to inactivity, dehydration, electrolyte imbalance (e.g., hypercalcemia, hypokalemia), bowel compression or invasion by tumor, nerve involvement, or medications (e.g., opioids, anticholinergics).

Assessment Interval history should be obtained, with special attention to the following symptoms: anorexia, nausea, vomiting, colicky abdominal pain, bloating, tenesmus, and diarrhea. Diarrhea may occur if liquid feces pass around a fecal impaction. A physical exam may reveal abdominal distension, right lower quadrant tenderness, and fecal masses. Fecal masses are most easily palpated in the left lower quadrant (descending colon), are moveable and not fixed to adjacent tissue, and will indent under direct pressure. Rectal examination may reveal hard, impacted feces; an empty, dilated rectum; or extrinsic compression of the rectum by a tumor, hemorrhoids, fissures, tears, or fistulas.

Management The aim of management is to prevent constipation from occurring. If it develops it should be treated immediately to avoid debilitating effects. If constipation occurs despite preventative measures, various interventions may be used, based on clinical findings. If soft fecal masses are palpated in the abdomen, and there is no evidence of distal impaction, a stimulant laxative may be used (Table 7).

If these measures are not successful, stronger cathartic laxatives (e.g., magnesium citrate) or an enema may be used. However, enemas are contraindicated in children with neutropenia or thrombocytopenia. If there is a large fecal mass in the distal colon and the child is unable to pass it, digital disimpaction may be necessary. If this is necessary, the child should be prepared for the procedure and premedicated with pain and anti-anxiety medications. Bulk laxatives (bran, Metamucil®) should be avoided in children with chronic constipation, as they can precipitate or worsen an intestinal impaction. If bowel obstruction is suspected, do not use laxatives.

In addition to laxatives and softeners, the following measures may help to prevent or alleviate constipation:

- Start a laxative regimen at the same time opioid therapy is initiated.
- Review the patient’s medication regimen and switch to less constipating drugs, if possible.

TABLE 7. MANAGEMENT OF CONSTIPATION

Dose	Comments
SENNA (SENAKOT®)	
• Children < 12 years: 1–2 tablets PO qhs • 2–4 years of age: Syrup: ¼–½ tsp PO qhs • 4–6 years of age: Syrup: ½–1 tsp PO qhs • 6–10 years of age: Syrup: 1 tsp PO qhs	Acts on wall of distal colon to stimulate peristalsis; natural vegetable product; well tolerated; does not cause cramping pain.
BISACODYL (DULCOLAX®)	
• Children 3–12 years: 5 mg PO qhs • Children < 12 years: 10–15 mg PO qhs	Irritates smooth muscle of the intestine to stimulate peristalsis; well tolerated; works in 12–24 hours.
LACTULOSE	
• Children: 7.5 ml PO qhs • Adults: 30–45 ml/dose PO tid	Produces an osmotic effect in the colon, stimulates peristalsis; may cause cramping; may take several days to have an effect; mix with fruit juice to improve taste.
DOCUSATE SODIUM (COLACE®)	
• Children < 3 years: 10–40 mg/day PO in 1–4 divided doses • 3–6 years: 20–60 mg/day PO in 1–4 divided doses • 6–12 years: 50–150 mg day PO in 1–4 divided doses • Over 12 years: 50–100 mg day PO in 1–4 divided doses	Allows increased absorption of water into stool, providing softening action; may take 1–3 days to have an effect; mix with milk, infant formula, or fruit juice to mask the bitter taste.
MINERAL OIL	
• Children 5–12 years: 30–60 ml PO in 2 divided doses • Over 12 years: 15–45 ml PO in 1 to 2 divided doses	Lubricates stool to facilitate passage; avoid use in children under 5 years due to the risk of aspiration; do not give with meals due to the risk of aspiration; may cause abdominal cramping.
GLYCERIN SUPPOSITORIES	
• Children < 6 years: 1 suppository 1–2 times/day • Over 6 years: 1 adult suppository 1–2 times/day	Draws fluid into colon and stimulates evacuation; works quickly; avoid in neutropenic or thrombocytopenic patients.
ENEMAS	
• Children > 12 years: Docusate enema; Add 50–100 mg docusate liquid to enema fluid, give as retention or flushing enema • Children > 12 years: Mineral oil enema; one adult enema used as retention enema	Docusate is a surfactant that eases passage of stool; mineral oil lubricates stool to facilitate passage; may cause abdominal cramping; works quickly; avoid in neutropenic or thrombocytopenic patients.

- If there is not a structural blockage of the bowel or suspected impaction, add fruits, vegetables, and other fibers to the diet. This measure may not be tolerated and needs to be individualized.
- Encourage fluid intake and increase activity level if practical.
- Encourage use of the commode 30-60 minutes after eating.
- Use bedside commode instead of bedpan, if possible.
- Provide privacy for bowel movements.

DIARRHEA

Although diarrhea is far less common than constipation in children with terminal illnesses, it still may occur and contribute to a diminished quality of life. If a child is passing more than three watery or loose stools in a 24-hour period, he or she has diarrhea. Diarrhea may be caused by intermittent bowel obstruction, fecal impaction, abdominal or pelvic radiation, chemotherapy, surgery, medications, malabsorption, or infection.

Assessment Interval history should include information regarding duration and frequency of loose stools, incontinence, and character of the stools (color, odor, consistency, presence of mucus or blood). A list of all current medications should be obtained and reviewed. On physical examination, particular attention should be paid to bowel sounds, presence of palpable masses or feces, abdominal tenderness, and the rectal area.

Management The following measures may help to prevent or alleviate diarrhea:

- Stop all laxatives.
- Use a high carbohydrate diet (BRAT – bananas, rice, applesauce, toast) to rest the bowel.
- Avoid milk products, fats, and protein until diarrhea has ceased.
- Give electrolyte solutions (Gatorade®, Pedialyte®), as tolerated.
- Consider IV/SC rehydration, depending on the child's overall condition.
- Manually remove any fecal impaction.
- Use anti-diarrheal medications, as appropriate (Table 8).

HEMATOLOGIC SYMPTOMS

In children with bone marrow disease, invasion of the bone marrow by tumor cells eventually will cause a decrease in the volume of normal marrow and a resultant drop in circulating red blood cells, white blood cell, and platelets. Depending on the extent of disease, and at what point in the terminal process this decrease occurs, various clinical manifestations will occur.

ANEMIA

Assessment The signs and symptoms of anemia may develop slowly. Weakness and fatigue may appear initially, and even in the absence of other symptoms may greatly decrease the child's quality of life. As anemia worsens, dyspnea, or shortness of breath, may occur. The child may develop headaches and dizziness, and be unable to carry out activities of daily living. On physical examination, a variety of signs may be present including: pallor, tachycardia, heart murmur, and gallop.

Fatigue often is overlooked, but can be debilitating. Health care providers should be aware of this phenomenon and include questions in their patient assessment to determine levels of fatigue. Fatigue may be decreased or resolved if patient care activities are grouped in such a way that they can be accomplished at one time. This will eliminate the need to interrupt the child repeatedly and provide periods for additional rest and sleep. Encouraging pleasurable, planned activities for the child also can help to limit fatigue.

TABLE 8. ANTIDIARRHEAL MEDICATIONS

Dose	Comments
LOPERAMIDE (IMMODIUM)	
Initial doses (first 24 hours) for 2–12 years: • 2–5 years: 1 mg PO tid • 6–8 years: 2 mg PO bid • 8–12 years: 2 mg PO tid After initial dose, 0.1 mg/kg doses after each loose stool (not to exceed the initial dose) • > 12 years: 4 mg PO x 1 dose; then 2 mg PO after each loose stool (maximum dose: 16 mg/day)	• For acute diarrhea. • Acts on intestinal muscles to inhibit peristalsis and increase transit time • Contraindicated in certain enteric infections.
DIPHENOXYLATE AND ATROPINE (LOMOTIL)	
• 2–5 years: 2 mg PO tid (not to exceed 6 mg/day) • 5–8 years: 2 mg PO qid (not to exceed 8 mg/day) • 8–12 years: 2 mg PO 5 times/day (not to exceed 10 mg/day) • > 12 years: 2.5–5 mg po 2–4 times/day (not to exceed 20 mg/day)	• For acute diarrhea. • Decreases GI motility with subsequent decrease in diarrhea • Structurally similar to narcotic analgesics, but has no analgesic properties • Contraindicated in certain enteric infections.
TINCTURE OF OPIUM	
0.25–0.5 ml/kg dose 1–4 times/day	• Decreases GI motility and peristalsis • Contains 45% alcohol • Use cautiously in patients receiving CNS depressants.

Management Blood products are often given during the course of some children's illness and treatment to manage side effects of therapy. In the terminal stages of illness, it is necessary to consider the benefits of continuing blood product support. The best benchmark for assisting parents in deciding about whether or not to continue blood product support is the child's current condition and quality of life. Typically, the decision to consider transfusion is based not so much on particular lab results as on clinical signs and symptoms, and their impact on the child's quality of life. If there are no other problematic symptoms, and the child is otherwise feeling well, transfusion therapy certainly is an option. Packed red blood cells 10–15 ml/kg can be given over four hours. If blood transfusions are given too rapidly, fluid overload will occur and furosemide will need to be given. Premedication should occur prior to the transfusion to reduce the risk of transfusion reactions (Table 9). If the anemia is persistent and severe and co-exists with other problematic symptoms, transfusion therapy may not be in the child's best interest. It may only prolong a lesser quality of life. Additionally, as the child becomes increasingly debilitated from disease progression, there often is a decreased clinical response to blood transfusions.

BLEEDING

Slow bleeding can have minimal effect on daily functioning, and the child may not be aware that it is occurring. However, subtle signs, such as fatigue, weakness, and shortness of breath, may occur. Children

TABLE 9. MEDICATIONS USED TO PREVENT BLOOD PRODUCT TRANSFUSION REACTIONS

Dose	Comments
DIPHENHYDRAMINE HYDROCHLORIDE (BENADRYL)	
Children and adults: 1 mg/kg IV or PO prior to transfusion (maximum 50 mg/dose)	Blocks the effects of histamine when released in response to allergic reaction.
HYDROCORTISONE (SOLUCORTEF)	
Children and adults: 2 mg/kg IV prior to transfusion (maximum 100 mg/dose)	Suppresses the normal immune reaction and inflammation.
ACETAMINOPHEN (TYLENOL)	
• Children: 10–15 mg/kg PO prior to transfusion (maximum 20 mg/kg/dose) • Adults: 325–650 mg PO prior to transfusion	Inhibits the synthesis of prostaglandins and hypothalamic heat regulating center.

who suffer an acute bleeding episode may experience weakness, anxiety, dizziness, or loss of consciousness. Bleeding can occur through the mucous membranes or skin, within a vascular tumor, or inside the body in one of the major organs (e.g., stomach, lungs, brain). Bleeding most often occurs during periods of thrombocytopenia, or into large, vascular tumors. The risk of bleeding increases with infection or fever, especially when the platelets count is low.

Assessment Interval history may include the following: presence of blood in emesis or stools, black tarry stools, nosebleeds, excessive bruising, vaginal bleeding, weakness, headaches, dizziness, excessive fatigue, and sleepiness. Physical examination may reveal: petechiae, ecchymosis, conjunctival hemorrhages, blood oozing from gingival tissue, epistaxis, tachycardia, heart murmur, and gallop.

Management For children exhibiting signs and symptoms of thrombocytopenia, the following measures can help prevent bleeding:

- Bathe daily, with special attention to skin folds and perineum.
- Use lotion to moisturize skin and prevent drying and cracking.
- Shave with an electric razor.
- Keep nails trimmed.
- Keep environment free from clutter and objects that may cause injury.
- Cleanse mouth after each meal and before bedtime.
- Avoid using mouthwash that contains alcohol, to prevent drying of mucous membranes.
- Use a soft-bristle toothbrush and avoid using dental floss.
- Promote regular bowel elimination and prevent straining with passage of stool.
- Use stool softeners or laxatives as needed.
- Avoid rectal temperatures, suppositories, and enemas.

If bleeding occurs, the patient and parent should be instructed to remain calm and notify the health care provider. If the patient is not thrombocytopenic and does not require a platelet transfusion, or is not experiencing a hemorrhagic event, the parent or patient can be instructed to try various interventions to control the bleeding at home. Pressure applied to a bleeding extremity or nose for at least 10-15 minutes may stop the flow of blood. Topical thrombin or epinephrine, with 1% lidocaine can be placed on a gauze pad and applied to the area. An ice pack may be applied for 10-15 minutes, as cold temperature also slows bleeding. If bleeding is from an extremity, it helps to raise the limb above the level of the heart. If blood is oozing from the gums, it may help to increase the frequency of oral care. If blood is noted in the urine, the volume of oral fluids should be increased.

If bleeding is persistent or distressing to the child and family, and a low platelet count is the suspected cause, a platelet transfusion is warranted. Six units/M2 of leukocyte-reduced, irradiated platelets can be given over one hour. Although leukocyte-reduced, irradiated blood products can reduce the risk of hypersensitivity reaction, premedication should be given (Table 9).

RESPIRATORY SYMPTOMS

Respiratory symptoms may be a common problem as the child progresses through the terminal phase of the illness. As the child becomes weaker, symptoms such as dyspnea, cough, and congestion can be distressing for both the child and caregivers. Respiratory symptoms, if not managed, can cause sleep disturbance, headaches, increased anxiety, and irritability (Goldman, 1994). It is necessary to assess the child's respiratory status thoroughly and to consider all potential causes of the problem so that management can be directed at relieving symptoms and improving respiratory comfort.

There are a number of causes of respiratory symptoms in children. The degree of discomfort is dependent on the nature of the disease. Children with cystic fibrosis and neurodegenerative diseases most likely will experience a moderate to high degree of respiratory discomfort as the disease progresses. Children with cancer can have respiratory discomfort related to superior vena cava syndrome, mediastinal masses in the chest, or metastatic disease in the lungs. Anemia may cause a child to have shortness of breath with exertion or, if more significant, at rest. Immobility and weakness can lead to ineffective cough, atelectasis, wheezing, and infections. Children also may experience anxiety related to changes in their physical condition or family stress, leading to increased shortness of breath.

Assessment Interval history should include the onset, severity, and nature of respiratory symptoms, as well as identification of what exacerbates and relieves the symptoms. Physical examination should focus on lung sounds, use of accessory muscles, skin color, nail beds and capillary refill, symmetry of the chest, and posture/positioning. As the child's condition deteriorates, observe for congestion and pulmonary edema, with notable ronchi and rales. The child may develop increased secretions, either thin or thick. In the final stages of the dying process, the child's respiration may become slow and shallow, progressing to Cheyne-Stokes breathing, characterized by irregular, deep, gasping breaths followed by long periods of apnea. This breathing pattern is not necessarily uncomfortable for the child, but can be very distressing to the family. It is important to prepare the family by informing them that such changes in breathing often signal progression through the terminal process and impending death.

Management Early in the terminal process, interventions for respiratory discomfort are aimed at improving respiratory effort. As the child becomes increasingly debilitated, the focus is on alleviating anxiety associated with respiratory changes and shortness of breath. It is important that the family be educated regarding the possible causes of the respiratory problem, management options, medications to be used, and expected effects. Interventions should also be aimed at providing the family with actions that they can take to improve their child's comfort. Interventions for respiratory discomfort include:

- Dress child in loose-fitting clothing.
- Raise head of bed 30–45° and use pillows to position child for optimal breathing.
- Decrease fluid intake.
- Keep air in room well humidified.
- Use a fan to circulate air.
- Limit smoke and allergens.
- Use guided imagery, relaxation, and deep breathing exercises.
- Perform oral-pharyngeal suctioning as needed.
- Administer oxygen as needed.
- Consider PRBC transfusion, if appropriate.

There are a number of pharmacological choices for managing respiratory symptoms. Opioids are useful in managing the sensation of not being able to breathe, as well as in treating a persistent cough. Anticholinergic medications assist in minimizing secretions. Bronchodilators promote increased air exchange in the lungs, and can be helpful alone or in conjunction with opioids. Anxiolytic drugs can help reduce anxiety related to the feeling of shortness of breath and improve respiratory comfort (Table 10).

INVASIVE INTERVENTIONS

Fortunately, medical and non-pharmacological management will keep the majority of children with respiratory symptoms comfortable. However, children with severe respiratory distress related to such complications as pleural effusion or pneumothorax may require invasive techniques such as pleurocentesis, thoracentesis, and/or chest tube placement. The benefits of such procedures should be weighed against the discomfort that the procedures themselves would create, and against to the child's general condition and quality of life. All non-invasive attempts at gaining comfort should have been exhausted before these procedures are considered. It is important that the child and family are well informed of the purpose of the proposed intervention, its likelihood of success, and the relation of the child's current symptom to the disease process.

CENTRAL NERVOUS SYSTEM SYMPTOMS

Children may experience a number of CNS-related symptoms during the disease process. Fever can occur in children with malignancies of the brain, neurodegenerative problems, and congenital anomalies. It also can occur in children taking anticholinergic medications. Some children experience daily fevers, without evidence of infection, which may not respond to antibiotic therapy. Generally, these fevers are related to disease progression and physiologic changes, and respond to antipyretic medication.

Restlessness/agitation and sleep disturbances can occur as a result of unrelieved pain, terminal metabolic changes (e.g., hypoxia, electrolyte imbalance), medications (e.g., steroids, opioids), fecal impaction, or urinary retention. Nightmares, anxiety, worry, and spiritual distress may also cause restlessness. Changes in sleep routines, depression, and emotional withdrawal can create agitation.

Seizures are rare in terminally ill children. However, they are possibly the most traumatic symptom for the child and caregiver to experience. Seizures result from complications such as increased intracranial pressure due to tumor, non-therapeutic levels of anticonvulsant medications, metabolic imbalance related to terminal process, and as a side effect of medications.

Assessment Ongoing assessment of children at risk for CNS symptoms at the end of life is imperative. Interval history should include the child's sleep patterns and changes in mood or behavior. In children with tumors of the CNS, congenital neurological anomalies, or neurodegenerative diseases, observation of gross neurological function provides information regarding possible causes of CNS symptoms. Children with a history of seizures should continue to have their anticonvulsant medications monitored and adjusted if this can be done without causing excessive distress. In situations where it is difficult to obtain blood samples without multiple attempts at venipuncture, adjustment and monitoring of anticonvulsant medications may be done based on clinical presentation.

As children become progressively weaker from the advancing disease, they will begin to sleep more. This can be very distressing to the family, and it is important to assist them in adjusting the family routine to provide time with the child during periods when he or she is awake. In the final days, the child may sleep the majority of the time. This is a sign that the child is in the final stages of the terminal process and death is imminent. Parents should be informed, prepared, and supported as these changes occur.

TABLE 10. MEDICATIONS TO IMPROVE RESPIRATORY SYMPTOMS

Dose	Indications/Comments
OPIOIDS	
Oxycodone • Immediate release: 0.1 to 0.3 mg/kg/dose PO q 4 to 6 hr • Sustained release: for patient’s taking >20 mg/day of oxycodone can administer 10 mg PO q 12 hr **Morphine** • 0.2 to 0.5 mg/kg/dose PO q 4 to 6 hr prn for solution of immediate release tablets • 0.3 to 0.6 mg/kg/dose PO q 12 hr for sustained release • 0.1 to 0.2 mg/kg/dose IV/SC q 2 to 4 hr **Hydromorphone (Dilaudid)** • 0.03 to 0.08 mg/kg/dose PO q 4 to 6 hr • 15 mcg/kg IV q 4 to 6 hr • Hydromet (solution combination of hydrocodone and homatropine) • 0.6 mg/kg/day divided 3–4 doses/day	**Indications:** • Dyspnea, shortness of breath, cough. • Cough or secretions. **Comments:** • First line drugs for management of dyspnea and persistent cough. • May need to titrate to comfort. • Manage side effects (N/V, constipation). • Dose is limited by the ability to manage side effects.
BRONCHODILATORS	
Albuterol Oral: • 2–6 years: 0.1–0.2 mg/kg/dose tid; max 4 mg tid • 6–12 years: 2mg/dose 3-4 times/day; max 24 mg/d • >12 years: 2–4 mg/dose 3–4 times/day; max: 8 mg qid Nebulized: • 0.01–0.05 ml/kg of 0.5% solution q 4–6 hrs **Beclomethasone** Oral Inhalation: • 1–2 inhalations/day 3–4 times a day; max: 10 inhalations/day	**Indications:** • Dyspnea, wheezing, pulmonary congestion. **Comments:** • May use in conjunction with opioids and other interventions. • Can increase heart rate and sense of anxiety.
ANTICHOLINERGICS	
Glycopyrrolate (Robinul) • 40–100 mcg/kg/dose PO 3–4 times/day • 4–10 mcg/kg/dose IV/SC q 3–4 hrs **Hyoscyamine (Levsin)** • Infant drops (< 2yrs): 2.3 kg: 3 gtts q 4hr; max: 18 gtts/d 3.4 kg: 4 gtts q 4hr; max: 24 gtts/d 5 kg: 5 gtts q 4hr; max: 30 gtts/d 7 kg: 6 gtts q 4hr; max: 36 gtts/d 10 kg: 8 gtts q 4hr; max: 48 gtts/d 15 kg: 10 gtts q 4hr; max: 66 gtts/d • 2–12 years: 0.0625–0.125 mg PO q 4 hr; max: 0.75mg/d • >12 years: 0.125–0.25mg PO q 4 hr; max: 1.5mg/d **Hyoscine Hbr (Scopolamine)** • 6 mcg/kg/dose IV/SC q 6–8 hrs; max: 0.3mg/dose	**Indications:** • Increased pulmonary congestion, oral secretions • Dyspnea related to pulmonary congestion or edema. **Comments:** • May use in conjunction with opioids and other interventions. • Assess for dry mouth, decreased sweating, fever and overheating.
SUPPRESSANTS & EXPECTORANTS	
Dextromethorphan • 2–5 years: 15 mg. BID • 6–11 years: 30 mg. BID • >11 years: 60 mg. BID **Guaifenesin** • < 2 years: 12mg/kg/d q 4 hrs • 2–5 years: 50–100mg q 4 hrs • 6–11 years: 100–200mg q 4 hrs • >12 years: 200–400mg q 4 hrs	**Indications:** • Use suppressant with dry, non-productive cough. • Use expectorant with wet, productive cough secondary to infection. **Comments:** • May use suppressant at bedtime with productive coughs to facilitate rest. • Limited effectiveness with expectorant if child is not able to take sufficient fluids.
ANTIBIOTICS	
Amoxicillin • 25–50mg/kg/day q 8 hrs **TMP/SMX** • 6–12 mg TMP/kg/day q 12 hrs (children > 2 months) **Augmentin** • 20–40 mg/kg/day (amoxicillin component) q 8 hrs; or 25–45 mg/kg/day (amoxicillin component) q 12 hrs **Erythromycin** • 30–50 mg/kg/day q 6–12 hrs	**Indications:** • Respiratory infections with common bacterial pathogens. • Discuss use and expected benefit with family. **Comments:** • Rule out viral cause of respiratory infection.
DIURETICS	
Furosemide • 2 mg/kg PO or 1mg/kg IV/SC adjust to response **Aldactone** • 3.3 mg/kg/d PO adjusted to response	**Indications:** • Pulmonary edema. **Comments:** • Consider potassium supplementation with furosemide. • Aldactone should be used if patient is on digoxin or if high risk for hypokalemia.
ANXIOLYTICS	
Diazepam • 0.1 to 0.3 mg/kg q 4 to 6 hr PO/IV/SC; max: 10 mg/dose **Lorazepam** • 0.03 to 0.1 mg/kg q 4 to 6 hr PO/IV/SC; max: 2 mg/dose	**Indications:** • Dyspnea, anxiety **Comments:** • Assess for over-sedation if used in conjunction with opioids.

Management Management of CNS symptoms should focus on eliminating the cause when possible, or managing the symptoms when necessary. Ongoing education of the child and family regarding the probable cause and possible treatments of the symptoms will increase the family's comfort with their ability to keep the child comfortable (Table 11).

Medical management includes medications to treat the underlying cause or reduce the severity of the particular symptom. It is important to consider additive effects of medications that may exacerbate CNS symptoms. Managing CNS symptoms requires a delicate balance between relieving problems and avoiding excessive sedation and other side effects that can be potentially distressing. Open discussion with the child and family regarding the level of discomfort that they can tolerate and still maintain a quality of life will help the health care team to determine the best combination of medical and nursing interventions (Table 12).

TABLE 11. INTERVENTIONS FOR CNS SYMPTOMS

FEVER

- Dress child in loose-fitting clothing.
- Use light cover and prevent shivering.
- Use a fan to keep air circulating in room.
- Place cool cloths to forehead, axillary area, chest, abdomen.

RESTLESSNESS OR AGITATION

- Encourage open communication between child and parent regarding prognosis, maintenance of comfort, and family's fears regarding the child's death.
- Assess spiritual concerns the child may have and intervene as needed.
- Use calm, reassuring conversation.
- Eliminate medications that may be contributing to the problem.
- Modify environment (e.g., provide soft lighting, favorite possessions, familiar people, pleasant scent).
- Play favorite music or videotapes.
- Use relaxation or guided imagery.
- Use massage, gentle touch (avoid painful areas and do not persist if not helpful to child).

SLEEP DISTURBANCE: INSOMNIA

- Use night-light and keep the child's door open.
- Maintain bedtime rituals as much as possible.
- Give a warm bath prior to bed.
- Avoid caffeinated drinks, chocolate.
- Use relaxation or guided imagery.
- Play the child's favorite music or videotapes.
- Encourage family to talk about the child's fears, dreams/nightmares.

SLEEP DISTURBANCE: SEDATION/SOMNOLENCE

- Give caffeinated drinks.
- Optimize time awake with family.

SEIZURE

- Reinforce seizure management strategies with family (i.e., remove objects from area that may injure the child, stay near child, **do not** put anything in the child's mouth).
- Have oxygen and suction available in the home.

SKIN PROBLEMS

Problems related to skin breakdown are less common in children. However, they can cause discomfort and, in the case of open wounds, can be quite distressing for the parent and child. Dry skin and pruritus are more common in terminally ill children.

Assessment Regular, thorough assessment of the skin is the most important aspect of preventing complications related to skin breakdown. Pruritus results from dry skin due to decreased fluid intake, medications such as opioids, biliary disease and renal/liver failure (due to the accumulation of metabolic by products), and rashes resulting from fungal, viral, and/or bacterial organisms. Skin breakdown and wounds most often are caused by immobility, declining nutritional status, incontinence, and, in rare circumstances, fungating tumors.

Management Dry skin and pruritus should be treated with skin care products and medications intended specifically to relieve these symptoms. Skin care interventions for pruritus include:

- Avoid harsh, drying soaps. Use mild, moisturizing soaps such as Dove®.
- Use oils in bath water.
- Use Aveeno® or oatmeal baths.
- Regularly use moisturizing lotions such as Curel®, Moisturel®, aloe vera, or Vaseline Intensive Care®.
- Dress in cotton clothing.
- Keep child cool.
- Keep fingernails trimmed and discourage scratching.

Skin care interventions for skin breakdown and wounds include:

- Teach caregiver to assess skin with each bath, and to report any red areas to nurse.
- Encourage mobility if possible.
- Reposition child at least every two hours.
- Use egg crate, gelfoam, or air mattress.
- Provide good perineal hygiene.
- Use "draw sheet" to reposition large child.
- Use pillows to maintain position and cushion bony prominences.

In the rare instance where a child develops an open wound or decubitus ulcer, appropriate wound care regimens should be instituted, as should increased surveillance for additional wounds. If the wound is infected and produces an odor, the use of topical or systemic med-

TABLE 12. CNS SYMPTOM MEDICATIONS

Dose	Indication	Comments
FEVERS		
Acetaminophen • 10–15 mg/kg/dose PO/PR q 4–6 hrs	• Fever	
Ibuprofen • 10 mg/kg/dose q 6–8 hrs (max 800 mg/dose)	• Fever	• Ibuprofen can cause GI irritation with prolonged use. • Use cautiously in patient with bleeding disorders, decreased platelets.
Indomethacin • 1–2 mg/kg/day in 2 to 4 divided doses	• Fever	• Indomethacin available in PR form. Same caution as Ibuprofen.
RESTLESSNESS/AGITATION		
Lorazepam • 0.03–0.1 mg/kg q 4–6 hrs PO/IV may titrate to a max of 2 mg/dose	• Generalized anxiety	• May increase sedation in combination with opioids • Can cause depression with prolonged use.
Diazepam • 0.1–0.3 mg/kg q 4–6 hrs PO/PR/IV may titrate to a max of 10 mg/dose Rectal gel: 0.2–0.5 mg/kg q 4–12 hrs PRN	• Generalized anxiety	• Diazepam also available in long acting form and oral solution.
Haloperidol • 0.05 to 0.15 mg/kg/day divide 2–3 times/day PO/SC/IV.	• Agitation not responsive to anxiolytics. • Agitation related to terminal restlessness.	• May increase sedation. • Monitor for extra-pyramidal side effects (EPS). • May give hydroxyzine or diphenhydramine in combination with haloperidol to treat EPS.
Midazolam • IV/SC: 0.025–0.05 mg/kg; titrate to effectiveness • Rectal: 0.3–1.0 mg/kg (max 20 mg)	• Myoclonus related to prolonged opioid use, neurologic spasticity.	• Very short acting. • Quickly reversed if overly sedated.
Phenobarbital • Consult hospice palliative care physician in regards to use for sedation.	• Refractory restlessness and agitation not responsive to other measures. • Produces sedation.	• For patients with intractable pain or other symptoms causing the child and family distress, sedation may be desirable to patient/family. • Sedation does not provide analgesia, pain medications should be continued.
SEIZURES		
Clonazepam • 0.01–0.03 mg/kg/d PO in 3 divided doses	• Absence seizure, akinetic and myoclonic seizures.	• Side effects include sedation, light-headedness, disorientation, agitation, restlessness, headache, and crying.
Lorazepam • 0.03–0.1 mg/kg q 4–6 hrs PO/IV/IM; max: 2 mg/dose	• Status Epilepticus	• Repeat twice at 15 to 20 min interval (do not exceed 4mg/dose).
Gabapentin • PO 8–35 mg/kg/day divided every 8 hrs. Round dose to nearest 100 mg	• Drug refractory partial and secondary generalized seizures.	• Lower side-effect profile. • Side effects include sedation, ataxia, nystagmus, and dizziness.
Phenobarbital • Status epilepticus 10–20 mg/kg IV until seizure resolves • Maintenance treatment 3–5 mg/kg/day IV/PO every 12 hrs.	• Treatment of generalized tonic-clonic seizures.	• Monitor serum concentration: therapeutic range 20–40 mg/ml
Phenytoin • 15–20 mg/kg IV as loading dose for status epilepticus • 5–10 mg/kg/day IV/PO maintenance dosing	• Treatment of generalized tonic-clonic seizures.	• Monitor serum concentration: therapeutic range 10–20 mg/ml
Diazepam • 0.2–0.5 mg/kg/dose, IV; max: 5 mg/dose	• Status epilepticus	• Do not give IM
Valproic Acid • 10–15 mg/kg/day in 1–3 doses	• Simple and complex seizures	• Monitor serum concentration: therapeutic range 50–100 mg/ml
SLEEP DISTURBANCES		
Lorazepam • 0.03–0.1 mg/kg q 4–6 hrs PO/IV/IM; max: 2 mg/dose	• Insomnia	• Can cause depression with prolonged use
Diphenhydramine • 1 mg/kg IV/PO q HS; max: 50 mg/dose		• Diphenhydramine may cause paradoxical excitement
Chloral hydrate • 25–50 mg/kg/d q 6–8 hrs.; max: 500 mg/dose		
Methylphenidate • 2.5–5 mg PO/a.m. and early afternoon	• Sedation due to medications.	• Do not give in late afternoon or evening.
Dextroamphetamine • 2.5–5 mg PO/a.m. and early afternoon		

ications may be necessary. There are a number of wound care products on the market, each with specific uses. Table 13 identifies common topical medications, and Table 14 provides a list of some of the available products and their indications for wound care.

PAIN MANAGEMENT

Pain in children is often not treated adequately. It is important for health care professionals to educate themselves and their patients and patients' families to correct common misconceptions. A number of common myths cause pain in children to be treated inadequately:

1 *Myth* Infants and young children do not feel pain.
Fact Even young infants possess the anatomical and neurochemical capabilities to experience pain. Younger children can experience higher levels of pain than older children; pain tolerance increases with age (Broome, Rehwaldt & Fogg, 1988).

TABLE 13. PHARMACOLOGIC MANAGEMENT OF SKIN PROBLEMS

Dose	Indication	Comments
PRURITUS		
Diphenhydramine 1 mg/kg IV / PO q 4 to 6 hr prn; max: 25 mg/dose	• Prevent itching related to opioids.	• May cause increased sedation with systemic use. • May cause agitation in young children.
Hydroxyzine 0.6 mg/kg/dose PO q 6 hr; max: 50 mg/dose		• May cause increased sedation with systemic use.
WOUND CARE		
Topical antibiotics • Bacitracin (with or w/o polymyxin B) • Neomycin (with or w/o polymyxin B) • Neomycin, polymyxin B, hydrocortisone • Metronidazole	• Prevent infection in minor cuts, scrapes, and burns. • Treatment of susceptible anaerobic bacterial or protozoal infections.	• Inexpensive, available OTC. • Brand name expensive; can be compounded by pharmacist to lower cost. • Use for odorous tumors.
Topical antifungals • Miconazole • Nystatin	• Treatment of superficial fungal infections caused by Candida species.	• Inexpensive; available OTC.

2 *Myth* Children are unable to tell you where they hurt.
Fact Children as young as three years of age can use a faces scale, point to where they hurt, or draw a picture illustrating their pain. Children may fear telling parents or health professionals about their pain because they worry about getting a 'shot' or returning to the hospital (Wong & Baker, 1988).

3 *Myth* Children become accustomed to pain.
Fact Children exposed to repeated or prolonged pain can experience increased anxiety and perception of pain (Zeltzer, Jay & Fisher, 1989).

TABLE 14. WOUND CARE PRODUCTS AND INDICATIONS

Debride	Absorb	Fill Dead Space	Protect from Trauma	Protect from Infection	Insulate	Keep Moist	Examples
TRANSPARENT ADHESIVE							
+A			+	+	+	+	Op-site, Acuderm, Tegaderm, Polyskin, Biocclusive
HYDROCOLLOID WAFER							
+A	+		+	+	+	+	DuoDerm, Restore, Tegasorb, Comfeel
SEMIPERMEABLE POLYURETHANE FOAM							
	+		+		+	+	Allevyn, Lyofoam, Epilock
ABSORPTION DRESSINGS							
+A	+	+	+			+	Hydragran, Bard Absorption Dressing, Sorbsan, Kaltostat, Duoderm Paste, Comfeel Paste, Debrisan
GAUZE (COTTON MESH, SYNTHETIC, HYPERTONIC)							
+ *	+	+					Gauze Dressings, Mesalt
GEL DRESSINGS							
+A	+G	+G	+			+	Vigilon, ElastoGel, Intrasite Gel, DuoDerm Gel
NONADHERENT DRESSINGS							
		+	+	+	+	+/-	Adaptic, Telfa Vaseline Gauze, Xeroform Gauze

A = Autolytic debridement G = Granulate form * If kept moist

Provided by JoAnn Dudly, RN, MSN, CWOCN, with permission.

4 *Myth* Children's behavior reflects their level of pain.
Fact Children have unique ways of coping; they may be active and playing normally, sleep, or become passive to pain. Children also may be 'taught' not to show pain or cry out (Favaloro & Touzel, 1990).

5 *Myth* Using drugs like codeine and morphine will cause the child to stop breathing.
Fact Medical research has shown that the risk of respiratory depression is very small. By far, constipation is the most common problem caused by opioids (codeine, morphine) (Kart, Christrup & Rasmussen, 1997).

6 *Myth* Presence of pain and use of morphine indicates worsening of disease and approaching death.
Fact Good pain control improves the child's ability to play, visit with friends and family, go on outings, eat meals, and get good sleep. Uncontrolled pain can lead to other complications including: anxiety, agitation, restlessness, poor sleep, and decreased appetite (Foley, 1996; Martin, 1998).

7 *Myth* Children become easily addicted to pain medicines.
Fact Pain medicines are no more dangerous in children than adults. Medical research shows that less than one percent of patients treated for pain develop an addiction (Foley, 1996).

Assessment Pain is both a sensory and emotional experience. Good pain assessment in children requires multiple strategies to provide qualitative and quantitative information. Qualitative assessment is a description of the location, duration, and characteristics of the pain, as well as factors affecting the pain. Quantitative assessment evaluates the intensity of the pain using a pain scale. Thorough pain assessment requires combining information from patient self-report, physical examination, behavioral observation, physiologic measures, and diagnostic results.

Management The current standard for the management of pain in children consists of four concepts: *by the ladder, by the clock, by the mouth,* and *by the child.* The World Health Organization Analgesic Stepladder is a multi-step approach to treating pain, and is a guide for initiating analgesic drugs and dosages that correspond to the patient's reported level of pain. Analgesic medications should be prescribed around the clock, as opposed to on an as-needed (PRN) basis, to ensure consistent pain relief. The least traumatic route of medication administration helps to minimize struggle between caregiver and child. Finally, medications should be tailored to the individual child's needs, level of pain, and past/present analgesic use. Tables 15 and 16 provide a review of common pain medications used for terminally ill children. For a more thorough discussion of pain assessment and management in children, please refer to WWW.CHILDCANCERPAIN.ORG.

TABLE 15. NONSTEROIDAL ANTI-INFLAMMATORY DRUGS TYPICAL STARTING DOSES

ACETAMINOPHEN
- 10 to 15 mg/kg/dose q 4 hr PO to a max of 650 mg/dose

ASPIRIN
- 10 to 15 mg/kg/dose q 6 to 8 hr PO to a max of 650 mg/dose

IBUPROFEN
- 10 mg/kg/dose to a max single dose of 800 mg q 6 to 8 hr PO

CHOLINE MAGNESIUM TRISALICYLATE
- 7.5 to 25 mg/kg/dose to a max single dose of 1500 mg tid PO

DICLOFENAC SODIUM
- 1 to 1.5 mg/kg/dose to a max single dose of 75 mg q 8 to 12 hr PO

NAPROXEN
- 5 to 7.5 mg/kg/dose to a max of 500 mg/dose q 12 hr PO

NAPROXEN SODIUM
- Same as naproxen

KETOROLAC
- 0.5 to 1 mg/kg as single dose IM to a max of 60 mg followed by 0.5 mg/kg IV q 6 hr to a max single dose of 30 mg.
- Max duration is 5 days (useful in short term pain management).
- There is limited data on use of oral ketorolac in children.

CELECOXIB (COX-2 INHIBITOR)
- 100 mg to 200 mg PO q day for patients > 18 years.
- No information in patients < 18 years.

ROFECOXIB (COX-2 INHIBITOR)
- 12.5 mg PO q day for patients > 18 years; max: 25 mg/day.
- No information for patients < 18 years.

COMPLEMENTARY & ALTERNATIVE THERAPIES

The use of complementary and alternative therapies by families with seriously ill children continues to grow. It is estimated that greater than 40% of Americans use complementary or alternative medicine (Calabresi, 1999). The vast amount of information available on the Internet, through news media, and advertisements on television, radio, and in print has created a more informed, assertive health care con-

TABLE 16. STARTING DOSES AND CONVERSION FACTORS FOR COMMONLY PRESCRIBED OPIOIDS

Starting Doses	Dosage Forms	IV Starting Doses
CODEINE		
• 0.5 to 1 mg/kg q 4 to 6 hr; max: 60 mg/dose	• Tablet, as sulfate: 30 mg • Liquid: 3 mg/mL	
ACETAMINOPHEN AND CODEINE		
• 0.5 to 1.0 mg/kg/dose of codeine q 4 to 6 hr; max: 2 tablets/dose; 15 mL/dose	• Elixir: acetaminophen 24 mg and codeine 2.4 mg/mL with alcohol 7% • Suspension: acetaminophen 24 mg and codeine 2.4 mg/mL alcohol free • Tablet #3: acetaminophen 300 mg and codeine 30 mg	
HYDROCODONE		
• 3–6 years: 5mL 3 to 4 times/day • 7–12 years: 10 mL 3 to 4 times/day • >12 years: 1 to 2 tablets q 4 to 6 hr; max: 8 tablets/day	• Tablet: hydrocodone 5 mg and acetaminophen 500 mg • Oral solution at: 0.5 mg hydrocodone and 33.4 mg/mL acetaminophen	
OXYCODONE		
• Immediate release: 0.1 to 0.3 mg/kg/dose up to 5 mg/dose q 4 to 6 hr • Sustained release: for patient's taking >20 mg/day of oxycodone can administer 10 mg q 12 hr	• Instant release: 5 mg • Sustained release: 10 mg, 20 mg, 40 mg, 80 mg	
MORPHINE		
• 0.3 to 0.6 mg/kg/dose every 12 hr for sustained release • 0.2 to 0.5 mg/kg/dose q 4 to 6 hr prn for solution of instant release tablets	• Injection: 2 mg/mL, 5 mg/mL, 10 mg/mL, 15 mg/mL • Injection, no preservative: 1 mg/mL • Solution: 2 mg/mL • Tablet: 15 mg (instant release) • Tablet, controlled release: (do not crush) 15 mg, 30 mg, 60 mg, 100 mg, 200 mg	• 0.1 mg/kg/dose • 0.1 to 0.2 mg/kg/dose q 2 to 4 hr; max: 15 mg/dose • **IV to PO:** 10 mg IV = 30 to 60 mg PO
HYDROMORPHONE		
• 0.03 to 0.08 mg/kg/dose PO q 4 to 6 hr; max: 5 mg/dose	• Injection: 1, 2, 3 & 4 mg/mL • Tablet: 2 mg, 4 mg • Syrup: Hydromorphone 1mg and guaifenesin 100 mg/5 ml • Suppository: 3 mg	• 15 mcg/kg IV q 4 to 6 hr; max: 2 mg/dose • **IV to PO:** 1.5 mg IV = 7.5 mg PO
METHADONE		
• 0.1 to 0.2 mg/kg q 4 to 12 hr; max: 10 mg/ dose	• Tablet: 5 mg, 10 mg • Solution: 1 mg/mL • Concentrate: 10 mg/ml • Injection: 10 mg/mL	• 0.1 mg/kg IV q 4 to 12 hr; max: 10 mg • **IV to PO:** 10 mg IV = 20 mg PO

sumer. Unfortunately, there are very few regulations regarding the claims that can be made with regard to various alternative therapies; nor are there clear professional and ethical standards that companies must maintain. For many parents who are facing the probable death of their child, there is very little they would not try to grasp the slightest chance at a *miracle cure.*

There are a number of factors that encourage the trend toward complementary and alternative medicine (Bullock and others, 1997):

1 Increased financial resources that allow some consumers to *shop around* for interventions when conventional therapy is not deemed effective.
2 Lack of finances for some consumers, which makes conventional medicine inaccessible and complimentary/alternative therapies more accessible.
3 Increased cultural diversity in the United States brings *old world* traditions toward health and healing in touch with conventional western medicine.

Additionally, there is a growing distrust of conventional medical care resulting from the impact of managed care, increased health care consumption versus available resources, and the often debilitating and painful tests and treatments required of patients.

Complementary therapies are considered interventions that are given in conjunction with conventional medical care and that focuses on promoting an overall sense of wellness. These therapies do not provide cure, but can provide care through improvement in quality of life, personal empowerment, and improved coping (Cattell, 1999: James, 1999). Physicians, nurse practitioners, nurses, and a number of individuals trained in a particular technique may use these therapies. Patients should be cautioned to look into the individual's qualifications in providing a particular complementary therapy.

Alternative medical therapies are those therapies that use unproven biologic substances to treat disease. Often the practitioners who use these therapies do not follow the conventional scientific rigor of testing for toxicity and randomized clinical trials to determine efficacy. Additionally, where trials or peer review of results have been conducted, there has been no efficacy shown for such treatments (Ernst & Cassileth, 1999). Tables 17 and 18 list some currently popular complimentary and alternative therapies, however they are in no way an exhaustive list of such treatments.

The major concerns associated with the use of complementary and alternative medications is the potential side-effects of herbs, nutritional supplements, and other biological substances taken in uncontrolled doses, and the potential for patients to abandon proven therapies that increase the chance of remission and cure. It is imperative that health professionals increase their knowledge of current therapies being used by their patients. Keeping an unbiased, open attitude toward a patient's use of these therapies will allow the practitioner to assess the use of such therapies and educate the patient and family regarding the possible benefits and dangers of their use.

TABLE 17. COMPLEMENTARY AND ALTERNATIVE THERAPIES

DIET AND PURGING

- Macrobiotics/Herbs
    - Chaparral
    - Flaxseed
    - Alfalfa
    - Burdock root
    - Red clover
- Macrobiotics/Herbs (cont.)
    - Cascara sagrada
    - Wheat grass
    - Essiac
- Megavitamins
- Vegetarian diets
- No-fat/Low fat diets
- Cleansing fasts
- Apitherapy
- Colon cleansing
- Enzyme therapy
- Detoxification

BODY MANIPULATION

- Massage
- Reflexology
- Acupressure
- Acupuncture
- Chiropractice
- Reiki
- Rolfing
- Exercise

PSYCHOLOGICAL MODALITIES (MIND/BODY)

- Music therapy
- Light therapy
- Art therapy
- Yoga
- Tai chi
- Bio-feedback
- Hypnosis
- Guided Imagery
- Progressive Relaxation
- Visualization
- Therapeutic Touch
- Aroma therapy
- Hypnotherapy
- Pet therapy

SPIRITUALITY

- Meditation
- Prayer
- Devotional reading
- Crystals
- Chanting
- Laying of hands
- Ritual or Ceremony
- Amulets
- Religious objects
- Shamanism

James, 1999; Cattell, 1999; von Gruenigen & Hopkins, 2000.

TABLE 18. UNCONVENTIONAL BIOLOGICAL TREATMENTS

- Traditional Chinese Medicine
- Ayurvedic Medicine (India)
- Immune enhancing vaccines/therapies
- Laetrile
- Shark cartilage
- Mistletoe
- Thymus therapy
- Essiac
- Hydrazine sulphate
- 714-X
- Antineoplastins
- DiBella 'cancer cure'
- Fresh cell therapy
- Oxygen therapies

Ernst & Cassileth, 1999.

TABLE 19. COMFORT CARE INTERVENTIONS

QUIET PRESENCE	Sitting quietly; not necessarily touching; unhurried calmness.
MASSAGE	Seek permission; define what is okay to do (feet/back); use oils or lotions that will not irritate the skin; play quiet music to aid in relaxation.
TOUCH	Holding hands, gentle touch with hand on body surface.
THERAPEUTIC TOUCH	Done only by a person trained in therapeutic touch (a method which works with a person's energy field to bring comfort and relief from physical and emotional pain).
MUSIC/VIDEO	Help to maintain links with what is familiar from home; children usually have favorites and may want to have them.
TOYS/BLANKETS	Respect the war-torn "blankie" and chewed up stuffed bear; do not lose it in the wash!
FAMILY GATHERINGS	Do backstage/footwork (an early birthday party or an early Christmas holiday gathering). Explore ways to create lasting memories, treasures, and rituals that keep the child's presence felt after his/her death.
PICTURE BOARD	Have family and friends gather pictures of times shared together, place them on a bulletin board near the bed where all can see them.
ROOM ENVIRONMENT	Encourage the family to bring things of comfort from home; modify the room according to developmental age and information available.
BOOKS	Many children enjoy being read to; engage the child in choosing an appropriate book; be aware of inappropriate books as well. Hearing is still very acute even though it seems the dying child cannot hear you.
FAMILY, FRIENDS, SPIRITUAL SUPPORT PERSON, PETS	Respect and enable the dying child to see people, pets, etc. At times, the request may seem very spontaneous and not practical, but to the child it may be part of finishing unfinished business.

Adapted from Hockenberry-Eaton and others: Essentials of Pediatric Oncology Nursing: A Core Curriculum. Association of Pediatric Oncology Nurses, 1998. With permission.

COMFORT CARE

Comfort care helps the child to feel relaxed and secure during the end of life. Essential comfort measures include touching, which is a powerful tool to calm fears and provide assurance that someone is present. A comforting environment will include sensory stimuli that are pleasurable to the child and family, such as favorite toys, favorite music or videos, or favorite fragrances. Often, the most effective comfort strategy is for a loved one to sit quietly at the child's side or lie in bed with her or him while quiet music plays in the background. Table 19 provides other comfort care strategies for use with children.

WHEN DEATH IS NEAR

PHYSICAL CHANGES

The child's progression through the terminal phase of the illness will be accompanied by an overall decline in the child's physical condition. However, children are unique in their ability to have *bursts* of energy and periods of alertness in the midst of their decline. Parents often can become exhausted and overwhelmed with *waiting for the inevitable,* and may ask frequently "how long" their child has left to live. In some instances, this question may be an attempt to determine what activities or events the family should try to accomplish. As the disease progresses and the child experiences more symptoms, the question may serve as a way for parents to ask how long they and their child will have to endure the dying process.

While it is impossible to predict the exact time of a child's death, there are some recognizable physical signs that indicate that death is getting closer. Initially, the child may begin to sleep more. Appetite will decrease, and the child may begin to take only small bites of food and sips of fluids. As the child begins to eat and drink less, urinary frequency will decline, and the urine will become more concentrated. Other physical signs that death is near include:

- Loss of sensation and movement in the lower extremities, progressing toward the upper body.
- Sensation of heat, body feels cool.
- Loss of senses.
- Confusion, loss of consciousness, slurred speech.
- Loss of bowel and bladder control.
- Decreased appetite/thirst.
- Difficulty swallowing.
- Change in respiratory pattern.
- Cheyne-Stokes respirations.
- Audible breath sounds caused by accumulation of pulmonary and pharyngeal secretion.
- Weak, slow pulse or rapid, thready pulse.

TABLE 20. CARE DURING THE TERMINAL PHASE OF THE ILLNESS

PHYSICAL CARE

- Provide frequent mouth care to prevent drying, cracking, and bleeding of lips and mucous membranes.
- Continue to maintain good hygiene by giving bed baths, using skin lotion, and giving frequent diaper changes.
- Continue necessary medications to manage symptoms and maintain comfort using IV (if access is easily established) or SC infusion. Discontinue unnecessary medications and procedures.

EMOTIONAL CARE

- Encourage family to discuss impending death openly with child and other family members.
- Encourage family to continue to speak to child in calm, reassuring voice.
- Provide for familiar surroundings and/or objects.
- Encourage caregivers to provide each other with periods of respite.
- Allow family time with child after the death and participation in the preparation of the body if they choose.

In the final few days prior to death, the child most likely will become less and less responsive. Breathing will become slow and shallow. Urine output may decrease or stop. In the final hours, breaths will become irregular, deep, and gasping, with long periods of apnea (Cheyne-Stokes breathing). The child's skin may have a pale, grayish blue color. It may be cool to the touch. The child's eyes may be slightly open. It is important to prepare the family for changes that will occur at this time, and to provide them with care-giving activities that promote a loving presence to the child's care. Reassure parents that these changes are a normal part of the dying process (Table 20).

EMOTIONAL CHANGES

When death is near, caregivers may fear that it will not be a peaceful experience. Although pain and symptom management should be employed to the very end, it is helpful to remind the family that, usually, a child will not have a final outburst of pain or period of intense suffering. During the final few days, the child may experience *visions* of people or *angels,* and may talk with them. They may begin to talk about heaven, or mention that someone is waiting for them. This may be a person who has preceded them in death. In the majority of circumstances, these *visions* provide a comforting presence and sense of reassurance to the child and family. It is important to reassure parents that these experiences are not necessarily frightening for the child, and to encourage the parents to be open to exploring these visions and ideas with their child.

Familiar and religious rituals surrounding the child's death are important. It is helpful to have an understanding of these rituals before the death in order to assist the family with arrangements to meet all of their needs. In the final hours, the family may begin the 'vigil', which is a natural human phenomenon where family and friends gather at the bedside. During this time, some families have played music or special videos, lit candles, recited prayers, or read favorite books. Family members or other trusted caregivers may tell the child that it's okay to leave. After the death, parents may wish to hold or spend time with the child's body. They may want to give the child a bath and dress them in a special outfit. Professional caregivers should ask the family if they would like to do anything special for the child after death, and give the family as much time with the child as necessary. It is important to remember that each family will have a different level of comfort with this process and, while *permission* should be given for the family to spend time with the child, it should not be forced upon the family. Professionals should provide the family with the option to spend time and provide personal care, offer to assist, or ask if the family members prefer for the professional to care for the body.

Awareness that the death is near allows the family to determine the location and circumstances of the child's death, which has been associated with positive bereavement outcomes. The presence of trusted professional caregivers also contributes to the satisfaction of family caregivers. Professionals can support the family during this time by providing honest information regarding the child's impending death, facilitating important religious or family rituals, attending to the comfort needs of family members, and managing pain and symptoms.

Psychosocial Care of the Family at the Time of Death · 5

AT TIME OF DEATH

At the time of a child's death, it is not unusual for parents to want to spend time, perhaps several hours, with the body. If the child died in the hospital, arrange for privacy during for this period of closure. If the body has tubing or other invasive measures present, remove them if possible. Encourage the family to hold the child if they desire to do so.

As a professional, there is no need to say anything; a meaningful embrace or hand on the shoulder can be sufficient to express your sorrow. You may ask the family if there is anyone they want with them at this time, and offer to phone that person. Be an advocate for the family. Give them all the information available about the circumstances at the time of death; families often need this information to gain closure. If the details are disturbing, tell the parents so and let them decide if they'd like complete information. Offer small bits of information at a time, succinctly and clearly; the parents will ask questions if they wish to know more. Even if the family was present, they may need information about what actually happened.

Address the comfort needs of the family: would they like a blanket or something to drink? Attempt to slow down the rush for decisions. Recognize that some families may want to stay in the room while the funeral home prepares to remove the body, while others will choose not to. Ask the family their preference and honor their choice. If no other support system is present to drive the family home, offer to arrange an alternative mode of transportation (e.g., taxi service).

HOW TO BREAK THE NEWS OF DEATH TO SIBLINGS

Hopefully, the well children have been involved with the ill child prior to the death; if not, however, the following guidelines will still apply (Grollman, 1996; Doka, 1995).

Using a calm voice and speaking at the comprehension level of the children, immediately tell the child of the death, preferably in familiar, comfortable surroundings (such as home). If the parents are unable to do this due to their own emotional reactions to the death, encourage them to select someone who is emotionally close to the child. Keep details simple at this point. If the children want to know more, they will ask questions. If no questions are forthcoming, ask the children if they have anything to ask. The children's natural curiosity may prompt requests for explicit details (i.e., "What will happen to the body now?" or "What happens during cremation?"). Encourage the children to talk about fears and concerns. Stay close to the children, available to hug and hold. Recognize that some children's response may be to change the subject or request to go play. Table 21 provides an overview of children's understanding and grief responses from a developmental perspective.

IMMEDIATE RESPONSES FAMILY MEMBERS MAY HAVE WHEN TOLD OF THE DEATH

Most often, the first response to the death of a loved one is profound shock. It is the mind's natural defense against facing extreme pain all at once. This occurs whether the death was anticipated or not.

Shock is quickly followed by disbelief and numbness; it doesn't seem possible that a loved one has died, and the natural reaction is to doubt the death ("I don't believe it!"). This denial phase is critical. It is an unconscious way of preventing emotional overload, and provides time for outer supports and inner resources to be gathered. Numbness softens the sadness to the point where it can be endured, and is a buffer that makes it possible to do what must be done in the immediate aftermath of a death (such as make funeral arrangements). There may be hostile reactions to the person who died or to others ("How could he do this to me?" or "It's your fault!"). Bodily distress, such as stomachache or headache, may be experienced, as well as panic ("Who else is going to die?"). Be aware of family members' preexisting medical conditions, such as increased blood pressure, heart problems, or history of mental illness. Intervene medically if necessary or arrange supportive measures.

SHOULD CHILDREN ATTEND FUNERALS?

A funeral gives children a way to acknowledge the death and honor the life of the deceased, as well as a way to receive comfort and support. For the funeral to be a positive part of the grief process, children need to be prepared, in clear, explicit terms, for what they will see and experience, and then given a choice about whether to attend the viewing of the body, the funeral, and the burial. If the child chooses not to attend, arrangements should be made for the child to stay with someone she/he feels close to. If the child wants to attend the funeral, someone should be appointed (someone whom the child feels a close relationship) whose sole responsibility will be to stay with the child and to comfort as needed. The child should be able, with supervision, to leave the funeral at any time.

GRIEF REACTIONS

As the numbness and denial give way to reality, many of the normal grief symptoms listed in Table 22 may be experienced. The quantity of reactions experienced, as well as their intensity, can leave the bereaved feeling disoriented and wondering if their grief is normal. Normalization of grief responses can facilitate healthy grief processing.

AFTER DEATH

PARENTAL GRIEF

Adjusting to the death of a child often is the most difficult task parents will face in their lifetimes. Parents trust that their child will outlive them; when the child dies, parents view the world as fragile and hostile. With this loss, parents also lose their own identities as protectors and providers, which can leave them questioning their role as parents. They are faced with learning to live without their child, struggling to hold on to memories while letting go of dreams for the future. The pain of grief often causes parents to withdraw temporarily from others, retreating into a world of solitude in which they can gradually acknowledge the loss.

A mother's role in the family is often that of the nurturer, who meets the family's emotional needs. Additionally, mothers frequently are the ones who facilitate communication between family members. After a child's death, the mother may find herself immobilized in grief and unable to nurture others. Intense sadness and pain can make mothers unable to function as the emotional center of their families, for they feel their own emotional state to be vicarious. Even the simplest tasks seem too hard; preoccupation with thoughts of the child makes concentration difficult.

The father often thinks that the least he can do is remain "strong" and in control to set an example. Who will hold the family together if he "falls apart." He may feel a need to "fix" other family members' grief. This common thinking often results in fathers postponing their grief work, which may result in excessive anger, triggered by inconsequential events. Little events that normally might not even get the father's attention may now trigger explosive outbursts. Over-involvement at work or the use of alcohol or drugs are ways that parents may use to escape the pain of grief. These methods, however, usually end in negative results.

TABLE 21. CHILDREN'S UNDERSTANDING AND RESPONSES TO GRIEF

Understanding of Death	Characteristic Behaviors	Interventions
AGE 0–3		
• Does not comprehend death. • Aware of constant activity in the house. • Aware of Mom and Dad looking sad. • Aware that someone in the home is missing.	• Altered eating and sleeping patterns. • Irritable. • Clings to others.	• Maintain routines but allow for flexibility. • Choose familiar and supportive caregivers. • Assign a support person for each child during funeral, burial, and other rituals. • Acknowledge all feelings of child and adult by naming feelings and giving permission to express anger and sadness in developmentally appropriate ways. • Give hugs when needed to help child feel secure.
AGE 3–5		
• Sees death as temporary and reversible; child continually asks if person will return. • May feel ambivalent. • Through magical thinking, may assume responsibility for the death.	• Concerned about own well-being. • Feels confused and guilty. • May use imaginative play. • Withdraws. • Irritable. • Regresses.	• Reinforce that when people are sad, they cry; crying is natural. • Read stories (see Resources Section). • Provide materials for child to draw pictures. • Encourage dialogue among family meetings. • Expect misbehavior as child struggles with confusing feelings. • Offer play with themes of death while providing supportive guidance. • Preschool and school age kids may benefit from knowing that the person is no longer breathing, unable to talk or other physical indicators that person is not alive.
AGE 6–9		
• Begins to understand concept of death. • Feels it happens to others. • May be superstitious about death. • May be uncomfortable in expressing feelings. • Worries that other important people will die.	• May seem outwardly uncaring, inwardly upset. • May use denial to cope. • May attempt to "parent." • May act out in school or home. • May play death games.	• Listen to determine what information the child is seeking. • Increase physical activity while role modeling stress-reducing behaviors. • Work on identifying more sophisticated feelings (i.e., frustration, confusion). • Encourage creative outlets for feelings (i.e., drawing, painting clay, blank books). • Preschool and school age kids may benefit from knowing that the person is no longer breathing, unable to talk, or other physical indicators that person is not alive.
AGE 10–12		
• Accepts death as final. • Has personal fear of death. • May be morbidly interested in skeletons, gruesome details of violent deaths. • Concerned with practical matters about child's lifestyle.	• May appear tough or funny. • May express and demonstrate anger or sadness. • May act like adult, but regress to earlier stage of emotional response.	• Encourage creative expressions of feelings. • Explore support group/peer-to-peer connection. • Establish family traditions and memorials. • Incorporate children into rituals, not just at time of death, but at important anniversaries (e.g., taking balloons to the cemetery; creating a special Christmas tree ornament which is always hung first; having birthday dinners and memory nights).
ADOLESCENTS		
• Has adult concept of death, but ability to deal with loss is based on experience and developmental factors. • Experiences thrill of recklessness. • Focuses on present. • Develops strong philosophical view. • Questions existence of an afterlife.	• Increased reliance on peers instead of family. • Moodiness and irritability. • May engage in risk-taking behaviors. • Appears rebellious and tests limits. • May act impulsively or with lack of common sense.	• Allow for informed participation. • Encourage peer support. • Suggest individualized and group expressions of grief. • Recommend creative outlets, (i.e., writing, art, and music).

TABLE 22. NORMAL GRIEF SYMPTOMS

PHYSICAL/BEHAVIORAL*

- Accident proneness
- Allergies/asthma
- Appetite changes
- Constipation/diarrhea
- Dizziness/dry mouth
- Heartache
- High blood pressure
- Hives/rashes/itching
- Indigestion
- Insomnia/over-sleeping
- Loss of appetite/overeating
- Low energy
- Low resistance to infection
- Migraine headaches
- Muscle tightness
- Pounding, rapid heartbeat
- Recurrent nausea
- Restlessness
- Sexual disinterest or difficulty
- Stomachache
- Tearfulness
- Weakness in legs

EMOTIONAL/SOCIAL

- Agitation
- Anger
- Angry outbursts
- Anxiousness
- Complacency
- Critical of self
- Difficulty in relationships
- Exaggerated positive behaviors
- Fear of groups or crowds
- Guilt feelings
- Indecisiveness
- Irritability
- Jealousy
- Lack of initiative
- Loss of interest in living
- Loss of self-esteem
- Moodiness
- Nightmares
- Rumination
- Sadness
- Suspiciousness
- Thoughts of own death
- Withdrawal from relationships

INTELLECTUAL

- Confusion
- Difficulty concentrating
- Disbelief/denial
- Errors in language usage
- Forgetfulness
- Inattention
- Lack of attention to detail
- Lack of awareness of external events
- Loss of creativity
- Loss of productivity
- Memory loss
- Overachievement
- Past-oriented

SPIRITUAL

- Anger at God
- Feelings of abandonment
- "Why" questions

**Any recurrent physical reaction should be evaluated by a physician to rule out the existence of a condition that may require medical treatment.*

WHAT IS HELPFUL?

Finding a way to express emotions is necessary for healing. This expression can be verbal, written, physical or creative. Finding a support system that actively encourages grief expression and reminiscing about the child, and setting aside time for quiet reflection, will facilitate the healing process. Parents may try to protect one another from their own grief. They may fear upsetting the other to the point of crying. This is unfortunate, because sharing grief often is therapeutic and allows parties to know what the other is going through.

SIBLING GRIEF

Children grieve differently than adults; the unrelenting pace of adult grief is too intense for children. While children and adults share the same emotions in grief, children do not grieve 24 hours a day, as adults do. Children grieve intermittently. As they grow, they will revisit the death and arrive at new understandings of it.

Children of all ages grieve the loss of a loved one. The extent of their understanding of death, however, depends on their age and cognitive maturity (Table 21).

FACTORS THAT POSITIVELY IMPACT A FAMILY'S GRIEF OUTCOME

- Surviving children are adequately prepared for, and participate in, the dying process and the funeral.
- Family possesses a willingness and ability to seek and receive emotional support from each other.
- Family has the willingness and ability to reach out for support from community systems (counselors, support groups).
- Parents possess positive coping skill, and model appropriate ways of expressing emotions to surviving children.
- Parents are emotionally available to surviving children.
- Parents are able to perform daily acts of living, functioning as needed to provide for basic needs of surviving children.
- Family has a support system that encourages active remembrance of the deceased child.
- Family experiences few changes in daily routines.
- Clear, non-euphemistic terms are used in discussing the death (*dead* as opposed to *passed on*).
- Each family member's emotions are recognized, validated, and supported.
- Consistent discipline is provided to surviving children.

- Family members maintain an ongoing relationship with the deceased child while reinvesting in life.
- Family restructures self, incorporating new roles and responsibilities for each member.
- Family recognizes that each member will grieve in his or her own way and time.
- Family views the crisis as an opportunity to grow stronger spiritually and emotionally.

EXTENDED FAMILY & FRIENDS

In reaction to the immediate family's grief, extended family members and friends may not know how to be supportive. Many people, even professionals, do not know what to say. Unfortunately, in an attempt not to upset the family, the decision may be made to avoid mentioning the child's name or discussing memories. This usually leaves the family feeling isolated in their grief and as if the deceased child has been forgotten.

Extended family members and friends also may experience profound grief at the death of the child. This reaction could be the result of the closeness of the relationship, unresolved grief issues, or fear of losing their own children. These individuals will experience symptoms similar to those described above.

SIGNS OF HEALING

It is important to realize that *healing* in grief does not mean that emotional pain is absent. Rather, it means that the pain of grief no longer will be consistently overwhelming and all consuming, as it is immediately after the death. The emotional pain will resurface throughout the family's lifetime, eventually becoming more manageable and less invasive of all aspects of life.

Emotional healing is evidenced when the individual no longer feels the need to escape emotions, but will acknowledge feelings of anger, fear, sadness, etc. as they arise. The individual will experience memories (both good and bad) without overwhelming fear of not being able to survive the accompanying emotions. Understanding that the best choices were made under the most difficult of situations will help allay feelings of guilt and regret. The individual will begin to find glimpses of renewed meaning in life, and will begin planning for the future.

It is important to remember that there is no magic timetable as to how long the intense pain of grief will last. Grieving is a learning process that takes time, and is unique to each individual.

WHEN IS PROFESSIONAL HELP WARRANTED?

Many of the so-called negative behaviors of grief frequently are short-lived and go away on their own. However, if any of the following behaviors continue *for several months*, a professional evaluation by a bereavement specialist should be encouraged (Worden, 1996):

- persistent difficulty talking about the deceased.
- persistent aggressive behavior, or behavior that takes the form of property destruction.
- prolonged physical symptoms (stomachaches, headaches, etc.).
- persistent sleeping disturbances or nightmares.
- persistent eating disturbances.
- persistent marked social withdrawal.
- persistent work/school difficulties or serious work/academic reversal.
- persistent self-blame or guilt, or a pervasive sense of unworthiness.

The two behaviors that require immediate professional follow-up, regardless of the length of time they last, are self-destructive behavior or expressions of intent to inflict harm on self or others.

CULTURAL IMPLICATIONS FOR CARE

Culture is defined as the learned, shared, and transmitted values, beliefs, norms, and ways of life of a particular group that guide their thinking, decisions, and actions in patterned ways. Culture shapes and determines responses to beliefs, values, perceptions, and behavior. Reactions of individuals and families within a specific culture reflect the cultural influences and the incorporation of unique experiences of those individuals and families. Understanding the common patterns of behavior within specific cultures, coupled with an awareness of the unique responses of individuals, provides caregivers with tools that can enhance communication and facilitate care across an array of cultures. Strategies for health care professionals designing culturally competent care are listed below. Table 23 highlights various cultural influences on health beliefs and practices related to medical care.

STRATEGIES FOR HEALTH CARE PROFESSIONALS DESIGNING CULTURALLY COMPETENT CARE

- Identify the individual's or family's cultural beliefs.
- Understand and respect the values reflected in all cultures.
- Provide medical interpreters to enhance the effectiveness of communication.
- Remember that, in some cultures, the age of a child is not an accurate predictor of experience with death.

- Avoid conclusions based on limited information about another culture.
- Ask questions about the beliefs and bereavement rituals of both adults and children within common ethic groups.
- Make allowances for partial assimilation into the dominant culture, especially for children.
- Ask family what cultural values are most important to them.
- Acknowledge the significance of collective losses for some cultures (i.e., loss of homeland, traditions).
- Examine one's own beliefs, as they may affect the role of caregivers in life and death experiences.

SPIRITUAL ASPECTS OF CARE

Many people search throughout their lives for religious and spiritual identity. Although interdependent, spiritual and religious beliefs are often interwoven. The spiritual dimension is the personal connection and meaning one finds with his or her God, whereas religion is the formalized connection between individual and their God through an institution of belief. In both spirituality and religiosity, there is recognition of a connection or desire to connect with self, people, environment, and the other (God, Higher Power, Allah, spirit) (Cairns, 1999). This feeling of connectedness aids in reflection of one's existence. Spiritual care can be provided through relationships with friends, neighbors, other lay persons, or religious affiliates. Knowledge of and sensitivity to the religious beliefs and spiritual dimensions of patients provides insight to the meaning and values of individuals (Table 23).

Guidelines exist to help in caring for patients from a variety of religious faiths (Table 24). Perhaps most importantly, careful listening and attentive observations of caregivers can help to promote fulfillment of the spiritual needs of the child and family.

Spiritual Aspects of Care was edited by Chad Hawkins, Chaplain, The Children's Program at The Hospice at Texas Medical Center, Houston, TX.

TABLE 23. CULTURAL INFLUENCES ON HEALTH BELIEFS & PRACTICES

ASIAN CHINESE

- A healthy body viewed as gift from parents and ancestors and must be cared for.
- Health is one of the results of balance between the forces of Yin (cold) and Yang (hot) energy forces that rule the world.
- Illness caused by imbalance.
- Blood is source of life and is not regenerated.
- Chi is innate energy.
- Lack of chi and blood produces fatigue, poor constitution, and long illness.
- Wide use of medicinal herbs procured and applied in prescribed ways.
- Folk healers are herbalist, spiritual healer, temple healer, fortune healer.

JAPANESE

Three major belief systems:

- Shinto religious influence:
  - Humans inherently good.
  - Evil caused by outside spirits.
  - Illness caused by contact with polluting agents (e.g., blood, corpses, skin diseases).
- Chinese and Korean influence:
  - Health achieved through harmony and balance between self and society.
  - Disease caused by disharmony with society and not caring for body.
- Portuguese influence:
  - Upholds germ theory of disease: Evil removed by purification.
- Kampo medicine – use of natural herbs:
  - Care for disabled viewed as family's responsibility.
  - Take pride in child's good health.
  - Seek preventive care, medical care for illness.

VIETNAMESE

- Good health considered to be balance between yin and yang.
- Believe person's life has been predisposed toward certain phenomena by cosmic forces.
- Health believed to be result of harmony with existing universal order; harmony attained by pleasing good spirits and avoiding evil ones.
- Belief in *am duc*, the amount of good deeds accumulated by ancestors.
- Many use rituals to prevent illness.
- Practice some restrictions to prevent incurring wrath of evil spirits.
- Regard health as family responsibility; outside aid sought when resources run out.

FILIPINO

- Believe God's will and supernatural forces govern universe.
- Illness, accident, and other misfortunes are God's punishment for violations of His will.
- Widely accept "hot" and "cold" balance and imbalance as cause of health and illness.
- Some use amulets as a shield for witchcraft or as good luck pieces.

AFRICAN AMERICAN

- Illness classified as:
  - Natural forces of nature against which there is not adequate protection (e.g., cold air, pollution, food and water).
  - Unnatural, evil influences (e.g., witchcraft, voodoo, hoodoo, hex, fix, root work); symptoms often associated with eating.
- Believe serious illness sent by God as punishment (e.g., parents punished by illness or death of the child).
- Self-care and folk medicine is very prevalent.
- Attempt home remedies first.
- May resist health care because illness is "Will of God."
- Prayer is common means for prevention and treatment.

HAITIAN

- Illnesses have a supernatural or natural origin.
- Supernatural illnesses are caused by angry voodoo spirits, enemies, or the dead, especially deceased ancestors.
- Natural illnesses are based on conceptions of natural causation: irregularities of blood volume, flow, purity, viscosity, color, and/or temperature (hot/cold).
  - Gas (gaz)
  - Movement and consistency of mother's milk
  - "Hot/cold" imbalance in the body
  - Bone displacement
  - Movement of diseases
- Health is maintained by good dietary and hygienic habits.
- Health is a personal responsibility.
- Foods have properties of hot/cold and light/heavy and must be in harmony with one's life cycle and bodily states.
- Supernatural illness treated by healers: voodoo priest (houngan) or priestess (mambo), midwife (fam saj), and herbalist or leaf doctor (dokte fey).
- Amulets and prayer used to protect against illness due to curses or willed by evil people.

HISPANIC/MEXICAN

- Health beliefs have strong religious association.
- Body imbalance between Caliente (hot) and Frio (cold) or "wet" and "dry" is a cause of illness.
- Some maintain good health is a result of good luck.
- Illness prevented by performing properly, through prayer, by wearing religious medals or amulets, and sleeping with relics at home.
- Illness is a punishment from God for wrongdoing, forces of nature, and the supernatural.
- Seek help from curandero or curandera, especially in rural areas. Curandero(a) receives his/her position by birth, apprenticeship, or a "calling" via dream or vision.
- Practice for severe illness – make promises, visit shrines, offer medals and candles, offer prayers.
- Adhere to "hot" and "cold" food prescriptions and prohibitions for prevention and treatment of illness.

PUERTO RICAN

- Subscribe to the "hot and cold" theory of causation of illness.
- Believe some illness caused by evil spirits and forces.
- Consult spiritualist medium for mental disorders.
- Santeria is system, and practitioners are called santeros.

CUBAN

- Prevention and good nutrition are related to good health.
- Diligent users of the medical model.
- Eclectic health-seeking practices: folk medicine of both religious and nonreligious origins; home remedies; in many instances, seek assistance of santeros and spiritualists to complement medical treatment.

NATIVE AMERICAN

- Believe health is state of harmony with nature and universe.
- Respect bodies through proper management.
- All disorders believed to have aspects of supernatural.
- Violation of a restriction or prohibition thought to cause illness.
- Fear of witchcraft.
- May carry objects believed to guard against witchcraft.
- Theology and medicine strongly interwoven.

Adapted from: Wong D, Hockenberry-Eaton M, Wilson D & others. (1999). Nursing Care of Infants and Children, 6th ed., St. Louis, MO. Mosby, with permission.

TABLE 23. RELIGIOUS BELIEFS THAT INFLUENCE HEALTH CARE

A word of caution must regularly be expressed when one is trying to speak absolutes about any religion. Within each denomination or belief system there are always variations. Geographic location, generation gaps, gender differences, or cultural diversity may impact these convictions. Whenever there are any doubts, the best advice is to always ask questions and seek the assistance of professional clergy. Chaplains or other professional pastoral care providers are a good source of information and resources.

BAPTIST

- **Birth:** Infant baptism is not practiced. However, many Churches present the baby and the parents to the congregation when they attend services for the first time after the birth.
- **Death:** It isn't mandatory that clergy are present at death, but families often desire visits from clergy. Scripture reading and prayer are important.
- **Organ donation/transplantation:** There is no formal statement regarding this issue. It is considered a matter of personal conscience. It is commonly regarded as positive (an act of love).
- **Beliefs regarding medical care:** Some may regard their illness as punishment resulting from past sins. Those who believe in predestination may not seek aggressive treatment. Fundamentalist and conservative groups see the Bible as the infallible word of God to be taken literally.

BUDDHIST

- **Birth:** Do not practice infant baptism.
- **Death:** Buddhist priest is often involved before and after death. Rituals are observed during and after death. If the family doesn't have a priest, they may request one be contacted.
- **Organ donation/transplantation:** There is no formal statement regarding organ donation/transplantation. This is seen as a matter of individual conscience.
- **Beliefs regarding medical care:** Believe that illness can be used as a tool to aid in the development of the soul. May see illness as a result of Karmic causes. May avoid treatments or procedures on holy days. Cleanliness is important.

CHURCH OF JESUS CHRIST OF LATTER DAY SAINTS (MORMON)

- **Birth:** Infant baptism is not performed. Children are given a name and a priesthood blessing sometime after the birth, from a week or two to several months. In the event of a critically ill newborn, this might be done in the hospital at the discretion of the parents. Baptism is performed after the child is eight years old. Church of Jesus Christ of Latter Day Saints feel that a child is not accountable for sins before eight years of age.
- **Death:** There are no religious rituals performed related to death.
- **Organ donation/transplantation:** There is no official statement regarding this issue. Organ donation/transplantation is left up to the individual or parents.
- **Beliefs regarding medical care:** Administration to the sick involves anointing with consecrated oil and a blessing performed by members of the priesthood. While this is usually requested by the individual or a member of the family, if the individual is unconscious, and there is no one to represent him or her, it would be appropriate for anyone to contact the Church so that the ordinance may be performed. Refusal of medical treatments would be left up to the individual. There are no restrictions relative to "holy" days.

EPISCOPAL

- **Birth:** Infant baptism is practiced. In emergent situations, request for infant baptism should be given high priority and could be performed by any baptized person, clergy or lay. Often in situations of still births or aborted fetuses, special prayers of commendation may be offered.

- **Death:** Pastoral care of the sick may include prayers, laying on of hands, anointing, and/or Holy Communion. At the time of death, various litanys and special prayers may be offered.
- **Organ donation/transplantation:** Both are permitted.
- **Beliefs regarding medical care:** Respect for the dignity of the whole person is important. These needs include: physical, emotional, and spiritual.

FRIENDS (QUAKERS)

- **Birth:** Do not practice infant baptism.
- **Death:** Each person has a divine nature but an encounter and relationship with Jesus Christ is essential.
- **Organ donation/transplantation:** No formal statement, but generally both are permitted.
- **Beliefs Regarding medical care:** No special rites or restrictions. Leaders and elders from the Church may visit and offer support and encouragement. Quakers believe in plain speech.

ISLAM (MUSLIM/MOSLEM)

- **Birth:** At birth, the first words said to the infant in his/her right ear are "Allah-o-Akbar" (Allah is great) and the remainder of the Call for Prayer is recited. An "Aqeeqa" (party) to celebrate the birth of the child is arranged by the parents. Circumcision of the male child is practiced.
- **Death:** In Islam, life is meant to be a test for the preparation for the everlasting life in the hereafter. Therefore, according to Islam, death is simply a transition. Islam teaches that God has prescribed the time of death for everyone and only He knows when, where, or how a person is going to die. Islam encourages making the best use of all of God's gifts including the precious gift of life in this world. At the time of death, there are specific rituals (bathing, wrapping the body in cloth, etc.) that must be done. Before moving and handling the body, it is preferable to contact someone from the person's Mosque or Islamic Society to perform these rituals.
- **Organ donation/transplantation:** Permitted. However, there are some stipulations depending on the type of transplant/donation and its effect on the donor and recipient. It is advisable to contact the individual's Mosque or the local Islamic Society for further consultation.
- **Belief regarding medical care:** Humans are encouraged in the Qu'ran to seek treatment. It is taught that only Allah cures. However, Muslims are taught not to refuse treatment in the belief that Allah will take care of them because even though He cures, He also chooses at times to work through the efforts of humans.

INTERNATIONAL SOCIETY FOR KRISHNA CONSCIOUSNESS

(A Hindu movement in North America based on devotion to Lord Krishna)

- **Birth:** Infant baptism is not performed.
- **Death:** The body should not be touched. The family may desire that a local temple be contacted so representatives may visit and chant over the patient. It is believed that in chanting the names of God, one may gain insight and God consciousness.
- **Organ donation/transplantation:** There is no formal statement prohibiting this act. It is an individual decision.
- **Beliefs regarding medical care:** Illness or injury is believed to represent sins committed in this or a previous life. They accept modern medical treatment. The body is seen as a temporary vehicle used to transport them through this life. The body belongs to God and members are charged to care for it in the best way possible.

(Continued on next page)

TABLE 23. RELIGIOUS BELIEFS THAT INFLUENCE HEALTH CARE (CONTINUED)

JEHOVAH'S WITNESS

- **Birth:** Infant baptism is not practiced.
- **Death:** There are no official "rites" that are performed before or after death, however, the faith community is often involved and supportive of the patient and family.
- **Organ donation/transplantation:** There is no official statement related to this issue. Organ donation isn't encouraged but it is believed to be an individual decision. According to the Watchtower (legal corporation for the denomination), all donated organs and tissue must be drained of blood before transplantation.
- **Beliefs regarding medical care:** Adherents are absolutely opposed to transfusions of whole blood, packed red blood cells, platelets, and fresh or frozen plasma. This includes banking of ones own blood. Many accept use of albumin, globulin, factor replacement (hemophilia), vaccines, hemodilution, and cell salvage. There is no opposition to nonblood plasma expanders.

JUDAISM (ORTHODOX AND CONSERVATIVE)

- **Birth:** Circumcision of male infants is performed on the eighth day if the infant is healthy. This ritual is performed by a Mohel (ritual circumciser familiar with Jewish law and aseptic technique).
- **Death:** It is important that the health care professional facilitate the family's need to comfort and be with the patient at the time of death.
- **Organ donation/transplantation:** Permitted and is considered a Mitzvah (good deed).
- **Beliefs regarding medical care:** Only emergency surgical procedures should be performed on the Sabbath, which extends from sundown Friday to sundown Saturday. Elective surgery should be scheduled for days other than the Sabbath. Pregnant women and the seriously ill are exempt from fasting. Serious illness may be grounds for violating dietary laws but only if it is medically necessary.

LUTHERAN

- **Birth:** Infant baptism is practiced. If the infant's prognosis is poor, the family may request immediate baptism.
- **Death:** Family may desire visitation from clergy. Prayers for the Dying, Commendation of the Dying, and Prayers for the Bereaved may be offered.
- **Organ donation/transplantation:** There is no formal statement regarding this issue. It is considered a matter of personal conscience.
- **Beliefs regarding medical care:** Illness isn't seen as an act of God rather it is seen as a condition of mankind's fallen state. Prayers for the Sick may be desired.

METHODIST

- **Birth:** Infant baptism is practiced but is usually done within the community of the Church after counseling and guidance from clergy. However, in emergency situations, a request for baptism would not be seen as inappropriate.
- **Death:** In the case of perinatal death, there are prayers within the United Methodist Book of worship that could be said by anyone. Prayer, scripture, and singing are often seen as appropriate and desirable.
- **Organ donation/transplantation:** Organ donation/transplantation is supported and encouraged. It is considered a part of good stewardship.
- **Beliefs regarding medical care:** In the Methodist tradition, it is believed that every person has the right to death with dignity and has the right to be involved in all medical decisions. Refusal of aggressive treatment is seen as an appropriate option.

PENTECOSTAL

Assembly of God, Church of God, Four Square and many other faith groups are included under this general heading. Pentecostal is not a denomination, but a theological distinctive (Pneumatology).

- **Birth**: No rituals like baptism are necessary. Many Pentecostals have a ceremony of "dedication," but it is done in the context of the community of faith/believers (Church). Children belong to heaven and only become sinners after the age of accountability, which is not clearly defined.
- **Death:** The only way to transcend this life; it is the door to heaven (or hell). Questions about "salvation of the soul" are very common and important. Resurrection is the Hope of those who "were saved." Prayer is appropriate, so is singing and scripture reading.
- **Organ donation/transplantation:** Many Pentecostal denominations have no statement concerning this subject, but it is generally seen as positive and well received. Education concerning wholeness of the person and non-literal aspects like "heart," "mind," etc., have to be explained. For example, a Pentecostal may have a problem with donating a heart to a "non-believer."
- **Beliefs Regarding Medical Care:** Pentecostals sometimes labeled as "in denial" due to their theology of healing. Their faith in God for literal healing is generally expressed as intentional unbelief in the prognostic statements. Many Pentecostals do not see sickness as the will of God, thus one must "stand firm" in faith and accept the unseen reality which many times may mean healing. As difficult as this position may be seen, it must be noted that, when death occurs, Pentecostals may leap from miracle expectations to joyful hope and theology of heaven and resurrection without facing issues of anger or frustration due to unfulfilled expectations. Prayer, scriptures, singing, and anointing of the sick (not a sacrament) are appropriate/expected pastoral interventions.

PRESBYTERIAN

- **Birth:** Baptism is a Sacrament of the Church but is not considered necessary for salvation. However, it is seen as an event to take place, when possible, in the context of a worshipping community.
- **Death:** Family may desire visitation from clergy. Prayers for the Dying, Commendation of the Dying, and Prayers for the Bereaved may be offered.
- **Organ donation/transplantation:** There is no formal statement regarding this issue. It is considered a matter of personal conscience.
- **Beliefs regarding medical care:** Communion is a Sacrament of the Church. It is generally celebrated with a patient in the presence of an ordained minister and elder. Presbyterians are free to make their own choices regarding the use of mechanical life-support measures.

ROMAN CATHOLIC

- **Birth:** Infant baptism is practiced. In medical facilities, baptism is usually performed by a Priest or Deacon as ordinary members of the sacrament. However, under extraordinary circumstances, baptism may be administered by a layperson, provided that the intention is to do as the Church does using the formula, "I baptize you in the name of the Father, the Son, and the Holy Spirit."
- **Death:** Sacrament of the Sick is the sacrament of healing and forgiveness. It is to be administered by a priest as early in the illness as possible. It is not a last rite to be administered at the point of death. The Roman Catholic Church makes provisions for prayers of commendation of the dying, which may be said by any Priest, Deacon Sacramental Minister, or layperson.
- **Organ donation/transplantation:** Catholics may donate or receive organ transplants.
- **Beliefs Regarding Medical Care:** The sacrament of Holy Communion sustains Catholics in sickness as in health. When the patient's condition deteriorates, the sacrament is given as Viaticum ("food for the journey"). Like Holy Communion,Viaticum may be administered by a Priest, Deacon, or a Sacramental Minister. The Church makes provisions for prayers of commendation of the dying that may be said by any of those listed above or by a layperson.

TABLE 24. NURSING CONSIDERATIONS FOR SPIRITUAL CARE

ASSESSMENT

- Observe the environment for religious articles.
- Observe if the child uses religious rituals, such as prayers or stories, or receives visits from spiritual leaders.
- Observe parents' religious beliefs (even when unspoken, this is where the child takes his/her direction).
- Obtain religious history.
- Ask open-ended questions to elicit the importance of religion to the child and family.
- Assess physical and psychosocial behaviors that are indicators of spiritual distress (anger, guilt, fear, alienation, sleeplessness, regression); assess family interactions and relationships.

PLANNING

- Be aware of needs related to specific religious beliefs.
- Consider the developmental state of the child, particularly with regard to lack of abstract thinking and the need for a sense of accomplishment and control.
- Develop a trusting relationship and include family members in the process.
- Teach family interventions to promote spiritual well being.
- Avoid promoting personal religious beliefs and attitudes – honor differences.

IMPLEMENTATION

- Offer opportunities for religious rituals and expressions if they are part of the child's spiritual life.
- Contact spiritual leader/chaplain
- Offer use of self by listening to the concerns of the child and family.
- Explore the spiritual dimension through the use of therapeutic play, bibliotherapy, and other forms of artistic expression, while involving family members; provide direction and choices to support management of the chronic condition.
- Seek assistance from pastoral care professionals

OUTCOMES

- Use religious practices, if relevant.
- Offer positive statements about meaning and purpose in life.
- Make statements that reflect forgiveness of self and others.
- Discuss restored relationships with significant others and the Higher Power.

Adapted from: Fulton RA, Moore CM. (1995) Spiritual care of the school-age child with a chronic condition. Journal of Pediatric Nursing 10, 224-231, with permission.

Helping Professionals Care for Dying Children · 6

Professionals providing care for children at the end of life experience many emotions, and reactions to the death of a child are influenced by numerous factors. The professional's previous experience with grief and loss influences his or her view of the death. The nature of the relationship with the child and family impacts the extent of the professional's grief and loss. Expectations for the child and the immediate circumstances surrounding the death can cause intense grief for those caring for the child. Professionals who feel a sense of helplessness regarding the situation and who were unable to participate in providing care during the final days often have difficulty letting go. The professional's own beliefs and values play an important role in assisting the individual to cope with the death of a child. Professionals should take time to reflect on their personal experiences with death.

RESPONSES TO GRIEF

The professional may experience numerous symptoms following the death of a child. Physical symptoms can include: insomnia or an increased need for sleep, gastrointestinal disturbances, alterations in eating patterns, lethargy, and exhaustion. Emotional symptoms can include: nervousness and tension, feelings of emptiness and heaviness, sadness, depression, anger, guilt, inability to concentrate, and loneliness. They may feel emotionally numb. Professionals may discuss the need to withdraw from patients and families whose uncertain futures might cause increased pain and grief.

STRATEGIES THAT HELP

- *Recognize the inevitability of the child's death.* One's own expectations for the child can cause the greatest grief, due to belief that something more should or could have been done to prevent the child's death. Work toward acceptance that providing the child with a comfortable and dignified death can promote comfort in the professional. Learn from these experiences, acknowledge feelings, and then let

them go. Avoid self-blame for situations in which one has no experience, and over which one has no power.
- *Develop knowledge and apply it.* Increase personal knowledge about the physical and psychosocial aspects of care in death, dying, and grief. Use this knowledge to deliver the best possible care to the patient and family. Sometimes the best gift from a child who has died is the increased skill, knowledge, and understanding that a professional can bring to the next situation.
- *Identify ways the work setting can provide support.* Changing assignments, giving time off, rearranging work schedules, providing mentorship, accessing critical incident stress management teams, participating in "bereavement" round, and multidisciplinary team debriefings are ways in which activities in work setting can help professionals deal with grief. Use briefing/debriefing sessions to share experiences with colleagues. Seek support from colleagues, friends, and professional grief counselors.
- *Briefing.* Letting others know what is happening while it is happening often helps caregivers anticipate and prepare for the death. For example, if individuals want to be informed when a child dies, notification can help nurses avoid coming into work and facing the impact of an empty bed.
- *Debriefing.* May take several forms. Whether it is individual or group debriefing, it is important to utilize a skilled facilitator who will not be caught up in the emotions of the situation. Skilled facilitators can lead the discussion as participants discuss the death, its meaning, their feelings and emotions, and the impact of the death on themselves, the work group, and others.
- *Find meaning.* What does this child's life and death mean to others? How has life been changed in a positive way by knowing this child and his/her family? What has the experience taught the care provider about life and humanity?
- *Separate work and personal life.* Develop a ritual or process for leaving work behind when off duty. As experience is gained in coping with grief, one is able to compartmentalize different aspects of life with greater ease.
- *Take care of yourself.* Continue proper exercise, nutrition, rest, and sleep. Create a routine that will assist with health promotion and illness prevention. Develop a balance between the demands of work, family life, and specific needs.
- *Say goodbye.* Find a way to say goodbye, whether by attending the funeral or creating one's own memorial or ritual. Writing a note to a bereaved family can mean a great deal to them and can help produce some closure in the relationship. Some facilities have memorial services for the children who have died. Many nurses have created their own rituals to honor the death of a patient who has touched their lives: lighting a candle, walking on the beach, reading a special poem, or listening to a piece of music.

Clinical settings where children with terminal illnesses are cared for do not frequently provide opportunities for caregivers to acknowledge their own feelings of grief and loss. There are a number of ways in which work places can support the professional caregiver:

- When a child is dying on an inpatient unit, assign one-to-one care to allow the caregiver to focus attention on the needs of the child and family, creating a sense of accomplishment in providing the family with a caring, positive experience.
- Provide primary caregivers time away from the unit after the death to reflect on the experience and its personal significance.
- Provide caregivers with the flexibility necessary to meet the individual child's and family's needs. Open visitation, allowing the family's personal effects or rituals, or arranging a visit from a loved pet allow staff to feel that they can support the family rather than enforce rigid institutional rules.
- Allowing caregivers who had close relationships to the deceased child time to attend memorial or funeral services provides closure.
- Encourage professionals who work in high-stress areas to take their vacation and personal time at regular intervals to reduce burnout.
- Encourage staff to participate in formal or informal stress management or support groups to facilitate recognition of stress and grief.
- Attend to staff members who show signs of complicated grief reactions and burnout, such as over-involvement with a child or family, spending personal time off caring for the family, or exaggerated emotional expressions of grief. Refer to the institutional Employee Assistance Program or encourage counseling.

EDUCATION & TRAINING IN END-OF-LIFE CARE

A major limitation in providing quality care to dying patients is the lack of education of physicians and nurses during their undergraduate and clinical training. This issue has been addressed recently by experts in end-of-life care in reviews of medical and nursing textbooks. Content on nine identified areas pertinent to palliative and terminal care was found to be seriously lacking in both medical and nursing textbooks. Relevant information in nursing texts was found to be inaccurate, outdated, and limited (Ferrell, Virani, & Grant, 1999). Medical text content was found to provide little helpful direction for medical students in managing a patient with a terminal illness, and focused primarily on prognostication and medical treatments to alter the course of the disease (Carron, Lynn, & Keaney, 1999). In addition to the identified lack of textual information on providing care at the end of life, clinical training for both nurses and physicians also has been shown to be lacking (Billings & Block, 1997; Papadatou, 1997). While there is limited information in published medical and nursing textbooks regarding principles of palliative and terminal care, there are a number of texts and journals devoted entirely to the subject. Therefore, the issue is not so much that information is not available, but that it is not being taught consistently in didactic and clinical environments.

One method of improving physicians' and nurses' skill in caring for dying patients is to combine didactic content with clinical experience and role modeling by experienced palliative care and hospice professionals (Ross and others, 1988; Driggers, Nussbaum, & Haddock, 1993). The goal of such training would be to increase basic knowledge and to impact care-giving behaviors that would improve both caregiver and patient satisfaction. Educational programs, health care institutions, and academic programs should make a commitment to providing professional caregivers with education and clinical experiences in principles of palliative care. Additionally, palliative and end-of-life care should be included in institutional quality improvement programs to assure consistency in care for all patients and families.

Health care professionals who care for children in the terminal stage of illness require education regarding pain and symptom management, and effective communication skills in order to effectively manage and guide these children and their families through the dying process. There is much satisfaction to be gained by providing compassionate, competent care to children and families during the final stages of life.

Resources on End-of-Life Care

BIBLIOGRAPHY

BEREAVEMENT

Crenshaw DA. *Bereavement Counseling the Grieving Throughout the Life Cycle.* New York: Crossroad Publishing Co; 1995.

Davies B. Sibling bereavement: research-based guidelines for nurses. *Seminars in Oncology Nursing*, 9, 107-113; 1993.

DeMaso DR, Meyer EC & Beasley PJ. What do I say to my surviving children? *Journal of the American Academy of Child and Adolescent Psychiatry.* 1997; 36: 1299-1302.

Fitzgerald H.*The Grieving Child: A Parent's Guide.* New York: Simon & Schuster ; 1992.

Foley GV & Wittam EH. Care of the child dying of cancer: Part II. *Cancer.* 1990; 40: 327-354.

Geis HK and others. Bereavement and loss in childhood. *Child and Adolescent Psychiatric Clinics of North America.* 1998; 7: 73-85.

Hogan NS & DeSantis L. Things that help and hinder adolescent sibling bereavement. *Western Journal of Nursing Research.* 1994; 16: 132-153.

Johnson J & Johnson M. *Children Grieve Too: A Book for Families Who Have Experienced a Death.* Omaha, NE: Centering Corp; 1998.

Kubler-Ross E. *On Children and Death.* New York: MacMillan; 1999.

Lehna CR. Children's descriptions of their feelings and what they found helpful during bereavement. *American Journal of Hospice and Palliative Care.* 1995; 12: 24-30.

Mehren E. *After the Darkest Hour, the Sun Will Shine Again.* New York: Fireside; 1997.

Miles A. Caring for the family left behind. *American Journal of Nursing.* 1993; 93: 34-36.

Norrie-Shortle C, Young PA & Williams MA. Understanding death and grief for children three and younger. *Social Work.* 1993; 38: 736-742.

Olive J. Storytelling for grieving children. *American Journal of Hospice and Palliative Care.* 1996; 13: 19-20.

Opie ND. Childhood and adolescent bereavement. *Annual Review of Nursing Research.* 1992; 10: 127-141.

Parkes CM. *Bereavement Studies of Grief in Adult Life.* New York: International University Press; 1972.

Pettle SA & Britten CM. Talking with children about death and dying. *Child Care Health Development.* 1995; 21: 395-404.

Rosen EJ. *Families Facing Death: Family Dynamics of Terminal Illness.* New York: Lexington Books; 1990.

Rosof BD. *The Worst Loss.* New York: Henry Holt and Company; 1994.

Seager KM & Spencer SC. Meeting the bereavement needs of kids in patient/families – not just playing around. *Hospice Journal.* 1996; 11: 41-66.

Shapiro ER. *Grief as a Family Process: A Developmental Approach to Clinical Practice.* New York: The Guilford Press; 1994.

Smith SC. *The Forgotten Mourners: Guidelines for Working with Bereaved Children.* London; Philadelphia, PA: Jessica Ringsley Publications; 1999.

Stewart ES. Family-centered care for the bereaved. *Pediatric Nursing.* 1995; 21: 181-184.

Walker CL. Sibling bereavement and grief responses. *Journal of Pediatric Nursing.* 1993; 8: 325-334.

Wolfelt AD & Mackey L. *A Child's View of Grief.* Fort Collins, CO: Center for Loss and Life Transition; 1991.

Worden JW. *Grief Counseling & Grief Therapy: A Handbook for the Mental Health Practitioner.* New York: Springer Publishing; 1991.

Worden JW. *Children and Grief: When a Parent Dies.* New York: The Guilford Press; 1996.

Worden JW. Bereavement. *Seminars in Oncology.* 1985; 12: 472-475.

Worden JW, Monahan JR. Caring for Bereaved Parents. In A Armstrong-Daily & SZ Goltzer, eds. *Hospice Care for Children.* New York: Oxford University Press; 1993: 122-139.

CHILDREN AND DEATH

Cook AS & Dworkin DS. *Helping the Bereaved: Therapeutic Interventions for Children, Adolescents and Adults.* New York: Basic Books; 1992.

Fitzgerald H. *The Grieving Child – A Parent's Guide.* New York: Fireside Book; 1992.

Goldman L. *Life & Loss – A Guide to Help Grieving Children.* Bristol, PA: Accelerated Development; 1994.

Grollman EA, ed. *Bereaved Children and Teens – A Support Guide for Parents and Professionals.* Boston: Beacon Press; 1995.

Wolfelt A. *Helping Children Cope with Grief.* Bristol, PA: Accelerated Development; 1983.

PHYSICAL CARE OF THE TERMINALLY ILL CHILD

Calabresi P. Medical alternatives to alternative medicine. *Cancer.* 1999; 86: 1887-1889.

Charles C, Gafni A & Whelan T. Shared decision making in the medical encounter: what does it mean? *Social Science and Medicine.* 1997; 44: 681-692.

Collins JJ. Intractable pain in children with terminal cancer. *Journal of Palliative Care.* 1996; 12: 29-34.

Collins JJ, Grier HE, Kinney HC & Berde CB. Control of severe pain in children with terminal malignancy. *Journal of Pediatrics.* 1995; 126: 653-657.

DeVebber LL. Symptom management. In: Doyle D, Hanks GW & MacDonald N, eds. *Oxford Textbook of Palliative Medicine.* Oxford: Oxford University Press; 1993: 691-699.

Foley GV &, Whittam EH. Care of the child dying of cancer. *CA – Cancer Journal for Clinicians.* 1991; 40: 327-354.

Goldman A, ed. *Care of the Dying Child.* Oxford: Oxford University Press; 1994.

Guylay J. Home care for the dying child. *Issues in Comprehensive Pediatric Nursing.* 1989; 12: 33-69.

Hill L, ed. *Caring for Dying Children and Their Families.* London: Chapman and Hill; 1994.

Hunt AM. A survey of signs, symptoms and symptom control in 30 terminally ill children. *Developmental Medicine and Child Neurology.* 1990; 32: 341-346.

McGrath P. Pain Control. In: Doyle D, Hanks GW & MacDonald N, eds. *Oxford Textbook of Palliative Medicine.* Oxford: Oxford University Press; 1993: 681-691.

Regnard C & Hockley J. *Flow Diagrams in Advanced Cancer and Other Diseases.* London: Edward Arnold; 1995.

Wrede-Seaman L. *Symptom Management Algorithms for Palliative Care.* Yakima, WA: Providence Hospice of Yakima; 1996.

PROFESSIONAL GRIEF DISTRESS

Beaton JI & Degner LF. Life and death decisions: the impact on nurses. *The Canadian Nurse.* 1990; 86: 18-22.

Davies B, Clarke D, Connaughty S, Cook K, MacKenzie B, McCormick J, O'Loane M & Stutzer C. Caring for dying children: nurses' experiences. *Pediatric Nursing.* 1996; 22: 500-506.

Davies B & Eng B. Factors influencing nursing care of children who are terminally ill: a selective review. *Pediatric Nursing.* 1993; 19: 9-14.

Larson DG. *The Helper's Journey: Working With People Facing Grief, Loss, and Life-Threatening Illness.* Champaign, IL: Research Press Company; 1993.

PSYCHOSOCIAL CARE OF THE TERMINALLY ILL CHILD

Armstrong-Dailey A & Goltzer SZ, eds. *Hospice Care for Children.* New York: Oxford University Press; 1993.

Bacon D. Spiritual and cultural aspects. In: A Goldman, ed. *Care of the Dying Child.* Oxford, New York, Tokyo: Oxford University Press; 1994: 132-144.

Bluebond-Langner M. *The Private Worlds of Dying Children.* Princeton: Princeton University Press; 1989.

Byrne CS. Speaking up for the little ones. *Hospice.* 1996; 7: 26-29.

Cairns AB. Spirituality and religiosity in palliative care. *Home Health Care Nurse.* 1999; 17: 450-455.

Doka KJ. *Living with Life-Threatening Illness: A Guide for Patients, Their Families, and Caregivers.* Lexington, MA: Lexington Books; 1993.

Lansdown R. Communicating with children. In: Goldman A, ed. *Care of the Dying Child.* Oxford, New York, Tokyo: Oxford University Press; 1994: 93-106.

Glaser, Barney, Strauss, Anselm. *Awareness of Dying: A Study of Social Interaction.* Chicago: Aldine Press; 1965.

Grollman EA. A parent's nightmare – a child is dying … enter the hospice worker. *Hospice.* 1996; 7: 19-22.

McQuillan R & Finlay I. Facilitating the care of terminally ill children. *Journal of Pain and Symptom Management.* 1996; 12: 320-324.

FAMILY RESOURCES

NATIONAL RESOURCES

CENTER FOR LOSS AND GRIEF THERAPY
10400 Connecticut Avenue, Suite 514
Kensington, MD 20985
(301) 942-6440

CHILDREN'S HOSPICE INTERNATIONAL
2202 Mt. Vernon Avenue, Suite 3C
Alexandria, VA 22301
800-2-4-CHILD or (703) 684-0300

RAINBOW, INC.
1111 Tower Road
Schaumburg, IL 60173-4305
800-266-3206

COMPASSIONATE FRIENDS
PO Box 3696
Oak Brook, IL 60522-3696
(630) 990-0010

THE CANDLELIGHTERS CHILDHOOD CANCER FOUNDATION
7910 Woodmont Avenue, Suite 240
Bethesda, MD 20814
800-366-2223

CENTERING CORPORATION
1531 N. Saddle Creek Road
Omaha, NE 68104-5064
(402) 553-1200

RAINBOW CONNECTION
479 Hannah Branch Road
Burnsville, NC 28714
(704) 675-9670

SOURCES OF BOOKS FOR BIBLIOTHERAPY ON END OF LIFE CARE

Berg PJ, Devlin MK & Gedaly-Duff V. Bibliotherapy with children experiencing loss issues. *Comprehensive Pediatric Nursing.* 1980; 4: 37-50.

Cohen L. Here's something I want you to read. *RN.* 1992; 55: 56-59.

Cuddigan M & Hanson MB. *Growing Pains: Helping Children Deal with Everyday Problems Through Reading.* Ann Arbor, MI: Books on Demand; 1988. Phone number: 800-521-0600.

Doll B & Doll CA. *Bibliotherapy With Young People: Librarians and Mental Health Professionals Working Together.* Libraries Unlimited; 1997. Address: PO Box 6633, Engleweek, CO 80155-6633. Telephone: 800-237-6124.

Fosson A & Husband E. Bibliotherapy for hospitalized children. *Southern Medical Journal.* 1984; 77: 342-346.

Kaywell JF, ed. *Literature to Help Troubled Teenagers Cope with Family Issues.* Greenwood Publishing Group, Inc; 1999. Address: 88 Post Road West, Westport, CT 06881. Telephone: 800-225-5800 or (203) 226-3571. Web site: www.greenwood.com

Mohr C, Nixon D & Vickers S. *Books That Heal: A Whole Language Approach.* Libraries Unlimited; 1991. Address: PO Box 6633, Englewood, CO 80155-6633. Telephone: 800-237-6124.

Pardeck JT & Pardeck JA. *Children in Foster Care and Adoption: A Guide to Bibliotherapy.* Greenwood Publishing Group, Inc; 1998. Address: 88 Post Road West, Westport, CT 06881. Telephone: 800-225-5800 or (203) 226-3571. Web site: www.greenwood.com

Pardeck JT & Pardeck JA. *Bibliotherapy: A Clinical Approach For Helping Children. (Special Aspects of Education, Vol 16).* Gordon & Breach Publishing Group; 1993. Address: PO Box 32160, Newark, NJ 07102. Telephone: 800-545-8398. Web site: www.gbhap.com

Pardeck JT & Pardeck JA.*Young People with Problems: A Guide to Bibliotherapy.* Greenwood Publishing Group, Inc; 1986. Address: 88 Post Road West, Westport, CT 06881. Telephone: 800-225-5800 or (203) 226-3571. Web site: www.greenwood.com

Pearl P. *Helping Children Through Books: A Selected Booklist.* Church & Synagogue Library Association; 1990. Address: PO Box 29357, Portland, OR 97280-0357. Telephone: 800-452-2752 or (503) 244-6919. Web site: www.worldaccessnet.com

Philpot JG. *Bibliotherapy for Classroom Use.* Nashville, TN: Incentive Publications; 1997. Telephone: 800-421-2830.

Wallace NE. Special books for special children. *Child Health Care.* 1983; 12: 34-36.

Ziegler RG. *Homemade Books to Help Kids Cope: An Easy-to-Learn Technique for Parents and Professionals.* Magination Press; 1992. Address: 750 First St. NE, Washington, DC 20002-4242. Telephone: 800-374-2721. Web site: www.maginationpress.com

WEBSITES FOR BIBLIOTHERAPY FOR END OF LIFE CARE

www.ghbooks.com
www.noble.mass.edu/nobchild/biblio.htm
www.hplhamilton.on.ca/children/booklist.htm

References

Bacon D. Spiritual and cultural aspects. In: A Goldman, ed. *Care of the Dying Child.* Oxford, New York, Tokyo: Oxford University Press; 1994: 132-144.

Billings JA & Block S. Palliative care in undergraduate medical education. Status report and future directions. *Journal of the American Medical Association.* 1997; 278: 733-738.

Broome ME, Rehwaldt M & Fogg L. Relationships between cognitive behavioral pain measures in children aged 3-7 years after surgery. *Journal of Pain and Symptom Management.* 1988; 5: 350-356.

Buchman R & Baile W. How to Break Bad News to Patients With Cancer: A Practical Protocol for Clinicians. *American Society of Clinical Oncology.* 1998; 203-208.

Bullock M, Pheley A, Kiresuk T, Lenz S & Culliton P. Characteristics and complaints of patients seeking therapy at a hospital-based alternative medicine clinic. *The Journal of Alternative and Complementary Medicine.* 1997; 4: 325-335.

Calabresi P. Medical alternatives to alternative medicine. *Cancer.* 1999; 86: 1887-1889.

Cairns AB. Sprirtuality and religiosity in palliative care. *Home Health Care Nurse.* 1999; 17: 450-455.

Carron AT, Lynn J & Keaney P. End-of-life care in medical textbooks. *Annals of Internal Medicine.* 1999; 130: 82-86.

Cattell E. Nurse practitioners' role in complementary and alternative medicine: active or passive? *Nursing Forum.* 1999; 34: 14-23.

Charles C, Gafni A & Whelan T. Shared decision-making in the medical encounter: What does it mean? *Social Science and Medicine.* 1997; 44: 681-692.

Doka KJ. *Children Mourning, Mourning Children.* Washington, DC: Hospice Foundation of America; 1995.

Driggers DL, Nussbaum JS, & Haddock KS. Role modeling: an educational strategy to promote effective cancer pain management. *Oncology Nursing Forum.* 1993; 20: 959-962.

Ernst E & Cassileth BR. How useful are unconventional cancer treatments? *European Journal of Cancer.* 1999; 35: 1608-1613.

Faulkner KW & Armstrong-Dailey A. Care of the dying child. In PA Pizzo & DG Poplack, eds. *Principles and Practice of Pediatric Oncology.* Philadelphia: Lippincott-Raven; 1997: 1343-1355.

Favaloro R & Touzel B. A comparison of adolescents' and nurses' postoperative pain ratings and perceptions. *Pediatric Nursing.* 1990; 16: 414-424.

Ferrell B, Virani R & Grant M. Analysis of end-of-life content in nursing textbooks. *Oncology Nursing Forum.* 1999; 26: 869-876.

Foley KM. Controlling the pain of cancer. *Scientific American.* 1996; 275: 384-388.

Foley GV & Whittam EH. Care of the child dying of cancer: Part II. *Cancer.* 1991; 41: 52-60.

Frager G. Palliative care and terminal care of children. *Child and Adolescent Psychiatric Clinics of North America.* 1997; 6: 889-909.

Goldman A, ed. *Care of the Dying Child.* New York: Oxford Medical Press; 1994.

Glaser BG & Strauss AL. *Awareness of Dying.* Chicago: Aldine Press; 1965.

Grollman EA. *Bereaved Children and Teens: a Support Guide for Parents and Professionals.* Boston: Beacon Press; 1996.

Harrington V, Lackey NR & Gates MF. Needs of caregivers of clinic and hospice cancer patients. *Cancer Nursing.* 1996; 19: 118-125.

James K. The joys and pitfalls of complementary therapies. *Australian Nursing Journal.* 1999; 6: 34.

Kart T, Christrup LL & Rasmussen M. Recommended use of morphine in neonates, infants and children based on a literature review: Part 2 – Clinical use. *Paediatric Anaesthesia.* 1997; 7: 93-101.

Lansdown R. Communicating with children. In: A Goldman, ed. *Care of the Dying Child.* Oxford, New York, Tokyo: Oxford University Press; 1994: 93-106.

Lansdown R & Goldman A. Annotation of the psychological care of children with malignant disease. *Journal of Child Psychiatry.* 1988; 29: 555-567.

Laizner AM, Yost LMS, Barg FK & McCorkle R. Needs of family caregivers of persons with cancer: a review. *Seminars in Oncology Nursing.* 1993; 9: 114-120.

Martin G. Experience talks: How we've managed pain and symptoms in our pediatric hospice patients. *Hospice.* 1998; 9: 21-23.

McGrath PA & Goldman A, Stevens MM, Davis B, Howell D, Eng B, Dominica F, Pollard B, Faulkner KW, Levetown M, & Carter MA. *Pediatric Palliative Care.* New York: Oxford University Press; 1998: 1013-1119.

Papadatou D. Training health professionals in caring for dying children and grieving families. *Death Studies.* 1997; 21: 575-600.

Rando TA. *Grief, Dying and Death: Clinical Interventions for Caregivers.* Champaign, IL: Research Press Company; 1984.

Ross M, Carroll G, Knight J, Chamberlain M, Fothergill-Bourbonnais F & Linton J. Using the OSCE to measure clinical skills performance in nursing. *Journal of Advanced Nursing.* 1988; 13: 45-56.

Spinetta JJ. Disease-Related Communication: How to Tell. In: J. Kellerman, ed. *Psychological Aspects of Childhood Cancer.* Springfield, IL. Charles C Thomas; 1980.

vonGruenigen VE & Hopkins MP. Alternative medicine in gynecologic oncology: A case report. *Gynecologic Oncology.* 2000; 77: 190-192.

Wong DL & Baker C. Pain in children: comparison of assessment scales. *Pediatric Nursing.* 1988; 14: 9-17.

Worden JW. *Children and Grief: When a Parent Dies.* New York: The Guilford Press; 1996.

Zeltzer LK, Jay SM & Fisher DM. The management of pain associated with pediatric procedures. *Pediatric Clinics of North America.* 1989; 36: 941-964.

Zerwekh JV. Do dying patients really need IV fluids? *American Journal of Nursing.* 1997; 3: 26-30.

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