

# Supportive Care for Infants and Toddlers with Special Health Needs

Raphael, 30 months old, has just returned to his child care program after a 10-day hospital stay during which he was diagnosed with asthma. His doctor has prescribed daily medication to be administered using a nebulizer. In the past Raphael handled most separations from his mother well, napped easily, and was successfully toilet trained. Now, during his first week back, he is extremely upset when his mother drops him off at the center; acts up at nap time, rarely sleeping; and has returned to diapers.

Darius is a three-year-old with sickle-cell disease. He requires oral antibiotics daily and lots of liquids to prevent his occasional episodes of pain and swelling in his hands and feet. Today at his early childhood program, his forehead is hot to the touch, and he seems panicked as he complains that his feet and hands hurt.

Recurring dehydration and pneumonia have resulted in four hospitalizations in Alicia's first year of life. She has been diagnosed with cystic fibrosis but has minimal symptoms and does not require regular medication or chest physical therapy. Yet she has not reached many of the expected developmental milestones: she does not sit alone or crawl, and she does not eat well. Her anxious single father has just enrolled her in a child care center.

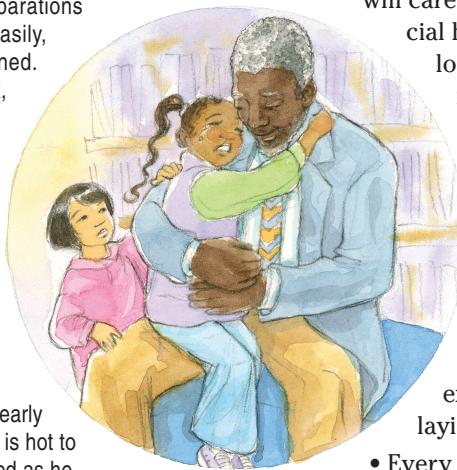
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## WHAT WOULD YOU DO IF ONE OF THESE CHILDREN WERE IN YOUR CARE?

Infant/toddler teachers—even those with years of training and experience—are often bewildered and even frightened by the challenge of supporting children with chronic illness and health issues and their families.

At some time in their career, most early childhood teachers will care for a child whose development is affected by a special health problem. Recent medical advances leading to longer lives and shorter hospital stays, current trends in managed care, more mothers working outside the home, and laws that require inclusion have increased the number of children with chronic illness and special health needs in early care and education programs.



We do not know for sure how many infants and toddlers have special health care needs, but here is what we do know:

- Children's emotional, physical, and intellectual experiences in the first three years of life are vital in laying the foundation for the future.
- Every young child should have regular checkups with a medical professional.
- Approximately 40 percent of children four years and younger have at least one hospital visit each year (National Center for Health Statistics 1999).
- Research (Vernon et al. 1965; Thompson 1985) repeatedly indicates that older infants and toddlers (six months to three years) are most vulnerable to the effects of hospitalization or a health care crisis.
- The effects of hospitalization-related stress in young children, such as behavior problems, sleep problems, or regressions in previously learned developmental skills, are often seen at home and in early childhood settings.

Early childhood staff face new challenges when a child with special health needs enrolls in or returns to their program. In addition to obtaining accurate current information about health status, treatments, and medications; developing health care and emergency plans; and determining appropriate adaptations to activities and the environment; teachers must be prepared to provide immediate and sensitive support for the special emotional and developmental needs of these children.

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## Impact of chronic illness and hospitalization

Just as every child is unique, so every chronic illness, health condition, and disability has a unique pattern of symptoms and requires a particular treatment. Yet regardless of their differences in diagnosis, children who are ill and their families face many of the same issues.

### Infants

Illness disrupts an infant's normal routines and rhythms, often resulting in loss of appropriate stimulation and inconsistent nurturing. A child may have a limited capacity to receive proper nutrition and to explore, which may disrupt physical,

social, and cognitive development. Furthermore, the distressing impact of illness may cause an infant's parents to withdraw emotionally, which can have a critical effect on the child's ability to develop secure attachments.

During hospitalization, a baby's sensory experiences may be limited and different from those at home. The sights, sounds, and smells of a hospital are often overstimulating. Social interactions may be intrusive, and health care teams are on constantly rotating shifts. In these circumstances it may be difficult for an infant to develop or maintain trust and to form normal attachments.



**Illness and hospitalization often threaten a toddler's developing autonomy.**

Hospitalized children may become cautious about seeking new experiences and require more reassurance from caring adults. Toddlers do not understand illness. Their magical and egocentric thinking may lead them to believe they caused their own illness or that their illness is punishment for bad behavior.

During hospitalization, being away from parents is the greatest concern even for a toddler who has learned to cope with routine separations. A child might view such separation as abandonment, a sign of lost love, or punishment. Toddlers may be frightened by unfamiliar surroundings and intrusive procedures by strangers. Hospitalization may limit opportunities to socialize or succeed in accomplishing simple tasks. Hospitalized children may show increased intensity in their reactions and behavioral responses to stress as well as changes in their daily habits, such as eating, toileting, and sleeping. Children may regress in any or all areas of development. Regression can be intensified by physical and emotional disruptions in parent support.

### Helping infants and toddlers cope

A young child with special health needs is first and foremost a child. As with all children, developmentally appropriate care requires an ongoing process of evaluating needs, planning and carrying out a course of action, evaluating results, reevaluating needs, and revising plans as necessary. Strategies that facilitate learning and

## Teacher Tips for Helping Infants and Toddlers

Here are some ways teachers can help young children cope with the effects of a health crisis or hospitalization:

- Be prepared for the need to reestablish trust, no matter how strong a child's prior relationship with you. Respond immediately to an infant's expressions of need or discomfort; soothe and comfort the child. Make an extra effort to maintain schedules that are in sync with the baby's rhythms, and be alert to the baby's cues that he is ready to interact or play, or that he needs a break from activity.
- Provide appropriate stimulation and freedom for a child to explore and master new experiences.
- Offer toddlers continual confirmation that they are loved and that trusted adults are there for them. Reassure them that the illness or hospitalization is not their fault and that it is not punishment for bad behavior.
- Maintain consistent schedules and provide choices to allow the child as much control over the environment as possible. Encourage mastery of self-help skills and socialization, but be patient—children often need time to regain previously mastered skills, such as toileting or taking turns.
- Support children's reliance on security objects such as a pacifier, blanket, or favorite stuffed animal and other successful self-coping strategies.
- Promote independence, but remember that all children need age-appropriate guidance and limits.
- Encourage and validate all suitable expressions of emotions. Like

all toddlers, those with special health needs struggle to sort out and express their emotions in an appropriate manner. Anger and frustration might be expressed aggressively in a way that results in a child harming himself or others. A limited vocabulary may prevent some young children from describing different emotions; others may have the skills but may not be willing to talk about feelings, especially if they are afraid those feelings will be considered unacceptable.

- Let children be the children they need to be, but recognize their maturity when they try to express themselves and cope with their world. While you may see regression in some areas of development, you may also see disproportionate growth in other areas as a result of the grown-up knowledge and experience that illness and treatment can bring.
- Be alert in your observations, but resist expecting all children with chronic illness to behave a certain way. Focusing solely on medical issues and developmental delays may make it difficult to see a child's strengths, which are the basis for continued growth. If problems do occur, don't automatically assume they are the result of illness. Children often behave according to adult expectations.
- Read books to children that present information about health care experiences in a truthful but encouraging manner and that include realistic illustrations or photographs. The presence of familiar characters like Big Bird, the Berenstain Bears, or Dora the Explorer can be reassuring.

development for all children are applicable, but some children may need extra help and more time for practice as well as some adaptations to the environment, activities, or materials.

## Developmental milestones

The sequence of developmental milestones is the same for all children—with or without chronic illness—but chronic illness and its resulting symptoms may slow the rate of development. Keep in mind that some toddlers with chronic illness or who have had frequent or prolonged hospitalizations may not have mastered the developmental tasks of infancy. An 18-month-old may need help developing trust and feeling secure, or a three-year-old may need help learning to feed himself (see "Teacher Tips for Helping Infants and Toddlers").

## Progress through play

Play is the means through which children learn, socialize, express feelings, and process their concerns and fears. Play promotes children's progress in all areas of development.

In addition to encouraging developmentally appropriate play for all children in their care, teachers can facilitate medical play that focuses on emotional issues related to health care. (See "Helpful Materials to Have in Your Classroom," p. 4.)

**Medical play.** Recently hospitalized toddlers often act out separation anxiety or medical procedures in dramatic play, which may reveal their fears about what happened or what might happen next. Children can pretend they are health care professionals and the dolls their patients. Through play, children can explore stressful experiences in a safe environment, helping children understand and gain some control over them. A child may reveal how he can be comforted if asked, "What can we do to make your doll feel better?"

Teachers can facilitate this type of play by taking the role of the toddler and allowing the child to play the grown-up or by asking questions about the dramatic play. Try to model and reinforce effective coping strategies and, whenever safely possible, let the child choose from alternative strategies. Consult with parents and available health care resources to learn as much as you can about any hospital stays or procedures the child will undergo and her reaction to them in order to help you respond appropriately. As always, keep the child's family advised of any concerns that are revealed through the child's play.

## Helpful Materials to Have in Your Classroom

Some play materials help young children cope with illness and health care experiences. Most are available in educational supply catalogs. They should be readily accessible so teachers can encourage children to use them on an ongoing basis, not just when a crisis arises.

Helpful materials include

- Books whose characters include children with all kinds of differences, including illness and disabilities. Have books in which the difference is the focus of the story and those in which the difference is not relevant to the narrative. Diversity should be presented as a natural part of the world.
- Books that explore going to the doctor, dentist, hospital, clinic, eye doctor, and so on. (Find book recommendations online at [www.childlife.org](http://www.childlife.org) in Information Central,

Daily Clinical Practice; and in Meyer and Vadasy's book *Sibshops: Workshops for Siblings of Children with Special Needs*.)

- Wall pictures that reflect the medical experiences in the previous point and that include children with all kinds of differences.
- Props and toys, such as eyeglasses (with lenses removed), dolls with walkers, and wheelchairs for dolls, reflecting people with special needs.
- Medical clothing for dressing up, such as child-size scrubs, surgical masks, and white lab coats.
- Medical materials like bandages, specimen cups, paper medicine cups, tongue depressors, and X-ray films. Include both real and toy medical instruments such as stethoscopes, otoscopes, blood pressure cuffs, and syringes (without needles).

Teachers can help toddlers explore medical items and use them to express themselves in art. Using materials like tongue depressors, specimen cups, and paper medicine cups in nonthreatening art activities allows children to become more familiar with the materials, reducing their fear of them. These activities often lead toddlers to express or discuss their experiences or the feelings associated with them.

**Active play.** Active play is another way young children resolve some of their feelings about difficult experiences. Safe physical play, such as banging, pounding, and throwing activities, provides appropriate ways to release energy and vent anger and frustration. Frightened or angry about all the injections they received, toddlers may pretend to give shots to others as they attempt to sort out

their feelings about this medical experience. If their actions hurt or frighten others, encourage toddlers to express their feelings but direct their actions to dolls or animal figures. Music and movement also allow infants and toddlers to express emotions and release energy.

## Young children and pain

**Encourage children to listen to their bodies and when they are in pain, to tell an adult who can help them.**

Pain is a personal experience that is often difficult to assess in someone else. Some young children hide their pain, some display it freely in seeking help, and others fall somewhere in between these extremes.

A child's willingness to reveal pain is influenced by many factors, including mood, current physical state, desire to please, fear, cultural beliefs, family customs, and the presence of a trusting, supportive person who the child believes will respond appropriately. Encourage children to listen to their bodies and when they are in pain, to tell an adult who can help them. Children need to express their pain and their feelings about it.

While cultures vary in their beliefs and attitudes about crying, from birth infants of all cultures cry spontaneously in response to distress. Crying is a natural and often automatic response to pain that can be helpful not only in alerting adults to children's pain but also as a method of releasing the tension and anxiety pain causes. It frequently relieves stress and pain, even if only temporarily, as many young children exhaust themselves by crying and then fall asleep.



### Infants

Even the tiniest infants can let you know they are in pain. Cries, facial expressions, and body language communicate a baby's need for help. She may become restless and cling or whine; have decreased activity or increased frantic activity; lose her appetite; or be difficult to console. Each baby's signals may differ, but the best gauge is to compare an infant's current behavior to her typical behavior.

### Toddlers

Most toddlers can tell us if they are in pain. Even if they cannot verbally communicate the source and level of their pain, in the presence of a patient, trusted caregiver, toddlers can usually accurately point to the site of pain. If they can't indicate on their own body, they might point to the spot in an illustration or photograph or on a doll's body.

Some toddlers are reluctant to say they are in pain, but changes in their normal patterns of behavior or movement may signal that something is wrong. A child who avoids putting weight on one foot may have an injury; restricted movement of an arm may be an effort to avoid discomfort; protectively holding the stomach may indicate tenderness. Experience, combined with input from a child's family and health care team, will help teachers learn a child's signals. The book *A Child in Pain: How to Help, What to Do* (Kuttner 1996) is an excellent resource for responding to young children in pain.

### Helping families cope

## The Cultural Context of Illness

Illness adds another layer to the context in which we view children and families; their behavior must be filtered through the illness, its limitations and its consequences. In addition, families' beliefs about illness influence their responses to it, and therefore influence their interactions with those who provide services.

A child's development can be fully understood only when it is viewed in the cultural context in which it takes place. When health problems arise, a family's culture, race, ethnicity, and religion influence the meanings attributed to a child's illness or disability and how, when, or from whom the family asks for help. It is not possible to know everything about the cultures of the children in our care; willingness to acknowledge them and learn more about them, including the "culture" of a child's chronic illness (see "The Cultural Context of Illness"), enables teachers to provide more supportive, sensitive care.

### Communication

During health crises, families need to believe they can trust their young child's teacher. They need a place to vent feelings and fears without being judged. They need input from teachers on how their child is coping. Be careful not to judge or add to any guilt a family may already feel.

Sometimes it's hard for parents to talk with their children about upsetting things. Illness, pain, and death are so difficult for adults to deal with that they often want to

shelter their vulnerable children from the anxiety these topics can produce. We know from experience, however, that helping young children understand what to expect can make it easier for them to handle a health care crisis or hospitalization.

If the child's health care team has not prepared the family for potential behavior changes, especially after a health crisis or hospitalization, teachers can provide important information. Explain that although not all children use the behaviors, the changes the family is witnessing are fairly typical for young children in similar situations. Parents often worry that regressions may be permanent. If their medical team has not indicated a lasting or permanent disability, help the family understand that with a little extra patience, attention, and reassurance, their child will regain his previously acquired skills.

### **Family involvement**

Quality child care encourages family participation in the program at all times, but it's especially important to maximize parental involvement when a child has special health needs. It helps the child feel safe and secure and gives early childhood staff opportunities to renew the family's confidence in their own abilities as caregivers.

Many parents are understandably overprotective when their young child is diagnosed with a serious illness or during and after a medical crisis. Teachers who model sensitive, supportive, and individualized child care may help ease families' fears. Show families how to accept the child's limits and, while protecting the child from danger and frustration, allow the child to return to normal activities whenever possible and provide opportunities for growth and development.

Families as well as the children in your care may need help from other professionals. Encourage families to get the support and services they need. (For more ideas about supporting families, see "Child Life Professionals in Hospitals," p. 7.)



### **Helping young siblings and peers cope**

The changes that occur in the lives of families coping with a child with chronic illness affect the other children in the family, as well as the child's friends and playmates in their early childhood program. Even very young children perceive changes in parental behavior, and they experience stress as their relationships with the important people in their lives are disrupted.

Teachers or out-of-home caregivers may become the most consistent figures in the lives of well siblings, and they can be an important source of positive support for children who have a hospitalized or chronically ill brother or sister. It's important for child care staff to be aware of any changes in residence or caregiving arrangements that might affect the children in their care. Often during the hospitalization of one child, parents send their other children to live with friends or relatives. Even the most loving and trusted alternatives cannot replace the well children's family, and the separation from their parents as well as siblings will have an impact. They need explanations to reduce the confusion and comforting to diminish the isolation.

## Child Life Professionals in Hospitals

Child life professionals focus on the emotional and developmental needs of children in the context of health care. A child life specialist holds a minimum of a baccalaureate degree in child life, psychology, child development, human and family studies, or another closely related field. For certification, a child life specialist must complete a 480-hour internship in a child life program, under the direct supervision of a certified child life specialist, followed by a comprehensive written examination given by the Child Life Council. Requirements to maintain certification include professional development hours, which can include lectures, college courses, and seminars related to direct and indirect patient care, as well as retesting with the Child Life Council at regular intervals.

The child life profession grew in response to increasing evidence that illness, chronic conditions, and hospitalization can disrupt the development of children and effective family functioning. Research demonstrates that the negative impact of illness and hospitalization can be modified by specific interventions. While other members of the health care team generally focus on medical issues, child life

specialists focus on supporting a child's strengths to minimize stress and anxiety in order to promote optimal growth and learning. As advocates for children and their families, child life professionals provide opportunities for children to learn, express themselves, and gain a sense of mastery. In addition, they facilitate socialization and family involvement in the care of their hospitalized child.

If a child in your care requires hospitalization, encourage the family to use child life services if available. Child life programs aim to "promote optimum development of children and their families, to maintain normal living patterns, and to minimize psychological trauma. Typically, child life professionals (1) supervise therapeutic and diversional play; (2) prepare children for and assist children during medical tests and procedures through education, rehearsal, and coping skill development; and (3) support families during hospitalization or challenging events" ([www.childlife.org](http://www.childlife.org)).

Find more information about child life theory and professionals at [www.childlife.org](http://www.childlife.org), the Web site of the Child Life Council.

one seems to pay much attention to special milestones they achieve. Furthermore, if no one helps them understand what is happening to their sibling, their family, and therefore their life, they may feel left out and isolated.

### Signs of distress

As with all young children, behavior change is often the best indicator that something is wrong. Just as you would for the child with chronic illness, provide opportunities for well

### Fear

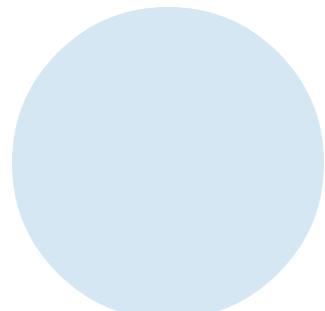
In spite of the uniqueness of each illness, child, and family, several reactions are common among healthy infants and toddlers who have friends or siblings with chronic conditions. One of the most common reactions is fear, which can come in many forms. The healthy friends or siblings may fear that they or their parents will get sick. They may become especially fearful if their sibling is taken to the hospital. Not understanding what will happen to their brother or sister at the hospital, toddlers often fantasize about terrible things that may occur, including never seeing their sibling again.

### Guilt

Younger children who are still in the egocentric and magical stage of thinking are especially prone to feelings of guilt. They may believe that they have caused their sibling's or friend's illness by something they did or said; perhaps they could have prevented it if they had been good. Others may feel guilty because in anger or frustration they have wished their sibling or playmate harm or even death.

### Jealousy

Healthy toddlers are often jealous of the extra attention adults offer their chronically ill siblings or playmates. Friends and family frequently give extra time, care, and gifts to sick children; even the attention provided by health care professionals can lead to sibling rivalry and resentment. When everything around them seems to focus on someone else, well siblings may feel rejected. Often no



siblings and peers to express feelings and resolve conflicts. Watch for behavioral cues that reveal positive or negative feelings and coping strategies. Some children may show a tendency to act out while others may withdraw.

If it appears that a well sibling or friend is having difficulty coping, let the family know of your concerns, being careful not to add to any guilt they may already feel. Let them know that you will do what you can to address these issues and offer to suggest ways they may be able to help their well child adjust, like setting aside a little time each day to spend one-on-one with the well child or making a bedtime video or audio recording of a parent reading the child's favorite story and saying goodnight if that parent cannot be with the well child at bedtime.

### Closing thoughts

When you become aware that a child in your group has special health needs, learn as much as you can about the relevant illness or condition. The more you learn, the more confident and supportive you can be. Seeking general knowledge about an illness does not replace the need for specific information about each child, but it provides you with important background information as well as resources you can share with the family. Most children's hospitals and the Child Life Council offer helpful information on their Web sites. Nonprofit and advocacy groups for specific conditions are also a good source of information and support.

Develop relationships with health care professionals and facilities in the area so that you can call on them when you or children in your care and their families need help and information. Building partnerships among families, teachers, and medical staff allows their combined expertise to provide effective supportive child care.

Professional development helps early childhood practitioners develop emotionally responsive practice and supportive environments for all the children in their care. Health care professionals from local hospitals and the community might conduct in-service training for child care staff on a variety of relevant topics as well as offer support for the emotional stress that accompanies caring for children with special health needs. For example, child

life specialists can suggest, and may be able to provide, developmentally appropriate activities for young children who are coping with their own or another's illness.

Children with special health needs represent a diverse, vulnerable, and often underserved population. By combining knowledge of child development with child life theory and practice, caregivers can provide sensitive and emotionally responsive support to these children and their families.

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