

When a Young Person's Health Becomes Problematic

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Chapter

In the best of all possible worlds children would not develop serious health problems. We associate youth with vigor, energy, and well-being. Whereas all parents expect their children to acquire an occasional cold, earache, stomachache, or even a childhood disease such as chicken pox, they typically do not consider the likelihood that their child will develop a serious illness that has no cure and that will require continuous adaptation due to compromised bodily functioning. Similarly, young children, who are normally egocentric and bursting with feelings of strength and invulnerability, are even less likely to understand or accept the constraints of a serious illness or disability. The child thinks that older people sometimes get sick and have to go to the hospital, but not “kids like me.” Therefore, the first challenge in working with medically compromised youth and their families is to help them deal with their initial fear, denial, and sense of unfairness in having to cope with all the pain and disruptions that accompany a serious health condition.

This book presents helping approaches to assist young people and their families handle in a positive manner the stresses involved in living with an illness or disability. Some conditions are evident at birth, and others may arise in early or later childhood or adolescence. The chapter authors discuss the multiplicity of factors that impact the coping ability of the child and family as they struggle to adapt to different acute and chronic health conditions, some of which may be life-threatening. Selected helping approaches that encourage positive attitudes and stimulate family and individual strengths are presented, together with developmental considerations that influence the patient, his or her siblings, and the parents.

Interprofessional Collaboration

Because helping a medically compromised child or adolescent inevitably involves input from a variety of professionals in different settings over many years, this book emphasizes the importance of interprofessional collaboration. Pediatricians, teachers, social workers, pastoral counselors,

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child life specialists, nurses, and many others typically are involved in any single health crisis. Part 2 of the book highlights the separate and collaborative roles of different professionals on behalf of youth who are coping with serious health and medical challenges. Each profession has its own focus, training, and language, but if children and families are to receive the best possible bio- psychosocial care it is imperative that all helpers be able to communicate with one another and acknowledge and appreciate their distinctive roles and contributions. This can be key to a positive outcome for the patient, the family, and the staff. We hope that the book will serve as a resource for social workers and other practitioners who counsel physically challenged children in medical, school, and community settings where they receive care and participate in various educational, recreational, and counseling programs.

The Incidence of Children's Health Conditions

Estimates indicate that between 10 and 15 percent of the children born in the United States have chronic health impairments of some kind. Many of these require lengthy and/or repeated hospitalizations and treatments that interfere with the child's usual activities (Clay, 2004; Phelps, 1998). In addition, several million children are admitted to hospital emergency rooms following severe and catastrophic injuries or illnesses. "Although many of their conditions [are] life-threatening, the large majority of clinically ill or disabled children survive to adulthood" (Perrin, 1989, p. xi).

A national survey of children's health (U.S. Department of Health and Human Services, 2005) collected data on more than 102,000 households in the United States with children under 18 years of age. Parents were asked to rate their child's health status in terms of five possibilities: excellent, very good, good, fair, or poor. The majority of parents (84.1 percent) reported that their children's health was excellent or very good. In contrast, the parents of 7.9 percent of children reported that their child currently had, or had had, at least one of a list of chronic health conditions that they ranked as moderate or severe. It is interesting that the percentages rose with the age of the child, from 4.4 percent among children from birth to age 5, to 9.1 percent among children ages 6 to 11, to 10 percent in the ages 12 to 17. Despite the many achievements of modern medicine, the fact remains that in the first decade of the twenty-first century a substantial number of children and their families continue to be burdened by serious health conditions.

The Most Frequent Pediatric Illnesses

According to Clay (2004), the most common high-incidence pediatric illnesses are the following:

- *Asthma*. Affects nearly 5 million children under the age of 18 in the United States.

- *Diabetes*. Occurs in about 15 to 20 children out of 100,000 under the age of 20 in the United States (Daneman & Frank, 1996).
- *Juvenile rheumatoid arthritis*. Estimated to affect nearly 200,000 children in the United States under the age of 18, with onset occurring as early as infancy and with most cases diagnosed between the ages of 1 and 4 (Cassidy & Petty, 1995).
- *Cancer*. May take the form of a blood cancer (e.g., leukemia or lymphoma), a solid tumor (e.g., neuroblastoma), or a brain tumor. Although all are being treated with increasing success, in some children the cancer is fatal.

Lower-Incidence Pediatric Medical Conditions

This list is selective and includes conditions that are not as frequent as those already mentioned but that also make physical demands on the child and require sensitive management in schools and other locales where the young person functions:

- *Heart conditions*. Congenital heart defects affect 8 to 10 children per 1,000; other conditions include heart murmurs and hypertension. Most congenital heart conditions are associated with other congenital conditions, such as Down syndrome (Clay, 2004, p. 26).
- *Seizure disorders, epilepsy*. About 40,000 cases a year are reported to begin in childhood; about 1 percent of the total population has epilepsy (Clay, 2004, p. 16).
- *Blood disorders*. Anemia, sickle cell disease, hemophilia.
- *Infectious diseases*. HIV, bacterial meningitis, hepatitis.

Other chronic and life-threatening conditions that are also frequently seen in children are cystic fibrosis, cerebral palsy, muscular dystrophy, blindness and hearing disorders, Down syndrome, and spina bifida. In order to be classified as *chronic*, the physical condition must be one that either actually does or is expected to (1) interfere with daily functioning more than three months a year or (2) cause hospitalization for more than one month a year (Wallander, Thompson, Alriksson-Schmidt, 2003).

These illnesses have certain elements in common that often become the focus of various psychosocial interventions. All require that the individual and family grieve and mourn the loss of good health in a young person's life. They also will necessitate various adjustments to the constraints of the disease or illness and adherence to the prescribed treatment regimen with ongoing follow-up. The responses of each young person will vary according to age- and illness-specific factors, but the pressures of stress and the need for adaptation lead to the development of anxiety and depression in many children (Auslander & Freedenthal, 2006).

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This book presents counseling and therapy approaches to assist families in helping their children to achieve the best quality of life possible in their specific circumstance. We also discuss some ways to assist the young person to reconceptualize his or her illness as one that is a manageable challenge despite its restrictions. Different counseling methods are presented that involve the identification and utilization of the *strengths* of these young people and their families, in contrast to emphasizing the *limitations and problems* associated with an illness or disability. Clearly, certain hardships constitute part of the situation and cannot be ignored. However, the strengths-based philosophy emphasizes hope and possibility, and these attitudes significantly impact not only the child and family, but also the professionals who work with them. Clinicians are often intimately involved with their patients and families. Evidence-informed practices promise the greatest results for patients and families and also serve to bolster the clinicians' attitudes about their work. The next section reviews the central concepts on which this helping framework rests.

Theoretical Perspective for a Positive Helping Approach

Several interlocking perspectives form the basis for a helping philosophy that emphasizes a positive framework to be used by professionals who are working with medically challenged young people and their families. This guiding philosophy rests on concepts in the following models of helping:

- Ecological perspective
- Strengths perspective
- Crisis intervention to deal with stress and coping responses
- Individual and family resilience

Each of these interacting perspectives bolsters helping efforts that breathe a spirit of optimism and possibility into a situation that otherwise might be viewed as discouraging or even hopeless.

Ecological Perspective

Rooted in the work of Bronfenbrenner (1979), this concept has been widely adopted to recognize the many spheres of influence that impact any one individual's life. Each person is affected not only by his or her family and relatives, but also by peers, by the community, and by larger social and cultural influences. Furthermore, these interactive elements are bidirectional; in other words, children are influenced not only by their parents' attitudes about an illness, but the parents, in turn, are affected by the manner in which the child responds. In addition, the patient and the parents respond to the clinician by looking for clues or "hidden messages"

in the practitioner's facial expression or tone of voice. The dynamics of this ecological person-in-situation relationship are not static, but evolving and ever changing.

Strengths Perspective

Introduced by Saleebey in 1992 and updated in 1997, this approach emphasizes assisting clients to "achieve their goals, realize their dreams, and shed the iron of their own inhibitions and misgivings" (Saleebey, 1997, p. 3). Such an inspirational philosophy becomes implemented through the following six statements of belief (adapted from Saleebey, 1997, pp. 12–15, as summarized by Openshaw, 2007, p. 67):

1. Every individual, group, family, and community has strengths.
2. Trauma, abuse, illness, and struggle may be injurious, but they also may be sources of challenge and opportunity.
3. We do not know the upper limits of anyone's capacity to grow and change; we must take the aspirations of individuals, groups, and communities seriously.
4. We best serve clients by collaborating with them.
5. Every environment is full of resources.
6. Caring, caretaking, and context are important.

As I read through these guiding principles I can't help but think that I would far prefer to be treated by someone who was following them in a hospital or clinic setting than by someone who was committed to a disease- or problem-focused medical model.

Crisis Intervention to Deal with Stress and Coping Responses

We all know how stress feels, and we realize that it can range in intensity from a slight irritation (e.g., being late for an appointment) to an overwhelming sense of anxiety (e.g., witnessing an automobile accident). Selye (1978) and Benson (2000) have written about the autonomic physiological changes in our bodies that occur in stressful circumstances. These often include increased heartbeat and changes in breathing and blood pressure that may be accompanied by either the impulse to get away from the situation (flight) or, alternatively, to fight it. Selye called this instinctive reaction the "fight or flight response" (Selye, 1978). People have different abilities to tolerate stress, based on their temperaments, the intensity of the particular stressful experience, and their past histories. Therefore, some people may respond with tears and depression when diagnosed with cancer, whereas other individuals may emphasize their strong intention to fight it. The diagnosis of an acute or chronic illness inevitably generates stress for anyone old enough to understand the terminology and its possible future course. When the stress response is

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acute, individuals may become so anxious that their functioning is impaired. In these situations, crisis intervention can be quite helpful initially in assisting young patients to employ some cognitive-behavioral strategies and expressive techniques to deal with their anxiety (Goodman, 2007). This will be discussed later.

However, young people have very different coping reactions depending on their level of cognitive development, the responses of family members, and even the expectations of their culture and social environment (Congress, 2004). Professional helpers must acknowledge and respect these variations in response and should subscribe to a philosophy of acceptance of individual differences, which sometimes includes the need to put aside and avoid expressing ones' personal feelings.

Individual and Family Resilience

Resilience has been defined as "the capacity to rebound from adversity strengthened and more resourceful" (Walsh, 2006, p. 4). As we think about the stresses of medical illness, we realize that this situation must be viewed through a systemic lens. According to Hauser (1999; quoted by Walsh, 2006, p. 12), "Resilience is woven in a web of relationships and experiences over the life course and across the generations." This statement clearly conveys the concept of a family ethos that might, for example, subscribe to the credo of never giving up. Certainly, parents and grandparents, both deliberately (in what they say) and indirectly (in their actions) convey to children and adolescents their views of acceptable and unacceptable methods of coping with adversity. Resilient families can somehow muster the strength to carry on even when all the cards seem to be stacked against them. Furthermore, family resilience involves not only how families survive, but also how they can "regenerate even in circumstances of overwhelming stress. It affirms the family potential for self-repair and growth out of crisis and challenge" (Walsh, 2006, p. 17). Although this concept may suggest a notion of "superfamilies," research suggests that with respect to *individual* behavior, children respond more positively when adults expect good behavior from them (Grusec, Goodnow, & Kuczynski, 2000). Probably the same dynamic would apply to families, thereby promoting their hardiness and resilience. A therapeutic model designed to support families of children with a chronic illness or disability includes the dynamics of hope, empowerment, reconnection, coping and resilience, and reframing (Morison, Bromfield, & Cameron, 2003).

The Language of Medical Conditions

Numerous terms have been used to refer to the physical status of people who have less-than-perfect bodies. Among these are the following:

- *Handicapped*
- *Physically impaired*

- *Hearing impaired*
- *Congenitally defective*
- *Disabled*
- *Chronically diseased*
- *Terminally ill*

All of these terms have very negative connotations and emphasize the deficits, losses, or disruptions created by the different conditions. A child who has more than one medical condition may be referred to as “multiply disabled.” On the other hand, terminology that emphasizes what the child *can* do and that focuses on strengths rather than limitations, employs the much less pejorative expression “children with special needs” (Webb, 2003). It is ironic, however, that school programs refer to “children with disabilities” in conformity with the Americans with Disabilities Act (ADA) of 1990 in order to qualify for federal assistance (Friend, 2005). Therefore, we may need to change the language of the laws in order to make it more child-friendly and to encourage schools to use more positive terminology in identifying and planning programs for children who qualify for special education.

The Attribution of Meaning Related to a Medical Condition

It is natural for individuals and families to look for a reason behind the diagnosis of a medical condition and to want to know *why* it happened. A 14-year-old diagnosed with diabetes asks: “Did I get this because I gained too much weight and because I didn’t follow the doctor’s suggestion that I should exercise more?” His mother wonders if she should have taken more vitamins or somehow behaved differently during her pregnancy. A young child may also think that he or she did something bad to cause the illness and views the illness as a form of punishment. Adolescents may blame themselves or their family heritage by attributing the illness (correctly or not) to “bad genes” or to the fact that their family did something neglectful, such as avoiding regular medical checkups. Sometimes the patients or family members verbalize these questions, but more often they are silent and keep their worries unspoken for fear of creating more upset in the family.

All these uncertainties swirl around and reflect the overriding feeling that *this should not have happened to me or my child and that someone or something is to blame*. As mentioned, people may not admit their inner feelings, fears, and worries, but they nonetheless ponder them, and many become anxious and/or depressed trying to figure things out. Sometimes children who sense that their condition is serious wonder whether it means that they are going to die. This is especially true in the initial stage

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right after the diagnosis. It helps to permit these fears to be spoken, because unspoken fears have a way of escalating. The social worker and/or child life specialist can play a critical role in helping the child and parent deal openly with their fears. Chapter 2 discusses the emotional impact of a young person's illness on the entire family system.

When the illness is one that appears to be inherited, the responsible parent may feel burdened with guilt, even when he or she knows that it was not within his or her power to control the genes that were passed to the child. Sometimes adults who recall their own parents' responses years ago to a sibling's illness unconsciously try to avoid repeating a similar situation in their current family situation. This dynamic was poignantly demonstrated in a novel, *The Memory Keeper's Daughter* (Edwards, 2005), in which one of the main characters, a physician, had had a younger sister who was born with a "weak heart" and died when she was 12 years old. The man grew up acutely aware of his mother's terrible and ongoing grief over his sister's fragile condition during her childhood, which culminated in her eventual death. These memories of his mother's relentless pain proved to be a decisive factor many years later when the physician delivered his own twin babies in the middle of a snowstorm because he and his wife could not reach the hospital in time. When the man realized at the moment of birth that one of his twins had Down syndrome, all he could think about was wanting to protect his wife from suffering grief similar to that of his mother's. He therefore made a split-second decision to give the infant with Down syndrome to the attending nurse, with instructions that she was to place the child permanently in a nearby long-term-care facility. The doctor then told his wife that their female twin baby had died in childbirth and that he didn't want her to see the dead infant. The book graphically portrays how this well-intentioned lie and secret came to control the man and his marriage, as well as the nurse, who actually decided to keep the child and raise her as her own daughter.

The birth of a baby with a medically compromising condition creates many complicated realities for the parents, as illustrated in this book. Professionals who are involved with such families should be prepared to deal with different reactions in various family members and to remember these powerful dynamics:

- Grief responses are inevitable, although they may be denied and hidden.
- Parents are mourning the loss of their anticipated perfect baby.
- Guilt, blame, and shame may dominate the underlying feelings of sadness.
- Family members often are protective of each other and may avoid discussions that could be upsetting.
- Different people respond differently in situations of loss, and often spouses misunderstand the reactions of their partners.
- The pain of loss recurs sequentially and repeatedly over many years.

- Children pick up cues from family members, whether verbalized or unexpressed.
- Counseling and/or therapy can assist the individual and family cope with their confused and upsetting feelings.

Issues of Identity, Competency, and Future Life Planning

When a young person is born with a serious and disabling medical condition and/or when he or she develops a serious illness in childhood or adolescence, this factor often takes center stage and becomes magnified in the individual's own and his or her family's lives. The need for repeated visits to the doctor or hospital clinic annoyingly conflict with a youngster's wish to participate in after-school activities, and the doctor's treatment protocol can interfere with going to a friend's house for a sleepover or on a weekend overnight camping trip with the Scouts. A disability or illness "all too often sets (young people) apart and (may be) used to define (them) in ways that minimize their humanity" (Lavin, 2002). Thus, Johnny who used to be considered by his teacher as the boy with the charming smile, now becomes, in his teacher's perception, "the boy with cancer." The disease, illness, or disability becomes a major element of the affected young people's identity, and this may seriously affect their ability to view themselves as competent and capable despite the disability, and it may affect their view of a future with exciting possibilities. Sometimes their appearance changes due to treatments (e.g., hair loss) and they may not be able to attend school because of a compromised immune system. On the one hand, these children may miss their peers, and on the other, they may be relieved not to have to appear in public, because of discomfort about their appearance.

Of course, the ultimate meaning of a diagnosis to an individual depends on his or her age and ability to comprehend its seriousness. A classic study of children's awareness of their disease and its fatal potential (Bluebond-Langner, 1978) indicated that youngsters go through five stages of understanding, beginning with knowing the name of their disease and its seriousness, to the final realization that death is a possible outcome if the treatment plan doesn't work. Children who regularly attend hospital clinics and who see and make friends with other ill youngsters there may talk about and compare their symptoms with these peers. Many of them become very knowledgeable about their conditions, their treatments, and their prognoses. Increasingly, hospitals and clinics that treat such young people offer services such as specialized support groups, printed materials about specific illnesses, and lists of web sites that provide information and contact with others. This educational process is empowering to the patient and the family. The appendix of this book lists numerous resources.

Infertility as a side effect of treatment is a reality that adolescent cancer patients must face. Sexuality and reproductive rights are sensitive

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areas to address with both patients and their families. Adolescents are easily embarrassed and may be resistant to an open discussion on the topic. However, preserving the ability to reproduce is of paramount importance. Clinicians working with the families must be sensitive to the religious and cultural background of the families and provide support and education on this topic. An excellent web site dealing with this is <http://www.fertilehope.org>. Even after treatment, late and secondary effects of cancer may occur, and secondary cancers are always a possibility. In these instances, long-term loss and grief counseling should be made available.

Examples of Children's Responses to Serious Medical Conditions

The prize-winning photographer Jill Krementz has published two books that illustrate how children come to understand their different medical conditions (Krementz, 1992 and 1998). The books present timeless portraits of children and youth with different disabilities and medical conditions. Each book consists of in-depth interviews and photographs of the young people, who range in age from 6 to 16 and who have been diagnosed with a variety of conditions and disabilities. Many of these interviews (summarized here with the author's permission) touchingly convey and support the concept of different reactions in children's level of understanding and acceptance of an illness. For example, a 10-year-old girl reported her experience when her mother told her (when she was 7 years old) that she had diabetes. She said that she burst into tears because she was afraid that she was going to die. The girl stated that even after her parents convinced her that this was not going to happen, she nonetheless felt that her life was going to change completely (inevitably, she was right). This would have been a good time for clinical interventions such as support and review of the girl's continuing abilities: that is, recognition of what she *could* still do, rather than focusing on her fears of possible illness-related obstacles in her future.

Another child who was 15 years old and who had had cystic fibrosis all his life grappled with the meaning of his illness. He attached a religious purpose to being ill. This boy, who went to church every week, developed the belief that there had to be a reason for his illness. In an interview he stated as follows: "God didn't just draw my name out of a hat. There has to be a reason why I'm sick . . . Sometimes I think that maybe he knew I'd have this [positive] attitude and he put me here so other kids who are sick can see me and say, 'Hey, you know, maybe he's right, maybe there *is* hope'" (Krementz, 1989, p. 105).

Although the majority of the children interviewed in these two books (14 in one and 12 in the other) convey very positive can-do attitudes despite their serious illnesses and disabilities, a few admit

to being depressed or even suicidal. This was the case with a 12-year-old boy who was born with a hole in his heart and who had a stroke during an operation soon after birth to repair his heart and who subsequently became paralyzed on one side of his body. This boy admitted to being very depressed at the limitations on his physical movements as he was growing up, and sometimes he felt that it was so bad he even wanted to kill himself. There is no indication that this boy had any counseling to help him; however, the youngster was somehow able to surmount those negative feelings, and he described how, at age 12, he gave a special presentation at school that included asking the audience try to tie one of their shoelaces and cut an orange with one hand so that they could begin to appreciate what it is like to live with paralysis on one side of their body! This same boy had taught himself how to deliver a one-handed serve in tennis, and at the conclusion of the interview he described his hope to learn to relax his spastic muscles through the use of biofeedback.

It was most impressive to me to notice in these very different personal histories how many of the young people managed to find a way to participate in sports despite their extensive disabilities. It seemed as if they were determined to prove that they *could* engage in physically challenging activities. In fact, while I was in the process of writing this chapter, the local newspaper reported the story of a 21-year-old South African man who had had both legs amputated below the knee when he was 11 months old and who was attempting to participate in the 2008 Beijing Olympics! His special prostheses ultimately served to disqualify him because they supposedly provided a mechanical advantage in running. Incredibly, this young man had previously participated in a variety of sports, including rugby and wrestling, and he had taken up running to recover from a rugby injury (*St. Petersburg Times*, 1/15/08).

As I reflected on this person's motivation and that of many of the disabled children in Kremenz's two books, my psychotherapy-based diagnostic thinking made me label their behavior as "overcompensation" or "denial." However, from the strengths perspective, I realized that these young people were refusing to let their limitations define their lives. While that attitude will help them succeed in many life tasks, one wonders how long it will be necessary for them to continue to prove to themselves and others that they are capable. Playing rugby with a prosthesis must take a great toll on a person! Therefore, I believe that it is appropriate for the counselor or therapist to give the suggestion to such young people that they do not need to continue to demonstrate these physical feats unless they truly want to do so. In all likelihood each person has *many* capabilities, including cognitive, musical, and artistic, in addition to physical. It may be that because physically compromised or chronically ill young people have such a strong need to prove their *physical* abilities, they ignore or minimize some of their other strengths. Therefore, if I were working with such youngsters in a counseling situation, I might try to have them consider goals that would enlarge their life horizons beyond success in meeting physical challenges. For example, instead of encouraging the boy

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with the one-sided paralysis to spend hours trying to perfect his one-handed tennis serve, I could have gently suggested that he might want to explore other, related areas of achievement that would not require two-sided functioning and make such demands on him. For example, he might consider applying his interest in sports by using a computer with one hand to become a sportswriter or a reporter for a newspaper or magazine. Such occupations could build on his success and self-pride without the frustration of trying to force his body to continue to perform and excel. For young people and adults who want to challenge themselves physically, the Special Olympics fulfills this need and can be very gratifying. However, the reality is that few will be able to make a career of physical activity. Some may decide to become special education teachers and coaches to younger medically challenged youth, and in this position they can take pride in their role as mentors.

Clearly, the 26 children described in Krementz's two books do not comprise a valid research sample, and they may not be representative of young people who undergo similar life stresses. Nonetheless, their attitude of high motivation for personal achievement is commendable, as is their sincere interest in helping other people understand their illnesses. Positive attitudes such as these were labeled "posttraumatic growth" in a research study with 150 adolescent survivors of cancer and their mothers and fathers a year after treatment (Barakat, Alderfer, & Kazak, 2006). The majority reported positive changes in their views of self, their relationships with others, and plans for their future (p. 417). Therefore, although the diagnosis of cancer may be considered to be traumatic, posttraumatic growth (as well as distress) may characterize the responses of those involved. While we realize that not all ill or disabled youth receive optimal care, some, if not most, do. However, even with the best of care, some patients succumb to their illness and die. Even so, the majority of ill children survive until adulthood, and this book intends to guide professional counselors in helping those children and their families maintain hope and positive expectations for their futures.

Who Are the Helpers?

Professionals Involved with Ill or Disabled Children

Children and adolescents with medical conditions must interact with many adult professional helpers when they are admitted to hospitals and later receive follow-up care in clinics, rehabilitation, and school settings. Table 1.1 lists many of the various specialists who can have crucial roles in treating these youth. The accounts of the life experiences of the 26 young people in Krementz's books documents how difficult it can be for them to have to form relationships with so many different adults who have so much influence over their lives. Whereas this book is addressed to counselors, social workers, and those who provide psychosocial interventions,

Table 1.1 Professionals Involved with Chronically Ill or Disabled Adolescents

Physicians	Health Specialists	Counselors
Pediatricians	Nurses	Social workers
Hematologists, oncologists	Physical therapists	Child life specialists
Neurologists	Speech therapists	Pediatric psychologists
Radiologists	Occupational therapists	School counselors
Pediatric orthopedists	Nutritionists	Pastoral counselors
Rheumatologists	Prosthetists	Art therapists
Gynecologists	Pain management practitioners	Play therapists
Endocrinologists	Complementary medicine practitioners (e.g., reiki masters, yoga teachers, and massage therapists)	Music therapists
Metabolic disease specialists		Drama therapists
Geneticists		Dance therapists
Gastroenterologists		Coaches
Nephrologists		Sex therapists
Physiatrists		Educational tutors
Ophthalmologists		
Adolescent medicine specialists		
Psychiatrists		
Critical care specialists		
Developmental specialists		
Pulmonologists		
Urologists		
Otolaryngologists		
Dentists		

Table 1.1 illustrates the wide range of specialists who may be involved in any one young person's care. Despite my best attempts, the chart may not be all-inclusive.

Just imagine being five or six years old and having to deal with one-half or even a quarter of these people! Even parents may find this daunting. Certainly, this expectation could seem overwhelming to a young child, and the ongoing assistance of a parent would be critical in helping the child remain cooperative and willing to follow the various prescribed treatments. For an example of such a scenario, Table 1.2 shows possible specialists needed to care for children with spina bifida.

Another problem for children with spina bifida is that they may develop latex allergy from repeated exposures in the course of numerous operations and other procedures; even a pair of protective gloves or a tourniquet may cause breathing symptoms, hives, or unconsciousness.

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Table 1.2 Possible Specialists Required for Children Born with Spina Bifida

Children born with spina bifida might see any of the following specialists

Physiatrist: To provide rehabilitation medicine, including bracing, physical therapy, and teaching specific exercises.

Neurologist: To prescribe and manage muscle relaxants for spasticity and to provide antiseizure medications.

Nephrologist: To manage recurrent urinary tract infections that may occur when children don't fully empty their bladders. This is referred to as *neurogenic bladder*; a complication after many infections may be kidney scarring. Also, decreased muscle tone in the abdomen and pelvis can lead to constipation and residual urine in the bladder. As these children get older, they must learn to perform self-catheterization in order to empty their bladders.

Older children who become sexually active may need counseling with a sex therapist on the topic of using latex condoms. A patient with a latex allergy would be advised to use a sheepskin condom underneath a latex condom. If the partner also has spina bifida, that person, in turn, would need to add a separate sheepskin condom as protection from latex exposure.

Because of the multiplicity of challenges, young people with spina bifida benefit greatly by affiliation with a "medical home," in which a primary care provider can synthesize and interpret the various recommendations into a care plan that clarifies the options available to the patient while also taking into account the patient's own expectations and wishes (Hom, 2008).

How Counselors Help: Various Helping Methods

Just as there are many helpers involved in any one case with an acutely or chronically ill child, there are numerous helping methods that may be used in counseling or therapy. Some of the methods depend on the background, training, and experience of the particular counselor. Other times, the nature of the services may depend on the staffing of a specific hospital or aftercare facility. Therefore, whereas we might agree that all hospitalized young people would benefit from some art or music therapy to help them express their feelings about their medical condition, many medical facilities do not have these trained specialists on staff. Fortunately, some professionals, such as social workers and child life therapists, have been trained to use art, play, and music as part of their counseling treatment,

Specific Helping Approaches

When medically compromised individuals develop mental health problems such as anxiety and depression, the use of crisis counseling, psychotherapy, and relaxation training have proven to be helpful (Auslander & Freedenthal, 2006). *Crisis counseling* is a short-term approach that focuses on anxieties, fears, and the various problems associated with a particular

disability or illness. The goal of this intervention is to help people feel more in control over their situation. However, in view of the long-term adjustment necessary to deal with most illnesses and disabilities, crisis intervention alone may not be adequate, since it usually is limited to 10 to 12 weeks. Other forms of psychotherapy may be appropriate when anxieties persist over a longer period of time. These might take the form of individual, group, or family therapy and employ various methods to reduce stress and improve coping (see Chapters 6, 9, and 10). Relaxation training has been quite successful in helping children and adolescents cope with anxieties associated with receiving injections and other painful and stressful medical procedures. Child life specialists are trained specifically to help hospitalized children deal with such anxiety-producing situations (see Chapter 5). Again, the *modalities* of treatment (whether provided individually, in the family, or in group meetings) will depend on available services and the specific needs in each circumstance.

Summary

Acute and chronically ill youth and their families must deal with intense tension at the time of diagnosis as well as ongoing stresses when their illness or disability progresses and may require successive medical operations or other treatments. These young people must develop physical and psychological strategies to deal with both the physical pain and the emotional distress associated with their conditions. Professional counselors play an important role in reducing this anxiety, and this book is dedicated to presenting numerous helping approaches.

As discussed, the age and developmental level of the young people involved will determine how much they can comprehend about the future implications of their situation. The family and social/cultural environment of the child or adolescent will help or hinder his or her adaptation. Professional helpers have a critical role in assuring that this environment is supportive rather than dismissive or unfriendly. When such children attend school, most are very sensitive about how their peers will respond to them. Often, classmates do not understand the restrictions of a disability or medical condition, and sometimes they make fun of children who are different. This adds another layer of stress for the child or adolescent who already feels very isolated and alone because of his or her medical situation. Teachers and school counselors can use the situation to help sensitize other children about individual differences, even as they also seize every opportunity to help the ill or disabled student demonstrate his or her abilities. Sometimes, the hospital social worker visits the school to discuss disease-specific information with the school personnel so that they will be in a better position to help the young person when he or she returns to school.

An acutely or chronically ill child needs various kinds of help from many sources. This book describes the roles of different professionals in

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providing the emotional and psychological support to assist medically challenged young people and their families. We hope that it will become a resource for all who interact with these children and that they and their families will benefit from the strengths-based, collaborative approach advocated here.

Appendix: Medical Resources

Web site of Medical Specialists: http://www.webmd.com/a-to-z_guides/medical-specialists-medical-specialists.

Chabner, D. (2003). *Medical terminology. A short course*. Philadelphia: W.B Saunders.
Steiner, S.S. (2002). *Quick medical terminology. A self-teaching guide*. Hoboken, NJ: Wiley.

References

- Auslander, W., & Freedenthal, S. (2006). Social work and chronic disease. Diabetes, heart disease, and HIV/AIDS. In S. Gehlert, & T. A. Browne (Eds.), *Handbook of health social work* (pp. 532–567). Hoboken, NJ: Wiley.
- Barakat, L. P., Alderfer, M. A., & Kazak, A. E. (2006). Posttraumatic growth in adolescent survivors of cancer and their mothers and fathers. *Journal of Pediatric Psychology*, 31(4), 413–419.
- Benson, H. (2000). *The relaxation response*. New York: HarperCollins.
- Bluebond-Langer, M. (1978). *The private worlds of dying children*. Princeton, NJ: Princeton University Press.
- Bronfenbrenner, U. (1979). *The ecology of human development*. Cambridge, MA: Harvard University Press.
- Cassidy, J., & Petty, R. (1995). *Textbook of pediatric rheumatology* (3rd ed.). Philadelphia: Saunders.
- Clay, D. L. (2004). *Helping schoolchildren with chronic health conditions: A practical guide*. New York: Guilford Press.
- Congress, E. P. (2004). Cultural and ethical issues in working with culturally diverse patients and their families. The use of the culturagram to promote culturally competent practice in health care settings. *Social Work in Health Care*, 30(3/4), 249–262.
- Daneman, D., & Frank, M. (1996). The student with diabetes mellitus. In R. H. A. Haslam, & P. J. Valletutti (Eds.), *Medical problems in the classroom. The teacher's role in diagnosis and management* (pp. 97–114). Austin, TX: Pro-Ed.
- Edwards, K. (2005). *The memory keeper's daughter*. New York: Viking/Penguin.
- Friend, M. (2005). *Special education. Contemporary perspectives for school professionals*. Boston, MA: Allyn & Bacon.
- Goodman, R. (2007). Living beyond the crisis of childhood cancer. In N. B. Webb (Ed.), *Play therapy with children in crisis. Individual, group, and family treatment* (pp. 197–227). New York: Guilford Press.
- Grusec, J. E., Goodnow, J. J., & Kuczynski, L. (2000). New directions in analyses of parenting contributions to children's acquisitions of values. *Child Development*, 71, 205–211.

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- Hauser, S. T. (1999). Understanding resilient outcomes. Adolescent lives across time and generations. *Journal of Research on Adolescence*, 9(1), 1–24.
- Hom, C. (2008). Personal communication, February 20, 2008.
- Krementz, J. (1989). *How it feels to fight for your life*. New York: Simon & Schuster.
- Krementz, J. (1992). *How it feels to live with a physical disability*. New York: Simon & Schuster.
- Lavin, C. (2002). Disenfranchised grief and individuals with developmental disabilities. In K. J. Doka (Ed.), *Disenfranchised grief: New directions, challenges, and strategies for practice* (pp. 307–322). Champaign, IL: Research Press.
- Morison, J. E., Bromfield, L. M., & Cameron, H. J. (2003). A therapeutic model for supporting families of children with a chronic illness or disability, *Child and Adolescent Mental Health*, 8: 3, 125–130.
- Openshaw, L. (2007). *Social work in schools: Principles and practice*. New York: Guilford Press.
- Perrin, J. M. (1989). Foreword. *How it feels to fight for your life* (p. xi). New York: Simon & Schuster.
- Phelps, L. (1998). *Health-related disorders in children and adolescents: A guidebook for understanding and educating*. Washington, DC: American Psychological Association.
- Saleebey, D. (Ed.). (1997). *The strengths perspective in social work practice* (2nd ed.). New York: Longman.
- Selye, H. (1978). *The stress of life*. New York: McGraw Hill.
- Times wires (2008, January 15). "Advantage" disqualifies amputee from Olympics. *St. Petersburg Times*, p. 1. Author.
- U.S. Department of Health and Human Services. (2003). *The health and well-being of children: A portrait of states and the nation*. Rockville, MD: Author.
- Wallander, J. L., Thompson, R. J., Alriksson-Schmidt, A. Psychosocial adjustment of children with chronic physical conditions. In M. C. Roberts (Ed.), *Handbook of pediatric psychology* (3rd ed., pp. 141–15). New York: Guilford Press.
- Walsh, F. (2006). *Strengthening family resilience* (2nd ed.). New York: Guilford Press.
- Webb, N. B. (2003). (Ed.). *Social work practice with children* (2nd ed.). New York: Guilford Press.

