

- threats to relationships with family, friends, and colleagues
- threats to the ability to remain in familiar surroundings
- threats to economic well-being

The response to the stresses imposed by the threat of chronic illness or disability depends on perceptions of the impact the condition has on various areas of life, as well as on individuals' capacity to cope.

Stress cannot be easily quantified, but it can be interpreted from the behaviors exhibited by those experiencing chronic illness or disability. When demands exceed psychological, social, or financial resources, stress may be manifested in a variety of ways, such as noncompliance with recommended treatment, self-destructive behaviors such as substance abuse, hostility, depression, or other harmful responses.

Individuals in the same situation do not necessarily experience the same degree of stress, and the amount of change or adjustment required is not necessarily an indicator of the amount of stress perceived. Those who are able to adapt and cope effectively and mobilize resources are more successful in managing stress and achieving more stable outcomes.

## COPING STYLE AND STRATEGIES

Coping is a constellation of many acts rather than a single act, is constantly changing, and is highly individualized. Coping mechanisms are learned and developed over time. Individuals use them to manage, tolerate, or reduce the stress associated with significant life events and to attempt to restore psychological equilibrium after a stressful or traumatic event. Everyone has developed a variety of coping mechanisms through his or her

life experiences, and each individual has a predominant coping style to reduce anxiety and restore equilibrium when confronted with a stressful situation. Coping is manifested through behavior. Coping behavior is *effective* and *adaptive* when it helps individuals reduce stress and attain their fullest potential. It is ineffective and *maladaptive* when it inhibits growth and potential or contributes to physical or mental deterioration.

Coping may be required not only for dealing with the initial diagnosis, but also for subsequent events. Conditions that are progressive with compounding limitations necessitate ongoing coping and adjustment to incorporate additional changes into daily life.

Individuals cope with illness and disability in different ways. Some actively confront their condition, learning new skills or actively engaging in treatment to control or manage the condition. Others defend themselves from stress and the realities of the diagnosis by denying its seriousness, ignoring treatment recommendations, or refusing to learn new skills or behaviors associated with the condition. Still others cope by engaging in self-destructive behavior, actively continuing behavior that has detrimental effects on their physical condition.

Effective coping must be viewed in the context of each individual's personal background and experiences, life situation, and perception of circumstances. Individuals tend to use coping strategies that have worked successfully for them in the past. When old strategies are no longer effective or are not appropriate to the new situation, new coping strategies must be implemented to neutralize events surrounding the chronic illness or disability and to adjust to any associated limitations. Effective coping enables individuals to attain emotional equilibrium, to achieve

a positive mental outlook, and to avoid incapacitation from fear, anxiety, anger, or depression. However, coping does not occur in a vacuum. The social milieu in which individuals find themselves can facilitate or discourage effective coping. In general, an optimum environment is one that helps individuals gain a sense of control by actively participating in decision making and taking responsibility for their own destiny as much as possible.

Coping strategies are subconscious mechanisms that individuals use to cope with stress. All individuals have predominant coping strategies to reduce anxiety and restore equilibrium when confronted with stress. The strategies they used in the past are often those employed when they are confronted with the stress of chronic illness or disability. The use of coping strategies reduces anxiety, helping individuals assume balance and productivity in their lives. Although these strategies can be helpful, overuse can be detrimental.

### Denial

The diagnosis of chronic illness or disability and the associated implications can be devastating and anxiety provoking. *Denial* is a coping strategy some individuals use to negate the reality of a situation. In the case of chronic illness or disability, individuals may deny that they have the condition by avoiding recommended treatment or by denying implications of the condition. In the early stages of adjustment, denial may be beneficial in that it enables individuals to adjust to the painful reality of their situation at their own pace, preventing excessive anxiety. When denial continues, however, it can prevent individuals from following medical recommendations or from learning new skills that would help them reach their maximum potential.

Denial of the chronic illness or disability can have far-reaching effects on others if, by denying the condition, individuals place others at risk. For example, proper precautions can greatly reduce the spread of some contagious diseases, such as tuberculosis or HIV infection. Individuals in active denial of their tuberculosis or its ramifications may neglect to take tuberculosis medications regularly, and those with HIV infection may have unprotected sex, putting others in jeopardy. Some individuals may put others at risk by denying their limitations, such as individuals who are legally blind but continue to drive even though driving has been prohibited.

### Regression

In regression, individuals revert to an earlier stage of development and become more dependent, behave more passively, or exhibit more emotionality than would normally be expected at their developmental level. In the early stages of chronic illness or disability, returning to the state of dependency experienced in an earlier stage of development can be therapeutic, especially if treatment of the condition requires rest and inactivity. When individuals continue in a regressive mode, however, it can interfere with adjustment and the attainment of a level of independence that would allow them to reach maximum functional capacity.

### Compensation

Individuals using compensation as a coping strategy learn to counteract functional limitations in one area by becoming stronger or more proficient in another. Compensatory behavior is generally highly constructive when new behaviors are directed toward positive goals and out-

comes. For example, someone who is unable to maintain his or her level of physical activity because of limitations associated with his or her condition may turn to creative writing or other means of self-expression. Compensation as a coping strategy can be detrimental, however, when the new behaviors are self-destructive or socially unacceptable. For example, someone who experiences disfigurement as a result of his or her disability may become promiscuous as a way of compensating for the perception of physical unattractiveness.

### Rationalization

As a coping strategy, rationalization enables individuals to find socially acceptable reasons for their behavior or to excuse themselves for not reaching goals or not accomplishing tasks. Although rationalization can soften the disappointment of dreams unrealized or goals unreached, it can also produce negative effects if it becomes a barrier to adjustment, prevents individuals from reaching their full potential, or interferes with effective management of the medical condition itself.

### Diversion of Feelings

One of the most positive and constructive of all coping strategies can be the diversion of unacceptable feelings or ideas into socially acceptable behaviors. Those with chronic illness or disability may have particularly strong feelings of anger or hostility about their diagnosis or the circumstances surrounding their condition. If their emotional energy can be redefined and diverted into positive activity, the results can be beneficial, making virtue out of necessity and transforming deficit into gain. As with all coping strategies, diversion of feelings can have negative effects if feelings of anger or hostility are chan-

neled into negative behaviors or socially unacceptable activities.

## EMOTIONAL REACTIONS TO CHRONIC ILLNESS OR DISABILITY

Sudden, unexpected, or life-threatening chronic illness or disability engenders a variety of reactions. How individuals view their condition, its causes, and its consequences greatly affects what they do in the face of it. They may view their condition as a challenge, an enemy to be fought, a punishment, a sign of weakness, a relief, a strategy for gaining attention, an irreparable loss, or an uplifting spiritual experience. Although emotional reactions vary, the following are common.

### Grief

Grief is a normal reaction to loss. Individuals with chronic illness and disability may experience loss of a body part, loss of function, role, or social status, or other perceived losses that lead to a reaction of grief. Although the grieving and the progression through stages of grief vary from person to person, a common initial reaction is shock, disbelief, or numbness during which the diagnosis or its seriousness may be denied or disputed. As individuals acknowledge the reality of the situation, the grief reaction may become more pronounced.

After repeated confrontations with elements of loss, normal adaptation results in a gradual change in emphasis and focus that enables individuals to accept the loss emotionally and to make the adjustments and adaptations that are necessary to re-establish their place within the everyday world. When the grief reaction is prolonged, individuals may develop a pathological grief reaction, which may become more disabling than the chronic illness or disability itself.

## Fear and Anxiety

Individuals normally become anxious when confronted with threat. A chronic **illness** or disability can pose a threat because of the potential loss of function, love, independence, or financial security. Threat causes anxiety. Some individuals fear the unknown or unpredictability of a condition, which provokes anxiety. For others, hospitalizations that immerse them in a strange and unfamiliar environment away from home, family, and the security of routine produce anxiety. When conditions are life-threatening, fear and anxiety may be associated not only with loss of function, but also with loss of life. Fear and anxiety associated with chronic **illness** or disability can place individuals in a state of panic, rendering them psychologically immobile and unable **to** act. Helping them regain a sense of control over their situation through information and shared decision making can be an important step in reducing anxiety and facilitating rehabilitation.

## Anger

Individuals with chronic **illness** or disability may experience anger at themselves or others for perceived injustices or the losses associated with their condition. They may believe that their chronic **illness** or disability was caused by negligence or that their condition was avoidable. If they perceive themselves as victims, anger may be directed toward the persons or circumstances they blame for the condition or situation. If they believe that their own actions were partly **to** blame for the chronic **illness** or disability, anger may be directed inward.

Anger can also be the result of frustration. Individuals may vent frustration and anger by showing hostility toward those

who have no relationship **to** the development of the chronic **illness** or disability and no influence over its outcome. Anger may also be an expression of the realization of the seriousness of the situation and its associated feelings of helplessness. At times, anger may not be openly expressed but rather expressed through quarreling, arguing, complaining, or being excessively demanding in an attempt **to** gain some control. Helping individuals express anger in appropriate ways and enabling them **to** experience a sense of control over their situation can help **to** resolve anger, which could otherwise be detrimental **to** successful rehabilitation.

## Depression

With the realization of the reality, seriousness, and implications of the chronic **illness** or disability, individuals may experience feelings of depression, helplessness and hopelessness, apathy, and/or dejection and discouragement. Signs of depression include sleep disturbances, changes in appetite, difficulty concentrating, and withdrawal from activity. Not all individuals with chronic **illness** or disability experience significant depression, and, in those who do, depression may not be prolonged. The extent **to** which depression is experienced varies from person **to** person. Prolonged or unresolved depression can result in self-destructive behaviors, such as substance abuse or attempted suicide. Individuals with prolonged depression should be referred for mental health evaluation and treatment.

## Guilt

Guilt can be described as self-criticism or blame. Individuals or family members may feel guilt if they believe they con-

tributed **to**, or in some way caused, the chronic **illness** or disability. Those who develop lung cancer or emphysema after years of tobacco use, or those who receive a spinal cord injury from an accident that occurred because they were driving while intoxicated, may experience guilt because of the role they played. In other instances, they may experience guilt because they feel their chronic **illness** or disability places a burden on their family or because they are unable **to** fulfill former roles.

Family members may experience guilt because of anger or resentment they have toward the individual with a disability. Guilt may also be associated with blame. Family members may actively demonstrate scorn or contempt toward the individual with chronic **illness** or disability, causing him or her **to** feel more guilty.

Guilt may be expressed or unexpressed and can occur in varying dimensions. It can be an obstacle **to** the successful adjustment **to** the condition and its limitations. Self-blame or blame ascribed by others is detrimental not only **to** the individual's self-concept, but also **to** rehabilitative efforts as a whole. Guilt that affects rehabilitation potential or well-being is an indication that referral **to** appropriate professionals for evaluation and treatment may be appropriate.

## **CHRONIC ILLNESS AND DISABILITY THROUGH THE LIFE CYCLE**

Development is not static or finite. It is a continual process from infancy **to** old age and death. Each developmental stage is associated with certain age-appropriate behaviors, skills, and developmental tasks that allow psychological and cognitive transition from one stage **to** another. Individuals' age and developmental stage influence their **reactions to** chronic **illness**

or disability and the problems and consequences they experience.

Each developmental stage of life has its own particular stresses or demands, apart from those experienced as a result of **illness** or disability. Chronic **illness** and disability at various stages of development can affect the independence, self-control, and life skills associated with these different developmental stages. Since the needs, responsibilities, and resources of adults differ from those of children, the impact of chronic **illness** or disability in later years differs from its impact in young adulthood.

Family members and others generally adjust their behavior **to** accommodate and **to** interact appropriately with individuals as they pass from one developmental stage **to** the next. When individuals experience chronic **illness** or disability, however, others may modify expectations of age-appropriate behavior, and these modified expectations may interfere with the individual's mastery of the **normal** skills required **to** meet the challenges of future developmental stages.

All aspects of development are related. Each developmental stage must be understood within the context of the individual's past and current experience. Those with chronic **illness** or disability must be considered in the context of their developmental stage and the way in which the their condition influence the attitudes, perceptions, actions, and behaviors characteristic of that stage. Stages of development serve as a guideline not only in assessing individuals' functional capacity, but also in determining potential stressors and **reactions**.

Problems and stresses at different developmental stages are similar whether individuals have a chronic **illness** or disability or not. Although there are no clear lines of demarcation between life stages and all