



IMPACT OF TERMINAL ILLNESS ON FAMILIES

Life-threatening illness affects not only the person who is dying, but also the entire family system including members inside and outside the home. The prospect of death and the loss of a family member place the family in a state of unbalance or chaos.

During the period of serious illness, the family can be as deeply disturbed and upset as the dying person. **Among the most difficult tasks faced by the family is that of dealing with their own emotions.** No family that has lived with a terminal illness can survive unchanged by the ordeal. However, the changes that result are distinct for each family system.

Some families may actually pull together and function better while others may break apart and never recover “normal” functioning again. It is not unusual for unresolved conflicts and resentments to surface when people are placed in the stressful situation of watching a loved one die.

The way in which families cope with a serious illness depends upon several factors:

1. past experiences (people tend to rely on ingrained coping strategies),
2. the dying person’s role in the family (coping may differ depending upon the person’s contribution to the family system, i.e., wage earner, primary homemaker, etc.),
3. the length of the illness (prolonged illness can be emotionally and financially taxing),
4. the presence of social supports,
5. cultural differences (culture can affect the type of emotion expressed, verbal communication and willingness to accept outside help),
6. age of patient, young/old
7. quality of marriage and family relationship.

Just as a terminally ill person progresses from a state of health to sickness, to dying; a family also progresses through various stages. It is important, however, to recognize that each family is unique and will respond to illness and eventual death in their own way.

According to Elliot Rosen (1990), the family progresses through three main phases:

(1) The First Phase – Initial Diagnosis

During the first phase of initial symptoms, diagnosis, prognosis and treatment, the family’s first reactions are **fear** and **denial**.

As the family begins acknowledging the prospect of loss, **anxiety** and **anger** may surface. This can result in a process of “scapegoat’ or trying to put the blame on someone for the fate they



must cope with. Care providers such as doctors, nurses, and Homemakers may take the brunt of this anger. Even the dying person may be chastised for somehow causing the disease through smoking, poor diet, overwork, etc.

During this time, the family may be highly disorganized and require assistance with planning for services and support. They will definitely need an empathetic listener.

(2) The Middle Phase – Living with the Illness

Once family members have adapted to the prospect of loss, they begin to live with the reality of a serious illness on a day-to-day basis. This second phase can be viewed as a kind of settling in period when care taking roles are assigned and carried out.

Fear is a common emotional response during this time, which is determined partly by the nature of the anticipated loss. For example, if the dying person is the wage earner in the family, there may be fears around finances; if the dying person provides most of the childcare, the fears may centre around child rearing.

In addition to caring for the sick person, the family also strives to take care of itself. This involves a difficult balancing act between competing demands and needs. Feelings of **guilt** often arise because there is never enough time or energy to attend as completely as possible to everyone's requirements.

The tedium of daily care is particularly taxing in the middle phase of the illness. If this period is long, the family becomes **exhausted** and understandably **impatient** with the dying person. Such feelings can again create a substantial amount of **guilt** and **anxiety**. Family members may begin to question their ability to care for the dying person. Fears around inflicting harm are common and often reinforced by the dying person, whose own concerns about pain produce **generalized anxiety** in the family.

(3) The Final Phase – Acceptance of Death

In the final phase, death becomes an expected outcome. However, family members may act differently depending upon their own personal attributes. It is not unusual for one person to be making funeral arrangements while another insists that the dying person is looking much better.