

## MODULE 5: MANAGEMENT OF CHRONIC AND TERMINAL ILLNESS

### ACUTE ILLNESS

Acute illness is believed to be caused by specific viral or bacterial agents and is short in duration, with no long-term consequences. An example is the flu.

### CHRONIC ILLNESS

Chronic illness is believed to be caused by multiple factors, including health habits, and last longer duration (more than 3 months), often with severe consequences. An example is heart disease.

#### *UNIT 1: EMOTIONAL RESPONSE TO CHRONIC ILLNESS- DENIAL, ANXIETY, DEPRESSION.*

Emotional response to chronic illness-

Immediately after a chronic disease is diagnosed, a patient can be in a state of crisis marked by physical, social, and psychological disequilibrium. If the patient's usual coping efforts fail to resolve these problems, the result can be an exaggeration of symptoms and their meaning, indiscriminate efforts to cope, an increasingly negative attitude, and worsening health. The chronically ill are more likely to suffer from depression, anxiety, and generalized distress. These psychological changes are important because they compromise quality of life, predict adherence to treatment, and increase the risk of dying early.

Three major emotional response to chronic illness comprise:

1. DENIAL, 2. ANGER, 3. DEPRESSION.

1. Denial- Denial is a defence mechanism by which people avoid the implications of an illness. It is a common early reaction to chronic illness. Patients may act as if the illness is not severe, it will shortly go away, or it will have few long-term implications. Immediately after the diagnosis of illness, denial can serve a protective function by keeping the patient from having to come to terms with problems posed by the illness when he or she is least able to do so. Over time, however, any benefit of denial gives way to its costs. It can interfere with taking in necessary treatment information and compromise health.
2. Anxiety- Following the diagnosis of a chronic illness, anxiety is also common. Many patients are overwhelmed by the potential changes in their lives and, in some cases, by the prospect of death. Anxiety is especially high when people are waiting for test results, receiving diagnoses, awaiting invasive medical procedures, and anticipating or experiencing adverse side effects of treatment. Anxiety is a problem not only because it is intrinsically distressing but also because it interferes with treatment. For example, anxious patients cope more poorly with surgery, anxious diabetic patients have poor glucose control, anxiety exacerbates sickle cell disease, irritable bowel syndrome, multiple sclerosis; and anxious MI patients are less likely to return to work on schedule. Anxiety is especially prevalent among people with asthma and pulmonary disorders. Symptoms of anxiety may also be mistaken for symptoms of the underlying disease and thus interfere with assessments of the disease and its treatment. Catastrophic thinking, that is, imagining and exaggerating how much worse things will get, can aggravate symptoms and complicate treatment.
3. Depression- Depression is a common reaction to chronic illness. Up to one-third of all medical in-patients with chronic disease report symptoms of depression, and up to one-quarter suffer from severe depression. Depression is especially common among stroke patients, cancer patients, and heart disease patients, as well as among people with more than one chronic disorder. At one time, depression was regarded only as an emotional disorder, but its medical significance is increasingly recognized. People who have intermittent bouts of depression are more likely to get heart disease, atherosclerosis, hypertension, stroke, dementia, osteoporosis, and Type II diabetes, and at younger ages. Depression exacerbates the course of several chronic disorders, most notably coronary heart disease. Depression complicates treatment adherence and medical decision making. It interferes with

patients adopting a co-managerial role, and it leads to enhanced risk of mortality from several chronic diseases. Depression is sometimes a delayed reaction to chronic illness, because it takes time for patients to understand the full implications of their condition.

### Assessing Depression

Depression is so prevalent among chronically ill patients that experts recommend routine screening for depressive symptoms during medical visits. Massive symptoms during medical visits. Yet assessing depression in the chronically ill can be complicated. Many symptoms of depression, such as fatigue, sleeplessness, and weight loss, can also be symptoms of disease or side effects of a treatment. If depressive symptoms are attributed to illness or treatment, their significance may be less apparent, and, consequently, depression may go untreated.

### Who Gets Depressed?

Depression increases with the severity of the illness and with pain and disability. These problems are aggravated in people who are experiencing other negative life events and lack of social support. In recent years, effective cognitive behavioural interventions have been developed to deal with the depression that so frequently accompanies chronic illness. Even telephone-administered cognitive behavioural therapy can improve depression. Treatment for depression may not only alleviate psychological distress but also reduce symptoms associated with the illness.

## *UNIT 2: PERSONAL ISSUES IN CHRONIC DISEASE*

### Personal issues in chronic disease

To fully understand reactions to chronic illness requires a consideration of the self, its sources of resilience, and its vulnerabilities. The self is one of the central concepts in psychology. Psychologists refer to the self-concept as a stable set of beliefs about one's personal qualities and attributes. Self-esteem refers to the evaluation of the self-concept—namely, whether one feels good or bad about one's personal qualities and attributes.

A chronic illness can produce drastic changes in self-concept and self-esteem. Many of these changes will be temporary, but some may be permanent, such as the mental deterioration that is associated with certain diseases. The self-concept is a composite of self-evaluations regarding many aspects of life, which include body image, achievement, social functioning, and the private self. 1.The Physical Self 2.The Achieving Self 3.The Social Self 4.The Private Self . The Physical Self Body image is the perception and evaluation of one's physical functioning and appearance. Body image plummets during illness. Not only is the affected part of the body evaluated negatively, the whole body image may take on a negative aura. For acutely ill patients, changes in body image are short-lived; however, for the chronically ill, negative evaluations may last. These changes in body image are important. First, a poor body image increases risk for depression and anxiety. Second, body image may influence how adherent a person is to the course of treatment and how willing he or she is to adopt a co-management role. Finally, body image is important because it can be improved through interventions such as exercise.

The Achieving Self- Achievement through vocational and avocational activities is also an important source of self-esteem and the self-concept. Many people derive their primary life satisfaction from their job or career; others take great pleasure in their hobbies and leisure activities. If chronic illness threatens these valued aspects of the self, the self-concept may be damaged.

The Social Self- Social resources, such as family and friends, can provide chronically ill patients with badly needed information, help, and emotional support. A breakdown in the support system has implications for all aspects of life. Perhaps for these reasons, fears about being abandoned by others are among the most common worries of chronically ill patients. Consequently, family participation in the illness management process is widely encouraged.

The Private Self- The residual core of a patient's identity—ambitions, goals, and desires for the future—

are also affected by chronic illness. Adjustment can be impeded because the patient has an unrealized dream, which is now out of reach, or at least appears to be. For example, the dream of retiring to a cabin on a lake in the mountains may not be viable if the management of a chronic condition requires living near a major medical center. Encouraging the patient to discuss this difficulty may reveal alternative paths to fulfillment and awaken new ambitions, goals, and plans for the future.

## **PSYCHOLOGICAL INTERVENTIONS OF CHRONIC ILLNESS**

Most chronically ill patients achieve a fairly high quality of life. However, adverse effects of chronic disease and treatments have led health psychologists to develop interventions to reduce their problems,

Anxiety and depression are intermittently high among chronically ill patients, an evaluation for these problems needs to be a standard part of chronic care

- **Pharmacological**

Reduce pain, depression in chronic illness patient

- **Individual therapy**

Individual therapy is a common intervention for patients who have psychosocial complications due to chronic illness. But there are important differences between psychotherapy with medical patients and psychotherapy with patients who have primarily psychological disorders:

1. Medical patients and therapists have episodic interactions only.
2. Collaboration with physician & family of the patient.
3. In therapy with medical patients, Defences are dealt with care as they may serve protective functions.
4. Therapist must possess a comprehensive understanding of the medical condition, modes of treatment & its physical & psychosocial implications.

## **PSYCHOLOGICAL INTERVENTIONS**

### **Brief psycho-therapeutic interventions**

CBT, targeting specific problems, such as fatigue, mood-related disorders, functional impairments, or stress. Even briefer therapies, such as CBT conducted over the telephone, can benefit patients, enhancing a sense of personal control and reducing distress.

Short term interventions to reduce distress. Information on what is to be expected during treatment (physical & psychological changes), normal expressions of psychological distress & depression, aiding communication b/w patient, family & health professionals, coping skills training.

Brief interventions through telephone, art therapy, expressive writing- enhance feelings of control, self-efficacy & reduce emotional suffering.

### **Patient education**

Disease specific coping skills training, imparting of knowledge, increase feelings of purpose & meaning in life, confidence in the ability to manage disease, internet also provides information, can clarify doubts & info on new treatment methods.

### **Relaxation, stress management & exercise:**

Relaxation training is a widely used intervention with the chronically ill, including asthmatics, cancer patients, and multiple sclerosis patients, among others. Combining relaxation training with stress management and blood pressure monitoring has proven useful in the treatment of hypertension

Meditation, mindfulness-based stress reduction (MBSR) being focused and fully aware of the present moment, learn not to react automatically improve

adjustment to chronic illness. Mindfulness meditation teaches people to be highly aware and focused on the present moment, accepting and acknowledging thoughts and feelings without becoming distracted or distressed by stress.

Acceptance and commitment therapy (ACT) has also been used with the chronically ill and helps patients to accept their illness experiences without avoidance or fruitless striving

### **Social support interventions:**

Promote recovery & longevity. Patients are helped to understand the benefits of social support, identify potential sources, learn to seek support, join community groups, interests.

### **Family support:**

enhances physical & psychological functions, promote adherence. They can make the difficult adjustments easier. Family may be given guidance/information so that they may take informed actions, encourage to be cheerful.

### **Support groups:**

specific groups for specific illness. Some are initiated by a therapist or are patient led. Share information, provide emotional and physical support, support to families, fight stigma, and develop motivation to continue treatment, techniques to overcome certain difficulties. Such groups are found to increase health & long term survival.

It is low cost & convenient but does not reach all of the needy, disproportionately distributed (available for the already privileged)

Most of these interventions are helpful but health care professionals need to be educated of their benefits. Psychosocial approaches to chronic illness need more research to establish credibility.

The techniques need more refinement, monitor the success rate and get popularized. These interventions can create awareness of the difficulties associated with chronic illness and their psycho social implications.

## **PSYCHOLOGICAL ISSUES IN ADVANCING AND TERMINAL ILLNESS ADVANCING & TERMINAL ILLNESS**

### **1. ADVANCED ILLNESS**

Advanced illness refers to late-stage chronic illness, when one or more conditions become serious enough that general health and function decline and treatments begin to lose their impact—a state that progresses to the end of life

### **2. TERMINAL ILLNESS**

A terminal illness is a disease or condition which can't be cured and is likely to lead to someone's death. It's sometimes called a life-limiting illness.

There is no set list of illnesses which are terminal. People who are terminally ill may have a single disease or a number of conditions:

Advanced cancer, dementia (including Alzheimer's), motor neurone disease, lung disease, neurological diseases like Parkinson's, advanced heart disease.

Sudden hitting of reality: Although many people die suddenly, many people who are terminally ill know that they are going to die for some time before their death. As a consequence, a variety of medical and psychological issues arise for the patient.

## PSYCHOLOGICAL ISSUES IN ADVANCING AND TERMINAL ILLNESS INCLUDES:

- Continued Treatment and Advancing Illness
- Psychological and Social Issues Related to Dying
- The Issue of Non-traditional Treatment

### ❖ CONTINUED TREATMENT AND ADVANCING ILLNESS

Advancing and terminal illness frequently bring the need

for continued treatments with debilitating and unpleasant side effects. There may, consequently, come a time when the question of whether to continue treatments becomes an issue. In some cases, refusal of treatment may indicate depression and feelings of hopelessness, but in many cases, the patient's decision may be supported by thoughtful choice.

DISEASE	DISCOMFORT /side effects
Cancer – radiation, chemotherapy	Discomfort, nausea, hair loss, fatigue. Etc
Advancing diabetics	Amputation of extremities, such as fingers or toes.
Advancing cancer	Removal of organ

## IS THERE RIGHT TO DIE?

An important social trend affecting terminal care is the right-to-die movement, which maintains that dying should become more a matter of personal choice and personal control.

### • Moral and Legal Issues

increasingly, societies struggle with the issue of euthanasia that is, deliberately ending the life of a person who is suffering from a painful terminal illness.

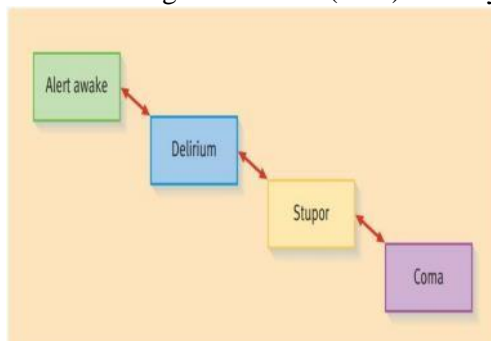
Euthanasia types: Active and passive Voluntary and involuntary

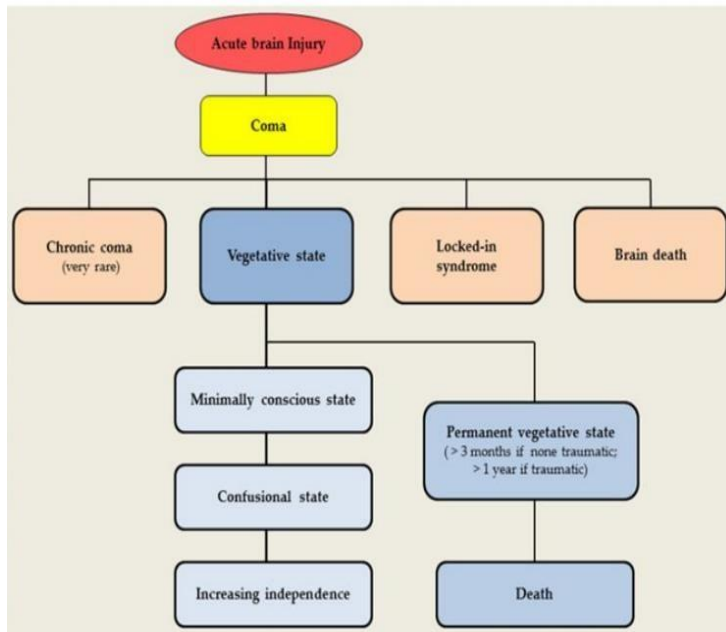
- **ACTIVE:** When most people think of euthanasia, they think of a doctor directly ending someone's life. This is known as active euthanasia. Purposely giving someone a lethal dose of a sedative is considered active euthanasia.
- **PASSIVE:** Passive euthanasia is sometimes described as withholding or limiting life-sustaining treatments so that a person passes more quickly. A doctor may also prescribe increasingly high doses of pain-killing medication, stop feeding a patient, removal of life supporting machine.
- **VOLUNTARY:** someone makes a conscious decision to seek help with ending their life, it's considered voluntary euthanasia. The person must give their full consent and demonstrate that they fully understand what will happen.
- **NON-VOLUNTARY EUTHANASIA:** involves someone else making the decision to end someone's life. A close family member usually makes the decision. This is generally done when someone is completely unconscious or permanently incapacitated.

### EUTHANASIA IN INDIA:

On 9 March 2018 the Supreme Court of India legalized passive euthanasia by means of the withdrawal of life support to patients in a Permanent Vegetative state.

The decision was made as part of the verdict in a case involving Aruna Shanbaug, who had been in a Persistent Vegetative State (PVS) for 40 years until her death in 2015.





### ❖ PSYCHOLOGICAL AND SOCIAL ISSUES RELATED TO DYING

- Changes in the Patient's Self-Concept
- Issues of Social Interaction
- Communication Issues

### CHANGES IN THE PATIENT'S SELF-CONCEPT

Advancing illness can threaten the self-concept.

As the disease progresses, patients are increasingly less able to present themselves effectively.

It may become difficult for them to maintain control of biological and social functioning.

They may be incontinent (unable to control urination or bowel movements); they may drool, have distorted facial expressions, or shake uncontrollably. None of this is attractive either to the patient or to others. These patients may also be in intermittent pain, Cognitive decline all affect self

### ISSUES OF SOCIAL INTERACTION

Although terminally ill patients often want and need social contact, they may be afraid that their obvious mental and physical deterioration will upset visitors. Thus, patients may begin a process of social withdrawal, whereby they gradually restrict visits to only a few family members.

But friends and family can prepare visitors in advance for the patient's state so that the visitor's reaction can be controlled; they can also screen out some visitors who cannot keep their emotions in check.

### COMMUNICATION ISSUES

As long as a patient's prognosis is favourable, communication is usually open; however, as the prognosis worsens and treatment becomes more drastic, communication may break down.

Each person involved may believe that others do not want to talk about the death.

Death itself is still a taboo topic in our society.

The issue of death is generally avoided in polite conversation; little research is conducted on death; and even when death strikes within a family, the survivors often try to bear their grief alone. The right thing to do, many people feel, is not to bring it up

### THE ISSUE OF NON-TRADITIONAL TREATMENT

As both health and communication deteriorate, some terminally ill patients turn away from traditional medical care.

Many such patients fall victim to dubious remedies offered outside the formal medicine and face serious consequences.

What prompts people to take these often uncomfortable, inconvenient, costly, and worthless measures?

1. Some patients are so frantic at the prospect of death that they will use up both their own savings and those of the family in the hope of a miracle cure.
2. In other cases, turning to non-traditional medicine may be a symptom of a deteriorating relationship with the health care system and the desire for more humanistic care

## **STAGES OF DYING, PSYCHOLOGICAL MANAGEMENT OF THE TERMINALLY ILL**

### **Kübler-Ross's Five-Stage Theory**

Elisabeth Kübler-Ross, a pioneer in the study of death and dying, suggested that people pass through five stages as they adjust to the prospect of death:

1. **Denial**
2. **Anger**
3. **Bargaining**
4. **Depression**
5. **Acceptance**

#### **DENIAL**

The first stage, denial, is thought to be a person's initial reaction on learning of the diagnosis of terminal illness.

Denial is a defense mechanism by which people avoid the implications of an illness. They may act as if the illness were not severe, it will shortly go away, and it will have few long-term implications.

In extreme cases, the patient may even deny that he or she has the illness, despite having been given clear information about the diagnosis.

Denial, then, is the subconscious blocking out of the full realization of the reality and implications of the disorder. The diagnosis of a terminal illness can come as a shock to a person.

The immediate response may be that a mistake has been made, that the test results or X-rays have been mixed up with those of someone else, or that the diagnosis will be reversed.

Shortly thereafter, everything suddenly seems to change. Plans—ranging from what to do tomorrow to what to do for the rest of one's life—may have to change.

The emotions most likely to accompany these initial feelings of disorientation are denial and anxiety.

Denial early on in adjustment to life-threatening illness is both normal and useful because it can protect the patient from the full realization of impending death (Lazarus, 1983).

Sometimes, denial lasts longer than a few days. When it does, it may require psychological intervention.

It may mask anxiety without making it go away.

Long-term denial of one's illness, then, is a defensive pattern from which a patient should be coaxed through therapeutic intervention.

#### **ANGER**

Denial usually abates because the illness itself creates circumstances that must be met. Decisions must be made regarding future treatments if any, where the patient will be cared for, and by whom.

At this point, according to Kübler-Ross, the second stage, anger, may set in.

The angry patient may show resentment toward anyone who is healthy, such as hospital staff, family members, or friends.

Anger is one of the harder responses for family and friends to deal with. They may feel they are being blamed by the patient for being well.

The family may need to work together with a therapist to understand that the patient is not really angry with them but at fate; they need to see that this anger will be directed at anyone who is nearby, especially people with whom the patient feels no obligation to be polite and well behaved. Unfortunately, family members often fall into this category.

## **BARGAINING**

Bargaining is the third stage of Kübler-Ross's formulation.

At this point, the patient abandons anger in favor of a different strategy: trading good behavior for good health.

Bargaining frequently takes the form of a pact with God, in which the patient agrees to engage in good works or at least to abandon selfish ways in exchange for better health or more time.

A sudden rush of charitable activity or uncharacteristically pleasant behavior may be a sign that the patient is trying to strike such a bargain.

## **DEPRESSION**

Depression, the fourth stage in Kübler-Ross's model, may be viewed as coming to terms with lack of control.

The patient acknowledges that little can now be done to stay the course of illness.

This realization may be coincident with a worsening of symptoms, tangible evidence that the illness is not going to be cured. At this stage, patients may feel nauseated, breathless, and tired.

Kübler-Ross refers to the stage of depression as a time for "anticipatory grief," when patients mourn the prospect of their own deaths.

This grieving process may occur in two stages, as the patient first comes to terms with the loss of past valued activities and friends and then begins to anticipate the future loss of activities and relationships.

Depression, though far from pleasant, can be functional in that patients begin to prepare for the future. As a consequence, it may sometimes be wise not to intervene immediately with depression, but rather to let it run its course, at least for a brief time.

The advice to let depression run its course obviously does not extend to clear cases of pathological depression, in which the patient is continually morose, unresponsive to friends and family, unable to eat, and basically uninterested in activity.

In these cases, a therapist may have to intervene.

## **ACCEPTANCE**

The fifth stage in Kübler-Ross's theory is acceptance.

At this point, the patient may be too weak to be angry and too accustomed to the idea of dying to be depressed. Instead, a tired, peaceful, though not necessarily pleasant calm may descend.

Some patients use this time to make preparations, deciding how to divide up their remaining

personal possessions and saying goodbye to old friends and family members.

At one time, researchers speculated that “giving up” might actually influence time of death, but that does not appear to be the case, similarly “holding on” to make it through a holiday or other major events does not appear to occur reliably either.

### **ADVANTAGES**

Description of the reactions of dying patients, her work was invaluable.

She has chronicled nearly the full array of reactions to death, as those who work with the dying will be quick to acknowledge.

Her work is also of inestimable value in pointing out the counselling needs of the dying.

Finally along with other researchers, she has broken through the silence and taboos surrounding the death.

### **DISADVANTAGES**

As a stage theory, however, her work has some limitations. Patients do not go through five stages in a predetermined order. Some patients never go through a particular stage. Others will go through a stage more than once.

Kübler-Ross’s stage theory also does not fully acknowledge the importance of anxiety, which can be present throughout the dying process.

No stage model can be infallibly applied to the process of dying. Dying is a complex and individual process, subject to no rules and few regularities.

## **PSYCHOLOGICAL MANAGEMENT OF THE TERMINALLY ILL**

Include:

- Medical Staff and the Terminally Ill Patient
- The Significance of Hospital Staff to the Patient
- Risks of Terminal Care for Staff
- Achieving an Appropriate Death
- Individual Counselling with the Terminally Ill
- Family Therapy with the Terminally Ill
- The Management of Terminal Illness in Children.

### **❖ Medical Staff and the Terminally Ill Patient**

Wards may be understaffed, with the staff unable to provide the kind of emotional support the patient needs.

Hospital regulations may restrict the number of visitors or the length of time that they can stay, thereby reducing the availability of support from family and friends.

Pain is one of the chief symptoms in terminal illness, and in the busy hospital setting, the ability of patients to get the kind and amount of pain medication they need may be compromised.

Prejudices against drug treatments for pain still exist, and so terminal patients run the risk of being under medicated for their pain.

### **❖ The Significance of Hospital Staff to the Patient**

Physical dependence on hospital staff is great because the patient may need help for even the smallest activity, such as brushing teeth or turning over in bed.

Patients are entirely dependent on medical staff for amelioration of their pain. And staff may be the only people to see a dying patient on a regular basis if he or she has no friends or family who can visit regularly.

Moreover, staff may be the only people who know the patient’s actual physical state; hence, they are the patient’s only source of realistic information.

### ❖ **Risks of Terminal Care for Staff**

Terminal care is hard on hospital staff. It is the least interesting physical care because it is often palliative care—that is, care designed to make the patient feel comfortable—rather than curative care—that is, care designed to cure the patient's disease.

Terminal care involves a lot of unpleasant custodial work, such as feeding, changing, and bathing the patient. Even more important is the emotional strain that terminal care places on staff.

The staff may burn out from watching patient after patient die, despite their best efforts. Staff may be tempted to withdraw into a crisply efficient manner rather than a warm and supportive one so as to minimize their personal pain.

Physicians, in particular, want to reserve their time for patients who can most profit from it and, consequently, many may spend little time with a terminally ill patient, unfortunately, terminally ill patient may interpret such behaviour as abandonment and take it very hard.

Accordingly, a continued role for the physician in the patient's terminal care in the form of brief but frequent visits is desirable. The physician can interpret confusing physical changes and allay anxiety by providing information and a realistic timetable of events.

The patient and the physician may also make decisions about subsequent medical interventions, such as the use of life support systems and the living will, as noted earlier.

At one time, it was widely believed that patients did not want to know if they were terminally ill, although research subsequently proved that belief groundless

### **Achieving an Appropriate Death**

Psychiatrist Avery Weisman (1972, 1977), a distinguished clinician who worked with dying patients for many years, outlined a useful set of goals for medical staff in their work with the dying:

Informed consent—Patients should be told the nature of their condition and treatment and, to some extent, be involved in their own treatment.

Safe conduct—The physician and other staff should act as helpful guides for the patient through this new and frightening stage of life

Significant survival—the physician and other medical staff should help the patient use his or her remaining time as well as possible.

### **Individual Counselling with the Terminally Ill**

Many patients need the chance to talk with someone about how they feel about themselves, their lives, their families, and death, and they need an opportunity to regain a sense of control over their lives.

Typically, medical staff cannot devote the kind of time required for this support. Accordingly, therapy for dying patients is becoming an increasingly available and utilized option.

Therapy with the dying is different from typical psychotherapy in several respects.

First, for obvious reasons, it is likely to be short term. The nature and timing of visits must depend on the inclination and energy level of the patient, rather than on a fixed schedule of appointments.

The agenda should be set at least partly by the patient. And if an issue arises that the patient clearly does not wish to discuss, this wish should be respected.

Terminally ill patients may also need help in resolving unfinished business.

Uncompleted activities may prey on the mind, and preparations may need to be made for survivors, especially dependent children.

Through careful counseling, a therapist may help the patient come to terms with the need for these arrangements, as well as with the need to recognize that some things will remain undone

Some thanatologists —that is, those who study death and dying—have suggested that behavioral and cognitive-behavioral therapies can be constructively employed with dying patients (Sobel, 1981).

For example, progressive muscle relaxation can ameliorate discomfort and instill a renewed sense of control. Positive self-talk, such as focusing on one's life achievements, can undermine the depression that often accompanies dying.

Many people find meaning in symbolic immortality, a sense that one is leaving behind a legacy through one's children or one's work or that one is joining the afterlife and becoming one with God. Thus, the last weeks of life can crystallize the meaning of a lifetime.

### **Family Therapy with the Terminally Ill**

Dying does not happen in a vacuum but is often a family experience.

As a consequence, family therapy can be an appropriate way to deal with the most common issues raised by terminal illness: communication, death-related plans and decisions, and the need to find meaning in life while making a loving and appropriate separation.

Sometimes, the therapist will need to meet separately with family members as well as with the patient. Family and patient may be mismatched in their adjustment to the illness. • For example, family members may hold out hope, but the patient may be resigned to the prospect of death.

A therapist can help family members find a balance between their own needs and those of the patient.

Other conflicts may arise that require intervention. If a patient withdraws from some family members but not others, a therapist can anticipate the issues that may arise so that the patient's withdrawal is not misunderstood, becoming a basis for conflict.

Both patients and family members may have difficulty saying what they mean to each other; therapists can interpret what patients and family members are trying to express.

For many families, terminal illness can be a time of great closeness and sharing. It may be the only time when the family sets aside time to say what their lives within the family have meant.

### **The Management of Terminal Illness in Children**

Working with terminally ill children is perhaps the most stressful of all terminal care.

First, it is often the hardest kind of death to accept. Hospital staff typically serve only limited rotations in units with terminally ill children because they find the work so psychologically painful.

Death in childhood can also be physically painful, which adds to the distress it causes. A common cause of childhood death is leukemia, which is not only painful in itself but is treated through a variety of stressful medical procedures: bone marrow transplant

Moreover, one must work not only with a confused and often frightened child but usually also with unhappy, frightened and confused parents

For these reasons, terminally ill children often receive even less straightforward information about their condition than do terminally ill adults.

Their questions may go unanswered, or they and their parents may be led to falsely optimistic conclusions so that medical staff can avoid painful confrontations.

However, it is clear that, just as is true for terminally ill adults, terminally ill children know

more about their situation than they are given credit for.

Children use cues from their treatments and from the people around them to infer what their condition must be. As their own physical condition deteriorates, they develop a conception of their own death and the realization that it may not be far off.

In some cases, death fantasies may be acted out by burying a doll or holding a funeral for a toy. Parents who know that their child is aware of his or her likely death would do well to tell to their child about it

Counseling with a terminally ill child can, in certain respects, proceed very much like counseling with a terminally ill adult. The therapist can take cues about what to say directly from the child, talking only when the child feels like talking and only about what the child wants to talk about.

In many cases, it is not just the terminally ill child who requires some kind of counseling but the family as well. Parents may blame themselves for the child's disease, and even in the best of cases, parents' fears may complicate the dying child's adjustment.

The needs of other children may go relatively ignored, and those children may come to feel confused and resentful about their own position in the family. It may also be difficult for parents to get good information about the nature of their child's treatment and prognosis.

