While dying is the ultimate loss experience, the stages that the terminal patient passes through provide broad guidelines for understanding all loss and the grieving process as well. In her ground breaking work, *On Death and Dying*, Elisabeth Kubler-Ross outlined the stages of the dying patient which have profoundly influenced the treatment of those suffering terminal illnesses.

• **DENIAL.** The person when first confronted with the fact that s/he has an illness that will bring about death is likely to be unable to take-in this information. The most immediate response is "This can't be true" or "This can't be happening to me." The fact of one's impending death is experienced as unreal and impossible.

Patients in denial are likely to make the rounds of many doctors looking for the one who will tell them that this is not a fatal illness. They want someone to "undo" the terrible and overwhelming news they have received. Under the best of circumstances, facing one's own mortality is very difficult. When faced with a "death sentence" the task of incorporating this news feels next to impossible.

Denial simply eliminates a painful, hard-to-bear truth. It simply isn't so. In denial, a patient may refuse to talk about his/her illness, not allow others to mention it, or maintain unrealistic beliefs about miracle cures or their ability to escape the fatal outcome.

It is important to realize that the dying patient's fear of death extends to a fear of being abandoned as well. Since death and dying have been such a "taboo" topic, little time or thinking has usually gone into considering the end of one's life. People respond with false optimism, discouraging comments (e.g., "Don't be morbid" or "Don't dwell on it"), or total avoidance. The dying person, sensing the discomfort of others, may avoid talking about themselves, their condition, or their fate out of sensitivity to others or to prevent being abandoned. Thus, they may not be denying their reality but avoid talking about it to protect those around them. The denial is not theirs. It is those around the patient who need the denial in order to remain present. It is always important in treating the dying to check out whose denial is in force.

Some patients never move out of denial. They need this coping strategy to function. It is therapeutically unwise and basically unkind to force a patient to give up this denial when it is truly needed.

 ANGER. Death is inopportune. Its coming is unwelcome and particularly in the young, it is untimely and premature. Who wouldn't

be angry at this cruel blow? There is life to be lived and accomplishments to be made. Usually, it is only the elderly who feel more sanguine about dying and that is not always true.

Dying patients rage at their impending death. Dylan Thomas stated his ambivalence about death very well when considering the death of his father: "Rage, rage at the dying of the light. Go not gently into that good night."

The anger takes many forms. As the condition of the patient declines, s/he may become angry at anyone who is healthy and who take daily activities for granted that the patient is no longer able to carry out. No one is exempted from the anger no matter how close or how good you may have been to the patient.

The dying patient's anger is hard to take, especially if you're very close to the person. Try to remember that you might feel exactly the same way if you were in this person's shoes. Being able to uncritically accept the anger without judgement helps the person to express these all important feelings. Letting the patient vent is a real help in allowing this person to rid him/herself of the anger at life coming to an end.

• **BARGAINING.** As patients come to some terms with their illness and its inevitable end, they may begin to strike terms for accepting it. They make bargains with doctors, caretakers, and even with God. "Let me live to see my daughter married." "If I could have just one more day in the country feeling well..." "Let me just complete this book I'm working on." The notion is, "and then I'll go quietly..." It is a method of buying time. It is the wish for a temporary reprieve from the sentence of death.

Do not expect the dying patient to keep his or her bargains. While made in relatively good faith, they are efforts to forestall the inevitable. The patient is still having understandable difficulty dealing with his or her end. This is a stop gap procedure and is best understood as a step being taken along the way.

• **ANTICIPATORY GRIEF.** The dying patient is losing everyone and everything s/he has ever loved and cherished in his/her life. Unlike those left behind who only loose the person, the dying have to give everything up. It's a formidable task accompanied by enormous sadness and grief. Often this is a period of very real depression. The dying patient withdraws and becomes isolated and may speak very little. It will be a time of "good-byes" and "farewells" and then a withdrawal into seclusion. This period can come well before the person

is even near to death. Often, the dying patient will keep contact with a few trusted people after having said his or her major farewells.

During this period the patient is sad and depressed. While a few people may be around, there may not be much conversation. Rather, there is just together time that is often spent in silence. The patient turns inward, thinking about the meaning of his or her life. It is a quiet time; a time of release.

Just being able to be with a person during this period is important. Words and conversation make way for silent togetherness. The patient is not abandoned, but neither does s/he reach out for the same level of connectedness. This is a hard time for the helper since there is really nothing to be done except to be present. Often, touch takes the place of conversation. Holding hands, a massage, or a gentle stroking of the forehead carries all the communication needed.

ACCEPTANCE/RESIGNATION. For some death is a defeat; a battle
fought and lost. For others, death becomes an integral part of life; a
natural end to the life experience. In coming to terms with death as a
part of life, the patient reaches a kind of acceptance of the life cycle.
For the former, death is a defeat and their adjustment a form of
resignation.

For the patient who can come to terms with their life and thus their death, acceptance breeds a peacefulness and composure. These patients often require less pain medication and seem to be at ease with themselves and with the people who remain around them.

For the dying patient, the nature of "hope" changes throughout the course of their illness. Hope at first is for the prolongation of life, for the cure of their illness. As time progresses and they negotiate the formidable task of coming to terms with life and death, the nature of hope changes. For some, it becomes the hope for the generation they have left behind. For others, it is the hope for peace in the after-life. And for some, it is expressed in the leaving behind of tape recordings or writings that can be shared with significant others after they are gone.

For the helping person, this, too, is a quiet time. Just being present is important. The patient may talk more now and simple listening is all that is required. The patient is, in a sense, somewhat prepared. Death is not an alien intruder. Rather it is an end in the process of life.

While medicine considers its hi-tech interventions "heroic measures," the real truth is that just being there for the patient is the real measure of heroism. When all that medical science can do is exhausted and one is left with nothing but one's presence, hanging-in is truly heroic. There is nothing left to do (not something that most of us feel comfortable with) but just to be. It can make all the difference.

There is always the danger that when stages are outlined, helping people feel the obligation to move people through the stages. This is a mistake and should be avoided. The dying patient often moves back and forth through all the stages during the progression of their illness. The stages provide guideposts to help us recognize where someone is at a particular point in time and provide us with an understanding of what we might do at that time to be helpful. Not everyone reaches acceptance and, as already noted, some never leave denial. Respect for the person is paramount in all that we do; we are not a better helper because we have battered someone into accepting his or her death. Nor are we less of a helper because the person has not completed all the stages.

The stages of dying are a useful framework for thinking about how people handle any and all losses. Those who grieve will move through many of the same stages. Those who divorce or break-up with a significant other or move to another town or retire will also traverse many of the same steps. Again, the stages provide a means for understanding where a person is in their coping process and provide us with a means of intervention (even when that intervention is to do nothing) that can be helpful to the person on his or her journey.

Barry Greenwald, Ph.D. www.hospicenet.com