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DESTINED TO DIE

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From the moment we are born, we are destined to die. Death is a part of the life cycle, an inevitable outcome of life that brings closure to a life story.¹

While it is true that our own death is inevitable and something that we must face eventually, many people think of it as happening in the distant future, at an old age, and to be considered seriously until then. For some who have had loved ones die in their lifetime, death is more familiar, and a painful reminder of their own finality -- a thought that is to be dismissed quickly from the conscious mind. For others, death is not something that can be quickly dismissed, because it is staring them right in the face and forcing them to confront not only what they don't want to, but something that they know so little about. This is the dilemma of the terminally ill.

It is my belief that if society were better able to cope with death, then perhaps the individual would be better prepared for his own death. Death has always been distasteful to people because it is such a frightening happening.² It is such an unpleasant and painful topic that no one wants to talk about it and discussions do not easily surface. How are we ever to understand it if it is never discussed? Perhaps we will never understand it fully, but we can at least try to prepare ourselves and others.

It hasn't been until recent years that death has been brought "out of the closet" and challenged. For instance, the medical profession is slowly recognizing the need for human relations skills in conjunction with scientific know-how. The clear, if unwritten, goal in the institutions where most of us will die has been: improve the patient's health, or if he is terminal, keep him quiet and comfortable until the end.³ No matter what, I believe a human being deserves more than just efficient physical care. He shouldn't be treated as a thing, but rather as a person with feelings and

emotional needs that must be met. In many instances, a person's emotional state has a direct influence on his physical state. Perhaps if medical staff were taught to be more in tune with people's feelings, it would be helpful for them as well as their patients when treating them. We might also consider introducing "death and dying" courses in our educational curriculum, whereby we could become more familiar with something we know so little about.

It is often hard for us to examine our own attitudes toward death and dying if we have not in some way been connected with it. If most people are lucky, they will never have to confront death in the abrupt way the terminally ill must -- they are usually told their days are numbered, and the realization of their impending death slaps them directly in the face. I have had friends and relatives close to me die and on those occasions have thought about my own death, but only briefly. I can remember many times saying, "We're all going to die someday and when my time comes I hope it will be fast, painless, and at an old age."

Unfortunately for me, I don't seem to be able to cling to those words anymore; my wish doesn't look as though it will be granted. Why? Because I have been diagnosed as being terminally ill, and like others in similar situations, my days are numbered. So, people have asked, "How do you face dying; how do you cope with knowing you have a terminal illness ...?" At a time earlier in my life, I probably would not have been able to offer any answers because I simply did not know. It all happened too fast and being forced to face my own death has caught me off guard. My thoughts and emotions are extremely inconsistent because they vary according to my moods. There is one thing that I am certain of though... I have never known such fear or lived with such anxiety as I have been living with for the past year and a half.

In her book, On Death And Dying, Elisabeth Kubler-Ross describes five coping mechanisms used by terminally ill patients in dealing with their own dying: denial, anger, bargaining, depression, and acceptance. Of course these five stages are often used by people facing some sort of stress situation that requires coping or adjustment (such as the loss of a friend or relative, or a dissolved relationship), but they are used here to illustrate best how a person learns to cope with and face the inevitability of his own death.

When I first read the five stages Kubler-Ross describes, I was

shocked and infuriated. I thought to myself, "How could anyone sum up people's reactions to facing death in five steps?" After all, I was an individual -- unique -- certainly not one who could fit into such a mold. Furthermore, I resented the fact that anyone could predetermine my feelings and actions before I had acted them out -- or could I not see that I was acting them out even then? The stage was certainly set; I was forced to confront my own death. Now I was expected to play the correct role as determined by the situation. And play the role I did, just as if I had been reading a script word for word. Often times we are so caught up in the situation that we are blind when it comes to seeing ourselves acting out a role, and we usually need others to open our eyes for us. I will attempt to trace the five stages of coping that Kubler-Ross describes by looking at my own life.

First Stage: Denial

About twenty-one months ago, I made a trip to the hospital for what I thought was a case of appendicitis and possible anemia. Dozens of tests were performed, but no one could seem to tell me what the problem was because it was not known -- or was it? Doctors have a wonderful way of neglecting to tell their patients much about their health -- especially when it is bad news -- because they want to protect them. By and large, physicians have in recent years sought to protect the dying from becoming aware that their fate is sealed.⁴ They use such excuses as "the patient is not up to hearing bad news", or "the patient is not strong enough right now to cope with the news." Well, for two months I was given the run-around; I was irritated and very impatient, and demanded my doctor tell me everything regardless of the results. Nobody (the doctor nor myself) dared to mention anything about a fatal disease. Though I thought about that possibility, I quickly rejected it because it just couldn't happen to me. After all, those things happened only in the movies.

Finally, one day I got a call from my doctor telling me he had some news about my problem, but he would not discuss it over the telephone -- please come over. For some strange reason, people who know me well always try to anticipate my reaction and prepare themselves accordingly. Unfortunately, my doctor did not know me very well and was very unprepared for my reaction. When I saw him, I demanded to know everything and proceeded to tell him he was not to leave the slightest detail out. Much to my dismay, he did in fact tell me everything, especially the things I really didn't want to hear. "We got the results from the tests ... not good ...

a type of cancer ... leukemia ... prognosis ... you probably will not make it to your twenty-first birthday" He talked more about treatments, remissions, hope, etc., but I had long ago shut him off when I heard the dreadful news; that was all that was important at the time.

My first reaction was indeed very predictable. I was in a state of shock -- I couldn't cry, laugh, or scream. I just sat there in disbelief. The first words out of my mouth were, "You've got to be kidding; there must be a mistake." I didn't want to hear it! At that point it seemed as though every goal and dream I wanted to pursue was shattered, because I'd never have the time to complete all I wanted to do. Although I often look at the denial stage as the shortest of all, I still find myself slipping back into it from time to time. I still sometimes find myself saying, "This is a bad dream and when I wake up everything will be alright." But I wake up and everything is the same as before; I still have that black cloud hanging over my head and the inevitable truth still looks me straight in the face. As much as I sometimes want to run and hide, there is no escape.

The denial continued in another way as well. For months I did not tell my family about my condition, and shared the truth with only a handful of people. For the longest time I tried to sort out my feelings about why I did this, and came to the conclusion that it was a combination of several things. I tried to protect my family from pain (and I let them down by doing so), and I was also very scared. I was afraid that if I told other people, they would pity me and that was the one thing in the whole world that I did not want to face. I guess I also thought that if I told my family, then I would be admitting the truth to myself, and durning that time I was not quite prepared for that.

As we can see, denial was used as a defense mechanism for me; it acted as a buffer to cushion the shock. We use the same type of mechanism when people who are close to us die. Eventually, the feeling of numbness fades and we begin to pick up the pieces and drop the use of denial in favor of a partial acceptance at least.

Second stage: Anger

When I found it useless to deny any longer, feelings of anger and resentment took form. Why did it have to happen to me? And why at this time of my life when I had everything to look forward to? I felt as though I was being robbed -- my future was being

taken away from me for no reason at all and I didn't like it one bit. My anger and bitterness were directed at anyone and anything. As far as I was concerned, everyone was to blame and I let them know it. Unfortunately, my doctor and my boyfriend took the brunt of my anger. I wanted to strike back at the world and hurt as I had been hurt and they were the most available targets at the time. Perhaps unconsciously I resented them -- or rather, resented their ability to look forward to enjoying a long life when I couldn't. I built up much bitterness even toward God. How could one who was claimed to be so loving and just allow such a dreadful thing to happen? Then, I became angry with myself. If I had only gone to see a doctor when I noticed early symptoms maybe all this agony could have been avoided. I was angered that I had been so stupid and foolish to let this happen to me. So, I not only blamed everyone I came in contact with, but I also blamed myself.

It was at great cost that I finally began to rationalize my actions and see how cruel and selfish I was being to people. I had hurt people who would have helped me through this trying period had I only shared the truth with them. How could I expect them to understand how I felt when I neglected to tell them the reason for my irrational behavior? It was at that point that I saw the need for a compromise.

Third Stage: Bargaining

The stage of bargaining is characterized by believing that maybe we can succeed in entering into some sort of an agreement which may postpone the inevitable happening.⁵ There have been many times when I have caught myself saying things such as, "Maybe if I start praying harder than ever, God will hear me and decide that it was all a mistake." When I think about it now, it never ceases to amaze me what one will do or think in a fit of panic and fear. All I really want is an extension of my life and I'll compromise in any way necessary. It was a type of bargaining that eased me out of the anger stage. At one point, I finally realized that I was hurting my family and friends by displacing my anger onto them. That in turn hurt me because there was no justification for making them miserable. My motives were not entirely unselfish though; I tried to convince myself that if I changed my present way of acting and was nicer to people, then perhaps I would be rewarded for my good behavior. That reward of course would only be recognized in terms of an extension of life -- anything else would be trivial and unimportant.

Sooner or later, we have to give up the bargaining tactics; if we are smart enough, we will realize that it is all in vain and it will only contribute to our denial which will probably make acceptance -- even if it is only partial acceptance -- that much harder to achieve. Also, when the terminally ill patient begins to see more symptoms of the disease progressing, he is quick to realize that his bargaining is not going to work.

Fourth Stage: Depression

Depression is probably the hardest to overcome and the stage that visits most frequently. When the terminally ill patient is constantly faced with recurring symptoms of the disease, it is a constant and painful reminder that they may not have much time left in which to live. The fight begins to be too much for them and is often seen as a losing battle.

Depression has been a very difficult thing for me to cope with over the past year and a half. I have never experienced such mental torment as I have knowing that I have a fatal disease and am probably going to die sooner than I am willing to realize. I don't think it would be so bad if the pain and my failing health were not constant reminders. They force me to recognize my own limitations, accept myself as I am, and hope that others can do the same. Staying useful and believing in my own worth and importance are the antidote for achieving my own peace of mind when dealing with depression.

Depression usually takes hold of me at my most vulnerable time -- when I am sick. I then become sad when I can see no encouraging results and I hurt. My life seems to be falling apart before me and there seems to be nothing I can do about it. There is nothing I hate more than people telling me not to look at things so grimly and then telling me to look at the bright side. Can't they see that at that point there is no bright side? I am in fact mourning the loss of my own life. The terminally ill patient should not be encouraged to look at the sunny side of things, as this would mean he should not contemplate his impending death.⁶ But we try to cheer people up when they are depressed. After all, we don't like to see people depressed because it can bring us down; also, no one wants to feel helpless. This is usually an expression of our own needs rather than of the one who is depressed.

I would be very foolish if I said I could handle this all by myself. When people are depressed, they usually feel helpless and

can't help themselves. They need people to help them see that they are indeed worthwhile and have much to offer, even if they can't see it in themselves. My feelings connected with depression have caused me and people close to me much pain. I have at times let my feelings of worthlessness dominate in my relationships, and have come very close to shutting people out of my life because I have felt I had nothing to offer them.

One particular instance comes to mind: my relationship with my boyfriend Alan. He had always been a source of great support to me when I was down and out. He offered me so much of himself -- especially his love -- which was very hard for me to receive at the time. I was always the one to give, and I guess I never learned the art of receiving gracefully. I felt very inadequate and not at all deserving of his love. I felt as though I had nothing to offer him in return. As a result, I declined not one, but two proposals of marriage. I couldn't offer him a long life together, because I wasn't going to have a long life; I couldn't offer him children either, because under the present treatments I was most likely sterile. My own fears and self-pity were the obstacles that inhibited me from looking at my true feelings in regard to myself and Alan.

It wasn't until after many discussions with Alan and others, and through much pain, that I was convinced that I did have a great deal to offer everybody just by being alive -- even if it would be for only a short time. So, on the third proposal I agreed; it was a great triumph for me. Unfortunately, the wedding never took place, since a short time later Alan was killed in an automobile accident.

Fifth Stage: Acceptance

If a patient has enough time and has been given some help in working through the previously described stages, he will reach a stage during which he is neither depressed nor angry about his "fate;"⁷ For the dying patient, it is usually when he sees that the struggle is just about over. This doesn't mean the patient holds no hope and is giving up, but rather he is more or less resigned to the fact that he is going to die and it may be quite soon.

Acceptance of my own dying has been a very hard thing for me to achieve over the past year and a half. I haven't achieved full acceptance of my fate yet, and I probably won't until I am liter-

ally on my deathbed. At that time, I suppose I won't have any choice but to accept. However, I think it is fair to say that I have partially accepted my fate. After all, it is rather difficult to deny any longer when test results get worse and my body keeps telling me it may not be much longer; pain increases and I just can't function in a normal way as I once could. But there is still an inkling of hope -- no matter how small -- that there is a chance for a remission; and I'd like to believe that I have the courage not merely to exist, but truly to live.

Part of my inability to cope with acceptance has been the fact that for a very long time I had not been able to share my feelings and grief with my family and allow them to help me through this. When I was told I had leukemia, I was afraid to tell anyone because I didn't want to cause any pain. Although I needed support, I guess I didn't want to face it myself. Most of my ambivalence stemmed from an encounter I had with leukemia two years before I found out about my own illness. At that time, I was going through a personal crisis which I didn't think I'd ever survive. My high school boyfriend, John, died of leukemia. Unlike me, he told his family very early and it nearly tore them apart. I was a witness to the pain, hurt, and fear that made a very close family fall apart. No one but John could accept his fate and it caused them all a great deal of pain. They smothered him, didn't allow him to discuss his own dying, and all of this was mental torment for him. He began to have guilt feelings and blamed himself for his mother's breakdown. He died shortly after; it was not easy for him. He carried tremendous guilt which should never have been. It made dying for him doubly painful, when it didn't have to be.

When I look at my reasons for not telling my family, I can't excuse my actions; there is no justification for what I did (or didn't do). I was just plain scared. Telling them the truth would be admitting it to myself, and I didn't want to do that to them or to me. John's death and what it did to his family was a painful reminder of what could happen to my family. I certainly didn't want to cause any more pain for them. My mother was already suffering considerably going through a divorce, and at that time I honestly didn't believe she could handle another impending loss. As time passed, it became increasingly difficult to tell her; the times I did manage to muster up some courage to tell her, she would always unknowingly make it even more difficult by saying things like, "I don't know I'd do without you" After I heard something like that, how could I tell her she would probably lose me sooner than she thought?

I think my parents had done a good job of raising me. One of the responsibilities of a parent is to teach a child to be responsible when he grows up. My parents accomplished that task and I believe I carried it a bit too far. Yes, I like to think of myself as a responsible person and I am; in fact, at times I am overly responsible. This has been one of the biggest obstacles to overcome. I have worried too much about other people's feelings, trying to protect them and not allowing them the chance to share their feelings with me. So many times I have heard people say, "Why are you trying to do it alone -- are you trying to be a martyr?" It pains me more than anyone could ever know for people to think that I'm trying to be a martyr. Yet the pain is self-induced, since apparently, through my lack of candidness, I have been giving that impression all along. I'm not trying to be a martyr; I certainly don't have the courage. I imagine this way of handling things has been a cry for independence more than anything else. All my life, I have been dependent upon my parents and my family to answer a great many of my needs. Now was the time to try to prove to myself that I could handle things and that I was indeed strong.

From the very moment I found out about my fate, I have wanted nothing short of acceptance -- but only if it would not make me give up the fight for my own existence. All this time, part of me hasn't wanted to accept reality, because I felt if I accepted my own death as imminent, all would be lost for me. I have had to try to keep a happy medium -- to consider the possibility of my own death, but know when to put it aside to pursue my life.

After-Thoughts:

I have tried to outline the five stages that a terminally-ill patient (myself in particular) goes through when faced with the tragic news of his or her own impending death. These stages do not have to follow one another consecutively, nor does one have to be completed before another is entered.

It is interesting to note that there is one element that is common to all, and usually persists throughout every stage: that element is hope. I honestly cannot imagine a person without hope in any situation. It is the one thing that cannot let a person down, and it may even help the suffering cope a little better and a little longer than they otherwise might. If nothing else, it gives a person who is dying a reason to shift his focus of attention and ability onto the attainment of a goal (a remission, or

just wanting to live one more day) rather than wallowing in misery and self-pity.

For me, hope has been the one thing that I haven't given up on. When I'm sick, tired, and depressed, I may say I give up hoping for a "cure," but I never really give up hope for my life because I believe in miracles. Hope in anything is a very important part of our lives; it can motivate us to do things that we never thought we were capable of doing. It is essential to my life, for without it I would have nothing, as well as be nothing. It can be a tremendous support when nothing seems to be going right or when it looks as though there is no way out of a problem situation. It can offer a purpose to one's life.

For these reasons, I think it is very important that the doctor treating the terminally-ill patient should allow for hope and not discourage the patient by telling him there is absolutely nothing more he can do to help him. This is adding insult to injury and could very possibly result in withdrawal for the patient. There should always be room for hope and we should not give up on the patient just because the test results say there is nothing more to be done. If there is hope, perhaps it can even help to make the suffering a little more bearable.

As I look at how I have dealt with the realization of my dying over the past year and a half, through the different stages, I have noticed much growth and much failure. I would only be kidding myself if I said this has not been a traumatic experience for me; but tragedy is a part of life and something that we can either learn a great deal and gain strength from, or submit to and let break us. In one sense, an experience such as this may even be a blessing in disguise. It has certainly allowed me the chance to get "in tune" with my own feelings and to take a better look at myself -- to recognize my limitations as well as my capabilities, a process which has often been extremely painful, not only to myself, but also to my family and my friends.

Because I was not honest with myself, or my family especially, when I first found out that I had leukemia and was going to die, I hurt them a great deal. I wanted to protect them, but the end result was losing all the trust they had in me. When I finally told my mother, she was naturally devastated -- but what hurt her the most was that I was not able to trust her enough to tell her the truth earlier.

In spite of all the confusion and pain, I have learned a lot about myself. I have learned to depend on myself as well as other people in times of need, because when the other people are not around when you need them, there is no one to lean on except yourself. That is not to say that the dying person should try to cope with things all by himself, because it is often too much for one person to handle alone. I have never known such support as when I finally let friends and loved ones help me. I will never be able to express my love and gratitude to all the people who have taken the time to help me through a very trying period. I can only hope that it is enough for them to know how I feel. They have truly taught me the meaning of love and friendship and I hope that I have taught them something in return -- if nothing else, to take the most out of life and appreciate all that is around me.

The most important lesson I have learned is to face my fears head on and to keep what little faith I have in myself because I am worth it. I think at this time I am beginning to learn to put my fears aside and concentrate on my goals more than ever because the fear can be very limiting.

I suppose my greatest fear was of what I would lose in dying -- this fear inhibited me from striving for my life. I think I have come a long way as far as coping, but there is still a lot more for me to accomplish and I certainly hope people will be there to help me. When the time comes for me to actually face my dying, I hope that I can approach it with courage, peace and dignity; until then, my only prayer is to be able to enjoy what I think would be the greatest victory of all, my own peace of mind.

Much of what I feel in my dealing with my own death, and what I hope to achieve, can be summed up in this poem:

"Let me not pray to be sheltered from dangers but to be
fearless in facing them.
Let me not beg for the stilling of my pain but for the
heart to conquer it.
Let me not look for allies in life's battlefield but to
my own strength.
Let me not crave in anxious fear to be saved but hope for
the patience to win my freedom.
Grant me that I may not be a coward, feeling your mercy
in my failure alone; but let me find the grasp of
your hand in my failure."

Rabindranath Tagore
Fruit Gathering⁸

The purpose of this paper has been two-fold: not only to fulfill a requirement for a course, but also to take a critical look at myself -- my attitudes, feelings, fears -- in relation to facing my own death, something I have needed to do for some time. If it is true that people best learn to die well by learning to live well,⁹ then I can only hope that I can live to practice what I have learned in my experience with dying.

FOOTNOTES

- ¹Theodore Lidz, The Person: His and Her Development Throughout the Life Cycle, rev. ed. (New York: Basic Books, 1976), p. 534.
- ²Elisabeth Kubler-Ross, On Death and Dying. (New York: Macmillan, 1969), p. 2.
- ³Robert E. Kavanaugh, Facing Death. (New York: Penquin Books, 1976), p. 6.
- ⁴Lidz, op. cit., p. 540.
- ⁵Kubler-Ross, op. cit., p. 82.
- ⁶Ibid., p. 87.
- ⁷Ibid., p. 112.
- ⁸Ibid., p. 1.
- ⁹Kavanaugh, op. cit., p. 6.