

Expanded Second Edition

# FACING LIFE THROUGH DEATH

The Experience of One Man Who is Both Patient and Counselor

by

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and the Helping Professional

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## PREFACE TO THE SECOND EDITION

Many kind and encouraging comments by readers of the first edition have prompted me to expand this booklet.

Readers felt that an expanded account of my experience with serious illness would lend greater meaning to the rest of the book. I have also included details about the work my wife, Phyllis, and I are doing in death and dying -- work which has grown out of our experiences.

When it comes to helping others face death, your effectiveness is determined by how comfortable you are with your own death. So you see, dealing with your death and helping others deal with theirs is very much the same problem. This is not to say that you have to be totally comfortable to be able to help another person. But you at least have to be willing to face your feelings and ask questions. In fact, when helping another deal with any personal problem, you must be willing to struggle with your own feelings, or you will be of no real help. The idea that you can be "objective" and "professional" and still deal with a person's deep problems is obscene and a mockery to the whole idea of caring.

-Steve Henderson  
Staunton, Virginia  
December 21, 1977

## ACKNOWLEDGMENTS

I am indebted to my friends, clients, and colleagues who have shared with me their experiences in facing death and helping others.

The many letters I receive from readers encourage me to continue learning and sharing.

I am personally indebted to Dr. Elisabeth Kubler-Ross for being my teacher and friend. She showed me that talking about death can be freeing and beautiful. By her friendship and sharing, she gave me a kick in the pants and told me to get at it.

My family has made this booklet possible. Their love and support helped turn my "condition" into a strong part of my life. My wife, Phyllis, has made life a joy, no matter how long it will be.

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## DEDICATED

To Mother, whose love helped me grow;  
To Dad, whose love keeps me alive;  
To Phyllis, whose love makes facing life a joy.

## LOOKING AT DEATH - MY EXPERIENCE

When I was four years old, I contracted a strep infection in the lymph glands of my throat. The strep spread to my kidneys, causing chronic glomerular nephritis, an irreversible deterioration of the kidney filters. This was not suspected or diagnosed until an exploratory operation in 1963, just before Phyllis and I were married.

Dramatic symptoms did not appear until 1965. Phyllis and I had been married for two years. During Christmas vacation, my feet kept going to sleep (initial nerve damage from uremic poisoning). Within a month, my red blood count was so low that I was transfused with four pints of red blood cells. And three weeks later, I needed three more pints.

Although my doctor was unable to share with me, I slowly became aware of the fact that I was dying. I got weaker and weaker; my blood pressure went up; I couldn't keep food down; poison oozed from my skin, and I even became tone deaf - a great blow to a singer. I became so weak that Phyllis and I moved from Iowa to Lansdowne, Pa., to live with my parents.

In 1966, most doctors were not even aware of the possibility of transplants. Dialysis -- the artificial kidney machine -- was not available, for all practical purposes. My whole family looked for ways to help. My folks contacted the National Institute of Health. NIH admitted my condition was terminal, but still would not recommend a transplant, because it was "too experimental." (Is death also experimental? I wonder what a scientist would say.)

Fortunately, I was accepted at the Transplant Center of the Medical College of Virginia, in Richmond. They were early pioneers in transplant experimentation. Dr. David Hume, "the father of the transplant," performed my surgery on May 12, 1966. I was 24 years old. The odds for success at that time were just over 50%.

I was lucky to have a live donor: my father. (He's alive and well!) This has created a special and intimate relationship between us. The transplant is a very concrete expression of love.

Before the transplant, Phyllis and I had to sign papers saying, "This person is terminally ill; he is going to die. This transplant is strictly experimental; there is no other hope." The reality of death was inescapable, yet it was the word "hope"

that dominated my mind. I was dying, but the transplant would save me. It was a time for celebration. The beginning of a new life. The end of troubles.

During the time of the transplant, our family of doctors, nurses, technicians, patients, and relatives supported and protected me. My new kidney didn't start working for one week. This didn't particularly upset me, because I was feeling O.K., and I didn't know that this was unusual with a live donor. About the time I realized that everyone else was worried, my kidney started working. That stuff was pure gold! The nurses put up a banner in the hall: "Henderson put out 72 CCs!" I cried every time someone waved at me.

Dad, whose operation was much more painful than mine, was out of bed for the first time and wheeling around the halls. He said, "I feel like I've just given birth."

I was soon up and around. The doctors didn't know what to do with me, because until that time, they had never had a transplant patient who was so "healthy." In a couple of weeks, I was in Self-Care and going home with Phyllis during the day.

On our wedding anniversary, one month after the transplant, Mrs. Andrews, the head nurse, apologized, "We need your bed. Would you mind going home for good?" What a great anniversary. For the next three months, I was to come in only twice daily for vital signs.

The transplant honeymoon was soon over, however. About two months after the operation, I had my first threatened rejection. At the same time, one of my fellow transplants totally rejected his kidney and was in critical condition.

My threatened rejection was mild. I recovered quickly, and was teaching severely retarded children full time, 3½ months after my transplant. But five months later, I had a serious threatened rejection, which kept me out of work for about two months. I was only able to work four-fifths time the rest of that year.

Over the years, as many of my friends with transplants died, I became more aware of my short life expectancy. [If I forget, there are always life insurance salesmen to remind me that I've already outlived reasonable expectancies. "Oh, yes," they assure me, "We can insure you! Our company just insured a man who had open heart surgery, chronic asthma, and a brain tumor -- and at only slightly elevated premiums." When I am turned down after all that, I figure someone is trying to tell me something!]

Although the steroid drugs keep me from rejecting my kidney, they cause many of the same effects as rapid aging. I have cataracts. There is tissue degeneration. I cracked four ribs coughing, and pick up every fungus infection that creeps my way. Because immunity is low, I suffered severe intestinal problems, shingles, and have had phlebitis four or five times. I have had eight major and sixteen minor operations in twelve years, and have been totally disabled for periods ranging up to fourteen months.

I struggled to achieve a balance between the fact that, realistically, my life expectancy was short, and yet, on the other hand, I might live a very long time. Could I realistically plan for next year, or even next week?

Sometimes I'd get depressed. "Wouldn't death be easier than all this uncertainty? Why kill me slowly? You may as well get it over with. I won't take any more." Each time I bounced back, it seemed as if something else would hit me.

But as I became more accepting of life, and thus of death, these questions became less important. As I integrated my "condition" into my life, it became a strengthening part of me. As I became more accepting of my life and death, the quality of my life has increased to such an extent that the length of life has ceased to be of great importance.

For the last two years, I've worked full time; my health has been very good, and my energy excellent (I can swim a mile in less than an hour). I enjoy the present and look forward to whatever the future may bring.

## H O W   D O   W E   R E A C T ?

People react to dramatic changes in their lives in many different ways. The way we react is determined by such factors as the emotional climate in our family, our religious beliefs, and the extent of pain and suffering we've experienced in the past. Reaction to death is very individual and unpredictable. There are, however, some common elements in the way most of us face dying.

I am organizing this section according to some of the stages introduced by Dr. Elisabeth Kubler-Ross (On Death and Dying 1969). It should be made very clear that this is merely an attempt to introduce you to ways in which many people react to death. Remember, however, you are not dealing with "many people". You're only dealing with one person and cannot afford the luxury of statistics. This discussion is only to give you some information that may be helpful to you in understanding what's going on with that one person. Your primary responsibility is to learn from that person, whether it is yourself or someone else.

You may react in all or none of the ways described. You won't necessarily react in the order presented here, and you may react in three or four ways at the same time. All of these possibilities are perfectly within the normal range.

You may feel that facing death is so scary and mysterious that you can't possibly empathize. Although the situation may be strange to you, I hope that this booklet will help you realize that the way you react to death is not so very different from the way you react to many other transitions. We can learn much about facing death from the way we face major changes in life, such as adolescence, marriage, divorce, changing jobs, etc.

I will be emphasizing the healthy and constructive roles that different emotional reactions play as I face major life transitions. Although I suspect that these emotions can be totally or partially unhealthy at times, I would encourage you to join me in being more constructive in looking at them. I think that by really accepting denial, anger, and depression as healthy, you will give the other person the kind of support and encouragement needed to learn and grow.

One of the difficulties in writing about something as important as death is that people may take what I write too literally. Once again, I emphasize that the person dealing with death, and only that person, is the authority. Forget your preconceived ideas and be willing to relearn from each person.

## RAIN, RAIN, GO AWAY

I'm not much of a morning person. When someone smiles and says "good morning" to me, I often say something sarcastic like "leave the morning alone and maybe it'll go away." When it comes to death, our whole society is in a kind of denial. Somehow, if we don't talk about it, maybe it doesn't exist. It shouldn't seem too strange that when facing death, I don't talk about it much. After all, if I haven't discussed it earlier in life, how am I going to start now?

I have used denial a number of times when I've faced difficult transitions. I was a very awkward adolescent. I tried to avoid the fact that I really was a struggling and obnoxious teenager. Most of my friends were either younger kids that I led in Boy Scouts or adults that I tried to relate to as equals. I felt that by ignoring my peers I somehow would not be one of them.

I found that even when the symptoms were quite obvious, I was not able to face death. This is not quite the same as saying I didn't know. I knew at some level of consciousness what was going on. Denial for me is saying, "I don't want to talk about it" or at least, "I don't want to talk about it with you". I may stay in a stage of denial for a long period of time with those that I love the most, because sharing feelings about death with them will hurt. But I may share it very openly with a friend or a nurse or a cleaning lady.

Sometimes I feel that if I simply deny something exists, I won't really have to face it. Maybe it won't hurt so much. Maybe it will even go away. As I begin to face my dying, I still may not share it with you; because I think you won't understand -that you will think I'm giving up, or that you will think I don't like life.

In general, society doesn't encourage me to step out of denial. Throughout most of my life, I've been told to "be optimistic, don't be discouraged, keep on fighting, never give up, look to the bright side of life". How can I talk with these people about dying? As I face dying, I go in and out of denial. I need denial pretty often. It is a way of backing off from the whole thing--my way of saying, "I've had enough. I need a rest. I don't want to deal with it right now." Denial is not merely a stage that I need to get through. It is a very healthy and constructive reaction. My mind and my body know what I can handle. I have ways of telling myself to back away from things and not take on more than I can manage. It's important that I listen to these messages.

So, if you're going to help me, don't try to talk me out of my denial. What right do you have to tell me that it would be more healthy for me if I was more "realistic"? You don't know me as well as I know myself. You don't have a right to make that decision. You'll find that if you try to push me out of my denial, I'll only become more defensive and will be much more likely to stick there.

#### HOW DARE YOU?

How dare you, Doctor, tell me there's nothing you can do? It's just a cop-out. How dare you, wife, make demands on me--make me worry about how you're going to manage things? How dare you, anyone, be healthy when I am so sick? What right do you have? You're not any better than I am. How dare you, God! How dare you stick me with this painful disabling disease? How dare you kill me? How dare you call yourself a just and loving God? How dare you, friend, say that I shouldn't be angry? What do you know about it? You're not going through what I am. You can't feel what I'm feeling. You can't know what I know.

As I face death, I have questions and I challenge what I have believed, and I am angry. I wonder, "Why me?" I feel the injustice of it all. I feel "unfaired against". Why shouldn't I be angry? After all, I'm not really that much worse than anybody else. Do I really deserve all of this?

I still feel anger at times. I have a transplant that causes me numerous complications, some of them quite serious. I wonder why I have to keep on having these problems. Why me? Most of my physical difficulties are internal. On the outside I look pretty healthy. Sometimes I'll go to a hospital and I'll see someone with a broken arm complaining and crying. I sometimes fantasize shaking them and yelling "What are you bellyaching about? Look at me! I'm really sick. I'm dying." I believe that's a pretty natural reaction. Now, for a person with my passive personality, it would be quite unnatural if I actually enacted my fantasy.

The anger I go through as I face major life changes, such as adolescence and death, makes me impatient with meaningless routine and institutions. I am much less willing to accept things because "that's the way they are" or "that's the way it's always been done".

Much of my anger is justified, so don't just tell me I'm going through a phase. I'm still very angry at the doctor who first handled me when my kidneys started failing. He could not share with me the idea that I was dying. I figured out for myself that I had a terminal condition. I confronted the doctor with the fact, and he still couldn't deal with it. All he would admit was, "You can expect to do less next year than this year". He was simply going to make me as comfortable as possible until I died. By his actions, he made it clear that he could not handle death. He added greatly to the loneliness of dying. The whole idea still seems outrageous and obscene. What right did he have to decide what I could handle? What right did he have to make decisions about how I'm going to live the rest of my life? If I had not come to a realization of death myself, I wouldn't have found the transplant, and I would indeed have died at that time.

I often get mad in the hospital, because I am expected to accept everything without question. Not only do I seem to have no rights, but, even more insultingly, I seem to have no brain. I am, supposedly, incapable of making any decisions for myself. That's very dehumanizing and makes me very angry.

Listen to me. Things may really be bad. I really may have too much pressure. I may be getting bad service. People may really be deserting me, either emotionally or physically. Don't just write off my anger as a phase. Stick with me through my anger. Take a look at what I'm angry about--maybe you could change things for me. Maybe you can be my advocate.

In my anger I may become obnoxious. Because you are helping, I may aim my anger at you. Try not to take it personally. Try to see the anger from my point of view. I think you'll find that you can share a lot of it. I am trusting you with my anger; I don't give it to just anyone.

A final word about anger to the deeply religious, and I put myself in that category. Don't worry about my anger towards God. God can handle it. You don't need to defend God. My questions, my challenging, and my anger towards God are not sacreligious. They are, in fact, a sign of a strong, sharing, living relationship. A relationship without questions or anger is shallow and unreal.

Although I'm not trying to deal with the grieving process in this paper, I would like to say something about anger as a part of grieving. Anger towards a loved one who has died is very common, and often carries with it a lot of unnecessary guilt. After all, how can you be mad at a dead person? It seems obscene and sacrilegious. On the other hand, why shouldn't you be mad? This person you have loved and cherished has left you alone and deserted you. Perhaps you have a family to raise all alone. You may have been left with many bills and inadequate life insurance. You have worries, you have decisions to make, and you will have to do it alone. What did you do to deserve this? You will have many feelings--love, grief, regret, and often anger.

### IT HURTS INSIDE

As I begin to face more and more the reality of my dying, it is very depressing. After all, if you love me and I die, you face the loss of one person. I face the loss of everyone. I'm not sure, but maybe I'll even lose myself. I'm depressed. Don't tell me I'm sick. I'd be sick if I weren't depressed when facing death.

I have my own feelings about depression, not only from facing death, but from looking at other important transitions, such as adolescence. I think depression is an inward-moving, sometimes at an open, conscious level, sometimes at a more subtle, preconscious level. It is looking inside at what I really am -- looking for my strengths and for the real essence of my soul. As I face death, I have questions such as "Who am I?" At any time in my life this inward searching, this groping with myself, is very painful. It means the stripping away of sham, of hypocrisy. It means destroying many comforting and safe defenses. I'm not sure what I'm going to find underneath. This is very scary. As I face death, I search frantically for meaning and for strength to understand and overcome.

When I'm searching, I don't want to share myself with you. That's distracting from my primary task. I want to withdraw. I want to pull into myself and look around and find out what's there. It's too bad more of us don't do this before we face death, because through this process we can find great strength and beauty and understanding.

For me, depression is the most painful reaction to the death experience, and I think it is the most difficult for those around me.

It is difficult for me to even admit that I ever was depressed. I was a little "blue" or "down", but never depressed.

When I get depressed, I am unable to make decisions. I'm so involved looking for meaning in life, that I can't make decisions even about simple everyday things. Perhaps this is a way of telling myself that I shouldn't be making decisions. I am in a very vulnerable position emotionally. If I make decisions, I will probably make stupid ones. Lynn Caine, in her book, Widow, said that she was very happy when she got depressed because she stopped making a lot of stupid decisions. As an immediate reaction to her husband's death, she made many financial and lifestyle decisions that she regretted for a long time to come. When she became depressed, she could no longer do this.

When I can't make decisions, don't make me feel guilty about it. Those decisions probably aren't too important anyway. The decisions may be about things that are only important to you. Perhaps you can help by making some decisions for me and taking daily pressures away when you can. Also help me to feel useful. Ask me what decisions I need to make for myself. Is there something I can do for you? Ask me!

Not only ago I was asked to counsel with a young lady who had an advanced case of cancer. This was a very active young lady who had been used to farm life, riding motorcycles, etc. She is now totally disabled and will not live long. She was referred to me by the hospital. When she didn't show up for an appointment, I went back to check with the doctor to see if I could find out why. He said that she was so depressed that they sent her to the psychiatrist for treatment. After all, she was "sick" and needed help. The doctor easily realized the mistake. This woman was not mentally ill at all. She was reacting very normally. After being labeled as "sick", even though unintentionally, her sense of trust in the ability of those doctors to help her was greatly diminished. She was unwilling to accept a referral from them.

What can you really do for me when I'm depressed? Nobody really likes to be around a depressed person. It only seems to make others depressed as well. I think the reason others get depressed is because of a sense of helplessness. Maybe what you can do is to realize that I am doing what I need to do in order to face what's going on. You need to understand that I'm looking for myself. That is something I'm going to do mostly alone. Don't try to talk me out of it. Stick with me-- love me, care for me. This love will help to give me the strength to continue this inner struggle--to continue this search for truth and understanding that is so important.

Remember, your desire to talk me out of depression may be your need, not mine. It may be for your comfort, not for mine.

## A C C E P T A N C E

### What Is It?

For me, acceptance is not having all my questions answered. The questions are still there, but somehow it's not quite so important to have the answers. Acceptance is a sense of peace--a peace not to be confused with resignation. Acceptance does not mean giving up. It is knowing that somehow things are going to be o.k.--that if I live, it will be o.k., and if I die, it will be o.k. Somehow there's a plan and there's a meaning to all that is going on. Somewhere within me there is the strength to understand and deal with whatever is coming.

Have you ever played the parlor game where you decide what you would do if you only had six weeks to live and all the money in the world? If you take this game seriously, it's a good way to look at your values and what's really important to you. Death forced me to look at my values and the quality of my life--was my life consistent with what I believed?

When I realized that I was seriously ill, I looked at my life and found that, despite regrets and hard times, there was much beauty, strength, and love. My view of death may seem simplistic, but I saw no reason why this love and meaning would not continue. Why should death be the end of all purpose and plan and love?

As I went within myself more deeply, I got in touch with parts of my consciousness I normally don't use. This helped me to see more clearly the nature of my soul. For me, this was an important factor in approaching acceptance. My soul is the part of me which is my very essence and yet a part of all the Universe and the Creator. It is independent from my physical and intellectual being and yet is the real proof of my being. My soul is my love in its purest form.

Acceptance of death is based on feelings I can neither prove nor express in any meaningful way. Yet I know that my acceptance of death has a basis in truth. This is something I know, not just hope.

Although people approach acceptance in different ways, some factors are shared by many. Generally, the way you accept death is closely related to the way you accept life. Also, if you have reached acceptance, you are never again afraid to die. This does not mean that you want to die. A person who truly accepts life is not afraid to die, and a person who is not afraid to die can fully embrace life. It's hard to say whether acceptance of life or death comes first--they must come together.

The question of what happens after death is largely academic to me. My acceptance is not based on knowing what is going to happen. For me, acceptance is based on knowing that things will be o.k.--that they will not get out of control. I do not need to know what is going to happen.

I find that it's not terribly important that I share my acceptance. I don't feel any need to convince you of my experience or to convince you of any great Truth I have discovered. Although my acceptance is very real, it is rather difficult to express, even to myself. At times, I am afraid that people will interpret my feelings as a rejection of life--as giving up.

You have many little deaths throughout your life. These can be preparations for facing death. You lose an object, a pet dies, a friend deserts you, a marriage fails, or you struggle through adolescence. How you face these losses and transitions may determine how well you accept death. You do not need to handle these losses gracefully, but you do need to learn from them rather than become bitter and destroyed.

If your family sees death and dying as a natural part of life and discusses it openly, you will undoubtedly find dying easier and less lonely. Through my work with the severely retarded and handicapped, I found meaning in suffering, which helped me face death.

In summary then, acceptance is a feeling of peace, derived from knowing that somehow everything is going to be o.k. It is not answering all the questions. The questioning helps me to grow; the answers are unimportant.

R E L I G I O N   A N D   D E A T H

I was going to survey the attitudes of major religions towards death. Then I thought, "Why should I get academic just because I'm talking religion? Why can't I make it personal?" There seem to be several reasons. One is that I don't want to turn anyone off. Others have found help in facing death from beliefs very different from my own. Who am I to say I have the answers? I guess I was going to survey all of the religions so that hopefully I would hit what you believe. It occurred to me, however, that this would be a bit stupid. After all, you already know what you believe. The only thing I can meaningfully share is what I believe.

I've always been able to make meaning out of hard times. I've received much love, and I believe man was created with a good deal of strength. I also believe that there is meaning and direction in the universe and that events are not without reason.

My belief in God and sense of my own humanity is a very personal religion. I find, however, that as I develop my personal sense of God, my religion becomes more universal. While I still retain my religion as personal, I find I have more in common with all religions. I consider myself an unorthodox Christian. The life and being of Christ speaks to me most effectively, and yet the Eastern religions and other Western religions speak to me as well. I can use the words of Christ or of Mohammed, of the fundamentalists or the liberal, of the Jew or the Catholic, with personal relevance and without hypocrisy. I consider myself a Christian, but I do not see my Christianity as exclusive. To me, belief in and acceptance of Christ do not narrow my perspective -- they make other beliefs more understandable and relevant. Facing death made my beliefs more personal and universal.

My belief in God derives primarily from love. I believe that the essential and perhaps only important part of my soul is my love. I see love as unreasonable, unending, and unearned. Surely that is divine. There have been times when I've wanted to consume my wife with love. I have been frantic to receive love from her, because she might realize her mistake or run out of love. As I've become more comfortable with my love and her love, I have found it easier to give and receive. I also learned of love from my parents, who have achieved the rare feat of loving without possessing.

Through human love, I have come to feel what God as love is all about.

There have been times when it wasn't important for me to believe in anything. I was a doer, not a believer. It was important for me to accomplish so that I could establish my worth. When facing death, accomplishments seemed very unimportant. My approach to life and self-worth was greatly changed.

Your beliefs may be very different from mine. In facing death, it is important that your beliefs are internal. That is, they are real and personal and affect the way you look at yourself and live your life. A dogmatic religion--a religion that is memorized and intellectualized without relevance--is of little help when facing death. The person with no religion at all, if indeed there is such a person, will probably accept death easier than a person with a purely external religion.

#### CHRIST AND ACCEPTANCE

Some Christians tell me that they feel very guilty when they express anger or depression. "After all," they say, "if I really believe in Christ, I wouldn't feel this way." Sometimes I feel like saying sarcastically, "Oh, yes, it's o.k. for Christ, but not for Christians."

Christ did get angry. According to the Gospels, Christ went into a rage and drove the moneychangers out of the Temple. He was quite violent about it. One lady pointed out, "That really isn't anger, that's righteous indignation." Is there really any difference? "Righteous indignation" is a term invented by those who can't accept that Christ was very human. I sometimes like to think that when I'm angry, I'm "righteously indignant", and when you're angry, you're obnoxious and stupid.

When Christ went to the Garden of Gethsemane to pray, shortly before His death, He was angry and hurt that the disciples could not stay awake and watch with Him. "They were too worn out with grief." (Matthew 26: 36-45) That's some of what depression is all about. Christ also was "sorrowful even unto death." (Mark 14: 34)

A beautiful example of acceptance is the prayer of Christ in the Garden (Matthew 26: 36-45). Essentially what Christ prayed was, "Now look here, God, I know it's all in the cards and everything, but if it's all the same to you, I'd just as soon not die." And I imagine God said something like, "That's o.k., Son. I know you don't understand, but you will some day. Things will be o.k. Everything is going according to plan." And Jesus said, "I still don't understand, God; but if that's the way things are supposed to be, I trust you. Thy will, not mine, be done." This acceptance, that somehow things are going to be o.k., brings peace.

#### RESPONSIBILITY OF THE CHURCH

Unfortunately, death is not often frankly discussed within formalized religion. Churches often deal with afterlife, but rarely deal with the stark reality of the moment of death itself or the process of dying. Many people conclude that if the church can't talk about death, it must be frightening or evil.

The church is an ideal place to discuss death. Religion, after all, is an attempt to grope with and understand the unknown. A living religion needs to deal with the meaning of life and death. The church should be a leader in lifting the cloud of mystery and pain and silence that surrounds death.

L I F E   A F T E R   L I F E

Dr. Elisabeth Kubler-Ross and others have done research into the afterlife experience. This has been done by talking to those who have had death or near death experiences. These people were clinically dead but were revived or spontaneously came back to life. Whether they were actually dead or not is a matter of semantics, and does not seem to be particularly important as far as our learning is concerned. An important book in this field is Raymond Moody's Life After Life.

Thousands have had near death experiences. I have talked with several myself. It is remarkable that nearly all report similar experiences. Their cultural, family, and religious backgrounds may determine the type of language they use; but they all report common elements. Most often described is a floating sensation at the time of death--floating out from the body and seeing the body from an observation place above. Those who have been mutilated find themselves whole. Many report going through a dark tunnel or shadowy area. This seems to be the transitional period. Nearly all report a sense of peace. This peace sticks with a person, and they are no longer afraid to die.

Most see a light. They describe this light as having definite personality and being. The light lovingly challenges them and brings knowledge and peace. Many call the light Christ. Whether the light is called Christ or not, the descriptions are remarkably similar.

Almost all people having near death experiences report that there is someone there to meet them. Perhaps it is a relative or a close friend or a religious figure, such as Christ or Mary. In general, the person needed to comfort them is there.

People who have had these experiences are hesitant to share them. Not only is the near death experience hard to put into words, but there is fear that you won't understand or that you will think they are crazy. The people who have shared with me rarely doubt the reality of their experience. They feel no need to prove its reality. The sharing of a near death experience is a gift carefully given to those open enough to receive.

It is not the purpose of this paper to discuss afterlife or to try to prove anything about its existence. I merely want to say a few words to open the topic for your consideration and to let you know that people are actively investigating afterlife, not only in the fields of theology and philosophy, but in science. This is a field that we need to continue to investigate to increase our own understanding about death. We need to keep our minds open and suspend our disbelief.

## A D I F F E R E N T D R U M M E R

Just what does "death with dignity" mean? For some, dignity means dying at home without medical support systems. For others, dignity is trying every possible machine and support system. To me, dignity means having choices and some control over the way I die. For most, death with dignity means dying the way you live. If you've been a fighter, you should die fighting. If you're an adventurer, perhaps you'd rather die in a plane crash than in bed. To help me die with dignity, you need to be close enough to me to know my meaning of dignity. Don't impose your own values.

Some of my friends with transplants have died in comas. I know that this could happen to me. It is, therefore, imperative that the important people in my life know me well enough to make decisions I would make. It is comforting that my wife knows my feelings well. I don't want to set up hypothetical situations for her and say, "If such and such happens, pull the plug." I don't know what decision I would make. I'm not sure at what point life becomes meaningless. I really don't know my limits until tested. Because my wife respects my feelings now, I trust her to be my advocate.

It is also important that my doctor knows me well enough to make decisions for me. I want my doctor to know me as a person, not just as a body.

## T H E D O C T O R ' S R O L E

I've already shared some of my anger towards doctors and my discomfort with professional objectivity. I've also had some wonderful relationships with doctors. The doctor that helps me when I'm dying will develop a personal relationship with me. Then I know I won't be deserted. I once had a doctor desert me when I had a complication he didn't understand. Imagine what would happen if I was dying! On the other hand, when I had a difficult pain problem, my home doctor simply told me, "I don't understand what's going on, but I'll stick with you--I'll keep on trying until we lick this thing." This doctor will not desert me.

A doctor's primary role is to prolong life. I'm willing to accept that. I also hope my doctor will support me when I'm dying; but this may be asking too much. Perhaps it is inadvisable and unrealistic to expect that these two roles be mixed. My doctor should realize, however, that he does have power over the way I die and should help me face death or cooperate with and encourage others who can fill this need.

I have, at times, been guilty of building doctors up as gods, capable of handling all problems. This puts an uncomfortable and unwelcome burden on their shoulders. I must take some responsibility for my own treatment. This may irritate my doctor at times, but in the long run it will ease the overwhelming sense of responsibility and failure when I die.

It's important that my doctor honestly face how he feels about death and dying. He must realize that he often makes decisions such as, "Should I tell him?" or "Should I use this machine?" in terms of his own needs and feelings rather than mine. My doctor does not have to be infallible. I am more comfortable with a doctor who is willing to share indecision and unknowing. This can improve our relationship and make us a more effective treatment team.

Perhaps a realistic treatment model is for the doctor to advocate for physical living and still have enough understanding of dying and openness to other helping professionals to make the best possible treatment team for the patient.

Because of the doctor's authority, it is important that he not delegate all responsibility concerning dying. It is important, for example, that the physician participate in telling me I am dying, and that he or she be present when relatives are told of a death. This is important in helping me accept the reality of death.

S H O U L D   Y O U   T E L L ?

I feel very strongly that doctors, relatives, and friends need to be very open with the dying person. The question of whether a person should be told they are dying has been battled around for years. It is difficult to debate, because you can't really prove what is right. There is no way you can design an experiment to prove the effects of telling or not telling. Individual differences are so great that we would have to be our own controls. You can't both tell and not tell someone in order to see the difference.

Many people who are told that they are dying already know. A dying person who is approached with an open, sharing attitude can often help in the telling. The process of telling someone they are dying should be a two-way conversation.

You may not be the one to tell me I am dying. Perhaps you are too close or just can't handle it. Remember, I may make it hard for you to tell me. Perhaps I'm not ready to discuss death with you, or I want to spare you the anguish. Don't feel guilty. Your role may be to find someone who can tell me.

Dying is very lonely. If you aren't able to tell me that I'm dying, then I know you really don't want to talk about it. That makes one more person I can't share with. Orville Kelly, author of Make Today Count, tells about a young girl that wrote to him. She said, "You have to teach me how to die. My parents have not told me I'm dying, but I know that I am. If they can't even tell me, I know they can't handle the topic. So I have to learn by myself how to die." Can you imagine anything so lonely and frightening?

If you don't tell me I'm dying, you take away a lot of my dignity. That's your way of saying that I'm not strong enough to handle it--I don't have enough emotional strength to deal with my own death. I have a right to decide how I die and how I live. Although I may soon come to the realization that I'm dying, you have robbed me of time and dignity if you don't tell me.

It is a little presumptuous of you to make the decision not to tell. Who are you to say I can't take it? You are not a god. In telling me that I'm dying, it's not necessary to tell me everything. If I really want to know the details, I will ask. You need to be willing to tell me enough so that I can ask more questions and share with you our common knowing.

You don't really need to be afraid of crushing me by telling me I'm dying. I have very good defense mechanisms. If I can't handle it, I won't hear it--I will simply choose to ignore the fact of death until I am able to face it. Telling me doesn't mean taking away hope. After all, even in the most hopeless situations there have been miraculous reversals. Sometimes there have even been mistakes in the diagnosis. In my case, I had "irreversible kidney failure" and yet I later had a transplant. Acceptance of death does not take hope away. The difference is that in acceptance of death, hope applies to both living and dying.

## C H I L D R E N

This paper applies to both children and adults. Although children may be limited in their communicating and intellectual understanding, they are usually more open and adept than adults in dealing with feelings. Anyone facing a life crisis is likely to communicate in symbolic terms. This is particularly true of children. We can see children's feelings in their drawings and play before they are expressed verbally. They may use both verbal and nonverbal symbolic language in communicating feelings about death.

Like all of us, children need warmth, attention, and security. Children need to be exposed to death as a natural part of life. They need to know about death and about dying. Children will often learn of their grandfather's death, never having seen him sick. This only makes death more scary and mysterious. One of the things that reinforces fear of death and illness in children is restrictive visiting in hospitals. If children were allowed to see illness and dying in hospitals, they wouldn't be so afraid of the hospital.

Young children are much more likely than adults to accept death as either a temporary condition or as a very natural part of life. When someone very close to a child dies, it is important that we listen to and share feelings with the child. Otherwise, their anger and loneliness will be overwhelming. We need to allow the child to express anger and depression. For example, a child may try to fill up the "empty feeling" by eating as much food as possible. The child may need concrete symbols of what the life of a dead person has meant to them. He or she may desire to keep an object of the deceased, perhaps an article of clothing.

When a child is dying, it is important for the child to have as much control as possible. He or she, too, deserves dignity and respect.

When helping, be sure to pay particular attention to siblings and parents of the dying child. They need a lot of support. For most of us, the dying of an innocent child is the greatest of all injustices and evokes very strong feelings. These feelings can be quite devastating if not dealt with in an atmosphere of constructive love and listening.

One of the statistics most disturbing to me is the high number of divorces in families after the death of a child. It seems that too few parents have the necessary inner and outer support available to help them cope with their feelings of guilt and outrage when their child dies.

C A N   Y O U   H E L P ?

BE THERE



One of my biggest fears of dying is the fear of being deserted. This is a justified fear. So many people have trouble handling death that they simply don't want to be around when I'm sick or dying. They feel awkward, helpless, and uncomfortable. They can't be present emotionally. It is, indeed, difficult to be around me, because it means you must face the idea of your own death. If you're going to be with me and share feelings, then it must affect the way you feel. Some of these feelings are very difficult to deal with. I may also be obnoxious.

I would like to share my image of many hospital visitors. Picture yourself with a huge six-foot cupcake. I can't really see you; it's hard to know who you are, or what you're feeling. All I can see is the cupcake. We talk about the cupcake. "Ain't the pink icing nice? Notice how I put the delicate little swirls in the center." "My goodness, the lacy ribbon even has 'Steve' written on it--what a thoughtful personal touch." The cupcake very effectively protects you and prevents meaningful interaction. It is not a gift; it's a shield.

Everybody has their own cupcake. Prayer can be a cupcake. Some ministers will pop into my room, pray at me for thirty seconds, and then pop out again. I want to be prayed with, not at. Cards, flowers, and the weather can also be used to shield.

Now please don't get the idea that I don't like cupcakes and flowers. I'm usually genuinely grateful, and they can boost my spirits. But if you really want to help me at deeper levels, don't use gifts as shields.

Being there means sticking with me through denial, anger, and depression, and not telling me I shouldn't feel that way. Being there means sharing my peace and joy and accepting my sharing as a gift.

## LISTEN

You must be willing to listen. To do this, you must accept me as worth listening to. By listening carefully, you can share some of my feelings. By listening, you can help me look at my feelings and understand them better. You can help me see my concerns and struggles in a broader perspective.

Listening doesn't mean sitting there and saying nothing. If you do that, I'll probably think you're asleep. Listening means letting me lead in discussing what's important to me. I may not always want to talk about heavy things. Maybe I just want to discuss the weather. Generally, listening means going beneath what I'm saying and reflecting back my feelings. It is my feelings that are really important. For example, if I ask you, "Will I ever get well?", I don't really want an answer. After all, I know the answer to that question better than you. Perhaps what I'm saying is that I'm discouraged or feeling hopeless and lonely. I would feel closer to you if you could share these feelings with me. Perhaps you could say, "You're feeling very lonely and discouraged." Don't worry about saying the wrong thing. If you miss the mark, I'll correct you.

People seem to have a particularly hard time listening to me when I'm depressed. They seem to feel that if they listen and reflect back my depression, they'll just encourage me to stay there. This is not true at all. If you're willing to listen and accept me in depression, you can help me to do more quickly what I need to do when depressed.

## UNFINISHED BUSINESS

One of the things that makes it hard to die is unfinished business. For a mother, this may be knowing that her children are going to be taken care of. For a father, it may be knowing that his wife knows where the insurance policies are. For a child, it may be knowing that his or her parents will understand and be able to accept death. It may be seeing a loved pet for the last time or getting a telephone call from a beloved teacher. It may be a prayer, or a chance to talk honestly with someone about death. If you're really going to help me die, then help me resolve unfinished business. Sometimes this can be done very simply by making an arrangement or saying a few words. You must listen to me to know what

my unfinished business is. People often have great difficulty dealing with this. They're uncomfortable helping someone to die. If you can form a personal relationship with someone who is dying, you will not have that uncomfortable feeling. You will see beauty and joy in helping someone finish up business in order to die in peace.

### CONTROL

Perhaps you think that if you had more skills, you would know how to help. Skills help, but caring is much more important. Remember, I am in control. Whether you can help or not will depend more on my ability to receive help than on your ability to help.

Don't be afraid of mistakes. It's hard to like someone who's perfect. Even if I'm very sick, I'm not so fragile that you can destroy me with a few goofs. If you really care, our relationship can survive most anything. If you think you know what to do, you probably won't listen too well. If you don't know what to do or say, at least you're on the right track. Only I can teach you how to help me.

### HUMOR

Sometimes when we speak to groups, someone will get upset because we laugh and smile and even joke. "This is grave business," they say. "You're not taking death seriously; you're denying."

When I was very sick before the transplant, people would come to visit "the dying boy." If I cracked a joke, some would look at me strangely, as if to say, "Isn't that pitiful; the poor boy's laughing in the of death."

But if you're lying in bed all day, you have plenty of time to play around with your mind. You see many of life's ironies more clearly. Humor can be an escape, but more often it is an effective way to cope and survive.

Don't be afraid of my humor or yours. It's a sign of our mental health and basic humanness.

### I DON'T WANT TO HEAR...

"I know just how you feel." Like hell, you do! Even if you have experienced something similar, my feelings are still different. My feelings are private; you can't have them. When you tell me,

"I've been through that myself," you're saying, "I could handle it, so why can't you?" Or I may think you're saying, "Well, it's really not so bad; why are you so worried?"

Even worse is telling me, "You're just going through a phase," or, "You'll feel better tomorrow." I usually interpret this as meaning that you don't want to take me seriously -- you don't want me to talk about it. So I don't.

Other unhelpful statements are, "We're all terminally ill," or "After all, I could get run over by a bus tomorrow." Oh, please, spare me that. There is a real difference between concretely knowing you are dying and some abstract idea that someday you will die. I am dying now.

#### TAKE CARE OF YOURSELF

If you're really going to be with me, you must take care of yourself. You must know your limits and be willing to touch your own feelings. I, too, have difficulty listening to someone who is depressed. I don't expect you to do this endlessly or effectively at all times. Let me know when you've had too much, but also let me know that you will be back. If you can express your limits to me, I won't be so afraid you will desert me. I know you will take care of yourself well enough that you can continue to be around.

Don't let me push you around and take advantage of you. It's pretty easy to do. After all, I have a condition, and I'll probably take advantage of it. I find it easier to receive from you if I know you're taking care of your own needs and I'm not dominating your life. If you don't take care of yourself, you only burden me with guilt.

#### WHAT DO YOU GET OUT OF IT?

If you don't get something out of helping me, I would rather you didn't help. When I help someone, it makes me feel important and beautiful. I can get high on helping, but often the biggest gift I can give is to let someone help me.

If you are able to receive from me, it is easier for me to receive from you. There are several things I, the dying person, can give you. First of all, I can be your teacher. I can teach you about death. I can teach you about feeling very deeply. Most

important of all, I can teach you how to help me. That's a lesson you must receive from me, because you can't get it anywhere else.

How much you receive from me may depend on how close you're willing to get to me and how much you can share your own feelings. There is heartbreak and fear and loneliness involved in being around death. There are also lessons to be learned about life, the soul, and love.

### L E A R N I N G   F R O M   D Y I N G

The lessons I learn from facing death depend on what I need to learn. It will be different for each of you. Facing death lifts much fear from my life. It helps me see events in a broader perspective, making individual happenings less scary. It increases the quality of my life, because it reinforces the importance of finding fulfillment and joy in the present.

I learned how to ask for help. This was an important and difficult lesson for me. I was forced to ask for help. I was stubborn enough that I needed something dramatic in order to learn this.

Facing death forced me to look inside myself and find new strength and meaning there. I was able to get in touch with my soul and the essence of my love. I became closer to God and closer to the universe.

Facing death has made my life less frantic. I no longer have to accomplish things in order to prove my worth. Facing death made my marriage even more sharing and growing and alive. Both sides of our family united and mobilized to give love and support in a way that was too concrete to take for granted.

My experience helps me understand the beauty of life and death and love, and how they are all part of the same experience. You see, I would be dead now if it were not for the love of my father. My father's kidney is inside me, and in a very real sense my father's love created a rebirth in me. His love continues to be the source of my very existence. I cannot imagine a more exciting and beautiful relationship than this. I would gladly go through the pain and suffering again to have this continuing experience of love.

To face your own dying or help someone else face theirs, you must be willing to find a lesson in that particular experience. If you cannot learn, you cannot find acceptance -- your own suffering will defeat you. If you can learn, you will be able to help the suffering in a sharing and caring way.

SUGGESTED READING

- Alsop, Stewart. STAY OF EXECUTION. J.B. Lippincott, N.Y. Famous journalist's account of his battle with cancer.
- Agee, James. A DEATH IN THE FAMILY. Avon Books, N.Y. Pulitzer Prize-winning novel of a child's reaction to his father's death.
- Caine, Lynn. WIDOW. Wm. Morrow & Co., N.Y. A first-hand account.
- Claypool, John. TRACKS OF A FELLOW STRUGGLER. Word Books, Waco, Texas. A minister struggles with anger toward God when his daughter dies.
- Frankl, Viktor. MAN'S SEARCH FOR MEANING. Washington Press, N.Y. Famous psychiatrist's struggle in a Nazi death camp.
- Henderson, Stephen. DO YOU WANT TO HELP ME? -- THE ART OF RELATING. A handbook for volunteers [\$1.50 prepaid]. Hendersons, P.O. Box 2726, Staunton, Va. 24401.
- \_\_\_\_\_. FACING LIFE THROUGH DEATH [\$1.75 prepaid. Same address.]
- Jury, Mark and Dan. GRAMP. Grossman Pub., Viking Press, N.Y. Poignant photos and text document an old man's death at home.
- Kavanaugh, Robert. FACING DEATH. Penguin Books, Baltimore. Former priest tells of his mistakes and learnings in helping the dying.
- Keleman, Stanley. LIVING YOUR DYING. Random House, N.Y. About all the endings and losses in our lives. How we choose our dying.
- Kelly, Orville. MAKE TODAY COUNT. Delacorte Press, N.Y. By the founder of a self-help group for the dying and their families.
- Kubler-Ross, Elisabeth. ON DEATH AND DYING. MacMillan Pub., N.Y. If you read only one book, make it this one.
- Lawrence, Margaret. THE STONE ANGEL. New Canadian Library, McClelland & Stewart Ltd., Toronto. Stunning novel about an old woman's death.
- Lund, Doris. ERIC. J.B. Lippincott, N.Y. A mother's experiences as her teenage son dies of leukemia.
- Moody, Raymond, Jr. LIFE AFTER LIFE and REFLECTIONS ON LIFE AFTER LIFE. Bantom Books, New York. Collection of near-death experiences.
- Morris, Sarah. GRIEF AND HOW TO LIVE WITH IT. Grosset & Dunlap, N.Y. Short, specific book on how to grieve someone's death.
- Piazza, Ben. THE EXACT AND VERY STRANGE TRUTH (paperback). Wonderful novel about a young boy facing the death of his parents.
- Pincus, Lily. DEATH AND THE FAMILY. Random House, N.Y. A therapist talks about the importance and dynamics of mourning.
- Rosenthal, Ted. HOW CAN I NOT BE AMONG YOU? Moving poems written by a young poet as he dies of cancer. Also available as a film.



#### ABOUT THE AUTHOR

Stephen Henderson has been teaching and counseling since 1966. He has an M.S. in Counseling Psychology from Iowa State University. Steve has done personal, educational, and occupational counseling of all kinds. Along with counseling the terminally ill, he leads workshops in relaxation and pain control.

Both Steve and his wife, Phyllis, are experienced leaders in group work, volunteer training, and death and dying. They have studied with Dr. Elisabeth Kubler-Ross and others.

Steve is also an accomplished tenor soloist and enjoys singing religious music, musical comedy, spirituals, and classics.

#### A NEW VENTURE

Steve and Phyllis sold their home (a 15-room Victorian castle in Staunton, Virginia) and most of their belongings in December, 1977. They bought a used motor home, and now travel full-time in this country and abroad, working in the field of death and dying. They lecture, counsel, sing, and lead workshops. They also provide skill-training for volunteers and professionals, and teach relaxation methods. They do this work as a service available to all, regardless of ability to pay.

Their work is made possible by contributions and fees under a nonprofit corporation, Full Circle Counseling, Inc. They work in cooperation with professionals and volunteers, service and church groups, and individuals.

If you would like to sponsor a program in your area, write the Hendersons, P.O. Box 2726, Staunton, Virginia 24401.

## ORDERING INFORMATION

You may order booklets or write to the Hendersons at this address:

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Full Circle Counseling, Inc., is a mobile service dedicated to the counseling and training of persons as they face change and crises in their lives, including death. This nonprofit corporation is formed to support the work of Stephen and Phyllis Henderson as they share their experiences with life and death and their counseling and training expertise. Services will be offered regardless of ability to pay. Contributions are tax-deductible.

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