



ELISABETH KÜBLER-ROSS IS THE AUTHOR OF

On Death and Dying

Questions and Answers on Death and Dying

Death: The Final Stage of Growth

To Live Until We Say Good-Bye

Living with Death and Dying

Working It Through

On Children and Death

AIDS: The Ultimate Challenge

The Wheel of Life

On Children and Death

*How Children and Their
Parents Can and Do Cope
with Death*

Elisabeth Kübler-Ross, M.D.

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*To Kenneth, Manny, and Barbara,
who taught me how to be a mom.*

* * *

I also dedicate this book to the parents and children who so generously shared their love and pain, their hopes and despair with me.

This is a heartfelt thank-you to them, the thousands of mothers, fathers, grandparents, and siblings who have shared their feelings with me—at the time of a terminal illness of a child, after a suicide, or after the discovery of the body of their murdered child.

They have all carried their burden and pain in their own personal way, and yet they share the sadness of the loss of a child, and they have emerged with compassion, understanding, and an increased capacity to love.

Let us hope that this book will help others to live more fully and with more appreciation for life—while we can share it together.

A human being is a part of the whole, called by us "universe," a part limited in time and space. He experiences himself, his thoughts and feelings, as something separate from the rest—a kind of optical delusion of his consciousness. This delusion is a kind of prison for us, restricting us to our personal decisions and to affection for a few persons nearest to us. Our task must be to free ourselves from this prison by widening our circle of compassion to embrace all living creatures and the whole nature in its beauty.

—ALBERT EINSTEIN

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E.K.-R.

Introduction

Reflections

I AM SITTING IN MY LIVING ROOM after a long week in New York running a workshop with eighty-five people, many of whom had a terminal illness or were contemplating the misery and senselessness of life or suicide. Many others had lost a child or a spouse, and a few came to grow, to appreciate life more fully, or simply to “recharge their battery,” to enable them to work better with those in need.

And while sitting here at my typewriter, I am looking out through the huge windowpane, watching the bluebirds and hummingbirds, a baby rabbit who crosses the porch, a salamander who looks into my house, and then suddenly I see an eagle high above the trees behind my vegetable garden. It seems to me that this is what paradise must be like: the trees and flowers, the hills and mountains behind, the blue sky, the peace and quiet of a place to which one can retreat.

My thoughts drift, and I see the Indians roaming this land, building the mounds for their dead. I hear their prayers to the wind and their mourning of the passing of one of their children.

Then, as if I were watching a movie of the old days, I see the settlers coming, the young men during the gold rush, their

dreams of the "Great West," where they would find a piece of land to plant, a place to raise a family, and a fortune. I see their wagons struggling through toward the West; I see their women sitting bent, hot, and tired; I see them cooking a meal in a kettle and taking shelter in a storm. I see these women getting pregnant and dreading the journey; I hear the cry of a newborn baby, and see the pride and the sweat on the father's face as he views his firstborn child. I see them dig a grave somewhere on the path to the West, and I see the young couple struggling on to survive, to start anew, again and again and again. Nothing has changed much in the last few thousand years, I think. Human beings have always struggled, hoped, waited, dreamed, made it, lost it, and started again.

Just then, a visitor drops by to deliver some items, and before she leaves she takes one look at my typing and says in a curious way, "How can you write seven books about dying and death?" And without waiting for an answer, she is off.

Isn't that a strange question, I contemplate. How many books have been written, how many medical libraries are filled with hundreds of books about pregnancy, delivery, home births, stillborns, Cesarean deliveries, nutrition for pregnant women, breast-feeding versus bottle-feeding of newborns, and every conceivable aspect of issues revolving around conception, development of the future human being in the uterus, and finally the birth of yet another human being into this world?

And all human beings are different, even before they are here. They have been conceived under different circumstances, have shared different lives and experiences within their mothers, have been loved or resented, have been threatened with abortion or other traumas, have been prayed over or lovingly touched, have been listened to and patted, or have been cursed before they were even born.

And then they are here to share this world with us, and all human beings have different lives, different experiences, numer-

ous people to face and to learn to get along with; and every encounter in their lives plants the seeds of their tomorrows. Has anybody ever thought about the trillions of possibilities that life offers each one of us?

And so it is with death—the culmination of life, the graduation, the good-bye before another hello, the end before another beginning. Death is the great transition.

To see and to study, to learn and to comprehend the ways, the thousands of ways this transition is made by people of all ages and all cultures, of all times and places, is a miracle just as great as birth is. It is greater, I would say, since it is the door of understanding into the human nature, the human struggle and survival, and ultimately, the human spiritual evolution. It gives us the only cues we have so far about the *WHYS* and *WHEREs* and the ultimate purpose of life with all its pain and all its beauty.

Yes, I have written seven books, but the more I study human beings in the face of death, the more I learn about life and its ultimate mysteries. Maybe that is a knowledge all thinkers of days gone by had when they expressed their thoughts in paintings, in poetry and sculpture, in words, and in whatever form they were able to express their sense of awe, of mystery, and of enigma about our daily companion that we call so unlovingly *DEATH*.

Those who learned to *KNOW* death, rather than to fear and fight it, become our teachers about *LIFE*. There are thousands of children who know death far beyond the knowledge adults have. Adults may listen to these children and shrug it off; they may think that children do not comprehend death; they may reject their ideas. But one day they may remember these teachings, even if it is only decades later when they face “the ultimate enemy” themselves. Then they will discover that those little children were the wisest of teachers, and they, the novice pupils.



I have been asked many times to formulate my ideas about Children and Death, since most of my published material has concerned itself with adults. So this book deals with the questions: How are children different from adults when faced with terminal illness? Do little ones also go through the five stages of dying? Are they aware of their impending death, even if parents or hospital staff do not mention the seriousness of the terminal illness? What is their concept of death at different ages, the nature of their unfinished business? How can we best help them and their parents, grandparents, and siblings during this time of parting? And last but not least, can we—in any way—reduce the ever-increasing rate of childhood suicide, one of the most painful separations?

The material in this book stems from a decade of working with dying children of all ages. It comes from the vast knowledge of parents who have gone through this ordeal, of mothers and fathers who have lost one, two—yes, even three—children. It comes from families who have discovered a child missing only to discover that their child was murdered, that there was no way they could protect their little one, that he or she is gone without a good-bye.

I want to use this opportunity to thank all those who have contributed to my knowledge, who have been willing to share their grief and pain, their growth, and their evolving wisdom and knowledge with me through discussion and letters.

I want to share with you, the reader, the inner knowledge of these dying children so that you can also grow and learn to understand the importance of the inner voice, to which we need to listen. It is my conviction that it is the intuitive, spiritual aspect of us humans—the inner voice—that gives us the “knowing,” the peace, and the direction to go through the windstorms of life, not shattered but whole, joining in love and understanding.

Remember also not to block and shield your surviving children from those pains of death but let them share in the care

of their sick sibling to the extent they can. One of my favorite sayings is:

Should you shield the canyons from the windstorms,
You would never see the beauty of their carvings.

Thank you for allowing me to share what we have learned from our children.

Chapter 1

Letter to Bereaved Parents

MY DEAR FRIENDS,

This is a letter to you who are in the process of losing a child. We have accompanied and followed so many moms and dads on this difficult journey, and this book is about the concerns they expressed and the lessons we learned.

As your child gets weaker and closer to death, you will wonder how much a child should know about the possible terminal outcome of the illness. I say “possible” because I have witnessed many miracles.

All children know (not consciously, but intuitively) about the outcome of their illness. All little ones are aware (not on an intellectual, but on a spiritual level) if they are close to death. They will ask occasionally, “Mom, am I going to die?” Or if they sense that you are unable to talk or even think about it, older children will write a poem or a page in their diary about it. They may confide in a friend or a special person who is not necessarily a member of the family, and thus more able to hear their often symbolic language. If they have a roommate in the hospital or a playmate in the hospital playroom, they may share their knowledge with another sick child. Few grownups ever know how many secrets are shared in such a way.

Every person, big or small, needs one person in which to confide. Children often choose the least expected person: a nurse's aide, a cleaning woman, or at times a handicapped child who comes to visit them in a wheelchair. They have brief but deep talks together that adults would marvel at, and since they have gone through the windstorms of life at an early age, they know things that others of their age would not comprehend. Thus God who creates us all compensates the little ones as they fail physically. They become stronger in inner wisdom and intuitive knowledge.

They are aware of your pains and worries, your sleepless nights and concerns, and you should not hide them. Don't go into their room with a false "cheerful" smile. Children cannot be fooled. Don't lie to them that you just chopped some onions. How many onions are you going to cut? Tell them you are sad and sometimes feel so useless that you cannot help more. They will hold you in their little arms and feel good that they can help you by sharing comfort. Shared sorrow is much easier to bear than leaving them with feelings of guilt and fear that they are the cause of all your anxiety.

Should the siblings be involved and informed? Yes, every brother and sister of a critically ill child should become part of the care in one way or another. If the patient is at home, the brothers and sisters should be given specific tasks in the care of the sick one. They may be responsible for bringing the favorite dog in for regular visits after school. They may help to make yarn handicrafts (like "Eyes of God," a favorite pastime for children six years and up) when the patient's physical body gets too weak to play or do much. Siblings can take responsibility for running the tape recorder with favorite music, or they can serve one meal a day as long as the little patient can still eat.

Healthy children should not be made to feel guilty if they continue to laugh and giggle, to bring friends home or watch TV, go to a dance or a ball game, just as no mother should be discouraged from continuing to go to the hairdresser or the

parents to an occasional bowling game or whatever they previously enjoyed.

The worst thing we can do to the terminally ill child and the rest of the family is to make a morgue out of the house while the child is still living. Where there is laughter and joy, shared love, and little pleasures, the day-to-day difficulties are much easier to bear. If the little patient is overprotected, if every whim or desire is met, if everyone is expected to tiptoe around the house, the outcome is usually disastrous for the survivors.

When Bob was diagnosed as having cancer, every wish of his was met by parents who had much unresolved guilt and regret. The toys became more exclusive, expensive, and excessive. Bob obviously tested his parents and believed that he should get everything he could out of them. He barely played anymore but demanded more and more attention. He had never felt loved but he knew he could get material things "instead." Was it his punishment? His revenge for having been cheated out of the most necessary ingredient of life, the gift of unconditional love?

His brother Billy watched in amazement, and later with anger and envy, when his brother received literally everything he asked for. Famous athletes wrote to Bob and sent him autographed basketballs and baseballs. He was taken to Disneyland and to the Bahamas. He was flown to Tennessee to see the Grand Ole Opry and into the mountains of Colorado.

Billy began to resent his brother and started to test his parents himself. He asked for little things first, then bigger ones—always with the same result. Father's answer was always a very angry, "No, you cannot have it. We can't afford it." When he questioned why his brother got everything, the answer was a stereotype: "Would you rather have cancer?" No, Billy would not like to have cancer. He would not like to have the bone marrow needles. He would not like to lose his hair. But what had one thing to do with the other?

Billy started to injure himself weekly, but no one paid attention to him. The parents were too preoccupied with his sick brother. When he asked for a sandwich for lunch, his mother snapped at him, "Can't you see I'm busy? Fix it yourself." Billy started to wet his bed and got a spanking for it. Later, a few months before his brother died, a teacher noticed that Billy was very cruel to a handicapped child who attended school in a wheelchair. But no one noticed it beyond that remark in his school files.

Billy took me to my car as I left my house call on my first visit to their home. As I opened the car door, I asked him to sit with me for a while and tell me how things were going for him. He looked surprised, "For me?"

"Yes, for you," I answered. "Such illnesses are much harder on the brothers and sisters than they are on the patient." He looked sadly at me and responded, "Do you know that I have asthma? But I guess that's not enough."

So it is important to remember to also be good to yourself and to the rest of the family. Continue to share among all of them, and do not overindulge the little patient: You only leave him with guilt and a negative feeling about his true worth. "Why is it that I never got these things, and now that I have cancer, everything is possible?"

A terminal illness usually costs a fortune, and even the best insurance may not cover all the costs. There are many foundations which may help in a variety of ways, but we have too often seen families who were left with bills for \$100,000 or \$200,000 after the death of a child. It would be far more meaningful if such family problems could be discussed at the dinner table, so the other brothers and sisters could share the concern and be able to offer voluntarily, and without pressure or guilt, to give up certain extra pleasures in order to contribute to the family's welfare. They would be left with a sense of importance and pride.

Many little brothers and sisters have also been taught how to give oxygen or how to gently suction their little patient so

they can offer contributions to the care of the patient, giving them the same sense of self-esteem. Those children will not wish their brothers (or sisters) to die in order to bring some semblance of a family life back into their existence. Children (siblings) who make such remarks in a burst of anger should not be punished. They are voicing a cry for help before it is too late, and understanding adults should spend some time alone with them and let them ventilate their frustration, sense of unimportance, and feeling of neglect.

Someone, preferably a family member or close friend, should spend some extra time with such children, taking them to shop, to fish, to play, or to a ball game, not only for pleasure but for the feeling that somebody still cares for them "although they do not have cancer."

Children of all ages who have been included in the home care of a terminally ill child are not shocked and traumatized by the final sight of a cachetic sibling, sometimes with a blown-up abdomen and blue marks on hands and arms. They see the sick one with different eyes; they communicate on different levels. Such sights shock only those who have not been part of the daily care of the sick child, but those visitors naturally will need to be prepared and informed before they enter the sickroom.

When a child dies, it is important that the family be allowed to be alone with the child who is making the transition. All brothers and sisters, regardless of their age, should be allowed (but not forced) to participate in this final being together. Many families have used this time for singing the child's favorite song, for a joined prayer, or for simply holding each other in a circle of togetherness before outsiders are allowed to come in.

Make your final good-bye and then take time out to rock your child, to wash him yourself if you choose, to dress and carry him out to the car which will take the body to the mortuary or whatever place is indicated.

While many families express a wish to move soon after the

death of a child, to get into another neighborhood "that does not remind us" of the tragedy or away from a streetcorner where the fatal accident occurred, this is *not* a healthy choice, and too many families have regretted such impulsive moves. To get beyond the pain, one must face and acknowledge it and move *through* the pain, rather than avoid it. Those who do fare much better in the long run and are able to face life's future windstorms without trying to run away from them.

To stay in the same home is also a blessing for the siblings, as their life has already been shaken up enough. They feel "in the way" during the last few weeks and months of the terminal illness of a sibling, and often their only support system is a school friend, a teacher or school counselor, or a buddy in the neighborhood. To uproot them at an intense, often unsettling grief period in their life is the worst thing we can do for them.

There are still too many families who wonder if the surviving children should be taken to a wake and a funeral. My question is "Why not?" Wasn't it their sister or brother who died? Why should they be excluded from this final farewell ritual which serves as the only sort of closure and beginning process of "letting go." The funeral is a public acknowledgment that a person significant in our lives has died. It is a ritual that signals acceptance of this reality and puts the physical body in a final place that can be visited later on, in order to make the separation gradual. The wake and funeral serve important purposes in the grief process, and those who are excluded from them feel that they are not an important part of the family.

If a sibling has much unresolved business concerning the child that died, he or she may refuse to attend the funeral. This choice is a sign of unfinished issues and should be respected as important. Children should never be forced to attend a wake or a funeral, but they should be encouraged to attend as a matter-of-fact reality, as they would share a meal with the family. If they refuse, the reason is often fear, guilt,

shame, or latent resentment toward the deceased or the rest of the family. Whatever the issue, someone should later, after the funeral is over, try to discuss it with the child in a totally loving and not judgmental way. Much preventive psychiatry could be done this way.

We have taken many siblings separately to a wake, before the adults visit, without parents who might be ambivalent about permitting other children to see the open casket. With their permission we make a special visit, if the children so desire, to allow the siblings to see the body and ask any questions they may have. Many little brothers and sisters want to touch the corpse and are, naturally, allowed to do so. Many of them bring a special letter or love note with them, a flower or a favorite toy, and quietly "snuggle it" under the pillow.

These are very touching moments and show us the love and care the siblings want to share in this final moment. If it is not contrary to the family's beliefs, we tell the children that they can talk to their brother or sister, that they will continue to be aware of them, and that sometimes they may even visit them in their dreams. Those children leave relieved and matured, and will be better prepared to deal with future deaths in their lives.

The first few days after the death and the funeral will be busy ones. There are so many things to think of, so many relatives to accommodate, so many doors to be opened and closed, so much mail to be answered. This generally is good, since the busywork will give us moments of distraction and sometimes even a smile or laughter, which we need.

It is after the neighbors have stopped cooking and the friends and relatives have gone that the loneliness and real grief begin. At this time, be good to yourself. Don't expect your grief to last forever or to be done with in a certain time. In fact, don't think at all. Go through your days as best you can. Cry when you need to cry, beat the pillow if you need to express anger. Cook your meals or attend to your garden, your children, your dog, or your job as you have done before. It will

be mechanical at first, but that's all right. You are entitled to grieve. Grief makes everything look darker—for a time.

Don't make a shrine out of your child's bedroom. But don't hide the photographs and reminders either. If you cannot decide what to do with toys, bicycles, or clothing, don't do anything. There is no rush about anything. Time is a human invention; in reality, it does not exist. Concentrate on the living, your mate, your parents who not only grieve for your pain but also for the death of a grandchild. Do things with your other children, so you can concentrate on living things and stop brooding for a while about realities that cannot be changed.

You will think for quite a while, "Is there anything I could have done differently? Is there anything that I omitted? Should I have noticed changes earlier, called in for another consultation?" Thoughts like this will haunt some parents for a long time, for guilt and fear are man's greatest enemies. Such thoughts are understandable, but you must remember that parents are never their children's doctors even if they have an M.D. degree. Parents are too close to their children to be their objective medical experts. Remember that all the guilt in the world is not helping a soul—least of all, it is not helping your child who died. Guilt will make you sick emotionally and, if you don't let go of it, physically.

Learn to accept slowly the things you cannot change, and concentrate on your living children and those who are part of your physical life. If you are lonesome, think of the thousands of lonesome people in your own neighborhood. Share your time and your love with them, and this will help you resist falling into the pit of self-pity.

There are so many group homes for unwanted children and teenagers where you could literally save a life, if you should dare to get involved with one of them. The suicide rate is frightening among them, and if you need love, give it and it will return a hundredfold.

Talk to your child who died, if it helps you. Share with

your child your progress and show that you can handle the windstorms of life, because the death of a child often is the teacher of unconditional love, and unconditional love has no claims, no expectations, needs not even a physical presence.

With love and blessings,
E.K.-R.

Chapter 2
The Beginnings of Life

AND A WOMAN who held a babe against
her bosom said, Speak to us of Children.

And he said:

Your children are not your children.

They are the sons and daughters of Life's
longing for itself.

They come through you but not from
you,

And though they are with you yet they
belong not to you.

You may give them your love but not
your thoughts,

For they have their own thoughts.

You may house their bodies but not
their souls,

For their souls dwell in the house of to-
morrow, which you cannot visit, not even
in your dreams.

You may strive to be like them, but seek
not to make them like you.

For life goes not backward nor tarries
with yesterday.

You are the bows from which your children as living arrows are sent forth.

The archer sees the mark upon the path of the infinite, and He bends you with His might that His arrows may go swift and far.

Let your bending in the archer's hand be for gladness;

For even as He loves the arrow that flies, so He loves also the bow that is stable.

—KAHLIL GIBRAN,
The Prophet

Not all children are expected with joy and excitement about the miracle of a new life, the miracle of the creation of a brand-new human being. At the time of this writing, fifteen million children are starving to death, not all of them in faraway continents where we can put them out of our minds. There are desperate children, hungry and needy children, all over the world, on every continent, in every country, in every city. Abortions prevent the birth of hundreds of thousands of babies, but they do not solve the problems. Until our attitude toward LIFE changes; until we are able to make a new and stringent commitment to the QUALITY OF LIFE; until we practice what so many give only lip service to, and we redefine our concepts of LIFE and LOVE, our society's problems will not be solved.

In some parts of the world (I have traveled and worked all over this planet), children are a natural part of life. One baby after another is born, and the family and tribes take care of them, feed them, nourish and raise them in an almost communal fashion. Children can always find someone who cares and who will share moments with them, someone who instructs them in the arts and crafts, and who teaches them how to survive physically, emotionally, and spiritually. Children are viewed as an asset, as they will ultimately become the provid-

ers of all needs, including food and care for the elderly; in this view, children prove the universal law that "all benefits have to be mutual."

The more children such a family or tribe has, the more they are guaranteed survival in their old age. As the next generation of adults, the children will take care of the harvest, of trade, of the maintenance of the village and the survival of its inhabitants.

The modern world has changed enormously in the last half-century. Since the advent of modern transportation, of the material philosophy of life, since technology and science have replaced our old spiritual values, life has changed and affected especially the upbringing of our children.

Do you remember when families lived in the same communities for generations? When everyone knew the pastor or rabbi, the doctor, the teachers, the grocery store owner, by their personalities and often by their first names? When children had a sense of belonging, and the whole community awaited the birth of a newcomer? When the elderly would knit and sew to prepare the children's first outfits by hand? When neighbors were ready to help in the delivery and welcome of the new baby?

In America in the 1980s most of us don't even know when a neighbor has delivered a new baby or if she has disappeared for a couple of days and then returned, although by chance we may hear that she had a miscarriage or a stillbirth.

How different this is from the days when aunts and grandma came to attend the young mother when she had her babies. Then older brothers and sisters were able to look in awe at the size of the newborn's tiny toes and fingers, hear the baby's first cry—the sign of life—and see the new baby take its first meal at its mother's breast. These are scenes imprinted in the minds of little children that they will never forget. These are moments of sharing, learning, growing, and awe.

Now couples often decide it is better to have a career and security first, and perhaps a child later. They prefer to save for