

# Facing Death *Discovering Life*



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*Life is only for love.  
Time is only that we may find God.*

— Bernard of Clairvaux

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## Introduction

In setting out to write this book on death and dying, I needed to take some time to consider the lessons I have learned from my experiences of death and from the privileged opportunities I have had to accompany others in life's final moments. Three experiences in particular came to mind.

I recall as a young boy driving with my father into the eastern corner of Algonquin Park. The logging road on which we travelled followed the route of the original trail along the Bonnechere River. Along the way my father would point out crosses that marked the spot where early settlers and loggers were buried, mostly men who had died in accidents along the river. Inside the park we would sometimes stop at the small deserted settlement of Basin Depot.

Here too a number of grave sites can be found. One is located beside a shallow brook in the shade of tall white pine trees. Some of the graves date back almost a century. Various people over several generations have taken on the task of maintaining the white rail fence that surrounds the graves.

As the years pass I find myself drawn back to this site each summer. I know that I will die one day and that I will leave the people I love. This yearly pilgrimage to Basin Depot reminds me of that fact. The memory of those journeys with my father also touches some deeper awareness — the awareness that every person's death touches me and opens me to a deeper questioning about the meaning of life.

The second experience concerns the death of my grandmother when I was twenty-three. She was diagnosed with cancer in early spring and had several months to prepare for death. During the weeks leading up to her death all her children and grandchildren had many opportunities to spend time with her. On the morning that she died her six daughters and the parish priest were at her bedside. Just moments before her death, she opened her eyes and said to my mother and aunts: "It's beautiful. I want you to know there's nothing to fear."

Those words have stayed with me over the years. Paradoxically, it was her dying and gradual diminishment that spoke powerfully to me about the mystery and immensity of life. Death is a passage into mystery, and this passage somehow affirms how precious life is. My grandmother's death taught me that while dying brings sadness and suffering, there is still room for life, and joy, and a deep sharing of life with others. Even when someone enters the final stage of helplessness, that person can still love and be loved. The dying person is alive and giving until the very last moments.

The third experience concerns the transformations that can occur in the interval before death. Over a period of eight years I accompanied a number of people in the final weeks and hours of their lives. This took place in a small northern aboriginal community where death and dying are still very much community events and where people almost always die at home.

The impact one elderly woman had on the life of the community during her final days was especially memorable. At the time of her death her children estimated she was over 100 years of age — no record of her date of birth existed. During my first years in the village I didn't see her often. She was frail and tended to stay indoors. As the time of

her death approached, however, she seemed to acquire a new energy, and she took on a new role in the life of the people.

As the oldest person in the village she was treated with great respect. Family members and friends stayed with her during the final days, keeping a silent vigil throughout the night. During those days, virtually every child, woman and man made their way to her small house to visit her. She had personal words for them all: to some she offered words of encouragement; to others she presented a challenge to set things right in their lives; and to the younger leaders she emphasized the need to put the good of the people ahead of their own interests. I witnessed myself how those words prompted significant changes in the lives of people.

That experience showed me that dying often has a way of revealing the unsuspected resources that lie buried in the depths of a person. People are always developing, and during the dying process transformations can, and often do, occur. Even as they are dying, most people can complete meaningful tasks and grow in ways that are important to them. Dying can bring a human being to become what he or she was called to become, and in this way can truly be an accomplishment.

A person's dying has an impact similar to that of a stone hitting the still surface of a lake. It sends out rings of disturbance from its centre in the form of feelings, thoughts and reactions. It affects others and stirs the depths of those who love and care for the person. As such, death can bring about the transformation of relationships. It was not uncommon to hear families talk about the last weeks of a loved one's life as a time in which they had never been more intimate, more open, or more loving.

These three themes — how death pushes us to question the meaning of life, opens us to the mystery and immensity of life, and lays open the possibility of transformation — provide the framework for this book and for addressing the fears, struggles, joys and accomplishments that people experience at the end of life.



This text has been written from a Christian perspective on death and dying. *Gaudium et Spes*, a document issued by the Second Vatican Council, underscored the Catholic conviction that God has called us to an endless sharing of divine life beyond death (no. 18). In our Eucharistic acclamation we proclaim our belief that the death and resurrection of Jesus has freed us from death: “Dying you destroyed our death, rising you restored our life. Lord Jesus, come in glory.” Scripture texts and theological reflections have been used to illustrate the themes of transformation and healing which are central to this book and to the Christian understanding of suffering and dying.

At the end of life many people come to a sense of peace in the process of letting go and growing into an unexplored spiritual realm. They often describe this movement to a deeper sense of the meaning of life and to a profound appreciation for the gift of life in terms of feeling closer to God. In writing about this process I have tried to respect the beliefs and practices of different religious traditions and to acknowledge that a person who is dying may or may not use religious terms to describe this experience.

This book will try to explore a paradox. Facing death and entering into the anguish and suffering that accompany it can be an experience in discovering life. Death, which we will all live one day, is not an encounter with meaninglessness; it is the fulfillment of life.

In focusing on dying in this way there are those who will say that I am sugarcoating the dying experience. They will remind me that death is certainly not beautiful, and can be painful and unpleasant. While I would not disagree, it is also true that many people who are dying say it is a time in which they feel vibrantly alive, perhaps for the first time ever.

We tend not to pay attention to most things in life. We are busy thinking and worrying about tomorrow. Death catches our attention and brings us to awareness, and that is where the experience of being alive arises. Perhaps that is why there is the prospect for growth and healing at the end of life.

This book is intended primarily for those who are dying and for those who may be facing the loss of a loved one. It is not my intention to try to provide answers to the pain and despair you may be feeling, but I do hope that these pages will bring some comfort. The final section of the book is intended for caregivers (family members, nurses, aides, doctors, pastoral care providers, and all those who work closely with those who are dying). Caring for another at the end of life involves an intimate journey in which a transformation occurs not just for the person who is dying but for caregivers as well. The caregiver, too, can experience healing.

I hope this book will contribute to the transformation of our culture: toward one that overcomes its fear and denial of death and learns how to integrate death into life. Facing death means embarking on a journey, one in which we will be taught more powerful lessons about life than about death.

## PART ONE: A SEARCH FOR MEANING

## Dying Today

People do not die today as they did in past centuries. Progress in the treatment of disease and important changes in people's attitudes towards suffering have dramatically changed society's understanding of death and its practice of care for the dying.

Amazingly, death is the last conversational taboo. The word itself is used with caution. Whenever possible it is avoided altogether. Our society spends billions of dollars each year on products that deny the body's gradual decay and encourage us to avoid the reality that we are in a process moving towards our death. Even in the funeral home we cosmeticize the cold realities of death so as to deny our transiency.

In his book, *Denial of the Soul*,<sup>1</sup> M. Scott Peck suggests this state of denial is so strong that even though the majority of people die gradual deaths they still deny the fact that they are dying. The denial of death and our inability to talk about it has led many people in our society to believe it would be legitimate to kill the dying. Peck says this has happened because as a society we have failed to recognize death as a matter of the soul — it touches those aspects of human experience that underlie and animate our lives. As a society, we have difficulty addressing matters of the soul or spirit. As a result, we miss out on the lessons to be learned from dying and fail to see it as the ground where human experience can be unified and deeply understood.

*We hide death as if it  
were shameful and dirty.  
We see in it only horror,  
meaninglessness, useless  
struggle, an intolerable  
scandal, whereas it is our  
life's culmination, its  
crowning moment and what  
gives it both sense and worth.*

Marie de Hennezel  
— *Intimate Death*

In the nineteenth century people in industrialized nations started to conceal from patients the fact that they were dying. It was thought better to spare people anxiety by hiding the seriousness of their illness from them.

Over the past century people have been excluded more and more from their own dying. Throughout the first decades of the twentieth century families provided all care for the dying, but in the 1950s responsibility for caring for the dying was gradually given over to health professionals.

Today, up to eighty per cent of the population take their final breath in a health care facility rather than in their homes. Too often that means dying in institutions where death is considered an enemy. Advances in medical science have made it possible to maintain the human body's vital functions long after the natural course of an illness would have destroyed them. Rather than being a natural process, death has become one that is controlled by human beings using sophisticated, but impersonal, machines.

Another factor that has influenced our understanding of death is the breakdown of community among us. Speaking at a National Prayer Breakfast in Washington in 1995, Mother Teresa described the situation well.

I can never forget a visit I made to a nursing home where they kept all these old parents of sons and daughters who had put them into the institution and forgotten them. In this home these old people had everything — good food, comfortable places, television, everything. But they were not smiling, and nearly everyone was looking toward the door. And Sister said, “This is the way it is nearly every day. They are expecting, they are hoping, that a son or a daughter will come to visit them. They are hurt because they are forgotten.”<sup>2</sup>

Her words describe the loneliness and lack of community many people experience in the final stage of life. It was this kind of suffering that moved her to establish the Hospice for the Destitute and Dying in Calcutta. Here, the sisters and the volunteers recreate a sense of community and caring around the dying person. Outside, the streets are teeming with people; the air is filled with the sounds, smells and heat of the city.

Passing into the hospice, through the doors and the thick walls, was like entering another world of quiet and serenity, a cool and calm temple. Never, in any hospital setting have I felt such peace. Here were people who had been picked up on the sidewalks, gutters or streets of Calcutta, near dead... They had been brought to the hospice so that once before they died, they could experience total and unconditional love... through the heart, soul, touch and eyes of these sisters and volunteers, who saw the beauty of their souls, even despite the wretched condition of their bodies and often their lives. They were lying on their pallets, and in the very air of serenity, they breathed in something ineffable and soul comforting.<sup>3</sup>

People have very real fears related to how and when they will eventually die. They fear unrelieved and intolerable pain; inappropriate or unwanted medical interventions, and an unnaturally prolonged life; they fear they will become worthless and unneeded; and they fear being a burden to their families.

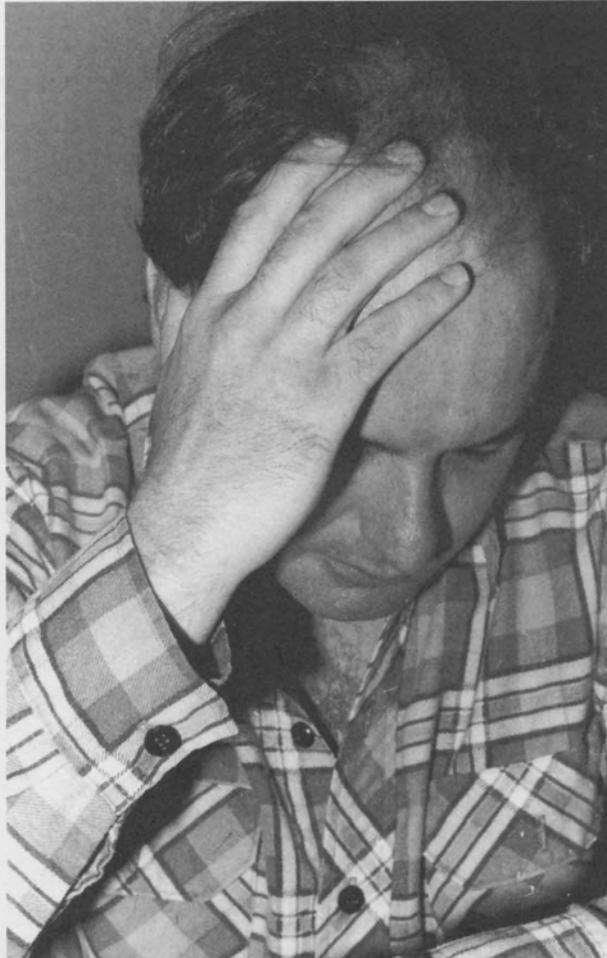
In recent years there have been signs of change in end-of-life care in North America, signs that people's fears are being recognized and that efforts are being made to respond to them. The development of palliative care, statements on the rights of dying persons, and the promotion of advance health care directives are signs that our society is looking for ways to talk about death and to find ways of caring for

*We drift toward death  
like leaky canoes being  
pulled by a waterfall,  
assuming that death is  
bound to be a horror, that  
nothing can be done except  
to paddle frantically  
against the current until  
the last ghastly moment.*

Tim Brookes  
— *Signs of Life*

the dying that affirm the value and meaning of life and enhance the quality of life of those who are dying.

One thing is clear, however. The root cause of much of the misery associated with dying today is the denial of death and the fact that our society has no positive vision with regard to life's end.



## Why Me?

When the time comes to face our own deaths, many questions are likely to well up within: Why me? Why now? What have I done to deserve this? In taking care of parents or grandparents as they die, in having to deal with the death of a child, or in facing sudden or accidental deaths, similar questions also arise: Why is this happening? How could God let this happen?

While it is undeniably true that time can heal all wounds in the end, it is that dark time between the wound and its healing that is so difficult. Thousands of people die each day, yet for persons who are dying, or when someone we love is dying, it can feel to us as though this has never happened to anyone before. It is as if no one else has ever known this pain and anguish.

The crying out of *Why me?* that is experienced in the face of death is a reaction to our not being able to run away any longer from the disappointment, failure and death that are part of the very fabric of our existence. In the *Tibetan Book of Living and Dying*, Sogyal Rinpoche says one of the chief reasons we have so much anguish and difficulty facing death is that we ignore the truth that nothing, nothing at all, has any lasting character.

Life may be full of pain, suffering and difficulty, but all of these are opportunities handed to us to help us move toward an emotional acceptance of death. It is only when we believe things to be permanent that we shut off the possibility of learning from change.<sup>4</sup>

*It is only when circumstances let us down, when we are forced to watch our security dissolve, that we glimpse the truth that we have not really understood at all, that we've been trusting to the wrong things, pinning our happiness on what we have rather than on what we are. When the chips are down and we face the breakdown of what made life meaningful, we are plunged into the night.*

— Erich Fromm  
*To Have or To Be?*

*If only my misery could be  
weighed, and all my ills be  
put on the scales!  
But they outweigh the sands  
of the seas...*

— Job 6:2

The search for meaning is well expressed in the biblical account of the sufferings of Job. Job engages in an endless questioning of his friends and of God demanding to know why he has been so sorely afflicted. Immersed in loss, suffering and illness, Job struggles with God and in the process he is changed. In the end, he does not receive an answer to his question. He realizes that he was not asking the right question and admits humbly: “I have uttered what I did not understand.”

At some point we need to stop asking ourselves *Why?* As Job discovered, there is nothing to be found there, nothing to understand. It is important to be patient in the absence of answers and to experience the questions. In fact, we may need to change our question and ask *For What?* As the stories of transformation presented in later chapters show, *For what?* seems to be the question that can lead to a discovery of meaning in the midst of suffering. Can I turn my dying or my suffering into a source of light and love?

## Where is God?

**F**or many of us, including many Christians, confronting death challenges our understanding of God and the relationship with God which we have nurtured and protected, perhaps over a lifetime. While knowledge of the inevitability of death may be within each of us, confronting the reality of our dying can cause us to question how a loving God could allow us to die.

Once again it is the biblical character Job who provides an example of how the dying person must reach out in a new way and in a new depth of faith to encounter the living God. Job was known to be a sound and honest man who loved God and “shunned evil.” As the story goes, God permits Job, whose life up to this point has been filled with riches and blessings, to be struck down with misfortune and sickness. In the midst of his suffering Job laments the loss of the God he thought he knew.

Like Job, most of us create a God with whom we are comfortable — a God who does not ask too much of us. In facing the losses and sufferings that are part of dying, we too may find ourselves asking: Where is this God whom I trusted and served? How could God abandon me at this time when I feel most in need?

It is difficult to imagine the anguish of the women, men and children who were taken into Nazi concentration camps to suffer cruel and violent deaths. There, prisoners were stripped of their identity, reduced to a number and denied respect for their human dignity. They were starved and beaten and sent to the gas chambers to die. Some gave up; others became as cruel and inhuman as their captors; and still others

*If only I knew how to reach  
God, or how to travel to God's  
dwelling...*

*If I go eastward, he is not there;  
or westward—still I cannot see  
him. If I seek him in the north,  
he is not to be found,  
invisible still when I turn to  
the south.*

— Job 23:3, 8-9

found the courage to sacrifice themselves so that others might survive a little longer. The inner turmoil these people endured must have led many to deep feelings of being abandoned by God.

In his book *Night*, Elie Wiesel provides a personal account of the anguish experienced by these people. He tells of being forced to watch a Jewish boy die a prolonged death on a gallows in Auschwitz. In this heart rending account he reveals how, in the face of overwhelming suffering, his eyes were opened to a new understanding of God's presence.

For more than half an hour he stayed there, struggling between life and death, dying in slow agony under our eyes. And we had to look him full in the face. He was still alive when I passed in front of him. His tongue was still red, his eyes were not yet glazed.

Behind me, I heard the same man asking:

“Where is God now?”

And I heard a voice within me answer him:

“Where is he? Here He is — He is hanging here on this gallows.”<sup>5</sup>

The losses and diminishment that are part of dying may be experienced as abandonment by God. That sense of emptiness, however, can also open up a space for a new and deeper encounter with God.

*There's a crack;  
a crack in everything.  
That's how the light  
gets in.*

— Leonard Cohen  
*Anthem*

## Pain and Suffering

**D**ying is hard; it is ugly. No one can presume to explain away the emptiness, finality and sorrow it represents. The best that we can do is to see death and dying in perspective by looking to our smaller sufferings and difficulties in life and finding in them the seeds for understanding and accepting death.

*God whispers to us in our pleasures,  
speaks in our conscience,  
but shouts in our pains:  
it is his His megaphone  
to rouse a deaf world.*

— C.S. Lewis  
*The Problem of Pain*

Pain and suffering commonly go hand-in-hand with an incurable illness. In understanding and responding to these realities in the life of a dying person it is helpful to maintain a clear distinction between pain and suffering. Pain is the physical distress associated with illness and disease that people may experience as they struggle with discomfort, disability and their inevitable demise. The pain or physical hurt people experience in dying can be made tolerable and manageable.

Suffering refers to the emotional, spiritual and psychological anguish that comes with losing all those things that give life meaning and purpose. Possessing a sense of the future, for example, is vital to feeling whole. The prospect of dying presents an overwhelming suffering because it can remove all sense of a future. When one's sense of self is threatened, suffering follows.

Ira Byock, M.D., author of *Dying Well*, has specialized for the past twenty years in care for the dying. In his writing he too makes a distinction between the physical pain of disease and the emotional and psychological suffering that comes as people face losing all they have been and all they have imagined they will be. He suggests suffering persists when a person's physical pain is ignored or judged

uncontrollable, or when a person's emotional anguish is not understood or is dismissed. "In my experience the personal, internal sufferings can be far more intense and require even more skillful intervention."<sup>6</sup>

Personal distress or suffering of some extent is universal among people who are dying. While gentle passages from life do occur, for most people the months and weeks that precede the moment of death involve an inner struggle as they confront physical diminishment and the loss of their abilities, roles and relationships.

*To every thing there is  
a season  
and a time to every purpose  
under heaven:  
a time to be born, and a time  
to die.*

— Ecclesiastes 3:1-2

The experiences of suffering that disorient us, putting into question everything that gave purpose and provided a sense of meaning, are both a natural and necessary part of human life. All of life is marked by times of growth and times of diminishment. With the passing of the years we each learn that a time of growth is preceded by experiences of suffering and powerlessness.

The essence of suffering lies in the fact that initiative is taken out of our hands. Such shocking losses as being laid off without warning or being diagnosed with a serious illness, or the great losses associated with the end of an intimate relationship or the death of a loved one, challenge us to clarify and reidentify who we are.

*I have found that one central  
discovery has stayed with me  
... that at the moment of  
greatest desolation we become  
aware that strength is available  
for all if we choose to avail  
ourselves of it.*

— Mary Craig  
*The Last Freedom*

Many people have spent their whole life withdrawing from suffering. But in confronting their dying they find they can withdraw from suffering no longer; there is no place to hide from death. Stephen Levine has worked for many years with persons who are dying. He has written about the growth people experience as they face the pain and suffering associated with dying. "Most people begin to open to their life not because there is joy, but because there is pain."<sup>7</sup>

*Unless a wheat grain falls  
on the ground and dies,  
it remains a single grain;  
but if it dies,  
it yields a rich harvest.*

— John 12:24

*In order to become myself  
I must cease to be what  
I always thought I wanted  
to be, and in order to find  
myself I must go out of  
myself, and in order to  
live I have to die.*

— Thomas Merton

For some people it may be their dying that causes them for the first time to look within. The unexpected and the unwanted can bring each of us face to face with the questions we have postponed all our life, investigating at last what is real. The value of unavoidable suffering lies not in the anguish of it, but in what we make of it and what we learn from it. In every life comes the awareness that there are some truths which only sorrow can teach, and that it is only through suffering that we come to self-knowledge.

The Christian approach to wholeness and healing acknowledges the link between suffering and wholeness. The Christian view of wholeness is one that begins with a sense of wonder in being. In that state we are open to being surprised. In the state of wonder we act out of reverence, appreciating the thing, person, or moment in itself. The person experiences the interconnectedness of self, others and God.

Life educates us about, and moves us toward, this sense of wholeness. Some of life's best teaching comes from suffering. In the Christian view, the process of wholeness involves "emptying" — the dispossession of everything we are. "For anyone who wants to save his life will lose it; but anyone who loses his life for my sake, and for the sake of the gospel, will save it" (Mark 8:35). Through this emptying the person progresses to oneness with others and with God.

The life of Jesus is a paradigm of the process that leads to wholeness and an example of the role suffering plays in its development. His birth recognized a divine origin and mission. His transition to adulthood was marked by time in the desert and the discovery of God's presence in the midst of solitude. In his life there was a place for times of work, rest and celebration. Prayer was his energizing centre in a life that knew disillusionment but not despair. His

acceptance of suffering moved him to love. He faced fear of death and passed through it into acceptance. He made death his own and it became a spiritual means of life for others.

For Christians, facing suffering in life and dying well mean living and dying as he did.



## Grief

Whenever we experience a loss, whether it is great or small, we tend to go through the same stages of grief, though with varying degrees of intensity. In order to be freed from the anxiety and suffering associated with the loss, we must first deeply experience the uncomfortable and unwelcome feelings associated with loss.

Different conceptual models have been developed to help persons who are dying understand their experience and to grow from it. Elisabeth Kübler-Ross's stages of dying (denial, anger, bargaining, depression and then acceptance) is one such model that has assisted people in understanding and passing through the transitions that are experienced during the dying process.

While the models may vary concerning the titles given to these transitions and the number of stages, they do identify similar phases in the grief experienced by persons who are dying.

For most people the first phase of grieving is shock and denial. The world seems to dissolve and the familiar landmarks that provided equilibrium in the past are lost. Jean Monbourquette has done extensive work on the grieving process. In assisting people to find comfort and meaning in times of grief he has noted that the human body has developed survival mechanisms that are activated in times of great distress. "When suffering is too great, the human body produces tranquilizing hormones, nervous connections fail, reality becomes blurry and emotions stagnate."<sup>8</sup>

*No one ever told me that  
grief felt so like fear. I  
am not afraid, but the  
sensation is like being  
afraid. The same fluttering  
in the stomach, the same  
restlessness, the yawning.  
I keep on swallowing.*

— C.S. Lewis  
*A Grief Observed*

As a result, this state of shock is often accompanied by a loss of energy and a debilitating lethargy. It can also cause the denial of reality. Such denial may take many different forms, but at its core is the person's inability or refusal to experience and acknowledge suffering.

Gradually, the intensity of the shock gives way to an increasing awareness of many emotions. For people who have never learned how to feel and express certain emotions such intensity of emotion can be a frightening experience in itself.

Some people report that in trying to cope with a life-threatening illness they feel a nagging resentment that the world around them seems to be moving along just fine, whereas for them everything has changed. This resentment may be accompanied by an intense longing for the past, for the way things were. It should not surprise us that people can sink into self-pity in the face of such emotions.

Depression, fear, anger, sadness, guilt, and powerlessness may all be part of the emotional merry-go-round experienced at such a time. By letting these emotions run their course and paying attention to their implications, this can be a very self-revealing time for people who are dying.

With deepening self-awareness may come the realization that there is unfinished business to address. This might involve the need to request or grant forgiveness, to pass on unfinished projects, or to find ways to say goodbye.

Nostalgia for the past — for the way things *were* — gives way to an acceptance of the present and the way things inescapably are *now*.

This movement represents an acceptance that the situation is not going to change. The person realizes it is he or she who must change. Such acceptance also represents the taking on of a new identity. The shattering of life can give rise to a clearer understanding of the way things are. It vanquishes the delusions and ambitions that often hold us in their grip, revealing how simple the real needs of a human life are.

When speaking about phases or stages of grieving, it is important to note that while such models may be useful for describing human experience, they should not be regarded as a rigid sequence to which all people are expected to comply. Not everyone experiences all these phases, nor do they experience them in the same order. Moreover, people do die without having resolved all unfinished business and without having transformed their suffering and grief into a spiritually meaningful experience.

Grief is one of the inescapable realities that we will all encounter in our dying. The period between the diagnosis of a life-threatening illness, to the onset of serious symptoms, and through dying is a time in which we will still have much to learn, and grief can be our teacher.

## Waiting – A Time for Prayer and Preparation

**I**n the West we attribute worth to ourselves and others only when we are busy achieving, succeeding, and rising to meet new challenges. We keep active in order to maintain our identity as doers. Not being active is regarded as wasting time. Dying is a movement from the active to the passive.

Several years ago a member of my family underwent a series of chemotherapy sessions for cancer. I would drive her to the clinic and to her doctor's office where we would spend many hours waiting: waiting for tests; waiting to meet with doctors; waiting for files to be located; and waiting for treatments. The three-week waiting periods between sessions were hard on her as she found even the simplest of tasks demanding. Waiting drains peoples' energy as they wonder, speculate, and expect the worst. In the midst of so much waiting it can seem that life is standing still. People feel isolated from the world of activity around them.

Such times of waiting and isolation can provide opportunities for discovering or renewing the place of prayer and meditation in life. Jesus' prayer in the Garden of Gethsemane the night before his death provides a model for us. Waiting for his arrest he prayed to his Father. Mark tells us that a great fear came over Jesus and he was greatly distressed. In solitude he poured out his fears to God. He used his time of waiting to gather strength for the events to come.

Throughout his life Jesus spent time in solitude, developing an attentiveness to God's voice within himself, a voice that called him

“the Beloved” (Mark 1:11). He lived his life from that inner place of love. Although he was hurt by rejection, resentment and hatred, he remained always anchored in the love of the Father.

Without solitude it is virtually impossible to develop a life of prayer. Solitude begins by setting aside a time and a place for God, and for God alone. In the beginning we may experience many distractions and find the stillness and silence difficult to tolerate. We may feel we are simply wasting our time. But once we have committed ourselves to spending time in solitude we begin to develop an attentiveness to God’s voice within us.

Every time you listen with great attentiveness to the voice that calls you the Beloved, you will discover within yourself a desire to hear that voice longer and more deeply. It is like discovering a well in the desert. Once you have touched that ground you want to dig deeper.<sup>9</sup>

By developing a place for solitude in life, waiting can take on a new light. Henri Nouwen writes: “We even start looking forward to this strange period of uselessness.”<sup>10</sup> In *Dying Well*, Ira Byock writes about the impact solitude and prayer can have in the life of a dying person.

The contemplative practice of prayer or meditation can provide a place of safety and distance — not from, but within, the experience. The ability to remain centred and “well within oneself” in the middle of distraction, doubt, anxiety and bodily discomfort is recognized by many cultures and religious traditions as being critical preparation for the transition from life.<sup>11</sup>

Waiting need not be time wasted. These passive times can become moments of growth in which the experiences of isolation and inactivity give rise to a life-giving solitude.

The Need to Talk About



## The Need to Talk About Death

**B**eing unhappy in our society is not popular. We abhor suffering and fear. As a result, we are ashamed and unable to speak about our needs, discomforts and fears.

Our inability to speak of sadness and death can contribute to the conspiracy of silence that usually surrounds dying persons. It is a silence that accentuates their suffering. How common it is to hear family members and friends scold the dying person who tries to speak of their dying with such words as: *Don't talk that way!* As a result, the dying person experiences the additional burden of having to protect others from their pain and distress.

The worst kind of isolation for those who are dying is not being able to say to the people they love that they are going to die. Those who care for the dying report that not being able to talk about or share with others what this time of dying means often results in mental anguish, a kind of delirium, or some manifestation of pain.

Despair, fears of uncontrollable pain, and worry about those being left behind, all must be able to declare themselves, even to cry out at times. In hospitals there is often a tendency to suppress any expression of emotion around a dying patient. Every effort is made to keep the person calm and quiet. The resulting silence is a lie that protects the living from the cries of the dying and from the frustration that comes in our inability to change things. It is a way of protecting ourselves from our own fears of dying.

*Jesus cried out in a loud voice,  
"My God, my God, why have you  
deserted me?..."*

*Again, crying out in a loud voice,  
Jesus yielded up his spirit.*

— Matthew 27:47,50

It is important to allow dying persons to speak about their dying and about the questions and issues that may be troubling them.

... the person who can say to someone else “*I am going to die*” does not become the victim of death but, rather, the protagonist in his or her own dying. It is a moment of standing up straight again, and of the return of an inner strength that nobody else knew was there. The person who can say “I am going to die” can conduct that departure [and] organize it...<sup>12</sup>

*I see the darkness I have  
been fighting  
is the purpose of my life.*

— Samuel Beckett

Ironically, people who have actually faced the prospect of their own death and talked openly about it often feel enlivened instead of depressed. This may be because our fear of dying and feeling unprepared for death is related to fear of the unknown. Talking about it helps to break through that fear.

## The Demand to Die

“I want to die.” “I demand to be given the right to die.” “Do something, I beg you.” Such expressions are sometimes heard by nurses, doctors and family members as they care for persons who are dying. These demands reflect a person’s deep anguish in confronting the intolerable. They occur when death appears as the only possible relief to overwhelming suffering.

*For my days are vanishing  
like smoke, my bones  
smouldering like logs, my heart  
shriveling like scorched grass  
and my appetite has gone;  
whenever I heave a sigh,  
my bones stick through my skin.*

*... my strength has already  
run out;  
tell me how much longer I  
have left.*

— Psalm 102: 3-5, 23

Marie de Hennezel is a psychologist who has worked for several years in a hospital for the terminally ill in Paris. In her book *Intimate Death*, she presents several accounts of people who in arriving at the centre, or in the course of their dying, demand euthanasia.

One such story is about a woman she has named Dominique. For three weeks, after arriving at the centre, Dominique begged for death. By treating her symptoms her pain and discomfort were eliminated. Her cries for death also ceased. One day she took a turn for the worse and would not get out of bed. Efforts to engage her in conversation proved ineffective. She began once again to complain of pain. The nurses were quick to notice, however, that her discomfort eased when someone would sit with her or when she was given an extended massage. At the same time her demands to die returned. Reassurances from caregivers that they did not have the power to give death, even if the technical means to do so did exist, seemed only to increase her frustration and rage.

Reflecting on her encounter with Dominique, de Hennezel suggests that the clenched fists and crying out that are characteristic of persons feeling such rage can be mistaken as signs of pain. In fact, they are often expressions of revolt and signal the need to release anger.

“I want to die,” she [Dominique] says. “Look at what I’ve become.”

She tells me about the steps of her calvary, her double mastectomy, the loss of her identity as a woman. She has no further interest in life. The picture is very black, very despairing. I listen with absolute attention. I am there for her, quite simply. Whenever the emotion intensifies, Dominique squeezes my hand. I do the same; our hands have their own conversation...

“Are you sure?” I ask. “That you have finished living?”

She seems surprised by my question. “Finished living?” I sense that she’s deep in thought, perplexed. “What do you mean by that?” she asks finally.

“Is there anything tethering you to life, keeping you here?”

I can feel that she’s getting more and more intrigued.

“There’s no one to keep me here anymore, no, but there are so many things still unsettled,” she says wearily.

There, I feel the fish bite the hook. So there’s something unfinished in the air. “Do you want to tell me about it? It might help.”<sup>13</sup>

For the next hour, Dominique poured out the story of her life, reassembling it piece and by piece and confiding her inmost suffering. Meeting with the palliative care team the next day, de Hennezel described for them her impression that Dominique’s cries and complaints were a cover for deep anger, not just against life but also against herself. Dominique carried many things within herself that needed to be settled, and her desire to put an end to life was all part of this. During the team meeting one of the nurses reported that since Dominique’s meeting with de Hennezel everything was peaceful and there was no talk of wanting to die.

*I desire to be delivered from earth and to become earth again. For death is better than life. I have been reviled without a cause and I am distressed beyond measure.*

*Lord, I wait for the sentence you will give to deliver me from this affliction.*

*Let me go away to my everlasting home...*

—Tobit 3:6

The process of dying attacks a person's physical integrity. The physical disintegration that takes place can turn people into strangers in the eyes of loved ones, especially when it is compounded by the ravages of surgery and treatment. Such torments give rise to sorrowful questioning in persons who are dying: "How long will this go on?" "Look at what is happening to me. Could anyone still love me?" "Would it not be better if I were dead?"

Persons who are dying need to be able to express their longing for death. Having someone with whom they can share this emotion, and the feeling that their desire has been acknowledged, can be a source of comfort and peace. In writing about this, de Hennezel is very clear that acknowledging this desire to die does not imply agreement to carry it out. The person needs to state what he or she longs for, and to be heard. "Being heard" does not mean "being obeyed."

Our society has begun to look on assisted suicide as the solution to suffering at the end of life. The story of Dominique, and the many people like her who enter into their suffering and their longing for death and through it come to peace and tranquility, suggests that legalizing assisted suicide is not the answer in responding to suffering.

Pain and other symptoms causing physical distress can be alleviated, even when they are severe. The personal suffering experienced over the loss of meaning and from the sense of impending disintegration can also be addressed. While it may not be easy, it can be done by responding with love and attentiveness to each person, one person at a time. Decoding what such requests for death are concealing can help to discover the key to unlocking the source of distress.



## PART TWO: THE IMMENSITY OF LIFE

### Accepting Our Losses

**F**or someone undergoing courses of chemotherapy the complete loss of their hair can be a traumatic experience. Most of us think of our hair as expressing something of who we are. Losing it feels like the loss of that part of our identity.

The various losses confronted throughout life tend not to adequately prepare people for the multitude of losses that are experienced in the months and weeks that precede the moment of death. In a relatively short span of time people must face the loss of all the things and all the people they love. The transition from being able to disabled, for example, is a difficult one. In our society, our work defines and shapes who we are. The loss of our ability to contribute and to create puts into question our sense of purpose and meaning in life. Illness and the deterioration associated with dying bring us to a deep knowledge of our fragility and dependence.

Life is a movement from dependence to dependence. As children we depend on parents, family and teachers. Through their care and love we grow towards greater independence. As we approach the end of life our need to be cared for by others returns and we become increasingly dependent once again.

The challenge of accepting our weakness and dependence on others is sensitively expressed in the life and writings of Jean Vanier, founder

of L'Arche, an international network of Christian communities that provide homes where people with and without disabilities choose to live and work together.

We live in a world where everyone wants to appear like this or that: to seem strong, intelligent, powerful, up and coming...

Each one of us finds it enormously difficult to accept himself as he is, with that extraordinary mixture of weakness and strength, ignorance and wisdom, light and darkness, love and hate. In fact, we flee from something that I'd call our vulnerability, our immense fragility.<sup>14</sup>

Dying brings us face to face with our vulnerability. We all die poor. In the final moments of life no amount of money or power can keep us from dying. To experience such vulnerability means becoming child-like. A child is not afraid of dependence nor of the longing to be loved and to love. Perhaps that is why, at the end of life, the simplest gesture — a word, a smile, a touch — can have such an overwhelming effect in the life of a dying person.

Becoming child-like is at the heart of the Christian message. God became flesh, taking on the defenseless and vulnerable state of a little child. The mystery of God becoming man can enable us to drop our defenses and barriers.

Then we can perhaps discover the extraordinary wisdom given to us by the Word made flesh, the Word who made himself a little child, who took on our human flesh, who took up our weakness. This is the great wisdom of Jesus Christ: "Don't be afraid of your weakness, don't be afraid! For it's at the heart of your frailty that you will discover the presence of God."<sup>15</sup>

*Unless you change and  
become like little children  
you will never enter the  
kingdom of heaven.*

— Matthew 18:3

*Jesus shared in our life  
"so that by his death...  
he could set free all those  
who had been held in  
slavery all their lives  
by the fear of death."*

—Hebrews 2:14-15

God's presence in the midst of loss and death is precisely the hope that Christians find in Christ. The core of the Christian faith is a man dying in pain and anguish after seeing his life crash around him in failure and in shame. At that moment Jesus shared with all people the painful realization of vulnerability and powerlessness. In and through Jesus God wanted to share not only our life, but our death.

Death for us is primarily a separation. It represents the loss of precious relationships and of our very selves. The Christian faith holds that Jesus died for us so that death no longer need be just separation. His death opened the possibility for our deaths to become a way to union and communion with all humanity and with God.

Becoming a child was God's way of sharing in our life. Transforming death was God's way of enabling us to share in God's life.

Teilhard de Chardin has written eloquently about the losses that mark our lives and the forces of diminishment that carry us from activity to dependence, from doing to being done-to, and ultimately from life to death. It is Christ, he says, who has transformed this universal power of diminishment and extinction into a life-giving factor.

God must, in some way or other, make room for himself, hollowing us out and emptying us, if he is finally to penetrate into us... The function of death is to provide the necessary entrance into our inmost selves.<sup>16</sup>



## Attending to Unfinished Business

*So many hearts I find,  
hearts like yours and mine,  
torn by what we've done  
and can't undo.*

— Leonard Cohen  
*The Song of Bernadette*

For virtually every one of us there will be unfinished business to attend to at the end of life — unresolved conflicts, broken relationships that have gone unhealed, or promises that have not been kept. Regret over such unfinished business can be one of the burdens people carry at the end of life.

In working with people who have experienced major losses in life, Jean Monbourquette has often encountered such feelings of regret. He encourages people to recognize that in entering into their grief, more often than not, they will be assailed by such unexpected feelings as fear, guilt, shame or sadness.

By nature, emotions are transitory and temporary. If you find that you are clinging to one in particular, it may be that an underlying emotion is not able to surface. A lasting feeling of anger is often the result of a deeply repressed psychological wound. A permanent attitude of sadness may feed on an unconscious rage... An uncontrollable fear may stem from an undercurrent of pain and rebellion. Feelings of guilt and shame often result from self-hatred and anger.<sup>17</sup>

Feelings of disappointment and guilt associated with the awareness of having unfinished business to attend to can have the effect of tethering a person to life. In *Beyond the Mirror: Reflections on Death and Life*, Henri Nouwen shares his personal story of a near lethal accident that brought him to a new understanding of the impact of such feelings in his life. Nouwen recounts the events that followed his being hit by a vehicle and describes his state of mind as he felt himself entering a shadowy land between life and death. He says he felt God's presence

in a very tangible way. It was like a homecoming in which he was enfolded in love. Yet, in the midst of these feelings of warmth and love, he became aware of a resistance within himself to this invitation to come home.

What most prevented me from dying was the sense of unfinished business, unresolved conflicts with people with whom I lived or had lived. The pain of forgiveness withheld, by me and from me, kept me clinging to my wounded existence....

In the face of death, I realized that it was not love that kept me clinging to life but unresolved anger.<sup>18</sup>

Addressing such unresolved conflicts does not necessarily mean undertaking great or heroic gestures. Writing even a brief letter to someone from whom one has been estranged can be the source of much needed peace. Having the opportunity to share unspoken or unresolved conflicts with another person can bring relief and comfort. At such times, the healing of past wounds can come from such simple realities as a touch or an embrace. Rituals of healing and of farewell are also valuable ways of bringing completion to such struggles.

In the Catholic Church the celebration of the Sacrament of the Sick recognizes that times of serious illness are also times of deep anxiety. In anointing with oil the person who is sick and in the laying on of hands the community prays that the person will be given God's grace in the face of illness and suffering. The ritual also provides the opportunity to acknowledge the need for reconciliation and to receive God's forgiveness.

A progressive illness can provide important opportunities to get one's affairs in order and to resolve and complete relationships. Doing so appears to be central to the experience of a peaceful death.

*Father in heaven,  
through this holy anointing  
grant our sister comfort in  
her suffering.  
When she is afraid,  
give her courage,  
when afflicted,  
give her patience,  
when dejected, afford her hope,  
and when alone,  
assure her of the support  
of your holy people.*

—Pastoral Care of the Sick:  
*Rites of Anointing and Viaticum*

## Forgiving at the End of Life

The previous chapter, which dealt with unresolved conflicts at the end of life, highlighted how strongly those who are dying can experience the desire to forgive and to be forgiven. The struggle people experience in dying is most often not a matter of leaving loved ones. The real struggle may have more to do with our leaving behind people whom we have not forgiven and people who have not forgiven us.

Norman Cousins, author of *Anatomy of an Illness*, profoundly influenced the interest in mind-body medicine that has developed over the last twenty years. Central to his experience was the discovery of the importance of mobilizing the natural resources of the body and mind to combat illness. In his writing he emphasized the liberating role and healing impact of forgiveness.

I have learned that life is an adventure in forgiveness. Nothing clutters the soul more than remorse, resentment, recrimination. Negative feelings occupy a fearsome amount of space in the mind, blocking our perceptions, our prospects, our pleasures. Forgiveness is a gift we need to give not only to others but to ourselves, freeing us from self-punishment and enabling us to see a wider horizon in life than is possible under circumstances of guilt or grudge.<sup>19</sup>

*What forgiveness does do is free us from the desire to exact payment.*

— Lewis Smedes  
*The Art of Forgiveness*

At the end of life the need for forgiveness is like an open wound waiting to be healed. People want to die whole and free of the burden of judgements that most of us carry. Brothers and sisters who have not spoken to each other for years can become friends again as one of them is faced with death. Persons who have suffered long and silently

with guilt find the courage to ask forgiveness, and in doing so experience liberation and healing. The realization that the time remaining is limited, and that one has a choice to leave life dominated by hatred and revenge or not, can allow for significant transformations to occur.

When we have suffered the deep hurts of abandonment, neglect, betrayal or violence we cannot simply erase the event from our history or from our minds. Forgiving does not mean forgetting the offense or pretending that it never happened. To forgive means choosing to free ourselves from vengeance and resentment. To forgive at the end of life is to refuse to carry rage and hatred against another person into death.

In her best-selling book *Blessings*, Mary Craig tells the story of her friendship with a Polish man named Stefan who was a survivor of the concentration camp at Auschwitz. He lived for many years after being freed, but gradually his health gave out. Before dying he wrote to Craig.

“I worry most of all,” said the letter, “about the children. What will they become?” Having written those words, he must have stopped to reflect on what he had written, for he crossed out the last sentence and wrote: “No, I must not worry about them. They are in God’s hands, and there is only one important thing for them. I hope they will learn to have compassion for others.”<sup>20</sup>

Craig describes how Stefan and his wife had suffered cruelly at the hands of men and women who did not show compassion. They carried the physical scars and afflictions of those cruelties to their deaths. And yet, at the end of life Stefan showed he had not allowed resentment or a desire for revenge to have the last word. He had learned it is compassion and forgiveness that keep humanity alive. It was this awareness of the importance of compassion, above all else, that he

*Then Peter went up to him  
and said,  
“Lord, how often must I  
forgive my brother if he  
wrongs me? As often as  
seven times?”  
Jesus answered “Not seven,  
I tell you, but seventy-seven  
times.”*

— Matthew 18:21-22

hoped his children would learn.

In the Christian vision, repentance and forgiveness are central to the wholeness (holiness) to which we are all called. Throughout our life, this means admitting mistakes and starting again. In Christianity sin is not punished. The scriptures and the words of Jesus reveal God’s desire to forgive and readiness to forgive again and again. Jesus reveals a God who waits for our return without resentment or a desire for revenge.

When we accept that we have weaknesses and flaws, that we have sinned against our brothers and sisters, but that we are forgiven, then we can grow to greater inner freedom and truer love. We can begin to accept the weakness and flaws of others. A forgiven person forgives. Forgiveness destroys the barriers that separate us and opens us to others.

At the end of life it may not be possible to deal directly with the person we may need to forgive, or from whom we need forgiveness. How do we seek forgiveness with or from someone who is no longer alive? As Stephen Levine points out, forgiving means freeing oneself.

Indeed, this finishing of old business once again reminds one that when two people are pulling on either end of a rope, it takes only one to let go of his end to release all of the tension between them.<sup>21</sup>

## Accepting Our Need for Others



## Accepting Our Need for Others

**I**llness and dying can break down the walls created by the self-reliance and independence that characterize most of our lives. Jean Vanier suggests that much of the hyper-activity in our world comes from the avoidance of relationships. We're afraid of encountering people, of striking up friendships with them, of feeling responsible for them and of opening up to our need for each other.

For people who are dying the need for success and prestige and concern over what others think of them cease to be the driving forces in life. The losses and suffering associated with dying can deepen their awareness of their need for others and their capacity for loving. In acknowledging their vulnerability people are often surprised by the generosity of others.

Fear about becoming a burden to loved ones is one of the greatest sufferings people experience in dying. People dread becoming dependent on caregivers and making them feel responsible for financial matters, household chores, as well as their physical needs. Caring for a person who is dying is demanding. In addition to caring for their own needs, family members may have to provide constant attention to the physical comfort of a loved one. Sitting with the dying person for hours and days to provide reassurance can also result in great fatigue.

Although caregivers may experience the demands as being overwhelming at times, many of them describe this time of caring for a loved one as a "sacred responsibility"<sup>22</sup> and a unique opportunity to express their devotion and reverence for the person they love. By

accepting their need for others and receiving openly their love and care, persons who are dying can help ease the pain and grief of the family.

*Just as a human body,  
though it is made up of many  
parts, is a single unit  
because all these parts,  
though many, make one body,  
so it is with Christ.*

*If one part is hurt, all  
parts are hurt with it.*

— 1 Corinthians 12:12,26

In his reflections on dying, Nouwen says the great hidden gift in our dying is the discovery of our unity with all people. He was convinced the joy that comes in discovering our sameness with others and our belonging to one human family is what allows us to die well. Instead of separating us from others, death can unite us with others.

Pilgrimage is a notion that is familiar to many Catholics. It involves leaving home, leaving what is familiar, and journeying with others to some prayerful site where we can bring our sufferings — be they physical, spiritual or emotional. Throughout the world various sites have become traditional locations for such pilgrimages, for example, Lourdes in France, Fatima in Portugal, and Sainte-Anne-de-Beaupré in Canada.

While the hope of a miracle is partly what draws people, it is a different kind of healing that is more likely to occur. Where the sick and maimed come together in crowds to proclaim their hope and their faith, or even just to acknowledge their fears, it is no longer possible to believe that one is alone, that one's suffering is unique. Those who are sick and suffering discover a solidarity with all those who are wounded.

This healing power [the experience of human solidarity] helps us not only to live our illness well, but also to die well. Indeed, we can be healed from our fear of death, not by a miraculous event that prevents us from dying, but by the healing experience of being a brother or sister of all humans — past, present, and future — who share with us the fragility of our existence. In this experience, we can taste the joy of being human and foretaste our communion with all people.<sup>23</sup>

## Sharing Our Story

Sharing their story gives people a sense of completion and peace in their final days. To tell the story of one's life a person must first give some shape to that life. For one person that might mean coming to see in life a beginning, middle and end. For another, a particular image may enable them to express the essence of the life they have lived. Whatever way it is done, once the telling has been accomplished the person seems to be able to let go and to die.

Those who work with persons who are dying tell us that in the time leading up to death many people also feel the need to pass on the things they love to the people they love. Leaving something meaningful with others is a way of saying "Remember me!"

During the time that I was writing this book my mother was living with terminal cancer. One Saturday morning I spent several hours with her cleaning out a closet in which had accumulated books, photos and other articles that she had collected over a lifetime. Not having the energy to help, she lay on her bed as I withdrew one item at a time and placed it beside her. In deciding what to do with each piece she would sometimes pause to tell me where the object came from, why she had kept it, and what it had meant to her. In letting go and passing on these things that were important to her she shared with me key moments in the story of her life.

On the night before he died Jesus passed on to his friends those things that were most important to him. In breaking bread and sharing a cup of wine he left with them the essence of who he was. It was his way of saying "This is what my life has been about. When you do this, remember me."

*We fear death, we shudder at  
life's instability, we grieve to  
see the flowers wilt again and  
again, and the leaves fall,  
and in our hearts we know  
that we too, are transitory and  
will soon disappear.  
When artists create pictures  
and thinkers search for laws  
and formulate thoughts, it is  
in order to salvage something  
from the great dance of death,  
to make something that lasts  
longer than we do.*

—Herman Hesse  
*Narcissus and Goldmund*



## Finding Dignity Amid Diminishment

One of the greatest sufferings experienced by terminally ill people is the feeling that they have lost their dignity. The loss of the ability to work and to fulfill roles as parent, spouse or community member can erode a person's sense of worth. Thoughts of not being able to care for one's basic needs, of relying on others to bathe or to evacuate one's bowels or bladder, of gradually becoming totally dependent, or of suffering dementia, cause people to wonder how dignity can be retained in dying.

Ira Byock describes how society reinforces the belief that the loss of normal capability and independence renders a person undignified.

Our society reserves its highest accolades for youth, vigor, and self-control and accords them dignity, while their absence is thought to be undignified. The physical signs of disease and advanced age are considered personally degrading, and the body's deterioration, rather than being regarded as an unavoidable human process, becomes the source of embarrassment.<sup>24</sup>

The stories of people who care for the dying challenge this belief. At first, many people do feel agitated and distressed in response to becoming helpless and dependent. They may believe they have become hideous or untouchable, that they "smell of death." When assisted by family and care providers who express love and patience, people who are dying and who feel they have lost their dignity do find ways to reclaim it. Many do come to accept dependency and the care they need with grace and dignity.

*What is REAL? asked the Rabbit one day, when they were lying side by side near the nursery fender,....*

*Generally, by the time you are Real, most of your hair has been loved off, and your eyes drop out and you get loose in the joints and very shabby. But these things don't matter at all, because once you are Real you can't be ugly, except to people who don't understand.*

— Margery Williams  
*The Velveteen Rabbit*

I have a good friend (I'll call him Robert) who is now forty-one years of age. For twenty years he has suffered from a degenerative disease that has gradually robbed him of his physical abilities and his capacity to care for himself. Eventually it will rob him of his life.

Robert is now almost completely blind. He is no longer able to walk, and, while he is able to sit in a wheelchair, he has lost almost all ability to move any part of his upper or lower body. In such a state he is completely dependent on others to feed, wash or move him. Several years ago he lost the relative independence he had enjoyed living with his parents when it became necessary for him to move into a long-term care facility. There, he has shared a small room with a series of elderly men, all of whom suffered various degrees of dementia before dying.

There probably was a time when the personal losses he has endured caused him to feel as though he had lost his dignity. Yet those who meet him are always surprised by his sense of humour and enthusiasm for life. I once asked him how he was able to keep up his spirits in the face of such losses. His answer was a simple one: "You accept the hand that life deals you and make the best of it." And that is what he has done. The awareness of his own dignity has led him to become an outspoken advocate for the dignity of those around him who are dying.

Among the cultural changes that are required if we are to integrate death into life is the need to put an end to the assumption that dying necessarily dehumanizes a person. As a person's physical condition deteriorates we tend to equate the loss of physical capability with a lack of emotional and mental capabilities. In doing so we treat the dying as less than living.

Dying is, in fact, a humanizing process that has the power to transform everyone involved. The dignity of persons needs to be recognized in the personal growth that can occur while people are dying. Even when illness leaves people helpless, they can still feel valued and worthwhile. The final phase of a person's life should be a time of satisfaction marked by feelings of self-worth and self-esteem.

Respect for the dignity of persons is a core value in the Christian ministry of caring for the sick and dying. In the Christian perspective people are inherently dignified — the human person has a dignity that cannot be lost or taken away. The commitment to care for another person in their dying is an expression of respect for their dignity as a child of God.



## PART THREE: TRANSFORMATION

## Fruitfulness in Dying

**A**mong the transformations that sometimes occur in the lives of persons who are dying is the discovery of a fruitfulness in what at first seemed only a dark and foreboding reality. For growing children each developmental achievement tends to be accompanied by feelings of mastery, a sense of ability and wellness, and, at times, even exhilaration (learning to ride a bike provides a good example). Ira Byock says the same feelings are expressed by people who may be said to have “died well.”

Often the challenge for a family, loved ones, and other caregivers is to recognize the opportunities for growth and development and to help the dying person achieve them.<sup>25</sup>

Marie de Hennezel provides a good example of this kind of development in her account of the changes that occurred in a patient named Marie-France who entered the palliative care unit with a great fear of any stranger getting close. Distress over her physical decay had caused Marie-France to retreat from everyone, leaving her isolated and longing for death.

As the people around her responded with affection and loving tenderness, not calling attention to her physical collapse, Marie-France gradually overcame her struggle with her physical deterioration.

*Some have told me they looked their whole life to find a teacher or a teaching that would bring them into some deeper wholeness and that at last it turned out to be their illness... For many, disease is the way back into life.*

—Steven Levine  
*Who Dies?*

*It did not matter what we expected of life but rather we had to ask ourselves what life expected of us.*

— Victor Frankl

On my way out, I see that Marie-France's door is open. She is alone, sitting in her armchair...

"I'm happy I came here before I die. I found goodness here. I didn't believe in it anymore. But you know the most extraordinary thing," she continues in the slightly lecturing way she always has when she talks to us,... "it's that I also feel the longing to be good. I'm not worth anything anymore. I want more than anything to die as soon as possible, and strange ideas keep coming up in me. For example, I tell myself I could offer up my death, and this long, painful preamble, for someone else's benefit."

"And are you thinking of anyone in particular?"

"Yes, my little autistic cousin. It's odd... I don't believe in God, but I tell myself that there's some kind of invisible solidarity. I would like to help him. I would like all this to have a point, all this suffering not go to waste."<sup>26</sup>

Final acceptance of one's dying often brings a peace with it which the person has never experienced before. The inner turmoil and outer unrest that are common during the dying process give way to a life-giving solitude. This sense of inner peace and harmony can have a profound effect on others, healing severed relationships, bringing together separated family members, and forging stronger family identities. In this way people make their dying a gift for others.

Those who care for persons who are dying are conscious of how much they receive from those who are dying. At the very end of life, when people may have lost their ability to relate or to express themselves, and may be able to offer only a smile, a touch, or their dignity in allowing themselves to be cared for, they teach us the meaning of simplicity and humanity. It is from the dying that we learn how to care and how to be human. Their lives continue to be fruitful.

*The life and death  
of each of us has  
its influence on others.*

Romans 14:7

*Before Dawn*

*As my father lay dying  
he opened his eyes  
and said to my mother  
"your face... like the moon"*

*deep in the night  
in that hospital room  
the cool light shone  
and I saw for the first time  
how it had been between them*

— Marianne Bluger  
in *Summer Grass*

In the Christian perspective life is a long journey of preparation — of preparing oneself to truly die for others. From childhood through to old age we are presented with new opportunities to live either for ourselves or to live for others. Henri Nouwen speaks about these choices as a life-long process of dying to self, so that we will be able to live in the joy of God and give our lives completely to others.

At the end of his life Jesus spoke to his closest friends of his approaching death. He told them that he was going to the one who sent him and that it was for their own good that he was going, because in going he would send the Spirit to be with them (John 16:4-7). Although he acknowledged that his death would bring sorrow, he always proclaimed his death as something full of blessing and hope. In fact, the fruitfulness of his life was only realized after his death.

Not only the death of Jesus, but our death too, is meant to bear fruit in other people's lives. The way in which we die will affect many people. If a person dies with much bitterness and anger, family and friends are left behind in confusion, guilt or weakness. Becoming defenseless and vulnerable, and accepting the love and care of family and friends, can be a final gift from the dying person. Through such acceptance he or she can help to ease the pain and grief of loved ones in a way that no one else can.

No matter how frail, incapacitated or disoriented a dying person may become, he or she still has something to give. The terminally ill bring to those who are well a profound experience of God. In this way they do us a service that may be even more valuable than the achievements and contributions made earlier in their lives, while they were still capable and strong. The death of each person is a reminder that each of us has infinite worth.

## Healing in Dying

**W**hat is healing? Is it possible to talk about healing in dying? In our time we are witnessing the recovery of a more holistic vision of the person and of health. Health is no longer understood merely as the absence of illness. Greater consideration is being given to the person as an integrated whole and to a perspective on health that recognizes the many factors that determine health.

This holistic vision recognizes we are comprised of biological, psychological and spiritual energies. If a harmonious balance exists between these various energies, then we are said to be in good health.

Such an integrated vision of the person also makes an important distinction between healing and curing. Curing focuses on reducing or eliminating the physical symptoms of sickness. But to focus on curing alone represents a failure to understand the true nature of the whole human being. In treating the disease we cannot neglect the human being who is sick. Healing has to do with wholeness. It is concerned with restoring our bonds with the deepest parts of ourselves and experiencing harmony.

When curing the body seems impossible, as in the case of a terminal illness, can we still hope to achieve healing and wholeness? In *Healing into Life and Death*, Stephen Levine suggests we have tended to think of healing as something opposed to dying, and in doing so have separated life from death. Healing is directly related to the process of letting life in. Levine believes the optimum preparation for death is a wholehearted opening to life in all of its twists and turns,

and that such a preparation for death can allow deeper healings to occur.

Confronting death pushes us not to be content with living life on the surface. It challenges us to enter into the heart and depth of things. It sends us back to the real questions in life. Perhaps this is why some people find that, despite their slow physical disintegration and the inevitability of death, in their dying they experience a sense of wholeness they have never known before.

If healing was as it seemed, the harmonizing of the disquieted, a balancing of the energies to bring about peace where before there had been war, then healing clearly was not limited to the body, or even to the visible. It includes the possibility of quieting even the deepest, unseen wounds -- the discomforts which make death seem a respite.<sup>27</sup>

Love is the optimum condition for healing. For some people the period just before death allows for significant healing precisely because their vulnerability and dependence on others open them to the experience of knowing they are fully accepted and loved as human beings. Drawing on the resulting sense of security and wholeness they can dare to be themselves in all their gentleness and love. It is this kind of healing that enables people to give themselves into the arms of death.

Health, healing and wholeness are at the heart of the Christian message. For example, the Hebrew word *yeshe* which is most often translated as "salvation" also expresses a broad, holistic concept which may more properly be translated as "health." The gospel accounts of Jesus' healing ministry, which constitute almost one fifth of the whole texts, express God's desire for our wholeness and healing.

*Believing our lives come to fulfillment in dependence requires a tremendous leap of faith.*

— Henri Nouwen  
*Our Greatest Gift*

*For I am certain of this: neither death nor life, no angel, no prince, nothing that exists, nothing still to come, not any power, or height or depth, nor any created thing, can ever come between us and the love of God made visible in Christ Jesus our Lord.*

— Romans 8:38-39

Healing in dying is related to embracing a new dependence. That's the mystery God has revealed through Jesus. He came as a child, totally dependent on others, and he died as a passive victim to the actions and decisions of other people. His dependence on God, which guided and sustained him throughout life, transformed his death into a new birth. Our dying involves a similar pattern of dependence, one which offers the opportunity to experience more deeply our identity as children of God.

Henri Nouwen was fond of noting that there is a paradox here. "Dependence on people often leads to slavery, but dependence on God leads to freedom." Once we come to the deep inner knowledge that we are being carried forward in love and that we will die into love, all forms of evil, illness and death lose their power over us. The acknowledgement of our fundamental humanity is a salve for our deepest wounds.

The greatest single source of health and healing in the life of any person flows from knowing oneself to be accepted and loved by the very Ground of all Being. To feel at home in the universe, to have a sense of meaning and destiny for one's life — these all bring and foster wholeness of mind, body and spirit. All these are the very things the Bible is about when you look to the core.<sup>28</sup>

## Letting Go

“**K**ee on fighting. Don’t give up.” Many people who are dying hear this type of encouragement from friends and family members. Such comments are intended to provide support and hope. And yet, at a certain point in the life of the dying person, they give rise to a dilemma.

Persons who are dying are most certainly alive. Even when sickness and suffering dominate and death is close, there is still room for joy and surges of deep feeling. The beauty of a sunset, the calming presence of a loved one, the comfort of a tender kiss — all these things can be the source of intense feeling. Still, the dilemma remains — “How long do I struggle? When do I let go?”

Some people, in realizing they have a short time to live, set about to complete certain tasks in the time remaining to them. They may even set a date as to when they intend to complete this work. It might be the birth of a grandchild, the marriage of a son or daughter, or some other celebration. Once the date has been reached, he or she surrenders gently to death. Letting go is all that is left.

Writing about her work with the dying, Marie de Hennezel describes a particular kind of unconsciousness or waking coma that most people fall into shortly before death. A person can still respond to the sound of their name or to a touch, but it is as though all remaining energy is being absorbed in a work that is taking place in the depths of the person. It is a signal of an impending departure.

*To trust  
is sometimes  
to surrender.*

— Victor Hugo  
*Les Misérables*

My own experience has taught me that these plunging dives into unconsciousness that characterize the approach of death often produce an outcome of well-being, of transformation, as if some spiritual exercise were working itself out deep in the soul.<sup>29</sup>

Dying may take a long time. For caregivers too, there are endless hours, long days and longer nights. In the last interval before death, during this time of a waking coma, no conversation is possible. Family members and friends can only watch quietly and patiently. The dying person may come out of their deep sleep. He or she may smile, make an unexpected movement, or offer some brief parting words — and then they are gone. The final moments often come quickly and unexpectedly.

It can be painful to witness the physical changes — the emaciation, the distorted features — that occur in the face of a loved one on the threshold of death. But at the moment of death another change may be visible. It seems an almost universal occurrence that people will remark about the peaceful expression that befalls a person in the moments after their death. It is as though the beauty of the person has returned. The face no longer carries the marks of long suffering. Many people are amazed by the atmosphere of peace that settles over those gathered around the person who has died. This may explain why some cultures believe the soul remains for a time near the body.

The concept of surrender — of letting go and giving up control — is central to Christian thinking. Surrendering to God's will is part of the daily life of all Christians. Surrendering to God's will in our dying is a statement of faith in which we say we can trust God with our destiny, even in death.

In the distress Jesus experienced in the Garden of Gethsemane, the

*I have been at the bedside of many dying people, and I have seen over and over again that, ultimately, this faith — which means acceptance of God's will — is all that matters. Without it, death is a terrifying nightmare; with it, one is mysteriously armed to meet the last moments willingly, and with joy.*

— Johann Christoph Arnold  
*I Tell You a Mystery*

night before his death, he revealed his honest desire to keep on living, yet he surrendered to God's will: "Nevertheless, let your will be done, not mine" (Luke 22:43). In the gospel accounts Jesus emerges as convinced that his death is God's will, but even more, that he can trust his life and death to God.

*The time has come for me  
to be gone. I have fought  
the good fight to the end;  
I have run the race to the  
finish; I have kept the faith...*

— 2 Timothy 4:7-8

Such surrender is not easy. It means relinquishing our desire to plan for the future and to know what lies ahead. It goes against all our natural tendencies, but with God's help we can learn to pray as Jesus did: "Father, into your hands I commit my spirit" (Luke 23:46).



## A Life is Over

*The moment of death is often a moment of great quietude and peace.*

— Stephen Levine  
*Who Dies?*

*What happens after death is so unspeakably glorious that our imaginations and our feelings do not suffice to form even an approximate conception of it.*

— Carl Jung

It is now a common practice in palliative care to allow for the bodies of patients to remain in their rooms after death for a more prolonged period than was the case in the past.

This gives the family time to gather in the place where so much was lived during the final days of a loved one's life, where final gestures of affection and goodbyes took place. It is a time of respect and reverence.

The rituals of washing and laying out the corpse provide an opportunity to pay tribute one last time. The caring efforts of nurses and aides to make the person look as good as possible can ease the anguish of the next of kin. After what may have been a long ordeal, they can find comfort in seeing the face of a loved one who has passed through suffering and reached peace again.

In *Intimate Death*, de Hennezel provides a moving description of the atmosphere of tenderness that envelops people in the presence of the body.

Patricia died this morning, after three days in a coma.... This afternoon, the team gathers and we stand around Patricia's body... Patricia's daughter asks me shyly to sing the "Ave Maria" that I sang at Patricia's bedside a few days before she died.

It's that memory that gives me the strength to start the song now, in front of the whole team, although there is a lump in my throat. A nurse starts to cry, and another puts an arm around her. There is a great deal of tenderness in the room, the shared emotion that passed day by day between Patricia and those who took care of her, and between Patricia and her family; it moves you in your bones.<sup>30</sup>

*After this, Joseph of Arimathaea ... asked Pilate to let him remove the body of Jesus. Pilate gave permission, so they took it away.*

*They took the body of Jesus and wrapped it with the spices in linen cloths, following the Jewish burial custom.*

— John: 19:38-42

*But the angel spoke...  
"There is no need for you to be afraid. I know you are looking for Jesus, who was crucified. He is not here, for he has risen, as he said he would..."*

— Matthew 28:6

The rituals surrounding death, different in every culture, are expressions of the dignity and value of persons. At the same time, they say something to the living — they verify the dignity and importance of living in the face of death. Every death brings a message for the living.

The time between death and burial is meant to provide an opportunity to console those who have lost a loved one. Gathering at the home where the bereaved family lives or visiting the family at the funeral parlor is not intended for the dead but for the living. The sympathy of friends and their physical presence provides much needed human warmth and kindness.

It warrants repeating that in our society death tends not to be faced. In fact, a great deal of energy is devoted to obscuring death's reality. Efforts to cosmeticize the body often seem designed to defy death. Very often every attempt is made to dispose of the body and to dismiss death as quickly as possible.

A Christian funeral or memorial service is not a time of denial. It involves a reaffirmation of Christian hope and an effort to take seriously humankind's needs in the midst of suffering. The service affirms the dignity and uniqueness of the person who has died. The homily provides an opportunity to demonstrate how God has been present in the life of the person. The funeral services also affirms the social nature of human beings. It enables the faith community to express support and comfort to those who mourn.

Through the funeral rites the community celebrates the Easter victory of Christ — his death and rising to new life. It reminds all who are gathered that in baptism we have become one with Christ and that we will pass with him through death into life.



## PART FOUR: CARING FOR PERSONS WHO ARE DYING

## Caring

Caring is at the heart of what it is to be human. Caring does not belong primarily to professionals, nor is it the response of an exceptional group of individuals. In *Caring from the Heart*, Simone Roach, C.S.M., writes, “Caring is, as it were, the call to be human. One cares in a variety of ways; that we care is what we share as human beings.”<sup>31</sup> The reaching out of one wounded human being to another is what nurtures and sustains humanity. Integrating death into life and caring for persons who are dying are essential to what it is that keeps humanity alive.

*Care, as I speak of it here, is the loving attention given to another person — not because that person needs it to stay alive, not because that person or some insurance company is paying for it, not because care provides jobs, not because the law forbids our hastening death, and not because that person can be used for medical research, but because that person is a child of God, just as we are.*

— Henri Nouwen  
*Our Greatest Gift*

Among the greatest challenges of caring for persons who are dying is dealing with the inevitable feelings of vulnerability and powerlessness. At the bedside of the dying person, many people feel extreme discomfort in not being able to do anything. It is difficult to believe that accepting our powerlessness and simply being present to the dying person is enough.

But, as important as technology and pharmacology are in responding to sickness at the end of life, what matters more is the quality of the care and presence persons receive as their bodies deteriorate piece by piece. It is then, as they undergo the great struggle of surrendering life completely, that people need the reassurance that comes from knowing they are not alone.

There are many ways that such reassurance can be provided: through words and prayers; through affection and gentle touch; through such basic acts as cleaning a person or offering a drink of water; and in the simple act of being present.

Henri Nouwen notes that dying people often experience their powerlessness as rejection and abandonment. That is because we often distance ourselves from those who are dying and treat them as fearful strangers, usually because they remind us of our own mortality. The fear of rejection, he says, is the deepest fear experienced by the dying person.

*Tell them not to be afraid of the dying. It is very simple. The dying need tender loving, nothing more.*

— Mother Teresa

Caring for others is, first of all, helping them to overcome that enormous temptation of self-rejection. Whether we are rich or poor, famous or unknown, disabled or fully abled, we all share the fear of being left alone and abandoned, a fear that remains hidden under the surface of our self-composure. It is rooted much more deeply than in the possibility of not being liked or loved by people. Its deepest root lies in the possibility of not being loved at all, of not belonging to anything that lasts, of being swallowed up by a dark nothingness — yes, of being abandoned by God.<sup>32</sup>

Caring for a dying person is an action that says clearly, “We are here with you and we will accompany you to the very end.”

## Notes for Caregivers

We shouldn't try to care by ourselves. On our own, we can quickly take on the anguish of the dying person. We can become overwhelmed by feelings of helplessness and powerlessness. Whenever possible, caring should be done with others. One of the great benefits of palliative care is the strength caregivers find working as a member of a team in responding to the needs of dying persons.



Caregivers — family members and professional care providers — often lack support. The emotional demands of caring for the dying take their toll on all concerned. The best care is provided by those who can support one another and share the weight of grief.



Creating an atmosphere of warmth and serenity around a person who is suffering emotional anguish is one of the most beneficial things we can do for them. Creating such an atmosphere can sometimes be more effective than tranquilizers or anxiety-reducing drugs.



Today, care providers do not always have as much time to spend with patients as they would like. It can be reassuring to know that a word, a smile, a touch, or just sitting for a few minutes and allowing the dying person to say what it is he or she is feeling, are important acts of generosity.

Such moments as giving a bath or helping someone to drink provide caregivers with the opportunity to offer affection and tenderness and to affirm a person's dignity. There is a way to take care of the body of a dying person so that we forget the physical disintegration that is occurring. This happens when people care for the whole person. The way we look at or touch a dying person can leave the person feeling they are nothing more than an object to be discarded, or it can reinforce his or her belief in the indestructible nature of their soul.



A person who is dying needs to be able to talk about death. He or she knows what is happening and is often more able and ready to deal with the truth than are caregivers. Some people worry they will not have answers to the questions the dying person may ask. Having all the answers is not so important — reassuring the person that they have the right to ask the questions may be enough.



In dying, many people worry about those they are leaving behind: Who will take care of my husband? How will my children manage? People can find some relief in putting words to their fears and having those fears acknowledged.



If a relationship of trust has been developed, people will ask for what they need. And the dying person often has a very clear idea of what it is they need in order to come to peace and to surrender to death. Paying attention to those needs can make all the difference in how a person dies.

*There is no need to be afraid.  
When the moment of your  
dying comes, you will be given  
everything that you need to  
make that journey in a graceful,  
elegant and trusting manner.*

— John O'Donohue  
*Anam Cara: A Book of  
Celtic Wisdom*

Usually, people do not feel ready to die. It is important to reassure them that dying is in many ways a private time between them and God, and that they will have the time they need.



The spirituality of those who care for the dying must be a spirituality of compassion. The sick and the weak are not just objects of charity and love. Rather, they are called to be sources of life for us all. Care for the dying involves, first and foremost, a choice to come close to another. Jean Vanier writes: “If we choose to come close to them, in some mysterious way they bring us to what is essential; they call us to truth, to competence, to compassion, and to centredness.”<sup>33</sup>



Sometimes there is no substitute for the touch of a hand. A touch that is given without any burden of desire or demand has the power to make a profound connection. It expresses the heart's warmth and can evoke a sense of well-being in another in a way that words alone cannot.



One of the hardest experiences in waiting for death is the feeling of being seen in the past tense, of being someone who *once was* important and whole. A person who is dying needs to be treated as a whole person.



Praying with the person who is dying can be a source of peace and comfort not only for the dying person, but for family members and care providers as well.

There comes a point when caring means keeping a silent vigil, when there's nothing more that can be done except to do nothing in the presence of the dying person. Marie de Hennezel describes a kind of joy that can be experienced in simply being present.

By spending time with the dying, I have learned to keep silent vigil with those who are asleep, or in a coma, and I have discovered the pleasure of just being there, not doing anything, just being a presence, alert, attentive, like a mother watching over her sleeping baby... Many of the people I've met at the bedside of the dying feel themselves to be useless and ill at ease in this situation of just being there and not doing anything. Some of the staff on the unit have learned that this, too, is part of their healing.<sup>34</sup>



Some years ago I went with a friend to visit a young man who was dying with AIDS. The last days of his life were spent in a palliative care centre here in the city. Both of us had known this man for quite some years. As it turned out he died just moments before we arrived. Entering his room, and seeing this man's body lying there, my friend immediately burst into tears. I, on the other hand, buried my grief and remained composed. Looking back on that night, it seems to me now that caring for the dying also means caring for those who are left to mourn. We need to create a place in our society for people to acknowledge their grief and to weep over the loss of someone they love.



Very often, the final words of a dying person provide caregivers with the strength to go on after the person has died. Such words from a weary and exhausted body represent one final gift. More often than not, they are an affirmation of life and an encouragement to live life to the full.



## Dying Cannot be Understood Simply As a Medical Event

**D**ying does not fit neatly into the goals and approaches of our current medical system. By and large, medical schools teach doctors to focus on treatment, relief of physical pain and cure. Medical care concentrates on illness and injuries; its goals are cure, prolongation of life, rehabilitation and the relief of physical distress. As such, medical training is not well geared for assisting clinicians to understand the personal dimension of dying.

The 1989-1994 Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment (SUPPORT) collected data on thousands of seriously ill hospital patients in the United States. The data provided valuable new knowledge, including the following:

- More than 50 percent of the study's patients were reported to be in substantial pain.
- Most of the patients who died spent their last days in an intensive care unit on a ventilator, unable to communicate with family and friends.
- Clinicians paid little attention to advance health care directives.
- The patients and their families often seemed "adrift and confused" about the illness and the care appropriate for it.<sup>35</sup>

There is growing recognition that persons who are dying are not well served by a medical model in which curative medicine is entrenched and the values of caring are subordinate. The process of dying, says Ira Byock, "cannot be understood simply as a medical event."

... dying cannot be reduced to a collection of diagnoses. For the individual and the family, the enormity and depth of this final transition dwarfs the myriad medical problems... The purely medical approach serves as a lens through which doctors analyze patients' experiences, but it goes only so far, and at its edges there is distortion. It is two-dimensional, and without the color, tone, or texture of life. It offers no place for the real stuff of human experience.<sup>36</sup>

If we adopt a different approach, and start by looking at the experience of those living with life-threatening illnesses and ask them about their needs, what they fear, and what they expect of caregivers, a number of themes emerge. First, dying is experienced as a spiritual journey. Second, dying is the source of considerable fear. People fear dying in unrelieved or intolerable pain. They fear their pain will not be managed well. They also fear physical abandonment and that dying will mean being separated from family, surrounded by machines and strangers. Third, and finally, at the end of life people no longer expect great results from medicine. These needs and fears provide insights into how to improve end-of-life care.

There is something in all of us that seeks the spiritual. It is a search for the sacred and a striving for a deeper sense of interconnectedness with the self, other human beings, and the Infinite. For people who are dying this search for the sacred rises to the fore. Searching for meaning, remembering, forgiving, reconciling, living and healing are all part of the spiritual journey that marks the final transition of life. Spiritual support is essential in care of the dying.

A growing number of medical schools are finding space in their curriculum for courses on religion and spirituality. The challenge remains, however, for the medical establishment to adopt an expanded view of health; a view that incorporates spiritual factors and responds to the spiritual suffering of those who are dying.

Why are so many people dying in pain? There are a number of reasons: some care providers fear the use of pain relieving drugs will become addictive; others confuse pain relief with euthanasia; people who are dying and who complain about pain often are not believed; and, finally, most clinicians learn only basic pain management interventions while in school.

Byock maintains that physical pain exists because doctors lack the will, not the way, to treat pain aggressively. With strong resolve from the dying person and the doctor, relief of physical suffering, he says, is “*always*” possible.

Eighteen years of clinical hospice experience has taught me, however, that physical distress among the dying can *always* be alleviated. The word “always” in this context may sound facile, but I use it deliberately... Pain is only “uncontrollable” until it is controlled. Pain and other physical symptoms caused by advanced disease usually yield to relatively simple treatment. This is not to say that symptom management is routinely easy. Effective therapy may require the efforts of a physician skilled in palliative medicine and a team of hospice-trained nurses, consultant pharmacists, and others... sometimes pain is so severe and so resistant to customary medicines and therapies that a patient is forced to accept sedation as the cost of comfort.<sup>37</sup>

Byock goes on to say, however, that over a period of ten years, in helping to care for hundreds of hospice patients, he had to resort to full sedation using an infusion of barbituate only once.

Pain is one of the most feared aspects of the dying process and profoundly affects a person’s physical, social and spiritual well-being. Care providers can make an enormous contribution to end-of-life care by assuring dying persons (and their families) that every effort will be made to relieve their pain.

Bridget Campion, a clinical ethicist working in Toronto, has written that one of the most pressing challenges in end-of-life care today is finding ways to make it possible for people to die well in our hospitals. Health care practice remains directed to saving lives and curing. For many health care professionals and families, death is viewed as a failure. If death is viewed as a failure, how do we view persons who are dying?

“It is essential,” she says, “to find worth in the dying patient by finding value in the dying itself.”<sup>38</sup> To value people in their dying would represent a major shift in perspective. The needs of the dying person would take on new meaning and importance. When this happens, the suffering, pain, joy and peace encountered in the act of dying will become a source of healing and transformation, not only for the dying person, but for caregivers and for society as a whole.



## CONCLUSION

### Facing Death, Discovering Life

**W**e all spend a lot of our time and energy worrying about what will happen to us. But life has its ways of teaching us that it's not what happens to us that is really important, it's the response we make to what happens.

How we respond to death and dying is no different. Our natural tendency is to behave as if death will never come. We shrink from it thinking it promises to bring only emptiness and suffering. We support each other in this lie and in doing so are robbed of the unique and powerful gift that is offered to us in the deaths of those we love and in our own dying.

In facing death and putting it at the centre of our lives we will come to see that alongside the suffering (and sometimes the horror) that surrounds death there is a depth of humanity to be discovered that cannot be found elsewhere. Within such a view death comes to be seen for what it is — the fulfillment of a life.

Much remains to be done to transform our culture's view of death and to make care of the dying an integral part of the life of the family and the community. We owe it to our grandparents, our parents, our brothers and sisters, and to our children to pursue such a dream.

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