

Living Thoughtfully, DYING WELL

As a medical doctor in the U.S. and India for five decades, and as someone who almost died several times from heart illness, Glen Miller has done his homework on preparing to die. Living and dying are entwined. Miller's book rivets the reader's attention with his and others' stories. Readers will be torn between *not* wanting to stop and *needing* to stop because of the emotional and content depth. Preparing for death, in the ways Miller instructs us, will make our dying easier for loved ones who survive. This book is important for family and church discussion. Each chapter ends with discussion questions; it concludes with a checklist of tasks to set one's "house in order."

—**Willard Swartley**, *professor emeritus of New Testament at Anabaptist Mennonite Biblical Seminary*

Readable, realistic, and spiritually relevant, this book is for anyone coping with chronic illness or aging care issues, who yearns for the opportunity to die a "good death." Dr. Miller navigates the choppy waters of health care in ways that preserve personal dignity, maintain a sense of control, preserve moral and spiritual values, and generate loving and sustaining memories.

—**Clair Hochstetler**, *manager of chaplaincy and pastoral care at the Canberra Hospital, Australian Capital Territory*

In a world where the reality of death may be denied or resisted through futile and expensive effort, we need a book that provides a realistic and healthy perspective on this universal experience. Glen Miller has written that book. Using facts, figures, and especially stories, he addresses the legal, physical, and emotional aspects of dying to help us see death, and especially our preparation for it, in a positive way. This book is an inviting and useful guide to specific actions we can take to make our death what we want it to be.

—**Joseph Longacher**, *MD, past president of Mennonite Medical Association, and past president of medical staff at Henrico Doctors Hospital, Richmond, Virginia*

With good humor and frank honesty, experienced physician Dr. Glen E. Miller explores healthy living and dying in *Living Thoughtfully, Dying Well*. Poignant stories of others' end-of-life experiences accompany Dr. Miller's recounting of his own nearly fatal third heart attack. Readers will be challenged with the inevitable issues they must prepare for as they face the physical, emotional, and spiritual transitions of aging. This is a must-read for families and church communities.

—**Ruth Lapp Guengerich, MEd**, mental health counselor, codirector of
Mennonite Women USA

Have you ever wished that you could talk with a family member about dying? Glen Miller provides reflective stories about his health journey, factual information about preparing for death, delightful humor, and thoughtful suggestions for conversation. Questions to guide discussions can be found at the end of every chapter. This book could facilitate conversations about choices and a good death by families or friends.

—**Mary J. Dyck**, associate professor at Mennonite College of Nursing, Illinois
State University

As a member of a monastic community I appreciate so much Dr. Miller's expertise and approach to the issue of thinking ahead to one's death. In his Rule for Monasteries, Saint Benedict urges monastics to "keep death daily before one's eyes." As communities we are intentional about having members die "at home," surrounded by caring community members. This book is written in a warm, accessible manner, with stories and anecdotes bringing the major points into contact with the human situation. Each chapter concludes with questions that will draw the engaged reader into reflection and, hopefully, decision making and action. Miller argues in a convincing manner that it is possible and desirable to have a "good death" which truly integrates one's deepest human, spiritual beliefs.

—**Abbot John Klassen**, Order of Saint Benedict, Saint John's Abbey,
Collegeville, Minnesota

Living Thoughtfully, **DYING WELL**

*A Doctor Explains How to Make Death
a Natural Part of Life*

Glen E. Miller, MD



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Introduction

THE ADVANCES in medical technology over the past fifty years have been breathtaking, extending life expectancy nearly a decade and giving millions of people a better quality of life. No one would want to revert to the past. But the advances in medical technology and treatment have created a new set of problems, especially regarding end-of-life issues.

The way we die has changed.

The way we die has changed. Before the advent of cardio-pulmonary resuscitation (CPR), magnetic resonance imaging (MRI), computerized axial tomography (CAT) scans, pacemakers, defibrillators, and automatic respirators, death was a relatively simple thing. Barring a life-ending accident, a person's health gradually declined due to aging or chronic disease. In 1965, most of what I could do for a patient was available in the doctor's bag I carried on house calls. There were relatively few options for diagnosis and treatment. With the advances in medical technology came the potential for many more diagnostic procedures and methods of treatment. Decisions must be made.

This need for decisions requires much more active participation from the patient and family than in years past.

The decisions made in the process of dying will determine the quality of the dying experience for the patient and family. Planning *where to die* is a critical part. There are times when death in an intensive care unit is unavoidable, but too many older people die there, connected to tubes and monitors and unable to communicate with their families. Visiting daughters and sons feels awkward, not knowing where to stand, let alone how to comfort their loved one. Ruth (chapter 4) was in exactly that situation, tethered to her bed with catheters and monitor wires. Her arms were tied to the side of the bed to keep her from pulling out the tubes vital to keeping her alive. Her last words to her family were “Untie me now!” They now live with the memory that their mother left this life agitated and out of touch with her close-knit family.

*Preparation starts with an awareness
of one's mortality.*

Ruth's death stands in contrast to my sister's death. Although she was dying of a brain tumor at seventy-four, Lois was calm and at peace, lying in her bed at home, surrounded by family members expressing their love and appreciation for her. She died as simply as she had lived, trusting in a loving God and resting in the comfort of her supportive community.

I gained impetus to write this book from my personal desire to plan for *my* good death. This became urgent as I realized that I'm dying myself. We all are, of course, but my situation is more acute. I've survived two heart attacks and two incidents of cardiac arrest. I don't know how long I can expect to live, but with my cardiologist's diagnosis of congestive heart failure, my life expectancy is certainly reduced.

What I wish for myself, I wish for all: a good death that allows us to leave this world as naturally and positively as possible. The prospects of a good death are greatly enhanced if steps are taken to prepare for it.

The process of preparation starts with an awareness of one's mortality. It is so easy to put off thinking about death. Even though I had made desultory efforts to prepare for death earlier, it was my cardiac arrest that grabbed my attention. This led to a conversation with family members about my wishes for medical care in my time of dying. Since about 85 percent of us will not be able to speak for ourselves at the end of life, I identified someone who understands my desires and will speak for me if I am unable.

Preparation will increase the possibility that dignity and privacy will be respected in the time of dying. Preparation will give both patient and family a sense of control when events tend to spiral out of control. Most importantly for me, loving family memories can be created that will allow conversation about my passing without feelings of remorse.

Chapters 5 and 6 contain many practical suggestions—divesting of possessions, preparing a living will and advance directives, and making funeral plans and plans to die at home. Chapters 7 and 8 deal with death as a spiritual event and provide ways to give expression to beliefs and values that can be applied to decisions for end-of-life medical care.

I have included questions and suggestions for discussion after each chapter. The takeaway from this book will be greatly enhanced as you discuss these issues with your family, Sunday school class, or a group of friends.

Some of my recent conversations in preparing to write this book were with Father Kilian, a ninety-year-old Benedictine monk at St. John's Monastery in Minnesota. We were two old guys from vastly different backgrounds and religious communities—Catholic and Mennonite—talking candidly about faith and the process of dying. The conversation we had on dying is in chapter 2. At the end of our last time together, we each prayed a blessing for the other. Kilian said, "I've never had a conversation like this before." Neither had I.

Newspapers, radio, and television are replete with programs talking about the need to plan for making good end-of-life healthcare decisions. In a recent California survey, 60 percent of respondents said that they were concerned with this issue, yet 57 percent said they had done nothing about it.

A good death takes planning. I hope that this book will encourage elderly persons and their families to actively prepare for that good death. With good preparation in your time of dying, *you will be more likely to*

- maintain your dignity and privacy;
- have a sense of control over events;
- die in a way that reflects the way you lived;
- create loving memories for your family;
- reduce your costs; and
- die at home.

Everyone deserves a good death surrounded by loved ones in an atmosphere of peace and serenity. That's what I want for myself and that's what I hope for everyone.

The Wake-Up Call

*In three words I can sum up everything I've learned about
life: it goes on. —Robert Frost*

CARDIAC ARREST!

The nurse yelled, “Someone call 911!” The keynote speaker of the evening had suddenly disappeared behind the podium, lying on the floor with a pool of blood collecting around his head. Mark, a battalion chief in the fire department, sprang into action. His training and experience had prepared him for situations exactly like this. He found no pulse and quickly confirmed that the speaker had collapsed because of a cardiac arrest. Kathy, a hospital-based nurse trained in CPR (cardio-pulmonary resuscitation) rushed to help. They cut off his blue blazer, shirt, and tie and began closed chest massage. Mark took charge with calm authority, calling on his years of training in CPR.

She later told me, “I thought you were dead.”

I was the speaker. My wife, Marilyn, had been sitting on the speaker's dais with me. About five minutes into my speech, she saw me suddenly keel over backward. The only sound was when my head thumped on the step behind me. She later told me, “I thought you were dead.”

Without any warning, my heart lost its effective rhythm and was no longer pumping blood throughout my body. The heart rhythm—ventricular fibrillation—left my heart a quivering mass, useless as a pump. The heart urgently needed an electric shock to convert back to a normal rhythm. Oxygen essential to my survival was no longer reaching my brain, heart, or other vital organs. Without oxygen, in a few minutes enzyme systems in cells would come to a halt and cells would begin to die by the millions or billions. After that, there can be no recovery.

Mark and Kathy started CPR, compressing my chest about 120 times a minute, squeezing blood from my now flabby heart to keep vital organs supplied with oxygen until the heart rhythm could be reestablished. Jeff, an anesthesiologist who was at the meeting only because his father catered the meal, also hurried to help. Mike, a county councilman with CPR training, took his turn at the exhausting work of the rapid-fire chest compressions.

The EMT (emergency medical technician) squad arrived seven minutes later. Their monitor recorded the chaotic beat of a struggling heart. Mark was greatly relieved to see that my heart converted to a functional rhythm after the first electric shock from the defibrillator. My heart was now beating in a coordinated way and responding to the pacemaker that had been pacing my heart for the past four years. I again had a pulse and blood flowing through my body from my beating heart.

Nancy, a local pastor, and Pat, a parish nurse, enfolded my wife in their arms as all this activity swirled about them. She watched as the squad loaded me into the ambulance. In the ambulance, Marilyn, who is a nurse, took comfort when she saw that I was breathing without assistance. She heard the squad members discuss where they were to take me and was greatly relieved to hear me say, “Take me home.” They rightly ignored me.

My resuscitation was a community effort that included a firefighter-paramedic, nurse, doctor, county councilman, parish nurse, hospital chaplain, and two pastors, each doing their part with compassion and competence. And, as if to cover all the bases, a Pentecostal pastor had prayed for my welfare. That's community in action.

CONFUSION GRADUALLY CLEARS

I had been speaking to a group of about 120 people at the annual meeting of the St. Joseph Valley Project whose motto is "Jobs with Justice." I was on the third PowerPoint slide that graphically illustrated the escalating cost of healthcare. That much I remember.

The first two days in the hospital are essentially lost to me—only snippets of memory remain. Yet the brain has a remarkable capacity to adjust. I was told that throughout these first two days I engaged in lucid conversations and responded to questions appropriately. I kept asking what had happened even though I was answered each time. I compared my medical training with that of my cardiologist in detail and a few minutes later asked him about his training again.

During that time I recall that my pastor, Mary, came to visit. She said, "I know that in the past months you have been talking about how we pray in situations like this. So how do you want us to pray for you?" I remember thinking that this was an important question and I made a conscious effort to concentrate. I replied, "Two things: that I have patience with what needs to be done, and that I can continue to have meaningful relationships."

The worst time in the hospital was during the second night. I woke up with a sense that I needed to do something and got out of bed. I stood at the side of my bed and realized I had no idea where I was. I thought, "I have been in this situation before when traveling. I will be able to figure out where I am." But

now, despite my best efforts and concentrating, I just couldn't get oriented. I was intensely frustrated. Suddenly, four nurses came hustling into the room. The smallest nurse came to me and got right up in my face and said, "Dr. Miller, you are in the hospital. You can't just get out of bed without help." This nurse seemed so agitated that I felt I needed to pacify her and patted her on the shoulder and assured her that I was all right.

I realized that I could have been permanently confused and disoriented.

I got back into bed and surveyed my room: I had a bed that understands five languages, a cardiac monitor dutifully showing each heartbeat, and a camera in the upper corner of the room. It dawned on me that the nurses had been watching me on the camera.

Then it hit me that I had been disoriented, unaware of where I was. I remembered other confused patients and how they tried to cover up their confusion. I felt I had embarrassed myself standing there at the bedside, disoriented, in my open-in-the-back hospital gown.

Later, after I had further recovered, a wave of gratefulness washed over me as I realized that I could have been permanently confused and disoriented with a brain that had lost its ability to remember. Each morning since then, as I get out of my bed, I am so grateful that I regained my mental faculties that allow me to feel and remember and interact with other people.

As I gradually regained my memory, I reflected on what was happening. I was interested in how my mind worked. On the third hospital day, I followed a long habit and asked for pen and paper to record my understanding of what was happening. I recorded notes that were chronological and insightful. After I arrived back home days later, I discovered two sets of nearly

identical notes. I recalled the second set but had no recollection of the first.

Also on the third hospital day, I told our son Ken, a medical doctor, that I wanted to talk to the cardiologist about his reason for doing a heart catheterization. Even though I was not functioning on all cylinders yet, this concern came from my interest in using the healthcare system as efficiently as possible and avoiding unnecessary expense.

Later that day, Ken came into my room holding the get-well card from Mother Teresa that I had received in 1996 after my first heart attack.¹ He held the card up in front of me and said, “Dad, you are the patient here.” Ken read the words of Mother Teresa to me, “‘Be the little lamb in the arms of Jesus who loves you.’ As Mother Teresa said, allow the doctors to do what they feel best.” I agreed to the catheterization, which was done the next day.

Part of who I am is reflected in my sense of humor. When my sense of humor returned, Marilyn was convinced I was on my way to full recovery of my mental capacity. On the third hospital day, Marilyn was helping me order my next meal. She asked, “What would you say to baked fish?” I replied, “I would say ‘Hello fish, how are you today? Was it uncomfortably warm where you were? Do you feel especially tender today?’” On my fourth hospital day I received a new pacemaker that is designed to shock the heart back into a normal rhythm if fibrillation recurs. I was assured that I could resume normal activity.

Having survived, I am left with a heightened sense of gratefulness for simple things: the love of family, just getting up in the morning to start a new day, and the prospect of continued

1. My first heart attack occurred in Calcutta. Among the get-well cards was one from Mother Teresa whom I had known over the previous five years. It was a postcard picture of Jesus carrying a lamb followed by sheep. On the lamb in Jesus’ arms Mother Teresa had written the word “You.” On the back side she wrote: “Dear Dr. Glen E. Miller, Be the little lamb in the arms of Jesus who loves you. I will pray for you [to] get well soon. God Bless You,” M. Teresa, MC.

participation in the things that give life meaning. I have been given more time; I know not how many days, weeks, months, or years.

As a doctor, I had been there dozens of times. I felt the sickening snap of brittle ribs breaking while performing CPR on an octogenarian. I know the feeling of futility when there is no response by the injured heart and the sense of failure as we stop our resuscitation efforts. Even today, some of these failures stick in my mind, like the father who only wanted to live to see his twin sons play basketball on their high school team. The immensity of the tragedy for this family struck me like a physical blow.

A tragedy that never seems to end is when the patient survives physically but her brain is damaged due to a lack of oxygen for too long a period. The degree of injury is relative to the length of time the brain was oxygen deprived. In severe injury, the person never regains consciousness and is in a permanent vegetative state. Less severe damage can cause lasting confusion, stroke-like weakness, speech problems, or loss of short-term memory. In these situations, the surviving family may live with their loved one for years, present in body only, reminding them of what might have been.

THE THIRD TIME

The cardiac arrest on the speaker's podium was the third time my heart trouble showed itself. The first time, in 1996, I was living in Calcutta, India. We were at a tennis club for the weekend celebrating our fortieth wedding anniversary. Early on a Sunday morning, while playing tennis, I gradually became aware of an all-consuming tiredness. I asked for a time out and when the aching fatigue did not improve, I walked to my room nearby. On that short walk, my physician instincts kicked in and I realized that I was having a heart attack. Marilyn reached the local physician on call who turned out to be a pediatrician.

In order to ensure admission directly to a cardiac care unit, we rehearsed the classical symptoms of a heart attack—compressing chest pain radiating to the left arm, sweating, and extreme tiredness. Marilyn and the taxi driver walked me from the hotel room to the curbside taxi and twenty minutes later we were in the hospital. My description of the symptoms had convinced the pediatrician, and I was admitted directly into the cardiac intensive care unit, where a major heart attack was confirmed.

During the first night in the hospital, I had a vivid dream. The images of that dream stick with me to this day. I was in the hold of a large ship, all by myself. There was a red door near the front of the room where the ship came to a point. The door swung open and I saw water rushing forward, telling me that the ship was backing away from the pier. I decided that if I was going to get off the ship, I needed to jump. I jumped to the pier and the dream ended.

The next morning I learned that during the night my heart had slowed to about thirty-three beats a minute. I was given an injection and my heart rate increased. I have no way to prove that my dream was at the same time as the slowing of my heart. But it was clear to me that if I had been in the Indian village two weeks before, thirty-six hours away from any medical care, I would not have survived.

With this heart episode, I pondered the question of why I survived. One answer suggested that I had special favor in the sight of God. I rejected that concept. On the other hand, I felt that I had survived for a purpose, that there was need for me to continue to contribute to those around me. Thereafter, each day I got up with a mild feeling of urgency that I needed to get on with the rest of my life, whatever that turned out to be.

Ten years later, similar feelings returned. I had been under medical care for my coronary artery disease. I had a meeting one hundred miles from my home and didn't feel well and had difficulty mustering the energy to go. Marilyn drove me to

the meeting. After returning home and a nap, I felt quite well. However, that evening before going to bed, I checked my blood pressure and found that my pulse was again thirty-three beats per minute.

In the hospital ER, the EKG (electrocardiogram) showed that I had experienced a small heart attack and blood tests indicated moderate heart muscle damage. I was admitted to the

*It was now three times that fate or luck or
a divine plan had allowed me to survive.*

hospital. The next day a heart catheterization showed that the main coronary artery was 95 percent blocked. This artery is so important to supplying the heart with vital blood flow that when it closes, the patient almost always dies. For that reason, this artery has the nickname “the widow maker.”

Several days later, I was placed on a heart/lung machine with my heart at standstill for about four hours. The blockages in four arteries were bypassed with vein grafts taken from my legs. The surgeon told Marilyn that sometimes they are unable to restart the heart in patients who had a previous heart attack. My widow maker artery *hadn't* closed and my heart restarted successfully. I had averted a major catastrophe and had again survived. That was the second time.

FATE, LUCK, OR DIVINE PLAN?

It was now three times that fate or luck or a divine plan had allowed me to survive against the odds. I felt a kinship with people who “miraculously” lived through a tsunami when others all around them did not, or with the person who survived cancer when another patient with a similar diagnosis did not.

On assessing this issue of why I survived when others didn't, my thoughts repeatedly turned to my good friend Mike. He is a gifted musician with the violin and drums and leads singing

in our congregation. As a physician, Mike's patients explicitly trusted him to guide their medical care. He is known for a high level of competence and unfailing kindness and gentleness of spirit.

Mike's patients and our entire community were shocked when he announced his retirement at age fifty-nine. His plans for retirement had been formulated one year earlier when he noticed that his ability to remember details and work through complicated problems was not up to his usual standards. He recalled that other male members of his extended family had early-onset Alzheimer's disease. An evaluation by a neurologist confirmed the diagnosis. Mike confided in his medical colleagues and office staff and made plans for retirement that would provide ongoing care for his patients. His forced retirement and diminished prospects for the future are a tragic loss to his family, his church, and his community.

Mike is a good friend. The thought kept returning to me that if I, nineteen years older than Mike, could somehow trade life's fortunes with him, I would happily do it. But that's not a choice either Mike or I have.

THE LASTING THOUGHT

I learned several things from my cardiac arrest. I knew the long odds that I would survive a cardiac arrest, and the even more remote possibility that I would regain my mental faculties. As I thought about this, I visualized a virtual parade of

There are things worse than death.

patients I had cared for who had physically survived but were left with severe mental impairment—Marvin, who was transferred back to my care from an out-of-town cardiac arrest and now was in a persistent eyes-wide-open vigilant state, looking like he was just about to wake up but never would. Or

octogenarian Maynard, who suffered multiple broken ribs in the resuscitation efforts and remained unconscious and on a ventilator for four days until he died. Less dramatic but no less tragic are the persons with gradual onset of dementia. I recall the daughter who faithfully recited the news to her silent and confused mother who comprehended nothing.

It was clear to me that there are things worse than death. I was determined to proactively prepare for my own time of dying.

QUESTIONS AND SUGGESTIONS FOR DISCUSSION

1. Who would you turn to if there is a sudden medical crisis?
2. What preparation have you made for a medical crisis?
3. Have you experienced a medical crisis or severe accident—your own or a friend's or relative's—that caused you to think that you will not live forever? Has the death of a friend or relative stirred this question in you? Share.
4. What does the phrase *mortality awareness* mean to you?
5. How can the church or a group of like-minded people help to keep in view the idea that life is precious and will have an end?
6. How does your faith inform you at the time of a crisis?

Living Thoughtfully, DYING WELL

As we grow older we start to wonder about death, asking, "How will I die? Will I have a good death? Will I suffer? How will my family respond? How can we manage the dying process better?"

Dr. Glen E. Miller, a retired physician who also has theological training, had his own wake-up call when he suffered a heart attack and determined to help himself and his patients go "gently into that good night." In a candid way, Miller invites readers into conversation about the spirituality of dying as he explores a variety of beliefs about death and dying.

With personal advice gleaned from his work with Mother Teresa among the dying of Calcutta, India, Miller provides rich guidance for those who are aging on the process of dying and how to make it better.

Wonderful . . . personal and powerful professional experiences woven into the story. It will be the standard vehicle for informing others of end-of-life measures. —**Dr. Joseph Martin**, professor of neurobiology and emeritus dean, Harvard Medical School

I often witness the heart-wrenching uncertainty of family members who must make treatment decisions for a critically ill loved one who had never expressed their own preferences for end-of-life care. Dr. Glen Miller offers an extraordinarily personal reflection on ways that thoughtful preparation for a "good death" can be part of a life well lived, and a gift of love to one's family. —**Douglas R. Smucker, MD**, hospice and palliative medicine fellowship, The Christ Hospital, Cincinnati, Ohio

Excellent book illustrating both the benefits and the burdens of treatment options . . . Will help the reader navigate healthcare options with greater knowledge, courage and peace. —**Rev. Kathleen Rempel Boschman**, manager of spiritual care, Concordia Hospital, Winnipeg, Manitoba

Dr. Glen E. Miller has faced death and has been given not just a second, but a third chance at life . . . Very useful in facilitating discussions with families who are confronting the death of a loved one. —**Father Killian McDonnell, OSB**, Benedictine monk, founder of the Collegeville Institute for Ecumenical and Cultural Research

Miller argues in a convincing manner that it is possible and desirable to have a "good death" that truly integrates one's deepest human, spiritual beliefs.

—**Abbot John Klassen, OSB**, Saint John's Abbey, Collegeville, Minnesota

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