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A Compassionate Journey

Coming Alongside People
with Disabilities or Chronic Illnesses



JOHN G. COOK

A Compassionate Journey

Coming Alongside People
with Disabilities or Chronic Illnesses



John G. Cook

Disability Concerns
Grand Rapids, Michigan



Disability Concerns, a ministry of the Christian Reformed Church, promotes the full participation of people with disabilities in the church

- by challenging congregations to eliminate barriers to this participation including architectural, communication, and attitudinal barriers,
- by assisting people with disabilities and their families to express their needs and offer their gifts to the church, and
- by providing information on disability resources and services.

To that end, the staff and volunteers of Disability Concerns seek to help churches become hospitable, inclusive, and healthy communities that intentionally seek

- to end the isolation and disconnectedness of persons with disabilities and their families,
- to nurture the spiritual lives of people with disabilities so that they become professing and active members of their churches, and
- to encourage the gifts of people with disabilities so that they can serve God fully in their churches.

We summarize this work of the church with four words: *Everybody belongs. Everybody serves.* More helpful information for ministry with people with disabilities can be found on our website, www.crdisabilityconcerns.org.

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I thank my wife, Sarah, for being such a crucial part of my convoy for so long!

John G. Cook

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I was hungry and you fed me,
I was thirsty and you gave me a drink,
I was homeless and you gave me a room,
I was shivering and you gave me clothes,
I was sick and you stopped to visit,
I was in prison and you came to me.

—Matthew 25:35-36, *The Message*

Preface

You have in your hands something I am very excited about: a booklet about joining people with disabilities or chronic illness in their journey. I'm excited about this booklet for three reasons. First, it has credibility because it was written by a man who has thought carefully about this aspect of ministry and who has a disability himself. Second, it has value because it gives perspective and practical ideas for practicing compassion. Third, it addresses a specific topic which for the most part has been addressed only in general terms.

The church, the beloved bride of our Lord Jesus, is called to be a compassionate community that brings the love of Christ to all people—including those with long-term challenges. But their experiences are foreign to most people. For instance, did you know that

- people with disabilities or chronic illness experience much higher unemployment and divorce rates than the general population?
- they have fewer friendships and are more likely to feel ostracized by others?
- they have lower rates of church attendance than the general population?

That's where this booklet is so helpful. Author John Cook brings us into the world of people who live with long-term disabilities or chronic illness, and then helps us understand how the church can share with them the compassion of Christ. In my editing of Disability Concerns' newsletter, *Breaking Barriers*, I come across many personal stories of people living with disabilities. A few of these have been added to the text.

This booklet is intended to be used in conjunction with a small group discussion on the topic. Some care teams may wish to cover the material over several months by reading a chapter for each regular meeting. Questions at the end of each chapter will facilitate discussion. Other groups may wish to devote a few hours to the subject in one block of time. A workshop outline is provided for this purpose in the appendix. However, individuals reading this booklet on their own will grow through the experience as well and will learn to become more compassionate caregivers.

We welcome your suggestions for improving this book or workshop. Also, we would love to hear stories from your own compassionate journey. Please email us at journey@crdisabilityconcerns.org or write us at

Disability Concerns
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We promise to read everything you send even if we are not able to respond.

This booklet is published by Christian Reformed Disability Concerns. The ministry of Disability Concerns began in the Christian Reformed denomination in 1982 with the intent of fostering healthy congregations by helping them include people with disabilities in all aspects of congregational life and ministry. Our hope is that *A Compassionate Journey* will contribute to this all-important work of inclusion. It's important to note that this material may be used and applied by Christians of many denominational backgrounds.

As Jesus became Immanuel, God-with-us, on the first Christmas, so we who are his followers incarnate the love of Christ as we show his love to one another. May God help us to journey together in his love each day.

Rev. Mark Stephenson
Director of Disability Concerns
Christmas 2007

Introduction

Are you ready for a godly nudge? We hope this little book, along with the accompanying workshop, will inspire you—compel you, even—to come alongside others in your congregation who live with chronic illness or long-term disabilities.

Let's begin by understanding a few terms we'll use in our conversation: *Illness* refers to a physical or mental ailment. A *disability* can be any physical, mental, emotional, or sensory condition that's severe enough to require significant adjustments in one's life. (In this book we'll focus particularly on *long-term* illness and disability as opposed to health ailments of shorter duration.) Using the phrase "people with disabilities or chronic illness" throughout this book can get a bit clumsy. Sometimes I shorten this phrase with expressions like "people with disabilities" or "people with illness or disabilities," but I always have the same group of people in mind: people living with long-term illness or lifelong disability.

Since we are talking about a compassionate journey, let's define compassion too. An Oxford dictionary defines *compassion* as "suffering together with another." Such compassion is not a one-way street. Two people, or an entire church, share in the work of compassion together. Most importantly, compassion builds on the presence and power of our compassionate God who has been there from the beginning and who goes before us as we walk alongside others.

Definitions matter. And so does language! A woman in a wheelchair may (rightly!) point out that she is not dis-abled—in fact, she has many gifts and abilities. In our conversation, let's not identify persons with their disability by calling them "the disabled" or "invalids."

One more language matter: What shall we call this business we're engaged in together? A fancy name might be *lay pastoral care* ("lay" meaning "non-clergy" and "pastoral care" meaning showing the love

and care of Christ to fellow congregation members for whom one has some formal responsibility). But simpler words will do nicely—words like *visiting*, *loving*, *caring for*, or *coming alongside* people with disabilities or chronic illness.

The primary focus of this book (and workshop) is how to make that happen. Clearly it's not just the pastor's job! Consider the title of an influential 1987 book by Melvin Steinbron, *Can the Pastor Do It Alone? A Model for Preparing Lay People for Lay Pastoring*. General training materials for extending compassion and care to fellow members (Coffee Break, Stephen Ministries®, small groups, and the like) help many people, but little material is available specifically for showing care to people dealing with chronic illness and long-term disabilities. Learning how to show compassion in our journey together is the intent of this book.

We will consider the difficulties and challenges that face those with chronic illness or long-term disability. (About 20 percent of the population falls into this category!) Such challenges can have substantial social, psychological, and spiritual implications not only for the person with the illness or disability but for his or her entire family.

We will also address the challenges and fears of those who are called to give care. You may find frightening the very idea of visiting someone with a long-term condition. You may wonder what you should do or not do, say or not say. Let me reassure you at the outset that God goes before you—you need only be a vessel for God's compassion. Your presence is the most important thing you can give.

Some people think that showing care to another means giving advice and seeking solutions, even trying to "fix" what is wrong. This perspective is called up short with questions like these: Where is God when nothing seems to change? Why doesn't he cure me? Ultimately, trying to "fix" things will lead us *away* from genuine caring.

Instead, we'll describe a way of caring that emphasizes *acting with* rather than *doing for*. Such care draws on God's compassion—God's willingness to go through life's valleys with all of us and bless us with spiritual well-being even as our brokenness persists.

This book and workshop are part of the good news the Bible proclaims. In Luke 14 Jesus declares that the invitation to the banquet of the new kingdom goes out to those who are poor, those who are sick, those who are lame. Congregations—including yours and mine—can extend this same delightful invitation. We can let the compassion of God flow through us as we seek to journey with, even suffer with, fellow members who live with chronic illness or disability. Easy to do? Not really. But Matthew 25 nudges us. . . .

Chapter 1

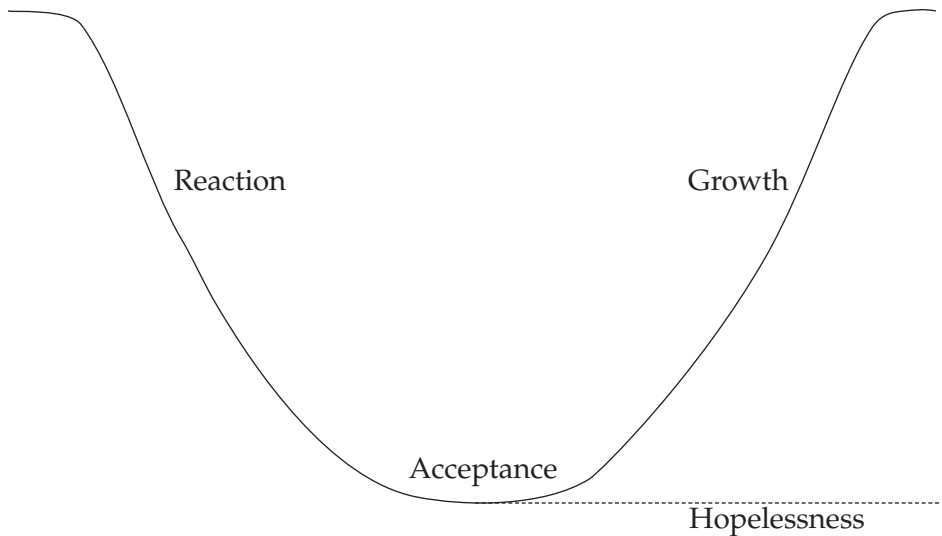
From Grief to Growth

Jeff knew that Dave and Marian Baker, a couple in his elder group, had been worried for some time about Dave's fatigue. When Jeff learned that Dave had been diagnosed with leukemia, he phoned to ask whether he could drop by. When he did, he found Marian and Dave very upset by the diagnosis.

It couldn't get much worse for the Bakers—or, in a way, for Jeff. His first question was a prayer from the heart: "Lord, how can I possibly help Dave and Marian?" This guidebook is intended to help all of us—from council member to care team member to caring friend—discover answers to Jeff's prayer.

Let's begin with understanding how people react to the diagnosis or onset of long-term illness or disability, and how they move on to adapt their lives and their desires to its reality. (I recognize that some people live with a disability their entire lives, but for most people disability or chronic illness enters their lives as an uninvited guest. This chapter focuses on those for whom a lifelong challenge enters their lives unexpectedly.) Recent research in this area can help us understand and then reach out to fellow church members in need of caring and support.

Dr. Gregg Albers, a Christian family physician, has identified a general pattern describing how his patients and their families frequently respond to an illness. That pattern may help us to journey with those in our congregation who deal with illness or disability.



- In the *reaction* phase a person usually responds with a marked emotional decline.
- *Acceptance* occurs only after someone has struggled to acknowledge the challenges and tasks posed by an illness or disability. Some people are unable or unwilling to accept the illness or disability and veer off course into despair and hopelessness. (I've added the dashed line to Albers' figure to illustrate this possibility, which I'll call *hopelessness*.)
- In the *growth* phase, the person begins to cope with a new reality, taking up the various tasks of life again as he or she is able. Even if physical and mental health does not rebound, the growth phase is usually defined by spiritual growth and a renewed sense of hope.

For some people, the valley dips briefly and growth appears soon. For others, such as an elderly person experiencing a series of losses of his abilities, there may be a number of valleys, one after the other. In either case, the pattern of reaction, acceptance, and growth can help us understand the path people take as they deal with illness or disability.

Phase 1: Reaction

Understanding the emotional ups and downs of others helps us join them on their journey—and that's just what we hope to do. So let's dig a little deeper.

Reactions to a life-altering diagnosis, as a rule, take the form of *emotions*. Personalities and situations vary, and so do emotions. Some peo-

ple are able to maintain an emotional balance by drawing on inner resources and support from a circle of family and friends. Many find strength in the conviction that God will never leave them nor forsake them. Others, however, may respond to a diagnosis with a raw emotional shock. Sometimes we can even speak of a *crisis*. Used in this sense, the word does not refer simply to an emergency but to an emotional state. In a crisis a person is filled with such emotions as anxiety and fear. At the same time he or she senses a loss of control. Everyday problem-solving strategies don't seem to work. A belief in God's faithfulness may be replaced by bewilderment or even by feelings of betrayal.

The reactions of many people will be somewhere between these two extremes, but in any case the onset of a serious disability or illness spells the threat of *loss*. For example, Grace's illness began with a series of minor physical problems that gradually increased over time. After many frustrating months of tests, Grace learned that she has multiple sclerosis. But even with the diagnosis, Grace doesn't know what the future holds because MS differs so much from one person to the next. Her losses will become clearer with time. For others, physical losses are clear and immediate. When Jack broke his back in an accident, he and his family knew immediately that he would never walk again. But it would take them years to understand how paraplegia would affect Jack's life. The notion of loss is crucial to our understanding of care to persons like Grace and Jack.

For Grace and Jack and their families, a series of questions will follow: What will happen next? How painful will it be? Will I die? Where is God in all of this? How will my life be different? How will I carry out my responsibilities to my family? Will I be able to work again?

A woman whose husband experienced a severe stroke told me: "I have lost the man I once married."

Albers describes different kinds of losses: the loss of *function* (the ability to walk, to digest food, to perform sexually), the loss of *part of the body* (a breast, a leg, a uterus), the loss of a cherished *role* (mother, student, social worker), the loss of *self-esteem* (a belief in oneself, a feeling of confidence), and the loss of *income*. He suggests that a person's emotions may become stronger (and more difficult) with time as the consequences of a diagnosis come into clearer focus. Such emotions may "become more devastating than the physical symptoms. . . . The emotional state can prolong physical symptoms . . . [and] be out of proportion to the severity of the physical illness."

Albers points out that these early emotional responses to loss often take the form of grieving. This is as natural and normal as mourning the death of a loved one. According to Albers, all grieving is emotional suffering that needs healing.

Studies confirm what we also observe in our everyday experience: usually persons and families going through strong initial emotions willingly receive help from others. That's a compelling endorsement for the ministry we're undertaking—simply to be there for fellow church members like Dave and Marian whose lives put them on a new and unwanted path. (When Jeff picked up the phone, he was right on track!)

When we are faced with chronic illness or disability, having someone who will walk with us can make a big difference. We're comforted and strengthened by others' caring presence, not to mention the gift of clearer thinking that also comes from "talking things through." Unfortunately, many people who go through the early phase of an illness or disability experience intense social isolation instead of the support and comfort of others that they need so badly. Why is that?

- People may not know which questions are important to a person or family in crisis. Like Jeff, we wonder what to say and how to be supportive.
- People may think it's best *not* to dwell on the loss and grief the person is dealing with—perhaps even mistakenly thinking they need to help him or her "be positive."
- Most often people—even compassionate, caring folks—simply lack courage. (Understanding how important it is to "be there" and to offer support can empower us to make that visit without needing to know what to say or how to "fix" things.)

Not only the person with the illness or disability but also the whole family needs our compassion and support. Consider the complexity of emotions felt by a young couple in your church who have just received the news that their newborn has Down Syndrome. Sharing both their joy and their tears on behalf of the family of God can be essential for the family's emotional and spiritual well-being.

Phase 2: Acceptance

Acceptance includes "taking on as a responsibility." For people reacting to the new reality of long-term illness or disability, acceptance means coming to terms with the situation: facing the truth of the new reality and discovering new ways to go on with life. While illness and dis-

ability have the power to deconstruct a person's life, acceptance empowers him or her to fashion life anew. This is easy to say, but the road to acceptance is rugged, with many switchbacks and potholes. Illness and disability change everything about our lives—how we function physically, how we see ourselves, how we relate to others, the roles we assume, and even the beliefs we hold dear.

In his powerful book *Lament for a Son*, Nicholas Wolterstorff says that people suffer when something prized is ripped away from them. Long-term illness and disability can rip away functions, body

parts, cherished roles, self-esteem, income, relationships, and dreams. For example, the dreams a couple had for their unborn child are taken from them when their child is born with significant disabilities. The couple must learn to love a child who is different than the child they had imagined. The man whose sight is slowing ebbing away because of a genetic disorder must learn anew how to be a father, husband, friend, and church member. He may lose his job and have to start over after twenty-five years at his old job, if he can find work at all.

Putting "acceptance" at the bottom of the valley may seem strange. I use the word "acceptance" not as an endpoint but as a beginning, an opening in the clouds through which hope shines and fresh courage breaks, even if only briefly at first. Acceptance is hard won and can be quickly lost. A young mother may begin to accept her son's severe autism, and then tumble back into grief when her husband leaves her.

In 1988 I was diagnosed with a form of multiple sclerosis. As the disease progressed, we were faced with increasing limitations. I say "we" because the impact on my wife has been at least as severe as on me. Along the way we've had to restrict or give up most activities outside our house, as well as all those minor tasks that need to be done inside the house.

I could no longer shovel snow, fix the toaster, or even change a lightbulb. We have sometimes found this difficult to deal with, as it means an ongoing redefinition of responsibilities. I have felt in some ways diminished as my wife has had to take on these tasks and assume a greater role in making decisions. She is doing the work, so she decides how it should be done. My special challenge is how best to encourage her. Her special challenge is how to keep me involved. It is a matter of serving and being served.

—Adapted from Glen Verhulst, "Meditation," *Breaking Barriers*, Winter 2003

Jacques Legault was born with cerebral palsy and spent his first forty years in an institution. He was given little stimulation there, but as social policies changed he was permitted to move into his own apartment in town. Every morning, regardless of the weather, he sets out on a four-hour trip through downtown, stopping to talk to everyone he meets. He is well-liked, always cheerful. His friends say he has a stubborn streak and sheer determination. Jacques has made a personal decision along the way. He tells others with disabilities to stop complaining and stop feeling sorry for themselves.

Acceptance in the face of suffering flows from the heart and spirit. For Christians, acceptance is a spiritual decision—a resolve to cling to God and to trust him.

While a major life change tests nearly everyone, acceptance is out of reach for some people. As illustrated by the dashed line of figure 1 (p. 12), some people continue to feel overcome by loss, frustrated by life, and despondent about their future. Instead of moving on to experience hope and growth, they may engage in a variety of destructive behaviors: refusing to take prescribed medicine, resorting to manipulative behavior, and expressing emotions inappropriately. They remain firmly rooted in grief, anger, and resentment. Hopelessness sets in.

The loving presence of another person along the journey can mean the difference between hopelessness and acceptance. Paul Tournier, a Swiss family physician, indicates that love and encouragement from others are *essential* in helping people accept a life marked by illness or disability. In his book *Creative Suffering*, Tournier writes about the pain of social isolation: “When the spirit is made to be silent, the body cries out all the more. . . . Deprivation without love spells catastrophe. . . . For the human personality the decisive factor in making deprivation bear fruit is love.” Therein lies our challenge as people called by the church to bring caring and support.

Tournier goes on to give this helpful guidance:

Do not attempt to implore or teach the other person to be courageous. Courage cannot be taught, but must be caught from persons like you, who are willing to be present. Acknowledge the other’s suffering, be attentive to it, be willing to hear expressions of emotions. Together, we must place the burdens that are revealed on Jesus.

One author provides a striking image of a *convoy* of social support, something everyone needs. During World War II merchant vessels shipped supplies for Allied troops overseas. On their own these ships would be easy prey to German air, submarine, and surface forces. By traveling together in convoys with the support of Allied warships, the merchant vessels often made the treacherous journey successfully. Life is difficult and can feel like a lonely trip in a dangerous sea. Together, we can be a convoy of support and encouragement to one another.

As Christ's followers committed to coming alongside those who are learning to live with permanent loss, our job is to visit, to listen hard, and to give loving support.

Phase 3: Growing

Spiritual and emotional growth are real possibilities for people (and their caregivers) who experience long-term illness or disabilities. But as in phases 1 and 2, the question remains: How can we provide ongoing love and support as we come alongside them and their family members?

We may be tempted to ask how well a person is "coping," say, with his wife's disability. But experts in the field warn health professionals to be very careful in evaluating the effectiveness of the coping strategies their clients use in adjusting to long-term illness or disability. We must heed this same warning. As we seek to preserve a person's dignity, sense of control, and power over his or her own life, our role is to be present, offering encouragement and companionship rather than judging and advising the person with regard to the coping strategies he or she chooses to use.

Instead of critiquing a person's coping skills, our role as helpers is to consider the *specific tasks* that people with disabilities (or their caregivers) face from day to day. This shift moves us from the role of judge to that of fellow traveler on their journey. The advantages of this approach are many:

- It acknowledges the various *dimensions* of the person's life and defines tasks accordingly.
- It is *active* and *realistic*, focusing on specific things that need doing.
- It presents possible *choices*, not single strategies.
- It grants people *freedom* to address tasks in their own way.
- It offers opportunities for *participation* by others and provides guidelines for helping.

Here's a summary of tasks we all face, but which pose greater challenges for people with long-term illness or disabilities:

Physical Tasks

The onset of chronic illness or long-term disability introduces a host of practical tasks for those directly affected—learning to work with medical staff, getting used to new medications and treatments (such as insulin injections or dialysis), eating differently, using a walker, to name a few. Each person approaches such tasks in a personal way. For example, someone I know fought the onset of his cancer ferociously, not yielding an inch. Another person may be more flexible, setting his sails to the new direction from which the wind is blowing, and be just as effective.

So how can we participate with people to whom we've pledged our involvement and support? In the case of physical needs, our care can be very practical. Simply saying, "Call me if you need anything," will be much less helpful than specific offers of support. People with chronic illness or disability may not have the energy to think of ways they need help. Specific offers like these will help: "May I get someone to clean your gutters this fall?" Or "Since your husband works during the day, do you need transportation for doctor's appointments?" *Beyond Casseroles: 505 Ways to Encourage a Chronically Ill Friend* by Lisa Copen gives, well, 505 specific ideas for helping.

Social Tasks

Illnesses and disabilities tend to isolate people. Physical disabilities make activities like jogging with friends or playing cards difficult or even impossible. Hearing impairments and speech difficulties may limit loving communication. Emotional disorders such as depression or anxiety disrupt relationships too. A family that has a child with an emotional impairment may hesitate to socialize, thus limiting their interactions with friends. No wonder the divorce rate for couples dealing with these challenges is higher than the general population. Disabilities are hard on many relationships and especially on marriage.

Many people with chronic illness or disability also feel isolated because of the way others treat them. We tend to avoid people in wheelchairs, people with unusual facial features or bodies, and children or adults with mental impairments. In a culture that promotes physical beauty and fitness, illness and disability are unwelcome reminders of our brokenness and mortality.

I am Judy Clausing. I have brown hair, blue eyes, big feet, and visual impairment. I am not Judy Clausing, the blind woman. Unfortunately, the latter is often how people see me. I have friends who have hearing or mobility impairments, and they also report that people often refer to them in terms of their disabilities.

So how should you treat a person with a disability? If you aren't sure what to do, ask her. It is usually better to ask what she needs, even if you think you already know. Each person is unique, and needs vary from person to person. Some people need a lot of assistance, while others require no assistance at all. Over time I have come to realize that asking for assistance is not a sign of failure on my part but only of my willingness to acknowledge that I need some help. I have come to terms with my disability and can say, "Yes, it is a limitation." Part of my reason for coming to this acceptance is that I now recognize that all of us, not just people with disabilities, have limitations of one type or another.

I think of children and smile. Children are very open to asking questions and letting their feelings be known. They come up to me and ask how I read, write, and so on. Be open, like children, and ask if you don't know the answer. Also be accepting like children. They frequently don't see the disability as a big deal. It's just another part of the person.

—Adapted from Judy Clausing, "Straight Talk,"
Breaking Barriers, Summer 1994. Used by permission.

How does the church stack up? Regrettably, we often contribute to this sense of isolation.

- Physical barriers like stairways can turn folks away.
- Communication barriers separate those with hearing or visual impairments from full participation in the life of the church.
- Attitudinal barriers isolate even more. Sometimes we cut others off with judgmental attitudes. Marcia Van't Land, a woman who uses a wheelchair, reports that others have told her that if she had faith, she would not be in that chair! (For a fuller understanding of how churches, often unknowingly, isolate and exclude people, check out the book *Human Disability and the Service of God*, edited by Nancy Eiesland and Don Saliers.)

So what can we do? Let's resolve to become more sensitive to (and disturbed by) barriers in our churches. We're created to live in community; when we see our fellow members withdraw, the whole body suffers. Relationships—made real through care, support, prayer, and love—are the means by which the church can enjoy wholeness and well-being.

Psychological Tasks

A 1990 study by Kenneth Pargament found that adjusting to life with chronic illness or ongoing disability may force people to face these psychological needs:

- the need to maintain self-esteem and personal identity
- the need to find continuing meaning in life
- the need for personal growth
- the need to believe in the future
- the need for intimacy and belonging
- the need for a safe place to release one's feelings

To give a specific example, as the population in Canada and the United States ages, the physical and emotional needs and concerns of our elderly members become more visible in church life. Author Harold Koenig, who writes for "pastoral counselors" working with older adults, points out that aging brings dependence on others and, too often, a diminishing sense of identity, including a loss of meaning and purpose in life.

Some psychological needs call for expert help, especially when a person is overtaken by hopelessness and despair. We don't have to do it all. However, simple personal attention from caring church members and friends goes a long way toward addressing these needs. Koenig's advice can be applied to caring church members helping anyone (not just elderly people) facing a loss: "Many times . . . older adults simply need to talk about and work through their health losses as a way of mourning or grieving those losses. An important phase of the normal grief process is talking about the loss with someone else. The pastoral counselor who actively listens to the patient, expresses sympathy and understanding, and validates the person's loss will help facilitate the grief process and speed the patient's recovery."

Spiritual Tasks

The word *spiritual* refers to the inner force that drives us, our spark of life, the essence of the story we tell with our lives. Two distinct aspects of our spirituality are important here: our *personal intactness* (our inner connectedness) and our life of *faith* (our commitment to God and connectedness to him). A disability can threaten to crush our spirit or kill our faith—or both.

First let's consider threats to our personal intactness. My friend Jerry has two adult children who have a severe neurological disorder. Jerry tells me, "You must understand that the disabilities of my children do not let up; in fact, they are progressive. For us they are like an ongoing death." I have seen that "gnawing at the spirit" with other people as well. It points not to a lack of faith in God but to a deep-down pain—life is certainly not meant to be like that! Many people living with illness will experience such pain in a less severe form, but it still touches their spirit, their spark of life. Their spiritual task is to deal with enduring losses, remain hopeful, and strive to live as whole, integrated human beings.

Although experiencing God's love certainly helps, evidence suggests that illness or disability can also challenge a person's faith. So in the second place we must consider this additional threat to a person's well-being. Charles Swindoll writes that in his experience it is very common for families facing health problems to turn to God for a cure, and to go through deep disappointment and disillusionment when that cure does not come quickly. Such families may interpret Scripture to promise that help will come quickly (see Ps. 91 and 103). When that does not happen, they ask "If God is all-powerful, why is my life like this?" (In my journey with chronic fatigue I too have had to deal with such questions.)

In fact, Jesus himself said that "the worries of this life" can choke the seed of the gospel (Mark 4:18). A disability or illness can pull someone closer to God or turn her away from him. (Note that a recent study showed that 90 percent of women who gave birth to a profoundly retarded child began to doubt the existence of God.)

Jesus also said that when trouble strikes us, the seed of the gospel can still flourish. Events in life can reveal our view of God to be unscriptural and force us through painful but ultimately wholesome change. Disabilities may force us to look at Scripture in a different way, to address wrong habits and views, and to experience God in a new and warm light—as in the case noted by Kenneth Pargament of a woman who saw God primarily as an authority figure when she was

healthy; later, when she experienced health problems, the woman began to taste God's love.

Our calling as caregivers to people who face spiritual challenges is to be present, to be attentive to the other's suffering, to hear expressions of emotion in confidence, and to bring his or her burdens to Jesus. With permission you will want to consult with your pastor as well on how best to help. In chapter 6 we delve more deeply into the importance of our continued presence in helping people with their questions of faith.

Discussion Questions

1. Describe a trial in your own life in which you passed through the phases of reaction, acceptance, and growth described in this chapter. What was each phase like for you? Have you ever experienced a period of hopelessness? If so, what was that like?
2. Describe ways in which you or someone you know had to take on new tasks as a result of a new reality caused by disability or chronic illness. Which tasks were the most difficult? Why?