

Chapter 1

A Wake-up Call

Michael Richard “Rich” Clifford was born on October 13, 1952, in California and raised in Utah. In high school, he excelled in chemistry and wanted to be a chemist. But in July 1969, his ambitions abruptly changed when Neil Armstrong walked on the moon. Rich wanted to be an astronaut too. In June 1974, Rich graduated from West Point with a bachelor’s of science. As a second lieutenant, he served at Fort Carson, Colorado. He was the top graduate in his flight class at the Army aviation school and became an army aviator. For three years, he served as a service platoon commander in Nuremberg, West Germany. In 1982 he completed master’s of science in aerospace engineering from the Georgia Institute of Technology and became an assistant professor of mechanical engineering at West Point.

He graduated from Naval Test Pilot School in 1986 and became an experimental test pilot and master army aviator, but his end goal was still to be an astronaut. He was selected for NASA’s Space Shuttle program in 1990 and two years later flew his first shuttle mission. In 1994, after his second shut-

COURAGE THROUGH CHRONIC DISEASE

the mission, Rich underwent a routine physical examination, which revealed the beginning stages of Parkinson's disease, an incurable neurodegenerative condition marked by trembling limbs, rigid muscles, and a shuffling gait. After months of tests, the physicians cleared him to fly. Since the doctors said he could still do his job competently, he told only his wife, sons, shuttle commander, and limited NASA crew about the diagnosis. From May 1994 to September 1995, he worked as the lead for space station vehicle and assembly issues. He was a veteran of three space flights and logged 665 hours in space, including a six-hour flawless space walk. In 1995, with the rank of lieutenant colonel, he retired from the Army. Rich left NASA in 1997 and worked for Boeing as director of operations and training for the International Space Station and then as deputy program manager for the Space Shuttle program. He is now retired, and even though his symptoms have progressed, he enjoys meeting other people with Parkinson's, sharing his story, and encouraging them not give up on life.

Rich Clifford led a very active life and did not imagine he would contract Parkinson's disease. He shows us that life is a mystery. We think we have all the time in the world. We have long-range plans, places to go, and things to do. We have no significant problems. Our job is rewarding, our family is pleasant, our home is comfortable, and we are proud of our accomplishments and our physical health. All is going well according to our standards, but will this remain so? We know life's circumstances can change in an instant or, as in Rich's case, over time.

What Is Chronic Disease?

A physical chronic disease is a health condition that persists and requires ongoing attention. Chronic diseases have increased because of advances in health care, longer life spans, and a change from fatal to manageable diseases. A chronic disease is usually prolonged or lifelong and may have no known cause or cure. Nevertheless, many chronic diseases are treatable. Although the terms disease and illness are used interchangeably, they are different. Diseases are usually lifelong and require management, while illnesses are usually short-term and can be cured. A disease is not as easy to deal with or to care for as is an illness. An acute illness usually has a distinct beginning, middle, and end with a return to the same level of health as before the onset of the illness. Because of complications, symptoms that come and go, long-term prognosis, and progression of the disease, chronic diseases do not seem to have the clarity or distinct treatments of acute illnesses. A disease can remain the same, be in remission, steadily get worse, or be cyclical.

The most common chronic condition, of which people may not be aware, is hypertension. Other common diseases include rheumatoid arthritis, chronic fatigue syndrome, Crohn's disease, fibromyalgia, and atherosclerosis. If we develop a chronic disease before the age of twenty, it can be called juvenile, as in juvenile diabetes or juvenile rheumatoid arthritis. Although they are unwanted, most of us will develop one or more chronic diseases during our adult life. However, not all of them entail physical pain. Even though chronic diseases cannot be cured, they need not be a dominant factor in our lives if they are managed appropriately.

Responding to the Challenge

The onset of a physical chronic disease is a common change. It can happen as suddenly as overnight or gradually develop over the years. Whatever the onset, we are not the person we used to be. Things are not quite the same. We must pay attention to our chronic disease needs because, if we do not, they will eventually take their toll. Since a chronic condition requires dependence on doctors and others, we are no longer ruggedly independent. Moreover, life becomes fragile and frightening when we cannot name the disease that is prompting the symptoms we are experiencing or when we do not know anything about the disease after it is diagnosed. When we do not know what is wrong, we are afraid. Our feelings can be raw and easily stirred up, and our imagination can run wild with worst-case scenarios.

To avoid imagining things, especially the worst and the morbid, the first priority is to get a definitive diagnosis. Before visiting the doctor, it is important to write down all apparent symptoms, how often they occur, how long they last, and uncommon incidents that do not appear to be disease related. A list is valuable because, while waiting for the doctor, we may think some symptoms have disappeared or some things are not worth talking about. An accurate diagnosis may take a long time because it can involve interviews, observations, blood tests and other assays, scans, and whatever else is needed. We may be asked to see different doctors or go to a university medical center. These are unexpected, unwelcome interruptions in our familiar daily routine. Diagnostic activities can be times of high stress, and we can burst into tears because of fear, anxiety, or confusion or for no apparent reason.

A WAKE-UP CALL

When we receive an accurate diagnosis, it can alleviate built-up stress. There is some relief. The unknown is now known. Our symptoms have a cause. Yet we wonder about new concerns. We ruminate about the possible effects of our chronic disease. Will it diminish us, make us a second-class citizen, an outsider, or a broken or useless person? We can really bombard ourselves with self-defeating images.

However, time will reveal that having a chronic disease does not mean we will become any of these things. Negative ruminations are a natural reaction, but they make coping more difficult. These thoughts occur more frequently during the early years but diminish in time as care for the disease becomes daily routine. A good practice is to strive to remain liberated from pessimistic thoughts and downbeat people, focus on the best in ourselves, and develop our creative gifts that sustain goodness and love.

In the beginning, our chronic disease may be our primary focus, but as time goes on, we move beyond that perspective. Our life has not ended; it just takes a new direction as habits and routines are adjusted to address our current needs. In time our disease takes its proper place and becomes incorporated into our routine. We learn to live more courageously and deal with things, like walking, which the average person takes for granted. We are not a diseased person; we are a person who happens to have a disease. And it is well known that diminishment in some areas can open the way to discoveries in other areas. Who we become is more vital than who we were.

When health concerns settle into their appropriate place in our lifestyle, we are defined not by what happens

COURAGE THROUGH CHRONIC DISEASE

to us, but by who we are as unique, valuable individuals. We can become better than we were before our diagnosis. A chronic disorder can teach us to “take the bull by the horns” throughout life. This phrase is based on the idea that holding a bull by his horns is a courageous and direct action that means we deal bravely and decisively with anything that is difficult, dangerous, or unpleasant. In chronic conditions, we deal with a specific matter in a direct manner; we confront a difficulty rather than deny or avoid it: “We choose to go to the moon in this decade and do the other things, not because they are easy, but because they are hard.”¹ In spite of frustrations and fear, we can navigate our journey with chronic disease and find that life is worth living. Helen Keller wrote, “Life is either a daring adventure or nothing. . . . Character cannot be developed in ease and quiet. Only through experience of trial and suffering can the soul be strengthened, ambition inspired, and success achieved.”²

A Time to Pause

We live *in hac lacrimarum valle*, in this valley of tears. Chronic disease can result in not being able to do something we were able to do before and, if it is degenerative, can include more losses as the years pass. There can be a change from being invincibly independent to being minimally or severely dependent. If we were fiercely independent before onset, it will be difficult to accept needing assistance in whatever form it takes. Assistance means a certain reliance on others for our physical needs and therefore decreased self-sufficiency. Yet if we think about it, is anyone really independent? Who doesn't need an electrician, plumber, computer technician, or

A WAKE-UP CALL

auto mechanic? Our lives are dependent on others and subject to circumstances beyond our control.

No two people experience life, or their chronic disease, in the same way. A chronic disease diagnosis can cause us to stop and reevaluate what is most important in our day and what means most to us. We can no longer kid ourselves. We may not feel, think, or act like we used to. There may be role reversals and lost dreams. However, as we let go of our former self-perceptions, we can forge a new sense of who we are and what we can do. It is time to reorient and renew ourselves. We gracefully move from a focus on our disease to a focus on living. We can change the way we think about ourselves. Although we may not have a choice regarding our loss, we can choose to pull through it: “All we have to do is look around us and we see that loss is one half of the process of life. New life can only come when there is a letting go of what was there before. This is the story of human existence from beginning to end.”³

Some chronic diseases are not visible to others. A person with a no-show disease appears to be in good health. Non-visible diseases include fibromyalgia, high blood pressure, high cholesterol, early stage heart disease, diabetes, and uterine cancer. Conversely, a chronic disease may be obvious through a physical deformity; the use of a cane, wheelchair, brace, or splint; or anything we can see. Certain long-term physical conditions can progress to needing personal assistance in daily activities such as hygiene, dressing, grooming, and eating. A chronic disease can result in at least one limitation in activities of daily living. Physical limitations can range from needing help with a fine motor task, like threading a needle because of a hand tremor, to being bedbound from a stroke. A long-term

COURAGE THROUGH CHRONIC DISEASE

disease can affect one body system or be systemic, affecting several body systems. A chronic physical disease requires periodic visits to the doctor and can have daily responsibilities such as medications or times for rest. It can reduce our level of activity, change our physical abilities, require diet restrictions, cause fatigue or muscle weakness, decrease range of motion, or limit mobility. Full-time employment may be reduced to part-time, or a home may need modifications. However, as we learn to deal with big and small issues, we can become stronger for it.

People with disabilities should not be defined primarily by what they cannot do. The limitation or disease is a peripheral element. What is central is a person's unique identity. We learn to cope with our disease, and down the road, coping becomes second nature. Someone may be disabled and have a magnetic personality, a well-honed talent, or a beautiful smile. A person does not need a totally functioning body to enjoy life or be loveable. An individual with a physical disability can be a well-integrated person and a blessing to society. We can see this in Rich Clifford and his Parkinson's disease.

Embrace the Lighter Side

An elderly gentleman named George had a stroke and went to a center for rehabilitation. After discharge, his occupational therapist went to his home to do an initial assessment. This was in the middle of July, and it was extremely hot outside. George met his occupational therapist at the door in a thick sweat suit, perspiring heavily. Come to find out, when he was admitted to the rehab center, he was told that he had to wear sweat suits. This was for ease of dressing while he exercised at the center. He thought he had to wear sweat suits for the rest of his life because he had a stroke. He was one

A WAKE-UP CALL

happy person when his occupational therapist suggested he change into shorts and a T-shirt. Because he no longer needed to wear a sweat suit, he grinned like a Cheshire cat all day.

In Proverbs 17:22, King Solomon says, “A cheerful heart is a good medicine, but a downcast spirit dries up the bones.” Dealing with a chronic disease can indeed give us periods of dry bones, but with the gift of humor, we can reinvigorate them. Finding humor in difficult situations is a lifesaver. Laughter preserves our sanity when dealing with difficult situations. It safeguards our dignity during undignified situations when we receive help from others or do things that are tedious and time consuming. Telling a funny joke can divert our thoughts from pain, keep our heart young, poke good fun at the embarrassments of a disease, or bring a smile to a disappointing situation. A playful or mischievous sense of humor can release pent-up frustration or break the ice for those who are ill at ease when they are with seriously sick people. Laughter is priceless. It alleviates daily annoyances that come with a chronic disease. It has a way of neutralizing the influence of one’s disease by giving the person more command, by decreasing unwanted sympathy, and by offering a constructive alternative to chronic complaints. Mirth decreases the effect of a chronic disease from its daily annoyances to its life altering events. Humor can help us look at a negative situation in a new way or understand it from a different viewpoint. By seeing new lights, we refrain from being trapped in the dark of troubling situations.

Positive humor is simple and fun loving. Who can forget those ubiquitous knock-knock jokes? “Knock knock” “Who’s there?” “A broken pencil.” “A broken pencil who?” “Never

mind, it's pointless." Cartoons, comics, or TV shows can also be the pause that refreshes. A good rule is to find something that is humorous each day. If we are receptive to the lighter moments, it will balance life's ironies and incongruences. We are all a little bit goofy and need to laugh at our silliness, especially when things get too serious.

Practical Steps for Coping with Chronic Disease

Practical help makes life easier. We must respect our own limitations and pain thresholds. In other words, stop or revise a task before you get exhausted or if it provokes pain that lasts for more than twenty minutes after the task is completed. Conversely, avoid taking advantage of people. Do not rely on overly helpful relatives or friends to do things that you can do yourself. Find alternative ways of doing things that are difficult because of your disease. You show respect for yourself when you work within the new boundaries of what you can accomplish. Household tasks can be redistributed to preserve your energy: Are there any that can be done less frequently or in an easier or more efficient way? Is a high-energy activity followed by a low-energy one? Do you rush through a task just to get to the next one, or do you complete it at your own pace and celebrate its completion? Our abilities and resources need to balance our expectations and desires. We find the mean between going too fast and going too slow, doing too much and doing too little, resting and exercising, working and playing, and praying and planning.

Stay up-to-date about managing your disease because treatments may improve and our needs at onset may change or be dif-

A WAKE-UP CALL

ferent several years later. Never has so much information about diseases and their related matters been available to us. However, cautiously screen information and ads that promise fast relief or the latest remedy or cure. To maintain a gentle acceptance of your chronic disease is to embrace wherever you are on the disease continuum. In other words, accept things as they are rather than as you would like them to be. As you look back on your years with a chronic disease, somehow you can sense that pain can be a channel for growth in ways you were unaware.

A chronic disease can cultivate a tough yet compassionate resolve, and over time we will develop an increased tolerance toward people who say odd things to us. For instance, a woman who uses a walker is at a restaurant with her friend. A young waiter asks her friend what the woman would like to eat, assuming wrongly that, because she uses a walker, she is not capable of ordering for herself. The woman thinks, “Everyone has limitations.” Most likely, the waiter has not had any significant contact with someone who uses a walker and saw the walker and not the woman. It is up to her to kindly teach him—people use walkers to walk just like they use forks to eat. Similarly, when people respond glibly to an assistive device by saying something like “keep smiling,” perhaps it is because they really do not know what to say and feel they should say something. They hope their words, although seemingly superficial, will help in some way. In reality they may feel as helpless as we do concerning the things that cannot be changed, and they may care for us beyond the expression of words. There was a time when many people had long-term relationships with their family doctor. He knew them and their families well. Today, however, with the limited amount of time physi-

COURAGE THROUGH CHRONIC DISEASE

cians spend with us, and care being distributed among several specialists, we need to actively participate in our health care. Being an active partner is more beneficial than being a passive patient. We are proactive by maintaining a dynamic attitude in managing and understanding our disease.

A team approach works well in health care. It can give the patient an active voice when communicating with health care professionals. The members of our team are our health care partners. Doctors are our primary partners. We follow their advice and ask questions as needed. Other members of our team can be a physical therapist, occupational therapist, psychologist, social worker, nurse practitioner, or caregiver. They too are contacted as needed. Within our health care team, we are the captain, as well as the case manager, regarding the care we desire. However, we neither overstate nor understate our own importance. We are team players. If we look at our team as human beings first, it is easier to see ourselves as a working partner with the others.

We need to pull our own weight regarding our health care and not depend on our doctors to fix everything, or to make our decisions, while we do nothing. The time a doctor spends with us is limited, so we use it wisely by organizing our thoughts, asking questions, and writing down answers. We raise concerns at the beginning of a visit instead of at the end. It is important that we like, trust, and respect our doctors. If we do not feel a sound connection to our doctor, we need to find another one. If we have several doctors, we keep them updated about the current status of our condition and changes in medication. We maintain responsibility by keeping our medical appointments and learning about the med-

ications we have been prescribed. We need to be responsible because the final decisions about our health care are up to us.

The Spiritual Realm

We must realize medicine's limitations. There is not a cure for everything. Some things cannot be fixed. More treatment is not always better. Sometimes there are no answers, and the best that can be done is to control the symptoms. However, healing is more than cure or symptom relief. It includes the ability to find new strengths, to learn more about ourselves, and to abide by sound guidance regarding well-being and the sacred quality of life. Even though we have frail physical health, we can excel in mental and spiritual health. Everyone has spiritual needs, and it takes a courageous person to admit to them. A chronic condition can be a wake-up call, or a renewal call, to fully embrace the reality that God truly exists and that we travel in a spiritual as well as an earthly landscape. The beliefs and practices of faith grounded in a time-honored religion can shape and direct our lives. Deep roots are rarely set within a free-form spirituality that has ambiguous moral and social values and contains a diverse mix of beliefs and new age thinking. Incorporating the practices of religion into our lifestyle fosters and strengthens a sense of well-being, optimism, tranquility, and altruism. It increases our network of friends and encourages us to abide by authority, such as by following doctor's orders. A person who is serious about his or her religion is less likely to do harmful things such as smoke, drink to excess, or engage in promiscuous or violent behavior. It is well-known that people who regularly worship God lead longer and happier lives. Living without God, who is infinite and ineffable, is a severe improv-

COURAGE THROUGH CHRONIC DISEASE

erishment: “Everyone needs to be touched by the comfort and attraction of God’s saving love, which is mysteriously at work in each person, above and beyond their faults and failings.”⁴

The Bible tells us we are made in the image and likeness of God. Grace assists us in striving to maintain that image by reaching upward and outward toward what is beautiful, good, and true. A chronic condition may provide the time to reflect upon and practice this art of reaching up to God and out to others, especially in little ways, which are the best ways. In a spiritual context, living with a chronic disease reveals that life is more about sharing and helping than about getting and spending.

The most characteristic expression of authentic religions is prayer. In the Christian tradition, prayer invigorates as it helps to form a secure identity based on the life and love of Jesus, who shows us the way to God the Father and teaches us how to pray. Prayer helps us see things in a way that sustains life. Prayer can recharge low energy, be a balm for our wounds, or be a boost for work that needs to be done. Deep prayer can be a wordless union with God. With him in our lives, everything has a higher purpose, even if we do not find out what it is. No matter what our circumstances, we believe God’s love surrounds us, enfolds us, and guides us toward our highest good. Prayer sustains our confidence in God and in ourselves.

Disease has been with us since the fall of humanity. By embracing the gift of faith, we can unite our suffering with Jesus’s crucifixion and offer it to God the Father for the betterment of humanity. Faith in Jesus reveals that suffering is not useless. Rather, it brings new meaning to life. We see beyond a broken world. Jesus’s teachings open our eyes to new ways of looking at things. We evolve from being indiffer-

ent about unfavorable aspects of life to thinking about how we can make them better. Learning about matters of faith is above and beyond reason. We may be drawn to investigate faith through academic pursuits, but faith in God continues to develop beyond the intellect. Many things on the spiritual journey cannot be fully explained or understood. Faith inspires us to live rightly and do good for others. It takes us into the deepest meaning of life and builds a strong relationship with God.

Faith gives us the assurance to never give up on hope. Like a bird that sings in the dark, a lighthouse in a storm, or a brilliant star in the night, hope is the beacon that guides us forward. Hope magnifies our vision to see brightness beyond the shadows and light beyond the dark. Like a sturdy vine that makes its way around obstacles and difficulties, hope is a strong companion on our journey. Faith and hope are like sturdy supports that keep us standing straight and moving forward.

Having a chronic disease does not decrease our value as human beings. More precisely, we can be remarkably resilient concerning our self-worth when we have a will to survive in the face of disease and when we perceive a horizon much larger than we see. At onset we can fume and fuss about our diagnosis, but in time we can gracefully accept and settle down to its reality. When something is taken away from us, perhaps it is making way for something better. We become peaceful about our diagnosis and limitations and strive to maintain an ongoing positive attitude toward our disease and ourselves. A chronic disease can be the push we need to develop healthier habits, to build inner strength, to learn new skills, or to search for a more profound meaning in life. How we handle

COURAGE THROUGH CHRONIC DISEASE

the difficulties caused by our disease can be a source of inspiration to others. Because of our lifelong disease, we can do much good, since we know what it is like to need help. We can reach beyond our personal circumstances to a cause or mission greater than ourselves. Coping with a lifelong disease can give us insights into other people's pain, strengthen our empathy, and motivate us to help others. Each of us has special gifts to discover and use well: "I am only one; but still I am one. I cannot do everything; but still I can do something; and because I cannot do everything, I will not refuse to do the something I can do."⁵

This book does not offer diagnosis or treatment for specific chronic diseases, nor is it a source for medical advice, which is for doctors. The text goes beyond the medical model and addresses the different aspects of a well-integrated human being who is striving toward a dignified, respectful way of life and who happens to have a chronic disease. These pages invite readers to observe and improve their quality of life and strengthen the various components that make up their personhood. In spite of, or even because of, a chronic physical condition, we can move forward and become better people. Having confidence in God and in ourselves, and responding positively to grace, endorses us as valuable and distinctive human beings who are summoned to the fulfillment of incredible potential for greatness and achievement.

Notes

1. John F. Kennedy, "Moon Speech," transcript of speech delivered at Rice University, September 12, 1962, <https://er.jsc.nasa.gov/seh/ricetalk.htm>.

A WAKE-UP CALL

2. Hellen Keller, *Let Us Have Faith* (Garden City, NY: Doubleday, 1940), 50, 51.

3. Joan Guntzelman, *God Knows You're Grieving: Things to Do to Help You Through* (Notre Dame, IN: Sorin Books, 2001), 88–89.

4. Francis, *Evangelii gaudium* (November 24, 2013), n. 44.

5. Edward Everett Hale, cited in *A Year of Beautiful Thoughts*, ed. Jeanie A. B. Greenough (New York: Thomas Y. Crowell, 1902), 172.

