

HOPE AND HELP *for* THOSE
PROVIDING SUPPORT



WHEN SOMEONE
YOU **LO**[✈]**VE** HAS
a
**CHRONIC
ILLNESS**

TAMARA MCCLINTOCK
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chapter one

GET READY FOR A LONGER LIFE

First, the good news: we are all living longer lives. Now, the bad news: we are all living longer lives.

Life expectancy has changed. Consider that the average life expectancy in 1920 was around fifty-four years of age. Today's life expectancy is between seventy-six and eighty years of age, though many of us can expect to live much longer. Already the number of people living well into their eighties and nineties is increasing, and chances are that many more of us will live to be centenarians. If we all could grow old in perfect health, aging would likely not be distressing. For many, however, illness is an unwelcome companion to aging. Taking into account the baby boomers, who represent the largest generation in history to age en masse, many more of us will confront illness than ever before.

Many diseases that used to end our lives no longer threaten us in the same way. For example, smallpox has been eradicated. We have vaccines for many diseases such as measles and polio. We have treatments for tuberculosis. Breast cancer, which was once fatal, is now often referred to as a chronic illness. Previously, most people who had heart attacks died. This is no longer so. Though some do, many more people survive due to our advanced understanding of treatment and prevention. Doctors used to tell patients to stay in bed after a cardiac event, and we know now this is the

worst thing people could do! Also, consider that aspirin has been shown in large-scale trials to be a major treatment and preventative medication for heart disease since only 1988.[1]

Modern medicine and medical treatments have come a long way in just the last few decades. People who are over seventy remember a time when all of the aforementioned diseases were fatal. Though the playing field of illness has been leveled somewhat, we now have new concerns. What does it mean that many of us live longer with chronic disease? Are we prepared? Do we even know what it means to be prepared? How do we help those we care about who become ill? Though many of us will struggle with minor or major illnesses of our own as we age, we will also likely see people close to us become ill. How can we help them and still take good care of ourselves? That is the purpose of this book. Loved ones trying to relate to and comfort those who are sick need their own tools for coping.

With the changes in the landscape of modern medicine, the nature of many illnesses has changed. One of the consequences of a long life is that those who become ill can stay that way for a very long time. Forty years ago, most people did not have to worry about chronic illness. Today, more than 133 million Americans, or 45 percent of the population, have at least one chronic condition, and 26 percent have multiple chronic conditions.[2] Chronic disease is the leading cause of death and disability in the United States.

Most of us are new to the terrain of chronic illness. Relatively and historically speaking, chronic and prolonged illness used to be a problem that affected few, not many. Heart disease, COPD (emphysema), arthritis, strokes, and Type II diabetes are all diseases that have changed the backdrop of illness. With the increase in lifespan, there is an increase in the number of and kinds of diseases that can plague us and those we love. In addition to the limitations these illnesses can cause, another new problem is that many more people struggle with chronic pain. All of these ailments reflect the good and the bad of modern medicine: many of us live longer, but many more live with chronic disease.

An unintended consequence of chronic illness is that many more of us serve in formal and informal caretaking roles. A recent AARP report notes that “in 2009, about 42.1 million family caregivers in the United States provided care to an adult with limitations in daily activities at any given point in time, and about 61.6 million provided care at some time during the

year.” [3] Increasing numbers of people who are ill will not only tax our economy and health care system, but also affect all of us emotionally.

Knowing what to say, what to do, and how to manage feelings when someone we love has a chronic illness is hard. Consider the following scenarios:

Your best friend of thirty years tells you she has been diagnosed with advanced cancer. She says she can't stop crying and can't imagine how she will manage chemotherapy.

Your husband of forty-eight years, who is now seventy, begins to act strangely. He uncharacteristically forgets to shower in the mornings, leaves his keys in the front door, and has started repeating himself. When you mention this to him, he tells you nothing is wrong.

You and your spouse have been having dinner with the same couple for years. Suddenly they disappear and are no longer available to meet. You contact the wife of the couple, and she tells you that her husband has just been diagnosed with multiple sclerosis.

Your mother, who has been living independently for most of her life, can't take care of herself anymore. She has been losing weight, forgetting to take her medications, and having trouble with walking and balance. You fear she will need to move into an assisted living facility.

Though all of these scenarios have varying degrees of emotional resonance, they contain a number of the same dilemmas. How do you manage your own anxiety about illness in general? How do you handle your nervousness about how to help or comfort those you care about who are ill? How do you deal with people who avoid you when they are ill? How do you articulate, as an observer, that you know something is wrong and want to help? And when someone does want to talk about the actual struggles of illness, like losing independence or fearing death, what do you say? How do you manage your own emotional discomfort? How do you communicate that you want to help; particularly when you are not sure that you can do anything to help?

In my work as a psychologist and psychotherapist over the last twenty years, I have explored these questions with spouses, children, extended

family members, and friends of those beset by illness. There are no guidebooks for navigating this complicated emotional terrain. For many of us, the thought of illness is scary and leads to feelings of helplessness. When illness impacts someone we love, there are a number of uncertainties. This chapter and subsequent ones will address what to do logistically, strategically, and emotionally, as well as verbally, when someone you love is ill. Moreover, this book will help you identify and manage your own feelings when confronted with a number of dilemmas related to illness. You will learn the ways you can help or hamper the recovery of people who are ill, the ways illness in others forces us to confront our own vulnerability, how to really help those who are in physical pain, how to manage the demands of caretaking, and how to deal with denial—in yourself and in someone who is ill.

Illness reflects a level of vulnerability that is rarely a part of social interactions. However, as we all age, illness becomes more in the foreground than the background. Being prepared emotionally can allow us to feel more confident in talking with people who are ill, acknowledge the ways that we may or may not be helpful, and most importantly, cope with our own emotions. Additionally, as we will see, though we may feel at a loss when it comes to helping people we care about who are ill, managing our emotions can have a powerful effect on the ones we love.

Why Loved Ones Matter

It is striking that emotional reactions, such as grief and feelings of helplessness, in loved ones of patients get lost in the complex and fast-paced world of medicine in this country. Let's face it; doctors barely have time to attend to the needs of their patients, much less those of family members or friends. Emotional encounters in the arena of medicine (such as a physician asking, "How are you coping with this?") are still relatively uncommon. When this question is asked, it is far too often directed at the patient, while loved ones stand by silently. At home, family members feel uncomfortable talking about their distress, because they don't want to seem selfish or appear as if they do not care about the person who is ill. In friendships, such awkward feelings persist as well. Friends often complain that they do not know what to do or how to help. These feelings are understandable; in the face of the suffering of someone we care about, talking about ourselves risks removing the focus from the patient. On the

other hand, when friends, partners, and family have a voice regarding their own emotions in response to a loved one's illness, they are more emotionally available to help. This availability is crucial, and not just for intuitive reasons. Managing emotions when dealing with illness helps not only us but the patients we care about as well.

Chronic illness is a family disease. By family, I mean to include all who are close to those who are ill. Partners, family members, and friends witness suffering and are all loved ones who experience illness vicariously. Their worry, helplessness, anger, guilt, and sadness often go unnoticed, and they feel alone with these emotions.

The lack of attention afforded to family members carries an ominous price. The psychological and physical health of caretakers suffer, with research showing that older adults who care for their seriously ill partners die sooner than people who are not caretakers.[4] Further, depression and anxiety are higher in family members (particularly those providing some aspects of caretaking) of patients with many kinds of illnesses, from dementia[5] to cancer.[6] Depression and anxiety are not just detrimental to psychological health; physical health is impacted as well, since depression and anxiety disorders serve as risk factors for several medical illnesses.[7]

And it's not just the health of family members that's at risk. When loved ones don't cope well, it affects the patient. Attitudes and behaviors of family members can influence how well patients take care of themselves.[8] When patients have positive and loving support, they are more likely to follow the advice of physicians. Additionally, stressful marriages and those that involve conflict can negatively impact health for reasons that are not well understood.[9] The importance of loved ones being able to manage emotions is not just intuitive; managing difficult feelings is crucial to both mental and physical health—for everyone involved.

Paying attention to yourself, as a partner, caregiver, friend, or watchful witness allows you to be more engaged with, and ultimately more helpful to, your loved one dealing with illness. It is not easy. But consider the work you do on your own emotional well-being to be an investment in your health and that of your loved one.

A growing body of psychological and medical literature, which will be described throughout this book, demonstrates not only that loved ones are as emotionally impacted by illness as patients, but also that when loved ones and patients think together about how to cope, it can enhance the

support loved ones are able to provide. Staying engaged is important. For example, the ability of loved ones to support patients who are ill can erode over time and loved ones can simply wear down and not be as supportive as they want to be. When this happens, it is often related to the difficulties loved ones have giving themselves permission to take care of themselves.

How to Manage Anxiety When Confronted with Illness

There is a funny paradox related to sickness. If we are ill ourselves, many of us cope by finding ways to take control. But when illness happens to someone we love, we are limited in the kinds of control we have. Because of this, illness can be terrifying. The lack of control as it relates to illness is perhaps one of the most difficult challenges we will face. Illness reflects vulnerability, and in the face of vulnerability, many of us want to jump into action. But there is only so much we can do. In the early stages of illness, we are often relegated to waiting for news, diagnostic information, and plans for treatment. Waiting and not being able to do anything can be scary. Consider the case of Ken and his wife, Carol:

Ken noticed an unusual growth on his leg. He pointed this out to Carol, and she suggested that he immediately seek medical attention. Ken called his doctor's office, which gave him an appointment one month later. Carol was enraged. She felt that Ken was being lackadaisical in the face of what might be something serious. But Ken felt that Carol's concerns were exaggerated. Ken kept his appointment for a month later, though the couple argued continually regarding whether this was the right course of action.

Carol's anxiety was paramount, but Ken's wasn't. Although Ken was able to tolerate the stress of not knowing what was wrong with him, Carol was panicked. She did multiple Internet searches regarding what illnesses could possibly explain Ken's situation, and she became convinced that Ken had something serious and life threatening. She was consumed with worry about losing Ken. The couple engaged in near-constant arguing that ended up causing a rift in the relationship. When Ken finally did see a doctor and found out it was a benign growth, Carol felt embarrassed. Although Ken eventually understood this behavior as the result of Carol's love and concern, the couple endured a month of fighting that was unnecessary.

Anxiety is difficult to manage, especially when it comes to the ones we love. In illness (or questions of illness), as partners, friends, or family members, we need to tolerate uncertainty. Carol eventually understood that her anxiety stemmed from how much she feared losing Ken in general, and that resulted in behaviors she regretted.

Despite this good outcome for Carol and Ken, there are many instances in which a friend, family member, or loved one must endure actual illness. In these cases it is also hard to know how to behave. Consider the situation of Ashley:

Ashley's mother had been in renal failure for the past three years. Though she was on dialysis, her health had started to fail. Ashley lived a short plane ride from her parents, but given her work schedule, she could not go home as often as she would have wished. As her mother's health started to deteriorate, Ashley felt increasingly guilty. When she called her parents and asked if she should come home for the weekend, they often said no, that they could manage without her. This left Ashley in a terrible bind. Should she demand to go home to see her parents? Or should she stay where she was and focus on work? Although this decision would be difficult for anyone, Ashley developed extreme anxiety, which kept her from functioning at work. She constantly worried about her mother, lost weight, and was unable to sleep at night.

Ashley's situation illustrates the extreme distress that is common among people who are concerned about an ill loved one but who are not immediately available to help. Though Ashley's parents seemed earnest in their advice for Ashley to continue to work until her mother's health worsened, Ashley's anxiety and helplessness impacted her ability to function. In such situations, it is hard to know what to do. And though any of us would feel anxious in similar circumstances, it's important to remember that our suffering does not help alleviate the actual suffering of the one we love.

Illness makes most of us incredibly anxious. This anxiety is obvious in some ways because we worry about losing people we care about. Illness also reminds us of our own vulnerability, and many people can feel stressed—tortured, even—by worries about their health and vulnerability to illness. Further, when someone we love is ill, our experience of their illness takes

place within the context of our relationship with them. When relationships have been conflicted or unsatisfying, it can intensify the anxiety we feel when people become sick. In subsequent chapters I will discuss many facets of how our relationships with others impact how we cope with their illnesses. As a starting point, however, it is important that loved ones become aware of and manage their own anxiety.

Techniques

Consider the following suggestions as a Band-Aid for dealing with anxiety in the short term. Getting control of the initial emotional discomfort we experience when someone we love is ill is often a needed first step so that we can think about other feelings.

Breathing Exercise

One of the best behavioral treatments for anxiety is a simple breathing technique, which can help to calm down our bodies in the face of stress.

Focus on your breathing. Notice if your breathing becomes shallow when you are nervous. This is common. Compare this to how you take deeper breaths when you are relaxed. Shallow breathing is a normal symptom of anxiety and is related to the fight or flight response, which will be discussed more in [chapter 7](#). Slowing our breathing down when we are nervous allows us to take control of the physical effects of anxiety. It is like a natural drug that tells our bodies we are safe. Use this diaphragmatic technique to slow breathing when you are anxious:

- Place one hand on your chest and the other on your abdomen. When you take a deep breath in, the hand on the abdomen should rise higher than the one on the chest. This ensures that the diaphragm is pulling air into the bases of the lungs.
- After exhaling through the mouth, take a slow, deep breath in through your nose, imagining that you are sucking in all the air in the room, and hold it for a count of seven (or as long as you are able, not exceeding seven).
- Slowly exhale through your mouth for a count of eight, or as long as you can. When all the air is released with relaxation, gently contract your abdominal muscles to completely evacuate the remaining air from the lungs. It is important to remember that we deepen respirations not by inhaling more air but through completely exhaling it.

- Repeat the cycle four more times for a total of five deep breaths and try to breathe at a rate of one breath every ten seconds.

It is important to practice this technique a few times a day, even when you are not anxious. The idea is to get your body and mind to recognize the difference between anxious and relaxed states. Additionally, practicing any relaxation technique, including diaphragmatic breathing, when you are relaxed allows you to develop and hone the skill of relaxing yourself. Being able to master this skill is important because you can then use it when you really need it.

Managing Worry

When we are anxious, our minds can kick into over-drive and we try to solve problems that cannot immediately be solved. Many people refer to an anxious mind as a rat on a wheel going nowhere. We may lie in bed contemplating how we could have handled a situation differently or imagining what we can do to help someone we care about. The problem with an overactive mind is that we can rarely act to make things better. For example, if you are lying in bed at 2:00 a.m. on a Sunday morning, there is likely little you can do to solve the problems you are worried about.

One way to soothe your mind in such a situation is to get out of bed and make a list of what you are worried about. Divide the list into two columns. One list should include actions you can take at a later time to solve a problem. Consider when you can take the action. For example, if you want to call your mother's physician, write down when you will do so. The other column should be worries that you can't take any action about. For example, you might write, "I am worried that my friend's cancer will come back." The goals of this exercise are to focus on what you can actually control and to place your worries outside of yourself as a way to postpone your worry. Tell yourself you will have plenty of time to worry later. Indeed, this is the great thing about worries: we can always come back to them! When we are worried, it is helpful to focus our energy on what we can actually do to take control and to tell ourselves that although we may not be able to do anything at the moment, we will try to take action when we can.

Life, Interrupted: When Illness Takes Over

Most of us take for granted the idea of good health. This is as it should be. Those of us who are born healthy and experience the health of those around us naturally expect that those we love will go on living healthy lives. Unfortunately, this is not always the case, and when someone we love gets diagnosed with a serious illness, it can be quite destabilizing. It can alter life as we know it. It can threaten the future of relationships as the vision of normal life quickly fades away. Things that other people take for granted, such as Saturday morning errands or a quiet Sunday brunch with family, are disrupted by the limitations of illness. Though life might have been hectic beforehand, when a loved one is diagnosed with an illness, it can change your entire worldview. And whether you are a partner, family member, or close friend, when someone we love is ill, normal life changes into a series of questions: “What will the future hold? Will we be able to exist as we did before? Will I be able to help my loved one deal with the terrifying uncertainty of this illness? And if I am alone to deal with all of this, how will I manage?”

Illness interrupts life. It changes everything that we come to expect from those we love. Such changes are disorienting. And since the person we love is the patient, we have to figure out how to help them and manage a plethora of disjointed feelings.

Although anxiety can be distressing, it can also help us. It can help us to mobilize our coping defenses. When we are trying to help someone we love with an illness, we can use it to harness the energy to fight, to encourage our loved one to fight, and to help find the right medical clinicians who can advocate on our loved one's behalf. But anxiety can also be paralyzing when we feel so overwhelmed that we stop functioning and don't know what to do. In the cases of Ashley and of Ken and Carol, we saw striking examples of well-meaning people who felt powerless in the face of a possible illness. They tried to manage their anxiety by being controlling or irritable, both of which served to make them even more helpless in terms of how they might cope. Though illness, or the threat of it, in someone we love can make us terrified, managing these feelings and anxieties allows us to maintain important relationships and helps us to help the ones we love.

The rest of this book addresses a variety of complex emotions as well as practical concerns that often impact people who are trying to help someone who is ill. Coping with anxiety is an important first step.

However, even if you can't figure out how to control your anxiety about illness, just knowing you are anxious is important. Many people I have seen throughout my career have been anxious but have not realized it. Being aware of and mindful about anxiety is crucial. In this tenuous time of a long life, many of us try to ward off feelings that make us uncomfortable. However, some level of anxiety about our long lives and related uncertainties seems to be the “new normal” of living in the twenty-first century. Fortunately, we can all learn how to manage anxiety and deal with what we are afraid of.

CHAPTER 1

COPING CHECKLIST

- We are experiencing an unprecedented time of aging and longevity. If you find yourself nervous about the future, know that you are not alone.
- When dealing with uncertainty about illness, trust that a patient can decide how urgently to seek medical attention.
- Manage anxiety through the diaphragmatic breathing technique described in this chapter. Only you can control your own anxiety.
- Deal with worry by writing down your concerns. Distinguish what you can and cannot control. Tell yourself it is okay to postpone your worrying and that you can come back to it later.

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