Coping *with* Chronic Illness

H. Norman Wright
Lynn Ellis

HARVEST HOUSE PUBLISHERS
EUGENE, OREGON

Unless otherwise indicated, Scripture quotations are taken from the Holy Bible, New International Version®. NIV®. Copyright © 1973, 1978, 1984 by Biblica, Inc.™ Used by permission of Zondervan. All rights reserved worldwide.

Verses marked AMP are taken from The Amplified Bible, Copyright © 1954, 1958, 1962, 1964, 1965, 1987 by The Lockman Foundation. All rights reserved. Used by permission. (www.Lockman.org)

Verses marked NASB are taken from the New American Standard Bible®, © 1960, 1962, 1963, 1968, 1971, 1972, 1973, 1975, 1977, 1995 by The Lockman Foundation. Used by permission. (www.Lockman.org)

Verses marked NKJV are taken from the New King James Version. Copyright © 1982 by Thomas Nelson, Inc. Used by permission. All rights reserved.

Verses marked TLB are taken from *The Living Bible*, Copyright © 1971. Used by permission of Tyndale House Publishers, Inc., Wheaton, IL 60189 USA. All rights reserved.

Verses marked MSG are taken from The Message. Copyright © by Eugene H. Peterson 1993, 1994, 1995, 1996, 2000, 2001, 2002. Used by permission of NavPress Publishing Group.

Verses marked NLT are taken from the Holy Bible, New Living Translation, copyright © 1996, 2004. Used by permission of Tyndale House Publishers, Inc., Wheaton, IL 60189 USA. All rights reserved.

Harvest House Publishers has made every effort to trace the ownership of all quotes. In the event of a question arising from the use of a quote, we regret any error made and will be pleased to make the necessary correction in future editions of this book.

Cover by Dugan Design Group, Bloomington, Minnesota

ADVISORY

Readers are advised to consult with their physician or other medical practitioner before implementing the suggestions that follow.

This book is not intended to take the place of sound medical advice or to treat specific maladies. Neither the authors nor the publisher assumes any liability for possible adverse consequences as a result of the information contained herein.

COPING WITH CHRONIC ILLNESS
Copyright © 2010 by H. Norman Wright and Lynn Ellis
Published by Harvest House Publishers
Eugene, Oregon 97402
www.harvesthousepublishers.com

Library of Congress Cataloging-in-Publication Data
Wright, H. Norman.
Coping with chronic illness / H. Norman Wright and Lynn Ellis.
p. cm.
Includes bibliographical references.
ISBN 978-0-7369-2706-2 (pbk.)
1. Chronic pain—Psychosomatic aspects. 2. Chronic pain—Alternative treatment. I. Ellis, Lynn. II. Title.
RB127.W75 2010
616'.0472—dc22
2009017211

All rights reserved. No part of this publication may be reproduced, stored in a retrieval system, or transmitted in any form or by any means—electronic, mechanical, digital, photocopy, recording, or any other—except for brief quotations in printed reviews, without the prior permission of the publisher.

Printed in the United States of America

10 11 12 13 14 15 16 17 18 / VP-SK / 10 9 8 7 6 5 4 3 2 1

Copyrighted material

Contents

1

A World *of* Pain *and* Frustration

There's an epidemic raging through our country. It's silent and raises no great alarm. Most people are unaware of it or they choose to ignore it. If you're reading this book, you're probably experiencing part of the epidemic. This illness takes over and regulates your life. Relatively invisible, it can't be seen like a broken limb or a visible deformity. This condition is one of the most glaring problems in health circles today, but it's largely discounted. In fact, you may feel ignored if you're suffering from it. Some people, including doctors and other medical personnel, believe if it isn't visible, "it doesn't exist." That's the prevailing mentality. Other than those struggling with the condition, few talk about the problem. What is this condition's name? Chronic illness.

Ninety million Americans had a chronic illness in 1987, and by 1998 it grew to 120 million. By 2030 it will probably be 171 million.[1] But the fact remains: Chronic illness (and the accompanying pain) is largely unrecognized.

"Chronic" is an interesting word, especially when it's linked to "condition" or "pain." A chronic condition has been defined as something that "is prolonged, doesn't resolve spontaneously, and is rarely cured completely." Can you identify with that? One doctor said that having a chronic illness is like having a career. You can do poorly or well at it. Doing well doesn't mean being cured; instead, it refers to your ability to cope and make needed adjustments. It's learning to live "in spite of." Some have lived well with chronic illness while others are crushed. Chronic illness means a life of uncertainty, including type of diagnosis (if any), treatment, duration, and what kind of future awaits you. Chronic illness is a life of certainty about having to face uncertainty, fears, and physical and mental anguish. Chronic illness means living with "invisible" symptoms that no one but you sees, feels, and are aware of.

As compared to diseases with clear-cut symptoms, chronic illness is often hard to describe accurately. You can't pin down what you're experiencing, which leaves you and others a bit puzzled. And it's difficult to measure some of the symptoms because of their complexity and the fact that some come and go without seeming to have a pattern. All of this lends itself to a diagnostic struggle. So does the fact that some symptoms could signify one illness or maybe another since they often overlap. Confusion exists in your mind as well as in the minds of medical professionals.

You may find it uncomfortable to talk about your symptoms with someone other than a doctor because of topic embarrassment: diarrhea, constipation, incontinence, cognitive impairment, depression.

Sometimes you may feel almost well, while other days you're incapacitated. This frustrates the people around you…and you. And you fear someday you'll remain incapacitated. Treatment may help…or may not…or may sometimes.

The diagnosis "it's all in your head" is a concern that comes and goes in your mind and in the minds of others as well. And in the minds of others some or all of the symptoms may seem nonexistent.[2]

How does chronic illness impact people? Listen to some who live with this illness:

- "It's been like taking some of your life away by taking pieces of it until there are so many things you used to be able to do that you can't do now."
- "It's just like when somebody dies. You grieve and you go through a cycle of disbelief, shock, anger, and so forth, but with this illness you end up like a hamster on a wheel where you just keep going around and around."
- "Why have any expectations? They just get crushed."

- "It's so different all the time. Today I'm fine and tomorrow it may be a different story. I could be knocked out. I have no predictability in my life."
- "It's not a typical depression. I'm dragged down by my pain and exhaustion."
- "I can't make big meals anymore. We have to limit the size of family gatherings."
- "I can't play racquetball anymore. I can't even clean one room."
- "I used to dislike going to work each day. I'd give anything to be able to work again."
- "I miss doing things for myself. I have to wait for others and I hate that."
- "I feel like a failure. I feel useless. I feel like a burden to my family."
- "My world has shrunk. I didn't choose this."
- "My struggle is keeping depression at bay. I'm on the edge of depression all the time and it doesn't take much to tip me into it. The illness goes in unpredictable cycles. When the illness is in a better cycle, the depression improves also. The other problem is trying to convince others that I really am sick when I look fine."
- "For years some of the doctors treated me like I had something mentally wrong with me. They prescribed addictive medications and then treated me like a drug addict if I called for a refill."
- "People don't understand and ask, 'Why do you go to bed so early?' If I don't go to bed at eight, I can't get up the next day. I can't do what everybody else can do, and when I try, I pay for it dearly. I have to learn to manage my life. I have to become my own doctor. And this is really hard."
- "When I woke up my head was killing me—my neck was messed up because of how I laid on my pillow. I have to be so careful—I just wanted to shoot myself because I laid on

the wrong pillow and then I thought, *I can't believe this. I'm getting a migraine and I'm in this pain again*. I'm really disappointed. Then I think, *What do I tell others?* It's going to be disappointing for others and what do I tell them? I can just hear the conversation, 'How are you doing? How'd you sleep?' And I'll say my head is killing me, and I'm getting a migraine. It's such a letdown for me and it must be a letdown for others. So I'm struggling with what to do. Do I try and hide it or do I tell them because it's a disappointment for the other person? It's hard for me to deal with this, and it must be for them too. They're going to think, *Here we go again, another day—another headache*. It's just one of our struggles we deal with."

- "It's a feeling of being 'less than.' It's weakness."
- "Even saying, 'I'm doing the best I can with this disease' is a problem. Perhaps it would be better if this were a disease like cancer. But it's like these diseases don't count. Even in my mind they don't count as much. Some diseases are more acceptable than others. I have all these diseases that have been verified, but I still have a hard time with them being legitimate. It's like fibromyalgia is legitimate and yet it's not."
- "It's constantly working through these issues in my mind again and again, and it's a lifelong process. It's not like taking an antibiotic one time and it goes away."

Perhaps you identified with many of these experiences. Your story could be similar. Trying to make others understand your invisible illness is difficult. When others hear about it, they often say, "You look fine. It's hard to believe there's something wrong with you."

Your New Reality

What can you expect when you're struggling with chronic illness? Plan to be misunderstood by others. People don't understand what you're going through, especially because the illness can't be readily seen. They may judge, be indifferent, or show pity rather than support you.

Isolation may be another experience forced on you. Confinement isn't a pleasant experience. You may spend thousands of hours by yourself. This isolation soon turns into feelings that add to your misery. Rejection can lead to fear, loneliness, anger, and resentment. Many people are uncomfortable being around those who are sick and would rather be with those who are healthy. So you become isolated, which leads to feelings of abandonment and neglect.

You also may experience monotony. Because of your illness, reading or writing or watching TV may not be an option. Some find that any type of sound is stressful. The lack of activity and involvement can lead to guilt as well as a damaged self-esteem.

Have you ever felt dehumanized? When you're sick, you're soon seen as "sick" and referred to as "sick." If you're hospitalized you may feel dehumanized by the routine. When you feel you've lost control of your life, this feeling grows.[3] One woman describes her struggle this way:

> I was at the mercy of others. How easy it was to waver between guilt (for being such a burden), contempt (because help wasn't forthcoming), fear (that no one would be there if I needed help), anxiety (that if I asked for help, I would be rejected), anger (at my body that refused to cooperate), self-pity (that I couldn't function normally), panic (from things I didn't understand), dread (that I would get worse, not better), despair, hopelessness, worry, irritability, and frustration![4]

Imagine you're in a group at your church and several are aware that you have a chronic illness. One individual comes up to you with what seems to be a simple question, "What is a chronic illness?" That's an excellent question since most people don't have a clue. A chronic illness is "forever" (with a few exceptions) and is often painful. And what accompanies it is fatigue, depression, and a number of other symptoms, depending on the specific condition. Chronic illness necessitates constant involvement with the medical community, which is expensive. Your life is changed, often drastically. How? Alterations include your daily lifestyle, future goals, vocational choices, recreational activities, relationships with family and friends, and your role in your family.[5]

There are other words to describe chronic illness. Perhaps two of the most descriptive expressions we hear are "uncertainty" and "unpredictability."

And this is what is so frightening. We all function better with certainty and predictability. It seems no matter what you do or how hard you try, you're out of control. Your expectations, dreams, and desires for your body may go unfulfilled. And solutions are not forthcoming. When you have a chronic illness, you contend with a force that has more power than you. It's an illness with an agenda, which it knows and you don't. Chronic illness seems to have a mind and will of its own. It tends to scramble your thoughts as it ravages your body. You may settle into a routine, but it's not one of your choosing. And the routine isn't always routine. Actually there is little you can count on with your illness.

With chronic illness you no longer plan years in advance. It's hard to plan for the next day because you don't know how you'll feel. Your body, which you used to know so well and was a friend, has become a stranger and, at times, an enemy. The author of *Being Well When We're Ill* describes the situation so well:

> When chronic illness or disabilities invade our lives, we lose our dreams of well-being, of how we expected to feel each day, of what we anticipated doing in our later years, of what we intended to accomplish with our lives. Some of our dreams are replaced by better ones, but some of our losses leave us inconsolable.[6]

Chronic illness is strange. It doesn't fit the usual pattern of illnesses where you get sick with symptoms, see the doctor, get some medicine, and get better. There is no orderliness to chronic illness; it's chaos.

We've compiled a list that depicts what many people with chronic illness feel. You may want to circle the words that describe what you experience. Because of the changing nature of this illness, you may encounter many of them.

afraid
aggravated
ambivalent
angry
anguished
anxious
apathetic
apologetic
apprehensive
ashamed
belittled
burdened
chaotic
concerned
confused
damaged
defeated
degraded

dejected
dependent
depressed
deserted
despairing
devalued
devastated
disappointed
disconnected
discouraged
disheartened
dismayed
distracted
distraught
distressed
doubtful
embarrassed
excluded
exhausted
fatigued
fragmented
frantic
frightened
frustrated
furious
grieved
guilty
helpless
hopeless
horrified
humiliated
hurting
insecure
insignificant
irritable
isolated
lethargic
listless
lonely
lost
miserable
misunderstood
needy
nervous
overwhelmed
panicked
pessimistic
powerless
rejected
reluctant
resigned
sad
scared
self-conscious
sorrowful
stressed
tense
terrified
tormented
troubled
unnerved
unsettled
unsteady
unsure
upset
useless
violated
vulnerable
weak
weary
worn
worried
worthless

Chronic illness, with its accompanying pain, can result in private anguish. Others don't see your symptoms or pain. All they see are changes in you and may respond with anger, tension, or emotional withdrawal. They can't tap into what you're experiencing or how you feel. This may result in you feeling alone, abandoned, and trapped—with no way out and no help. It's similar to the reactions of those who experience grief over the death of a loved one for the first time. You may say, "I'm going crazy!"

When you live with chronic illness and its constant companion of pain, there's another resident as well: fatigue. You probably feel exhausted. Do you know what the word "exhaust" means? It comes from a Latin word meaning "to draw out of." Daily life is a struggle because you feel empty, all used up before you even get out of bed. Your resources are drained, and you feel 50 to 100 years older than you are.

So what do you do? You hang on to hope and concentrate on what you're able to do. You learn how to turn your life over to God's care and seek His comfort and strength.

For many with chronic illness, pain and fatigue become a constant. Admitting and accepting this doesn't equal resignation. In fact, it's more of a release! This is the first step of accepting the reality of the situation and discovering you are more than your illness.

Victory vs. Détente

Many images of illness and our responses draw on the language of combat: We *battle* illness and pain, *fight* infections, and *defend against* germs. Illness is an *enemy* to be *struggled with* and *defeated. Victory* over cancer is sought. Even fatal illnesses are to be constantly attacked in the hopes of medical advancements *(reinforcements)*. The dying patient who wages a valiant battle to the death wins a resounding eulogy.

While chronic illness requires constant vigilance and may be reminiscent of war, ultimately there is no definitive battle to be won. There is no hill to take, no specific achievement to point to, such as remission or a cure. And a lifetime of being at war is extremely draining. Is a truce or détente the best we can hope for…or maybe a negotiated peace?

The way we speak about illness affects how we live with it. The war imagery obligates and even inspires us to resist. But chronic pain, which causes us to focus on surviving and coping, is often described using euphemisms such as "challenged" and "differently abled." This mutes the reality of the pain and suffering involved and can turn the natural sorrow, anger, and anxiety people experience into character defects, calling to mind defeat and resignation.

When you enter into the world of chronic illness you have so many decisions facing you of how to respond it's overwhelming. Each A or B choice contains risk and uncertainty. Which of these have you engaged in or considered?

A. You ignore symptoms, appear strong, and risk getting worse.
B. You overreact to every little twinge and pain.

A. You explore the possibility of a miracle cure, which could bring health and financial risks.
B. You choose to trust one doctor.

A. You keep your illness to yourself and carry the burden alone.
B. You talk openly to everyone, which could generate self-pity.

A. You demand that others treat you as normal, which doesn't allow them to share their concerns about you.
B. You let them cater to you, but worry about becoming dependent.

A. You push your body to override your illness so you "have a life" but you'll probably get worse.
B. You choose to be safe and overly cautious, which limits you.

A. You live with the fear of the worst happening.
B. You see each good day as a gift.

A. You choose to live with anger and resentment.
B. You focus on your blessings and perhaps risk a life of denial.[7]

When you have a chronic illness, your perception of yourself changes, and often not for the best. Some describe themselves as "deficient" or "defective" or they identify who they are by their illness: "I am fibromyalgia," "I am arthritis," "I am chronic fatigue," "I am lupus." This misidentity doesn't recognize their unique, God-given talents, skills, personalities, and characteristics. They need to separate their illness from who they really are.

A healthy response came from a woman who said, "I am not my fibromyalgia. I am a person not an illness. I am not just my hurting joints and muscles. I am more than this. I am more than my body. I am a choice person, a child of the King. I am loved just as I am."

How do you see yourself? How do you refer to yourself?

Remember, your illness may limit you, but it doesn't define you. Chronic pain may control some aspects of your life, but you are in charge of most areas…as well as your thoughts.[8]

Why Me?

Have you asked, "What happened to me? Why am I sick? Why do I have to suffer?" There are many reasons illness and disease occur. Some are physical—the immune system is too weak, too strong, or otherwise impaired. In a weakened state the strength of certain pathogens (bacteria, viruses, fungi, for example) is too much and overpowers the system. Or with an autoimmune disease, your system goes haywire and looks at certain good cells in your body as foreign invaders and says "they've got to go," so they're attacked by friendly fire. Why does this happen? No one really knows. It's a puzzle why these disorders exist, why some cells tell the immune system to attack, or why the system can't tell the difference between the good body cells and the bad invader cells.[9]

We're all aware that at some point in our lives we'll be sick. We hope that each experience will be temporary. If told that we have a disease, we hope it will be brief, pain free, and curable. If diagnosed with one that is permanent, we hope it is painless and not terminal. We hope it affects only the physical realm and not our mental capacities. We hope its symptoms are manageable and observable enough that they elicit support and sympathy from doctors, friends, and family.

But when chronic illness hits, the impact is total—body and mind. Often the mental stress is as painful as the physical. Most who live with a chronic illness will have additional struggles due to the reactions of people around them. Many will respond with help and support. And some are very knowledgeable. Some provide well-meaning but useless advice:

- "You really need to see this doctor. Everyone says he's the best, so don't waste your time with others."
- "You need to start treatment now before it's too late."

- “My stepsister has the same thing, and she’s fine. It wasn’t that painful for her.”
- “Don’t worry. It’s in God’s hands. Just remember Romans 8:28, ‘In all things God works for the good of those who love him.’”
- “You have what? That disease will change you more than you realize.”
- “This may sound strange, but this could turn out to be a real blessing in your life.”
- “Have you ever thought that maybe God is trying to get your attention through this?”
- “You know, God only gives problems to those who can handle them.”[10]

Knowing what comes next, in general at least, is a commodity we all want for security. With certainty, we can relax and move forward. Without it we’re like a boat without an anchor, constantly drifting and running into rocks and underwater hazards. The statements just shared confirm our uncertainty, which leads to another struggle—doubt. What makes it worse is that it’s self-doubt. You begin a continuous debate within your mind: “Am I really sick or not? Yes—no—I’m not sure. It feels like I am, but what if I’m not?”

Uncertainty takes an incredible amount of mental energy which, in turn, drains physical energy. And adding to your self-doubt are the responses of others, especially when you see suspicion and skepticism on their faces or sense them in their voices. The more you receive these negative responses, the more you tend to believe your doubts.

The best response is, “When in doubt, believe.” You know yourself and your body. Document your symptoms by writing them down. Keep a journal. Believe they’re true…because they are. The pain and symptoms are real. You’re not dependent on others to validate what you are going through. They’re not experts on you. Refuse to give others control over you. Yes, there are some aspects of your chronic illness you have no control over, but you do over your thought life.

Unfortunately, self-doubt won't exist by itself. Other negative variations spiral, and sufferers end up not liking themselves. As one said:

> What's to like about myself in this condition? I question my condition and what I'm experiencing. If I can't be certain about that, how can I be sure about my own qualities and what I have to offer? Sometimes I find myself believing what I think others must think of me, and of course it's not positive.

Self-doubt creeps into your decisions about life, the future, and God.

> I look at others and they can rest in being certain about everything. My beliefs about God and who He is and what He does have crumbled. I wanted to get married, but that's not a given anymore. And how can I support myself? I can't even finish college now, so the promise of the degrees and the profession I hoped for have vaporized. No wonder I don't like me or feel secure.

"Am I going crazy?" chronic illness sufferers ask constantly. You wonder, as do friends, family, and even doctors, "Is this real or is this all in my head?" With uncertainty, doubts about your sanity make inroads into your thought life. When a doctor hints or subtly suggests, "Perhaps it's more in your head than your body," and then asks if you've ever thought of seeing a counselor, self-doubt arises almost automatically.

When my (Norm) wife, Joyce, experienced her battle with fibrocitis (now called fibromyalgia) years ago, her doctor suggested she see a psychologist "just to make sure this is really a physical disease." She did… but it didn't make the illness go away. But just the suggestion fed her doubts.

Everyone has his or her own style of being sick. Does that sound strange? Perhaps, but we all "learned" how to be sick. Some of us want attention, and some want isolation. Some admit to being sick while others fight it and keep on going no matter what. When I was younger (in my thirties), I finally would admit that I had the flu and couldn't get out of bed. But I still wouldn't give up and give in. I even recorded a class lecture lying in bed and had Joyce take it out to the seminary and play it for my students. There are some people with chronic illnesses who are just as determined to not accept their conditions.

Think back to when you were a child. What did you learn about being sick? You learned how to behave when you were ill and what to expect from others. You developed beliefs about being sick. Some learned it's all right to express how they really felt while others learned to suffer in silence. Some learned how to use being sick to get what they wanted. Some received the attention they desperately wanted but never received when they were well. Some learned that in order to receive love, illness was the way. Others learned that the result of being sick was isolation and rejection. When you were a child, you also learned how to respond to pain. One woman said:

> I soon learned when I was sick as a child that I was seen as an inconvenience. I was tolerated because I was sick. Maybe I caused more work for them or maybe I disrupted their schedule. But I learned—keep my pain to myself. That was as bad as being sick. The problem is, what I learned then, I do now. It's so hard to let others know. I guess I started keeping all those experiences in my mind.

Your Experiences

1. Who were the caretakers in your life when you were sick as a child?

2. How did they respond to you positively?

3. What negative responses did you experience from anyone?

4. How are the messages or experiences from your past influencing your responses today?

5. How would you like to respond to people today regarding your situation?

6. How would you like others to respond to you regarding your chronic illness?

Affirmations

Read these affirmations aloud for encouragement. You might keep them in a special place so you can refer to them when you're feeling down.

- I'm not alone with my chronic illness.
- I'm not the only one to think what I've been thinking or feel what I've been feeling.
- I can find new ways to respond to others to gain a greater amount of support and understanding.
- I can implement a new approach to accepting my illness and experiencing God's care and concern for me if I need to.

Prayer

Merciful and healing Lord, for some reason which I do not understand, the usual pattern of my daily life has been disrupted…

Sit beside me now and help me to learn the purpose which this illness

> *is to accomplish. Help me to see how much and how often I have relied on my own strength, my own cleverness, my own ability.*
>
> *Forgive my pride that will not let me depend on You.*
>
> *In my illness help me to see that I am truly well when I remember that I belong to You…Fill me with the life of the Spirit, that in Christ I may be blessed and be a blessing to others.*
>
> *Hear my prayer in Jesus' name. Amen.*[11]

* * *

Recommended Reading

To learn more on chronic illness, we recommend these books. Some are written from a Christian perspective, others are not.

Dawn, Marva. *Being Well When We're Ill.* Minneapolis: Augsburg Fortress, 2008.

Donaghue, Paul, Ph.D., and Mary Siegel, Ph.D. *Sick and Tired of Feeling Sick and Tired: Living with Invisible Chronic Illness*. New York: W.W. Norton & Co., 2000.

Edwards, Laurie. *Life Disrupted.* New York: Walker & Co., 2008.

Sverlach, Carol, M.A. *Just Fine: Unmasking Concealed Chronic Pain and Illness.* Austin: Avid Reader Press, 2005.