

A Leader's Quick Guide to Chronic Illness

Many of the people under your care are suffering with chronic illness. For some, it seems obvious to those around them. Things like visible disabilities and/or illnesses like cancer are more commonly what people think about when talking about long-term illness. However, many more people are suffering with more invisible illnesses and are often misunderstood or neglected because their illness is less visible. People with conditions causing chronic pain, exhaustion, or mental illness are often overlooked.

Pay close attention to this statistic from the Canadian government.

“44% of adults 20+ have at least 1 of 10 common chronic conditions

- Hypertension 25%
- Osteoarthritis 14%
- Mood and/or anxiety disorders 13%
- Osteoporosis 12%
- Diabetes 11%
- Asthma 11%
- Chronic Obstructive Pulmonary Disease 10%
- Ischemic Heart Disease 8%
- Cancer 8%
- Dementia 7%¹”

This means almost half of the adults in your congregation are struggling with their health. As we move through this guide, we will hear what people struggling with their health would want you as a spiritual leader to know.

Believe us / But you don't look sick

When asked what they wanted their leaders to know, many people with chronic illness responded with simply, believe us. Particularly when illnesses are invisible, many people are not believed or their pain/illness level is not believed. A listening, believing ear can be the first step in creating a supportive environment. You cannot judge someone's energy or pain levels simply by looking at them; you must listen to their experience. Create an environment where people feel comfortable

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talking to you and feel seen, heard, and believed. Just because someone doesn't look sick doesn't mean they aren't.

Spoon Theory

Christine Miserandino first wrote about the spoon theory. You can click on her name to read a longer article or read a [summary here](#).

If you have not heard of it, spoon theory is the illustration that everyone with chronic illness gets only so many “spoons” worth of energy each day . While a healthy person may not have to think about the energy required to do a small task such as getting dressed or doing their hair, someone with very limited energy has to think about and portion out their energy, often having to choose between tasks in a day so as to be able to complete what is most important. We would encourage you to get familiar with and read these articles related to spoon theory as they will help you to understand and also learn a familiar term in the chronic illness world.

The Spoon Theory

DYSAUTONOMIA INTERNATIONAL
AWARENESS ADVOCACY ADVANCEMENT

The Spoon Theory is a creative way to explain to healthy friends and family what it's like living with a chronic illness. Dysautonomia patients often have limited energy, represented by spoons. Doing too much in one day can leave you short on spoons the next day.

If you only had 12 spoons per day, how would you use them? Take away 1 spoon if you didn't sleep well last night, forgot to take your meds, or skipped a meal. Take away 4 spoons if you have a cold.

1 spoon icon	2 spoons icon	3 spoons icon	4 spoons icon
get out of bed	bathe	make & eat a meal	go to work/school
get dressed	style hair	make plans & socialize	go shopping
take pills	surf the internet	light housework	go to the doctor
watch TV	read/study	drive somewhere	exercise

The Spoon Theory was written by Christine Miserandino, which you can check out on her website www.butyoudontlooksick.com.

www.dysautonomiainternational.org

Changeable days

“But you seemed fine yesterday” is a common phrase when someone suddenly says they can no longer attend an event or church. Chronic illness can be a roller coaster ride with great highs - days of lots of energy or feeling less pain - followed by lows - days of great pain or very little energy. This can also be true of mental illness, with good days and bad followed closely together. Just because someone seemed fine one day doesn't mean the next will follow or they are “getting

better” or on a continuous upward trajectory. Chronic illness ebbs and flows greatly. Things like the weather, new medications, the ability to exercise, the disease itself, and many more can cause changeable days.

No comparison

“Well, at least it’s not cancer!” Clients have told me they have been offered this phrase as a sort of comfort when talking about their illness. Comparing one illness to another is offensive and brings an unnecessary competition-like feeling to the conversation. It makes the person with the illness feel diminished and like they must have something to prove. Phrases like, “Well at least it’s not cancer,” are often said when the person doesn’t know what else to say but wants to offer something. But sometimes, words are not needed. Get comfortable with the silence or simply say, “That’s hard.”

Don’t offer unsolicited advice

While often well-intentioned, unsolicited advice can be one of the most frustrating reactions people with chronic illness face. They are usually under the care of highly trained and skilled professionals giving them treatment plans. Often, unsolicited advice means they would have to expend a lot of energy to do a ton of research, go against a prescribed treatment plan, or cost them a lot of money. When dealing with chronic illness, energy, treatment plans, and finances are held in a delicate balance. Also, illnesses are so specific that what works for one person doesn’t necessarily work for another. People also experience pain, exhaustion, and disease differently.

Finances

Being chronically ill is expensive. Even with our healthcare system, there are many out-of-pocket expenses, specialized natural treatments, and pain treatments not covered by benefits such as massage, lost income, specialty food, and more. Not all, but many people who are ill are also struggling financially. This is one practical area the church can step into. Paying for or organizing volunteers to do jobs around the house, helping with medical bills, and offering rides to medical appointments are just a few of the ways the church can step in financially.

Parallel trauma

Very rarely is the person with chronic illness suffering alone. Family members are often feeling the weight of the illness as well. The spouse, parents, siblings, children, or other caretakers sometimes suffer parallel trauma. Imagine this scenario. A young child has to go in for open heart surgery. This child faces a lot; if diagnosed with a chronic heart condition, they may face many years of repeated medical trauma. But the rest of the family is not unscathed. The siblings

are introduced to a lot of fear, separation from their parents, disruption of their lives, and anxiety about their sibling's health. The parents can experience even more trauma than the siblings from watching their children undergo surgeries and procedures. When shepherding someone with chronic illness, it's important also to acknowledge the whole family unit has unique needs. Checking in with the spouse and/or the parents is an important ministry.

Suffering shapes our views of God and people

When people are suffering, you have the unique ability to be the hands and feet of God's love to them. So many people with chronic illness have been forgotten, abandoned, judged and often have to be absent from social situations like corporate worship. Because they have been forgotten, this can also shape their view of God. It is easy to assume that the poor treatment we receive from humans mirrors the treatment we can expect from God.

Don't forget about us

No one wants to be left behind, left out, or forgotten. Yet, many people with chronic illness are. Whether they need to self-isolate because of immune systems, miss worship because of pain, or miss volunteering because they simply don't have the energy, they are often left behind and then forgotten. Remembering, including making accommodations for, and listening to those with chronic illness ensures they are helped to understand what an important part of the body of Christ they are, no matter their productivity. I Corinthians 12 tells us that those we would call weak are actually essential. Making the suffering know that they are essential to your church is so life-giving. Remember, you are in for the long haul when dealing with the chronically ill.

Resources

I Peter

Galatians 6:2

I Corinthians 12

II Corinthians 4:8-10

Psalm 46

[Chronic Illness: Walking by Faith by Esther Smith](#)

[What To Say When You Don't Know What to Say by H Norman Wright](#)

[Suffering: Gospel Hope When Life Doesn't Make Sense by Paul David Tripp](#)

[Disrupted Journey: Walking with Your Loved One Through Chronic Pain and Illness by Nate Brooks](#)

[Embodied Hope: A Theological Meditation on Pain and Suffering by Kelly Kapic](#)