A Guide to Coping with and Caring for Chronic Illness

Part 1 - Coping With Chronic Illness

There are certain seasons or circumstances of life that can be overwhelming, leaving you feeling helpless and very vulnerable.

One of the most disoriented times in life is when you or a loved one is facing a chronic illness.

During a time like this, you need to know you can trust a God who not only knows how to calm storms but will also walk alongside you through it.

Jesus is always present with you and will be your hope and salvation. One of the primary ways Jesus comes to you in the middle of your storm, is through other Christ-followers. That's why you can be assured of two realities:

- Jesus is present in your storm.
- Your church is present in your storm.

Whether you are facing the illness or a loved one you are caring for is, this will be a helpful resource for you as you embark on this journey.

We know this can be an overwhelming experience. Feelings of helplessness and desperation can become more prevalent and difficult to navigate. Chronic disease can be challenging to cope with for a variety of reasons, including:

- Limited mobility/physical activity: Some chronic illnesses may limit a person's ability to move around or be as physically active as they once were.
- Needing help with care: Many people are used to doing basic tasks, such as cooking, cleaning, and caring for their hygiene, without assistance. Some chronic illnesses may mean a person requires help, which can lead to feeling of frustration or embarrassment for some.
- Feeling helpless: Chronic illness can be debilitating, especially when a person is unsure how long they will have to deal with the disease. This can make them feel helpless and negatively impact their mental health.

Helpful Reminders When You Are the One Facing an Illness

- Know that it is not your fault.
- Maintain a balanced perspective.
- When possible, find joy in the adversity.
- Focus on treatment opportunities.
- Enlist a "patient" advocate for yourself.
- Hobbies can be helpful outlets.

You may be used to doing things on your own. However, during this time, having a team, or community to help with spiritual support, organization, planning, and emotional support is important.

Think of the right people for each category and write their names and phone numbers down in this diagram.



Once your team has been built, be thinking about how each member can assist you at this time. You may be used to doing things on your own, so your will have to remind yourself that there are team members to help you.

Part 2: Caring for Someone with a Chronic Illness

Why Support of Someone with a Chronic Illness is Important

It is clear in scripture that we are called to. (Galatians 6:2 "Bear one another's burdens.",) Jesus praises his followers who saw people in need and responded in love. (Matthew 25:34-40)

While being treated by medical professionals is helpful and necessary for those with chronic illnesses, it's been shown that social, emotional, and physical support, particularly from a friend or family member, can help alleviate stress levels and decrease depression levels, especially with support for long periods of time. Showing up to bring faith, comfort and hope can make a significant impact on someone with a chronic illness and can have benefits such as:

- Better health/fewer health problems due to lower amounts of stress
- Feeling encouraged, which can serve as motivation as they navigate the condition.
- Better mental health, such as lower likelihood of loneliness and depression

How to Offer Support to Someone with Chronic Illness

While offering support is important, it can be difficult to determine what is helpful or what actions are beneficial for those with chronic conditions. If you want to support a loved one with a chronic illness, there are a Do's and Don'ts that are worth remembering.

1. Encourage the sufferer by being a good listener who is present with the person in his or her suffering.

Jesus loves a good listener! Just being present with someone in their pain, even in silence, shows love and care for the person. Keep in mind, being present with Job for a week in his pain and saying nothing, is the only thing Job's friends did right!

While you may have opinions on what is best for them, ultimately, they are living with the condition, and their perspective matters regarding their care.

It's important to actively listen to the person when they are sharing things with you about their chronic illness. Often, a person will feel more open to sharing what they need with people they know can be trusted and who make them feel validated.

(James 1:19 "Be quick to listen, slow to speak")

2. Ask Them What They Want or Need:

Listening is important, but it's also essential to directly ask a person what they want or need. It can be difficult for people living with chronic illness to ask for help or support, including older adults, so initiating those conversations can be a huge help.

There are a few things to keep in mind when asking:

• Don't be discouraged if they don't give a solid answer: Some people may struggle to have an answer or may not want to come across as a burden. Assure them it's okay not to know and ask again another time.

- Ask specific questions: Rather than asking generic
 "What do you need?" questions, opt for more
 specific ones such as "Do you need someone to go
 get you groceries?" or "Do you need someone to
 pick up your medication?" which will help a person
 feel more inclined to accept your suggestions.
- 3. Be Empathetic and Encouraging. It's important to distinguish that empathy (when you can understand someone's feelings, even if you're not experiencing them directly) differs from sympathy (when you feel sad or pity someone's suffering or misfortune). People with chronic illness likely won't respond well to a person pitying them but will be much more open to someone trying to understand their feelings and thoughts.

Some ways you can show empathy are:

- Not dismissing what they are going through: It's important not to downplay their experience. Instead, putting yourself in their shoes can help give muchneeded perspective.
- Be understanding: Despite best intentions, chronic illness can, at times, unexpectedly wreak havoc on someone's mind and body. If your friend or loved one needs to cancel plans or isn't as upbeat or cheerful as usual, let them know it's okay. It's important they don't feel they are a burden or feel

unnecessary guilt for something outside of their control.

- Acknowledge how they feel: Letting them know you understand them, and their feelings is essential, rather than assuming you already know or showing no interest at all.
- PRAY!!! Praying with them is a powerful encourager!
 And when you pray for the person without him or
 her being present, reach out and let them know you
 are praying for them.

4. Remind them of what they already know is true.

Even the most theologically and biblically learned individuals, including pastors, need to be reminded of the truth as they struggle with illness and suffering. Remind the person of the goodness of God in Scripture. Remind them of how God has shown His goodness to them in the past. Remind them of the eternal realities and perspectives we have as Christians. Even if the sufferer can tell you all these things themself, speaking these truths to the person is powerful, comforting, and encouraging.

(2 Peter 1:12, 1 Thessalonians 5:11)

5. Point them to Jesus who knows their struggle, as He suffered and struggled too.

Pointing the person to the unlimited grace of God in the midst of their suffering and illness is important, not only with passages like Ephesians 1 that speak of God's love, but also in passages that show Jesus' suffering on their behalf such as Isaiah 53, Acts 2:23, Hebrews 2:14-18, 4:11-16, 5:5-10, 10:32-34, 12:1-13. Understanding firsthand, a piece of what Christ endured for us, along with our own suffering lets us see more of God's grace and know Him more intimately.

6. Don't Engage in Toxic Positivity

When faced with bad news or seeing loved ones go through tough times, it's tempting to try to frame things through an optimistic lens. However, this can potentially lead to more harm than good and can lead to toxic positivity—which means fixating/demanding only happy/positive expressions when dealing with unfavorable circumstances. Some examples of toxic positive phrases that may be said surrounding chronic illness include:

- "Well, it could be worse!"
- "Look on the bright side!"
- "Everything happens for a reason."

Toxic positivity is different from optimism, in that optimism tries to look at a situation's positive viewpoint but does not require forced happiness. Optimism can be encouraging but can be hurtful when used to ignore or invalidate a person's feelings or experiences.

When someone with a chronic illness expresses feelings of sadness, anger, embarrassment, or helplessness, responding with a quick positive response can make the person feel like they are not allowed to have any negative feelings regarding their situation, which can lead to shame or guilt. Instead, some helpful responses could be:

- "I'm sorry, that sounds difficult to deal with."
- "I can't imagine how this feels, but I'm here for you".
- "That sounds frustrating can I help?"
- "I want to support you however I can."

Validate their suffering but remind them that joy can always be found in the Lord. (*Psalm 16:11*)

7. Don't Give Unsolicited Advice.

In attempts to help, people feel the need to share advice to provide some sort of help or aid to a person with an illness, even if it wasn't asked for. While this can be done with good intentions, it isn't often beneficial.

Rather than giving unwarranted advice, you can alternatively respond in a few ways:

- Listen to what they are saying without offering opinions. (*Prov 18:2 "A fool takes no pleasure in understanding, but only in expressing his opinion"*)
- If you feel strongly you have something to share, ask first if they are open to hearing suggestions.
- Be present and engaged with them without focusing on your version of the situation. (Gal 6:2 Carry each other's burdens...")

In conclusion, if you, or someone you know, is struggling with chronic illness, I want to encourage you to hope in God. Though the trial may

be great, the faithfulness and mercy of God is greater. Trust that God's mercy, love, and faithfulness will overwhelm the suffering you experience. Do not be afraid. He is with you. He is for you. He loves you.

Helpful Resources:

Books:

- The Chronic Illness Workbook: Strategies & Solutions for Taking Back Your Life - Patricia A Fennell
- Beyond Pain: Job, Jesus, and Joy Paperback Maureen Pratt
- Sick and Tired of Feeling Sick and Tired: Living with Invisible Chronic Illness - Paul J. Donoghue & Mary E. Siegel
- Unmapped Darkness Finding God's Path for Suffering -Thomas Finch
- Jesus Calling Sarah Young
- Peace in the Storm: Meditations on Chronic Pain and Illness - Maureen Pratt
- Hope When it Hurts Biblical Reflections to Help You
 Grasp God's Purpose in Your Suffering: Kristen
 Wetherall & Sarah Welton
- You Can Trust God to Write Your Story: Nancy DeMoss Wolgemuth
- It's Not Supposed to be This Way: Lisa Terkeurst

Websites:

CaringBridge

<u>http://caringbridge.org/</u> (for every type of health journeyto share, connect and rally support)

Caregiver Action Network www.cargiveraction.org

National Alliance for Caregiving www.caregiving.org

Home Care Providers:

Visiting Angels Home Care (785) 284-5500 1100 SW Wanamaker Rd #8 Topeka, Ks 66604

Grace Home Care (785) 286-2273 1215 SW Gage Blvd Topeka, Ks 66604

Phoenix Home Care & Hospice (785) 260-6444 2945 SW Wanamaker Dr. B Topeka, Ks 66614