

# The Silent Pain Of Chronic Illness

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## The Silent Pain of Chronic Illness

Suffering from chronic illness can present a very lonely and difficult journey. It is a place that many don't understand and others don't care to understand. Oftentimes, part of the battle is finding people that will stick by your side despite your pain or disabilities. There are many obstacles along the way and we need to have companionship and understanding to assist us on the rocky road we travel. I have written this brochure as someone who suffers from chronic illness. I know the journey well and cope on a day-to-day basis, just as you may. You are not alone, there are many of us out there suffering and, unfortunately, in many instances we suffer in silence. My hope is that the information in this brochure can bring some understanding to not only the sufferers but those who journey with them.

### What is chronic disease?

Chronic disease is any disease lasting three or more months as defined by the U. S. National Center for Health Statistics. These are illnesses that cannot be prevented with vaccines or cured by medication, nor do they disappear. The individual with the illness is a victim for a lifetime.

Many of these illnesses are preventable and are brought on by health damaging behaviors, such as excessive smoking, drinking, bad diet, or lack of physical activity. Others could not be prevented by any means—they are hereditary or incidental such as arthritis, fibromyalgia, heart disease, diabetes,

asthma, mental disorders and many others. Regardless of the cause, they can frequently mean a lifetime of pain, medical attention and changes in lifestyle.

85% of Americans older than 65 have at least one chronic health condition. Nearly one in two Americans (approximately 133 million) have a chronic condition. By 2020, about 157 million Americans will be afflicted by chronic illnesses, according to the U.S. Department of Health and Human Services.

Approximately 96% of people who live with a chronic illness have an illness that is not visible. These people do not use a cane or assistive device for movement and they appear perfectly healthy.

### Getting a diagnosis



Getting a diagnosis for the illness can take months and sometimes even years. There are so many diseases, and some of them rare. It is a process of elimination for doctors to diagnose what the illness is. The patient may endure many doctors' visits and myriad medical tests. The tests can be painful and expensive, with many producing no results other than the need for more tests.

During this time, the patient may experience frustration, fear, despair and depression. The majority of patients question why a diagnosis is not easier to attain and why it takes so long.

The reality is, the doctors only have a certain amount of information in a very complex body system to start their investigation. When appearance does not give them an answer, they have to begin looking at the internal workings of the body. This takes time and patience.

You can liken this situation to a person investigating a crime. There are a lot of possibilities and often many suspects, but everything has to be observed, tested, and narrowed down before you begin to gain answers.

### **Misconceptions**

Many people hear that someone has a chronic illness and they assume they will eventually regain their health. The word chronic means “constant”, so the illness is here to stay. These people will never feel physically whole again.

People will say to a chronic disease sufferer, “I hope you feel better soon”. It’s a nice sentiment but usually not a reality for the person who is ill. More often than not, they hide their pain from others to spare them the details. Few people have the patience to listen to how the sufferer is feeling.

A common statement is, ‘If you are chronically ill, why do you look healthy?’ Nothing could be more frustrating to the ill person than for others to assume that if you have a disease, it has to show on the outside. Most chronic illnesses are invisible to others.

Another common misconception is that ,if the person is out and about, they must be feeling ok. Most chronic sufferers fight their illness and pain as much as possible and will attempt to function at the best level possible. If they go somewhere today,

that may mean they have twice as much pain the next couple of days due to the effort.

### **Your diagnosis**

It is vitally important to get a diagnosis so the appropriate medical treatment can begin. Usually there is treatment that can either slow down the progression of the illness or relieve some of the symptoms.

Gaining your diagnosis may be frightening, stressful, confusing, and cause financial burdens. It is advised to have a confidant to help you through this process. Doing this alone will only add to your fear and stress. It is also helpful to have someone with you to help you remember all that the doctors are telling you.

Make a list of questions to ask your doctor to help you gain understanding. Also, write down all your symptoms so that you can convey accurate information to the health care professionals. Keep a notebook with symptoms, treatments, and dates. It can be quite helpful to you and your physician to refer back to, to determine when certain issues occurred.

### **Do your homework**

Research your doctors. Ask the physician who diagnosed you all the questions that come to mind. Feel free to get a second opinion from another physician to gain confirmation before you accept the diagnosis.

Research your illness. If you use the internet, ensure that the sites you are getting information from are accredited medical websites. As you know, not everything on the internet is true. Some sites may contain information that is false

or misleading and could frighten you further. It is helpful to have a friend or family member do this with you. If you are already upset about your diagnosis, they may be able to help you keep the information in perspective.

Researching your physician or surgeon is just as vital as researching your illness. You want to make sure that the best doctors available are working with you. This is especially true with surgeons because they are performing invasive procedures which need to be done 100% correctly.

### Self-care

Listen to you doctor! It is vitally important to follow your doctors' instructions regarding physical care – diet, exercise, and medications. Some people may never understand your physical challenges, but never allow others to push you beyond your abilities. Always fight for mobility, but only you and your physicians can determine what your body can manage physically.

It is equally important to learn the best means of coping with the emotional side of your illness. This may mean counseling to help you learn coping skills to maintain the well-being of your mind. Doing so is not a sign of weakness. Treatment for your mental health is just as important as your physical care. Each person with chronic illness must learn to adjust their body and mind to cope with a permanent disability.

### Lifestyle changes

Most people with chronic illnesses will require lifestyle changes. The chronically ill person usually suffers pain. For some the pain may be minimal, but for others it may be all-

consuming. Energy levels are often very low which creates issues with daily routines. You must learn to honor the abilities or inabilities of your own body.

While most of these changes require adaptations on the part of the chronically ill person, the people in their homes must also make changes to accommodate them. There are times when the person in pain can become very negative or depressed. Often a spouse is unable or unwilling to make the changes required to stay in the relationship. The responsibilities of the spouse can be many and varied and may go far beyond the normal expectations placed on the spouse. Never feel guilty about this. You are not a burden. If it becomes an issues, seek marital counseling.

Depression in the chronically ill is 15-20% higher than for people without chronic illness. This frequently requires medication and therapy on a consistent basis.



Chronic illness may rob some of the ability to work, maintain a household, or care for children. Their social life is dictated by their physical abilities and many friends and family do not have the patience to alter plans to accommodate the disability of the

ill person. Many people do not understand the challenges and the pain that the chronically ill may face on a daily basis.

The chronically ill need to learn which people are there to be supportive and which just cause them further stress. Attempt to educate your friends and loved ones and, if they still do not understand, be patient with them as you wish them to be patient with you. Some people will be there for you and accommodate your physical limitations while others may drift away.

Life, at times, takes an about face and becomes a life you don't recognize as your own. You will adapt to your abilities and develop a new normal for your life.

### **Taking Steps**

The process of adapting to your illness can be a long and complicated one. It takes time to figure out what your body and mind can cope with and when you need to stop certain activities. When you push beyond your limits, your body will likely let you know in a very unpleasant manner. Realizing that your body can only take a certain amount of stress is a process of learning. Once learned, you need to adhere to your limitations and boundaries to avoid further pain or damage to your system.

Have courage. Know that if you are unable to do something one day, it does not mean you won't be able to do it on another day. When your body says no, listen, but don't stop trying to maintain a life outside of your home. Keep in touch with people you care about and help them understand what your illness is and how it makes you feel. People are much more willing to be patient if they have an understanding of your challenges.

Let others know that, if your illness could be managed by certain actions or treatments, you would pursue them. There are many illnesses that can be treated, but only to the extent that

the person can function at a certain level and can go no further.

When people are aware of your level of ability they will usually learn what you are capable of doing and where the bar has been set too high for you. Your friends and family need to understand that when you don't accept an invitation it doesn't mean that you never want to be asked again. Do research – there may be medical devices available to assist you. You may find a way that makes it possible to enjoy the activity the next time they ask.

### **Letting go of guilt**

The chronically ill tend to blame themselves. Whether your illness was caused by your own actions or not, there is no point feeling guilty. If your illness was caused by bad habits it is done and cannot be changed, so, let go of the guilt.

If your illness is hereditary or incidental, remember that you have done nothing to cause your illness and there is nothing you could have done to prevent it.

Remember, life goes on. We need to learn to cope with aspects of our lives as they are presented and not concern ourselves with what we cannot change.

### **Realize you are not your illness**

It is very common for people with a major illness to begin identifying with their illness. You may feel you are no longer the individual you were born to be, but a sad substitute. Sickness exists in your body but you are not your sickness. You may suffer pain, aches, and hurt, but do not allow that to define you. You must maintain your identity and focus on the positive aspects of who you are and try *not* to focus on your illness. For

example; if you are an artist, you are still an artist, just one who happens to have an illness. Do not claim your illness as your personality. If your illness limits what you normally do, learn to do it another way, or, if necessary, find something else you can feel passionate about.

### **Envy**

This can be an extremely difficult emotion to deal with. You may feel envious of your husband because he can work out every day. You may be jealous of your friends for having the energy to go shopping. You may envy the person at the table next to you enjoying dessert when you have diabetes and can't even have a bite. The list goes on and on.

The best way to deal with this is to learn to be happy for their abilities and not focus on your own disabilities. It takes a lot of practice and patience to learn to do this, but, over time, it will bring you to a place of peace and acceptance.

### **You are not alone**

Knowing that others suffer does not change your suffering, but it helps to know you are not alone. This does not mean we rejoice in others' pain, it means that we are in this together. We can pray for each other and learn empathy for others. Who can understand the pain of someone more than someone who suffers on a daily basis? When you are feeling isolated or alone in your illness it is good to find a support group.

### **Use your pain for good**

It is amazing that some of the most chronically ill people are the ones who reach out to help others the most. They understand that others in pain need someone in their lives to care

about them.



Ill people need the understanding and empathy that many people without illness can't provide. You live it every day. You have been down many of the paths that others will be experiencing for the first time, and can give sound advice on the situation. You can also introduce chronically

ill people to coping skills that assisted you on your journey.

Find a ministry your body can manage in order to assist others. Even if only for a limited time each week, this is going to boost your feeling of self-worth while benefiting others who need your assistance.

### **What Others Can Do to Assist You**

Once others have an understanding of your limitations, if they would like to help you, it is a good idea to let them. Don't ask all the time, only when you really can't cope with something yourself. It is best to do things for yourself as long as it is possible and keep your body moving.

If you must turn down an invitation due to your disability, let people know you would love to be asked again, you are just not physically able to go this time.

Let your friends and family know what your physical boundaries are. It is especially important to keep your family informed.

Many people suffering from chronic illness are afraid to talk

about their illness because some people judge or they just don't want to hear about it. Remember, they do not live in your body and have no idea what you are coping with. That being said, it is important to remember the difference between informing and complaining. You inform and answer questions but do not make your illness the topic of conversation whenever you speak to others. Complaining gets tiresome for others and does not help you focus on positive parts of your life. You can have a full and exciting life despite your illness. You just need to seek new ways of doing things.

Let your family help you around the house. Children can help with chores but you should maintain your own participation when you can. If your husband understands how you feel, he can be your biggest advocate and helper. If he does not understand, be patient; over time he will see the reality of your situation.

It helps to have someone you can talk to openly at any time. If you have someone who can walk with you through the diagnosis process and subsequent treatments it will keep your mind more at ease.

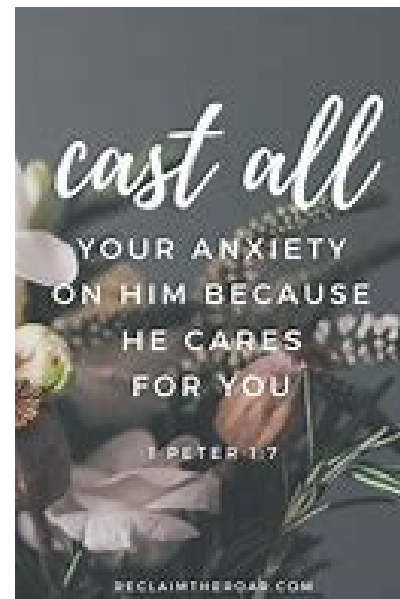
Do not be upset with people when they don't spend time with you if you haven't asked them to. There are many people, especially from church or ministry groups, who want to help but don't know how. Let them know what you need, even if it is just a visit or a phone call. Those things go a long way when you are struggling with pain.

If you find yourself ceasing to communicate with others, this is a warning sign for you. It is time to get out of your home and rejoin society. If you lack the desire to do so it is time to

seek counseling in order to accomplish this. It is extremely easy to fall in to depression when your body hurts and will not work normally. Do not allow the depression to take over your life, you can do this with the proper coping skills and determination.

The most important thing people can do for you is pray. There is nothing greater than the love of God; he is the great healer.

### Speaking of God



When you are well enough, attend church, a Bible study or prayer group. There is so much comfort in praying for others and having them pray for you. The Christian community will show you the most kindness, understanding and help you will find anywhere. They are striving to live as Christ lived and Christ certainly understands your pain. Hugging other people in your Christian community will bring a

connection you won't find elsewhere. Take advantage of what God has provided so freely. Never give up on yourself. There is a reason you are here no matter what the limitations of your body may be. Keep pushing forward in mind, body and prayer.

### Prayer

There will be times when you are in pain and it may be difficult to pray. Remember, one word spoken to God is prayer. Call on his name until the words come to your mind and heart. If you

would like some help getting started, read the prayer below and you will soon find your own heart bringing the words to you.

Here is a simple prayer to help you in the process. You can read this every day until you are moved to speak your own prayer.

*Heavenly Father,*

*I praise you for all the blessings in my life. You have given me so many things to be thankful for.*

*Lord, I am struggling with my diagnosis and also my pain. I do not understand why I have to live this way the rest of my life. Please help me accept my illness and learn to move forward.*

*Please help me with healing, God, if that be your will, but if I am not to be healed, please help me cope with pain in the best way possible. You are the Great Healer and I know you never leave me.*

*Amen*

## Scripture References

### Isaiah 41:10

<sup>10</sup>So do not fear, for I am with you; do not be dismayed, for I am your God. I will strengthen you and help you; I will uphold you with my righteous right hand.

### James: 5:14

<sup>14</sup>Is anyone among you sick? Let them call the elders of the church to pray over them and anoint them with oil in the name of the Lord.

### Matthew 11:28

<sup>28</sup>Come to me, all you who are weary and burdened, and I will give you rest.

### Philippians 4:19

<sup>19</sup>And my God will meet all your needs according to the riches of his glory in Christ Jesus.

### Proverbs 4:20-22

<sup>20</sup>My son, pay attention to what I say;  
turn your ear to my words.

<sup>21</sup>Do not let them out of your sight,  
keep them within your heart;

<sup>22</sup>for they are life to those who find them  
and health to one's whole body



## About Spiritual Care Support Ministries

### Exodus 15:26

<sup>26</sup>He said, "If you listen carefully to the LORD your God and do what is right in his eyes, if you pay attention to his commands and keep all his decrees, I will not bring on you any of the diseases I brought on the Egyptians, for I am the LORD, who heals you."

### Psalms 107:19-21

<sup>19</sup>Then they cried to the LORD in their trouble, and he saved them from their distress. <sup>20</sup>He sent out his word and healed them; he rescued them from the grave. <sup>21</sup>Let them give thanks to the LORD for his unfailing love and his wonderful deeds for mankind.

### Exodus 23:25

<sup>25</sup>Worship the LORD your God, and his blessing will be on your food and water. I will take away sickness from among you,

### Psalms 30:2

<sup>2</sup>LORD my God, I called to you for help, and you healed me.

Spiritual Care Support Ministries is a nonprofit, non-denominational 501(c)3 organization. All services are provided free of charge. SCSM relies on the generous gifts of people, companies, and organizations to continue the work God has given us to do.

If you or someone you know is in need of personal support, if you would like to participate in a project to help SCSM, or if you would like to aid us financially, please contact us.

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# Spiritual Care Support Ministries

*Reaching for a hand and touching a heart*

## MISSION STATEMENT

Spiritual Care Support Ministries provides support, education and a Biblical perspective to those who are ill, dying, grieving and experiencing personal loss, and to those who journey with them.

## VISION

To establish a local, national and international resource center to provide ministry, training and a retreat for those who are ill, dying, grieving and experiencing personal loss, and to those who journey with them.

## VALUES

God's Word

Prayer

Value Every Human Life

Integrity

Confidentiality

Excellence in Everything We Do



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