

Waking Up the Nation,
One Reader at a Time...

PUBLIC HEALTH ALERT

The First Five Steps to Take After a New Diagnosis



by Lisa Copen

I easily can remember the day that my life shifted into a new kind of normal when I was diagnosed with rheumatoid arthritis. At the age of 24, having dealt with a few weeks of swelling in various parts of my body, sometimes to the point of being disabling, my doctor called me at work with the test results. I had a positive rheumatoid factor, she explained, which most likely meant that I had rheumatoid arthritis. Faking confidence, I asked her, "On a scale of 1 to 10, 10 being normal, what can I expect my life to be like from here on

out?" She did not wish to answer, but after I told her I needed some kind of scale to know what side I was up against, she reluctantly replied, "If you are lucky maybe a six."

Within days, I realized that everything in my life now be impacted by my disease & that there would be no such thing as "normal" again. Every detail of my life would change from the simple struggle to open a door, to stand from the chair, to walk across the room, or to shift gears in my car. Although my carefree lifestyle & attitude would stay imbedded within my heart & personality, it would take a back seat while I attempted to simply try to learn to function while in severe pain.

A few weeks ago, a friend from high school who was recently diagnosed with rheumatoid arthritis, searched the internet for information

on the disease, & ironically ended up on the Rest Ministries website, where she realized she had known me nearly 25 years ago from a high school of only 300 students.

We exchanged e-mails a few times & it is my hope that she found them encouraging. When I reflect on what I would've liked to have heard from someone who has lived with a chronic illness for years, upon my new diagnosis, these are the five things I find of most value to pass along.

[1] Get in touch with the national foundation or organization that is dedicated to supporting people who live with a chronic illness that you have recently been diagnosed with. Explain to them that you have just found out about your diagnosis & that you would like the most basic information. They may drop some brochures to

you in the mail or send you to their website.

Despite the fact that you may have not had a chance to grieve your diagnosis yet will likely make this to seem discouraging, & if you begin to get things in the mail & are not ready to read them, put them aside for later. The important thing is to know that this organization will likely be the one that will provide you with the most current & objective scientific treatment options & you will want to be "in the know." As your doctors are making suggestion for medications for you to start, & you are torn about them because of the long list of side effects, these organizations will be your best source of objective information.

[2] Know when to stop reading about your disease. There are millions of books, websites, podcasts, & more which

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will tell you how you can cure it, delay the progression of the disease, or most effectively be treated with alternative treatments. The important thing is to glance over critical health & illness organizational websites so you are aware of where you can go to find information when you need it.

You should be aware of some of the symptoms that may occur because of your illness so that if they do occur, you can attribute them to it. However, don't bury yourself in reading everything you can get your hands on. It will simply become too depressing, & many of the anecdotes that other people share may never apply to your life.

[3] Don't lose hope about your situation. It seems there are new scientific discoveries on a weekly basis that may change how your illness progresses or is treated. For example, I have now lived with rheumatoid arthritis for 16 years & recently had four joints replaced in my left hand due to deformities & loss of abilities. But my medical team, a hand surgeon, rheumatologist, & a physical therapist, have all said

that they rarely see these kind of surgeries now due to the new family of drugs available in the last 10 years that has rapidly slowed down the progression of the disease & destruction of the actual joints.

Even if there is not an immediate cure, as we scientifically grow closer to being able to know our exact DNA, we will be able to pinpoint which medication will best treat our disease, without having to jump from one medication to another, losing months & years sometimes of our health, in order to find which one works best. Hope & a positive outlook will have a profound effect on your disease & your life. So don't give up & assume that your illness will be disabling.

[4] Think about who you would like in your life to be able to talk to about what you are emotionally & spiritually experiencing due to the recent diagnosis. The person may be someone you meet in an online forum for your disease, it could be a pastor, mentor, counselor, or even a good friend who is able to listen without trying to fix it. The most important thing is that you have an oasis where

you can share what you are experiencing without feeling like you may be judged or where you will receive ignorant comments such as "no pain, no gain." Check out your local support groups for your illness, or other support environments such as HopeKeepers, which is a unique small group Christian support environment for those who live with illness or pain.

Also, consider your personality & how you are best encouraged. Would you feel most refreshed by sharing what you are going through with just a friend, one-on-one, at a coffeehouse? Or are you homebound, & signing onto a website every day to receive encouragement & prayer would be beneficial? Remember, whatever works best for you at this time, may not best meet your needs in six months, so do not feel like you are stuck with a particular group or mention. Be willing to try new forms of support to find which best works for you.

[5] Ask yourself "What foundation do I have in my life that will help me through the difficulties that I will be facing?" Even if your illness does not progress rapid-

ly, the daily aches & pains, as well as the emotional roller coaster & spiritual "why?" questions you will have, will leave you searching for a deeper meaning in life than simply solving your problem with a cup of hot tea. As a Christian myself, I honestly do not know how people live each day with a chronic exasperating illness who do not know the Lord.

This is what keeps me together: believing that my pain is never wasted, & that God always has a purpose & plan for it; acknowledging that God is always in control of my life & that of my circumstances come as no surprise to Him; & firmly surrendering to the fact that He has any specific purpose for my life & that any limitations I have experienced because of my illness will not hinder His plans. Even if you are not a spiritual person, you will likely find yourself facing those middle of the night blues, & I encourage you to look up a biblical website like Bible Gateway & read through some of the Psalms. If you are unfamiliar with them you may find yourself pleasantly surprised to see that most of the people

who lived during these times faced severe hardships, deep depression, many doubts, & yes, even chronic illnesses & disabilities.

So, to sum it up, be well informed, set reasonable boundaries for the quantity of information you will intake, keep hope alive, find support through people, & then search for what will get you through the darkest of moments when the information & people you have counted on disappoint you. Discover a purpose in the pain that is greater than that which the world will tell you. if you put your life on hold completely you will have regrets later on. As the late John Lennon once shared, "Life is what happens to you while you're busy making other plans."

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