The Stress of Living with a Chronic Illness

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In recent years, much has been published about the ways in which stress can trigger or exacerbate medical conditions such as high blood pressure and heart attacks. In contrast, little has been written about the stress caused by having a chronic medical condition. Ordinary daily life is stressful enough for most human beings. Living with chronic illness imposes additional demands and pressures that are often unknown or misunderstood by the general public.

In this article, I will outline some of these types of stress and identify some of the ways in which a psychologist can help you live well despite illness.

Acute vs. Chronic Illness

First, chronic illness must be distinguished from acute illness. Acute illness refers to a temporary medical condition that has a predictable recovery time. For example, the flu, a broken leg, even some forms of surgery. In these situations, there is pain and discomfort and impatience for recovery, but the person knows they will eventually regain their original sense of health.

In contrast, chronic illness refers to an ongoing condition with no end in sight. This means that the person cannot look forward to a future when health is restored, cannot tell themselves that they just have to be patient and eventually will be back to normal. There may be possibilities of the condition getting worse over time and lifestyle restrictions that are often imposed for the rest of one's life. Chronic conditions include, for example, asthma, diabetes, AIDS, severe allergies, chronic pain, traumatic brain injury, Parkinson's, etc.

With acute illness, family and friends extend sympathy and caregiving, knowing that the need is temporary. With chronic illness, family and friends may develop compassion fatigue over time, becoming less patient or less willing to take care of special needs or listen to ongoing complaints. They may not understand exactly what you are experiencing, fail to recognize the kind of emotional support that you need, or simply become emotionally drained after a certain period of time. You may also feel a sense of guilt in needing help from caregivers or fear that you will become dependent upon them.

The Symptoms of the Illness

Every chronic illness has its particular symptoms that make you feel unwell and make it difficult to function in daily life, including physical discomfort, tension, fatigue, and weakness. Symptoms typically interfere with ordinary human acts that healthy persons take for granted. You may find it hard to breathe or talk, to sleep or stay awake, to sit still or find a comfortable position, to walk or move quickly without losing your balance, to eat or drink without digestive problems, to feel comfortable in your own skin without pain. Some symptoms are visible, others are invisible yet felt nonetheless.

If you cannot function on automatic pilot and do taken for granted actions, you must slow down

and pay attention to your body. When you pay attention to a body that is in distress, you may become overwhelmed by emotional reactions. It is common to feel sadness or despair, anger or frustration, anxiety or panic, which make you feel worse and contribute to the perception that illness is unbearable or impossible to live with.

Coping with Medications, Physicians and Insurance Companies

People with chronic illness are typically responsible for treating themselves with medications. You are expected to follow sometimes complicated instructions. You must take the right dose of medication, at the right time, with or without food, without improperly combining medications, have it available when it is time to take it, get refills, etc. It can feel overwhelming to accomplish these tasks and at the same time do ordinary obligations and errands such as grocery shopping, cooking, cleaning, laundry, going to work, physician appointments, etc.

Side effects from medications or treatments are common. Sometimes you have to stop taking needed medications because the side effects are so uncomfortable. You may start taking additional medication to treat the side effects of the original medication. It can feel never-ending and increase your level of suffering.

Often there is an insufficient amount of time to get questions answered in appointments with physicians, and bureaucratic delays with insurance companies. Sometimes there are medical errors, misdiagnoses, or experiences with insensitive physicians. You may feel fear or anger regarding physician consultations and avoid getting needed medical care or fail to comply with medical recommendations.

Working Harder than Ever

People with chronic conditions often try to be as independent as possible to avoid imposing a burden on family and friends. Some people are motivated to prove that they can still do what they used to be able to do. If you are in a career position that you don't want to lose, or need that job to provide for your family, you may work harder than ever, not ask for any special considerations, and make sure that no one knows the pain you are feeling.

Many people with chronic illness are high achievers who compensate for their limitations. They often succeed with extra effort. The problem is the toll it takes on stress levels. Over time, there is a cumulative effect.

Identity Crisis

Because of the changes in your life imposed by illness, you may feel that you are "not yourself". You may feel that others are treating you like "an ill person" who is not the person you are or have been. You may feel stigmatized in public, socially isolated in private, and/or feel a sense of shame in having your condition.

Feeling deprived of beloved pleasures can feel particularly devastating. For example, if you used to love cooking and eating with family and friends, but now have severe diet restrictions, losing a sense of joy associated with food can create a major impact. You may feel extremely

disturbed if your life used to revolve around certain sports or physical activity that you can no longer do.

You may become moody, irritable, depressed and/or anxious, in ways that you never were before. You may start to think "I'm not much fun to be around anymore", stop attending social events or stop returning people's calls, feeling self-conscious about your mood and preoccupation with medical issues.

There is so much you cannot control about your illness that you may develop a need for more control in other areas of your life. You may become irritated with others if you feel they are taking control away from you. Sometimes others may imply that you have brought illness upon yourself or are not using enough willpower to control your illness. This can increase your stress levels and suffering. You may be annoyed by ignorant or rude remarks made by strangers or intrusive questions by well-meaning friends.

There are often fears of what will happen if something critical is forgotten or done incorrectly. Hypervigilance may be triggered, a sense of always being on guard, thinking "Did I forget something?" or various types of "What if?" worst case scenario worries that make it difficult to sleep at night, or create such a level of tension that it is difficult to relax or enjoy times when you would ordinarily do so.

How a Psychologist Can Help

To live well despite illness requires emotional support from people who understand how it feels. Research on resilience over time shows that human beings can emotionally survive the worst traumas if they have at least one person in their lives who is consistently supportive and encouraging. The most damage is done when we feel alone and isolated.

As a licensed psychologist who lives with my own chronic conditions, I know it isn't easy. But a therapist with experience with chronic illness will see the person you are in spite of illness, who still has many gifts to give the world and much joy to feel. She or he will listen to your tales of woe and help you improve your knowledge, skills, and abilities so you can build upon the foundation of your inner strengths. Over time, you will learn to focus on controlling what you can control and develop the capacity to manage stress by keeping it to a tolerable minimum.

You will learn to recognize thoughts and behaviors that add to your suffering and keep you trapped in self-defeating patterns. Healthy and unhealthy methods of stress reduction will be identified so you understand what activities tend to lead to positive outcomes and which ones make you feel better temporarily but lead to more problems in the long-run. You will learn a range of relaxation techniques so you can find one or more that are genuinely helpful and are practical for your particular lifestyle.

With compassion, understanding, and perspective from a trained professional, you can develop a sense of health in the midst of illness and thrive despite adverse circumstances. Illness may prompt you to change bad habits you always wanted to change but were never a priority until now. You may discover a newfound appreciation for life, feel profoundly grateful for your loved ones and other ways in which you are fortunate...because you *are* more than your illness.

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