Living With Chronic Illness Builds Courage

by Pauline Salvucci, Self Care Connection

The challenge of living with chronic illness isn't always apparent when you're first diagnosed. This is just the beginning. It takes time to understand your illness, the treatment options available, and how living with illness will affect your life and the lives of your partner and family.

Being sick is like being on a roller coaster -- you can be up and hopeful one minute and down and doubtful the next. Your illness can take unexpected and unpredictable turns. One disease can dispose you to or give rise to another. This can be frightening as well as exasperating. Finding medication that works, being committed to following a good treatment plan and maintaining honest, direct and open communication with your healthcare providers takes time, energy and skill. But this is only part of the picture. Living with illness affects every part of your life and every significant relationship you have.

If you're still able to work, you find yourself in the position of having to make decisions about what and how much you tell your employer and coworkers, especially if your illness requires you to make time adjustments to your work schedule. Responding to and dealing with coworker's responses or reactions can be a challenge. Saying too much makes you vulnerable to unwanted questions, saying too little may raise questions of 'special treatment' and elicit criticism or even jealousy. Yet, not being able to work means giving up your role in the workforce as a productive employee -- and facing the economic changes and problems of not being able to financially provide for yourself or your family.

When you live with chronic illness, every aspect of life takes on a new dimension. Your daily decisions and choices are examined through a new lens, and you often find yourself carefully weighing the ramifications and possible outcomes of your choices. But, wait. Wasn't this the way it always was? Isn't this something all intelligent and responsible adults do? Yes, of course. However, living with chronic illness broadens the scope of that decision making process. The question isn't only how will this decision or choice affect you, but also, how will it affect your illness which in turn affects you and the choices and decisions you continually make.

Obviously, this is a demanding aspect of living with chronic illness. It's also the measure of your courage. Living with illness affords ample opportunity to be courageous in living your life to the best of your ability. Why is this so? Because when limitations and diminished control over the effects of illness are part of your daily life, your choices and decisions become the stuff from which courage emerges.

The fact is, if you're living with chronic illness you are courageous. In the process of meeting life's challenges, you have learned and are continuing to learn how to meet your fears and move beyond them. Perhaps you don't think of yourself as particularly courageous or even confident. Maybe it's time to take a closer look. These four questions will help you do that.

1. What have you learned about yourself since you were diagnosed with a chronic illness?
2. What initially held you back from learning these things about yourself?
3. What did you learn from the times you felt most discouraged?
4. What will your legacy be to those who know and love you?
No one knows the journey you and your illness have taken better than you do, and no ones knows more than you, the challenges you've met and the wins you've achieved. Acknowledge and embrace them. Celebrate your courage.

© Pauline Salvucci 2001 Pauline Salvucci, M.A., is the author of numerous articles on self-care and personal development, including the popular "Self-Care Now!" booklets available through Amazon.com.

Make a Place for Your Illness and Put It in Its Place

by Pauline A. Salvucci, MA.

SelfCareConnection.com

"A place for everything, and everything in its place." That may be a fine idea if you're eyeing the clutter on the living room floor, or a pile or two of old magazines and catalogues collecting dust in a corner. But what has it got to do with chronic illness? A lot.

Chronic illness is never a welcomed guest in anyone's life. However, when it becomes a visitor in yours, in many cases, it's there to stay. How you cope with your illness will determine, in great part, how well you live your life. Of the three primary factors which measure your ability to cope: your attitude, the social context of your life, and the quality of resources available to you, your attitude becomes the foundation upon which the others build. Making a place in your life for your illness may sound like a strange thing to do, but it's a crucial step in learning how to cope with illness and putting it in its place. Here are some suggestions:

Acceptance and denial are normal steps toward making a place for illness. When you begin to accept your illness, you open yourself up to see what's on your plate. Then you can begin to interact with it and make a place for it. When you deny your illness, you close yourself off to yourself, and you shut down. Feeling both acceptance and denial are normal responses to chronic illness. Being sick makes you different from healthy people. And, if your illness isn't visible, you may deny it more than if it were. Accepting illness is a process. It doesn't happen all at once. Don't be harsh on yourself when you fluctuate between accepting your illness and denying it. Acceptance isn't something you do once and for all. Acceptance lives in the present moment. Little by little as you accept your illness, you make room for it in your life.

Adapting to change takes time and patience. Like an onion, you peel off one layer of change at a time. The changes you often are faced with will stretch and challenge your ability to adapt. You may have to let go of, or even say goodbye to some parts of your life, either for a time, or perhaps permanently. Grieve this loss. Perhaps create a ritual to say goodbye, but don't deny those parts of your life which you enjoyed and which were important to you. They are a very real part of your history and deserve your respect. Your life is different than it was before you became ill, but don't treat your past and the things you enjoyed as if they never existed. As you make the changes your illness requires, you can become more flexible and creative in adapting to change. An idea that may help you is to keep a journal of the changes you've already made and how you made them. This can serve as a reminder of your accomplishments, and as a guide for making other changes. As you develop a greater degree of flexibility in adapting to change, the easier change becomes.

Befriend your illness as a part of your life. Chronic illness is your daily companion You already know how it affects your body. Now get to know what you feel and think about it, and especially how you treat it. If you consider your illness an enemy to be crushed, or an unwelcome guest
which you refuse to tolerate, or even an interloper you must annihilate, how will you allow your illness to be what it is, a part of your life which you can learn to befriend? Do you remember what Lincoln said about a house being divided against itself unable to stand? If you're divided against yourself by refusing to know your illness, or by waging war against it, how will you come to befriend it? Consider giving your illness a name and talking with it. Speak from your heart and your passion. Write down everything you think and feel about it. Don't keep your thoughts running around in your mind creating havoc. Then, listen to what your illness says to you in return. If you find this difficult to do, don't be discouraged. It is difficult, but there are rewards. An uneasy alliance is better than none at all.

Do you feel as if you're losing yourself? Do you feel as if your blue moods are turning into dark depression? Is inertia increasingly becoming more a part of your life? Do you do less for yourself on the days when you could be doing more? Do you isolate yourself from your loved ones and friends? If over a period of time, you are regularly experiencing these feelings and can't shake them, don't hesitate to find professional help. Ask your doctor to refer you to a therapist whose specialty is working with people with chronic illness. These therapists can help you to make your way through difficult times. Yes, it's important to talk with your friends and family, but talking with a professional can be very freeing. They are available to help you sort out your experiences and the many feelings and thoughts you have about yourself and your illness. This isn't the time to "tough it out", or attempt to dismiss your feelings with a mind over matter mentality. Allow yourself to get whatever help you need. It can make a real difference in your life.

How often during the course of a day do you talk about your illness or refer to it? Do you feel it's taking more of your time and energy than you would like it to? That can happen, especially when you are initially diagnosed and you're learning about your illness and trying to figure out your relationship with it. If it becomes a habit, and you feel as if you're losing perspective, here's a way to regain your balance. Create "talk space". Choose a comfortable place in a room in your home and make time to talk about your illness with your partner and your family. Let them know what you're experiencing and thinking. This is a time for honest sharing, for you and for your loved ones. Allow this "talk space" to be the place and time where you discuss your illness. Keep the rest of your home an "illness free talk zone". This will allow you and your family to enjoy one another's company and conversation without reverting to the topic of illness.

Seeing with new eyes doesn't mean looking through rose colored glasses. When it comes to putting your illness in its place, you might try seeing with new eyes. When it takes you more time to do just about everything, when simple tasks frustrate you because they're not so simple to do anymore, when the familiar becomes foreign, when you can not do the many things you once loved doing, maybe seeing with new eyes can help. If you were an artist and can no longer paint, you can still go to museums or art galleries. If you can't do that, you can enjoy art on the Internet since it offers you access to the world's best museums, galleries and art exhibits. If you worked with your hands and can no longer use tools to do a job or hobby, teach someone else to do what you know how to do so well. Share your knowledge and lend your expertise. If you loved nature and the outdoors, but can no longer hike, drive along some of the scenic roadways and enjoy the beauty and majesty of nature. Find a way to keep what you have been passionate about in your life. It takes time, work, patience, spirit and heart to make a place for illness in your life. Seeing with new eyes is both a tribute to courage and the ability to put illness in its place.

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