NIU EMPLOYEE ASSISTANCE PROGRAM

I Have a Chronic Illness So Now What

In the beginning…

You are healthy and your identity is built around what you are able to do and how your body helps you do it. When you first begin to acknowledge something is wrong, your reaction is disbelief and may become denial. As your body gives you more persistent signals that something is wrong, your disbelief or denial give in to fear and the need to find out what is wrong. After a diagnosis, the feelings of disbelief and fear become more intense and turn into shock. At this time, your world seems surreal. “This isn’t happening to me… I thought it was… If only I had… Somebody should have…” all become things you say to yourself as you try to regain control over your life and reestablish normalcy. A chronic illness does change what is normal for you and as someone experiencing cancer said, “I do not like this new normal and these side effects do NOT suit me!” At this point, you recognize that your normal has changed, you start to acknowledge a significant loss, and your grieving begins (Coping with Grief).

Acknowledging you have a Chronic Illness…”So now what do I do?”

Eventually, you give up the questioning and “if only” statements and focus on dealing with your treatment and its effects. You are now on a roller coaster of too much information, too many decisions, and too many intense feelings. This is an uncertain and overwhelming time as you decide where you will receive treatment and what that treatment is. If the treatment involves surgery, you are dealing with the both the surgery and its risks, along with the findings from your surgery. With surgery, you are also dealing with the impact of surgery on your body and what it takes for your body to heal from the surgery, let alone heal from your illness. Surgery shows you how quickly you can go from being able to do things to not being able to do the most basic of living tasks. You become aware of how thin the line is between being able to take care of yourself and needing assistance. People who have always been healthy find this particularly difficult and cannot believe how long it may take to recover from just the surgery. Perhaps before you have completely recovered from surgery you are starting treatment for the disease or condition that was the diagnosis that required surgery.

Once treatment for your chronic illness begins, you have to live with whatever the treatment is doing to your body and your spirit. It is at this time that you really begin to experience how much you cannot count on your body and feelings of anger may emerge, because you feel your body has betrayed you. This triggers a grief response as you mourn the loss of your body’s ability to do what it has always done. You may feel hurt, scared, and angry which may translate into intense angry at the world and everyone in it. Or, you may feel intense fear and sadness which translates into being very helpless and overwhelmed with life. Sometimes, what you have lost is clear immediately and many times it is a slow process. The changes in your stamina, physical abilities and energy have a profound impact on your identity, competence, worth and desire to do things. Even your likeability feels questioned as “who likes someone who doesn’t do much, is too tired, or is a burden.” This uncomfortable sense of intense uncertainty continues for awhile depending on the particular illness and treatment.

Your doctor or team of doctors is critical to your health so these relationships become very important. If at any time you start questioning, “Is this the right doctor for me,” listen to yourself. Trust your instincts. The doctor(s) you start with may not
be the doctors you continue with. How you are treated by your medical team and how well they listen to you is as important as the doctor’s credentials, experience, and the convenience of the doctor’s location. Also listen to the doctor’s language. Are you “the diabetic” or “the person with diabetes”? This difference in language reflects the difference in how you are treated, and lets you know if your medical team sees you as the whole person you are. Remember, this is your treatment and you are making the decisions. Second opinions may be necessary to make the right decision for you, and the right doctor understands this.

Throughout treatment you look forward to when treatment may end or, with a chronic illness, when you find the treatment that works for you, so you can go back to “normal.” Your mind is consumed with what is happening to you, what all this means for your life, you loved ones and friends, and the activities you love to do. After awhile you may begin to question, “Is this as good as it gets?” This is when the reality that you have lost your health becomes clearer. You are grieving the loss of your life as you knew it and you want your healthy life back to the way it was. Your feelings at this time are very intense and as difficult to deal with as what is scaring you. Arthur Frank in At the Will of the Body: Reflections on Illness discusses how the medical profession or well meaning friends may dismiss your grief experiences (anger, fear, sadness, and tears) because of their own discomfort and need to have you back to “normal.” Accept what you are feeling and the waves of grief as they come (Coping with Grief). Remember, you will not always feel this way.

Coping with Accepting a Chronic Illness…“Is this as good as it gets?!?”

Losing your health is a big loss; allow yourself to be angry and to cry. Anger connects you with what you have lost and what that loss meant to you. Crying is the beginning of letting go and an important part of healing which allows you to begin to accept what you can do. Crying is part of grieving and the tears will come when you least expect it. Sometimes crying is uncomfortable for your loved ones. It is important that you allow yourself to cry and let your loved ones know what they can do to comfort you. Most of their discomfort is feeling helpless and not knowing how to comfort you, so teach them; it will help both of you. Everyone grieves differently and every phase of your grief will be unique to you. An important component of grieving is to recognize you are grieving and be able to talk about what you have lost and the feelings you have.

Sharing is an important part of healing and redefining your identity, competence, and worth. For meaningful sharing you need to get beyond the social niceties of being upbeat and positive and be able to talk about what you are struggling with accepting and how you are feeling. Pushing down the “negative” feelings doesn’t make them go away, instead it takes a great deal of energy that you do not have. It is important to acknowledge what you’re feeling and struggling to accept. Find a support group or someone who has experienced the same illness or impact of treatment to help reduce your sense of isolation. The other person can be helpful when nothing feels okay. Remember, not sharing what you are feeling and what is happening, makes everything more scary to you and your loved ones.

Tips for sharing, an important part of healing:

♦ Share your feelings about how this chronic illness has changed your life with your loved ones and friends. If you share your anger, fear, frustration, sadness, pain, tears, and even laughter, then your family, loved ones and
friends will feel they can also share all of their feelings about your condition with you. Talking about your chronic illness will help you and your loved ones accept what is happening.

♦ Use the name of your health condition and maybe give it a name or let your loved ones and friends name it. This condition is going to be with you for a while.

♦ Buy books that everyone in your family can read and leave them where anyone can just pick it up. If there are any books with humor…all the better. A favorite for people and families dealing with cancer is by Christine Clifford, Our Family Has Cancer, Too!

♦ If there are things you don’t want to share, or you do not have someone you can share with, try journaling. Buy a special notebook and journal about your thoughts and feelings. Buy journals for your loved ones. Journaling will bring clarity to what you are experiencing and will help you let go of some of your “fearful and negative” thoughts and feelings.

♦ Remember to laugh and find joy wherever you can.

♦ Attend a Support Group. Available online at: http://essmail.ess.niu.edu/mailman/listinfo/chronicill

In your mind, being likeable and having something to offer in any relationship becomes questionable, because you feel you can’t count on your body, you believe…“How can anybody count on me?” Much of how you define yourself and your identity is what you do, and when your doing is compromised, so is what you think we have to offer others. Shifting your focus in relationships from doing to being is difficult. To understand that your presence is what is important and whatever you share is of value and worthy is very difficult when your sense of worth is connected to what you do. You may believe you sound like a “broken record.” Remember, people in your life care about you, not just what you can do. Let them know what you need just as you want your loved ones to let you know what they need.

Your feelings of betrayal create a lot of anger toward your body and at life. Anger zaps the little energy you have, so it is important to acknowledge your anger and grieve the loss of what you can no longer do. Then, you can move toward accepting what you can do. As you accept your physical limitations, you can begin to make accommodations for yourself so you can continue to do some of what you love. When you focus on what you can do, you start to enjoy your doing. Remember doing some of what you love to do is better than doing nothing, so take it slow and enjoy your breaks. As a gardener once said, “I focus on appreciating the beauty of the flowers and not focusing on the weeds because I can only do what I can do...a little at a time with lots and lots of breaks appreciating the beautiful flowers!”

When you have an invisible chronic condition, it is very hard to accept your physical limitations. Since people do not see the physical signs of your condition, it is easy for them to forget or not understand. It becomes more important with an invisible chronic illness that you accept your limitation and speak to the accommodations you need, because others may not understand. It is hard to accept that doing your best may vary depending on how you feel physically. This is true for everyone, but people with a chronic illness generally think, it is only true for them. No one works at their peak level 100%
all the time. Accepting your limitations, allows you to make the necessary accommodations so that you can be stronger and continue doing what you love longer.

**Resources that may be useful at different times during your process of coping.**


*Bernie S. Siegel is a surgeon who has written many books and tapes focusing on healing. You can find many of Dr. Siegel’s books and other resources, information, books, CDs, and a biannual newsletter at [www.ecap-online.org](http://www.ecap-online.org). The ECaP website is owned and operated by Meadville Medical Center's Mind-Body Wellness Center.*

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