

COPING WITH CHRONIC ILLNESS

(This is adapted from the book *After The Diagnosis* by Dr. JoAnn LeMaistre.

Copyright © 1985, 1993, and 1999 by JoAnn LeMaistre.)

JoAnn Le Maistre received her Ph.D. in clinical psychology, delivered a daughter, and learned she had multiple sclerosis all within the period of a few months. Dr. LeMaistre has developed a successful practice counseling patients and their families. She is a sought-after speaker, lecturer, and teacher. Her books, After The Diagnosis, and the hardbound edition, Beyond Rage, have helped thousands of chronic illness patients, their families, and health care providers to cope effectively. Her daughter has now graduated from college. And Dr. LeMaistre has learned to live a full life, in spite of the handicaps of her MS. She is an inspirational example of what it means to be able-hearted when you can no longer be able-bodied.

Traditionally, the experience of serious illness has been approached in two ways: (1) a gloomy perspective of resignation, self-denial, and helplessness, or (2) a Pollyanna approach that denies altogether that there has been a real trauma. Both of these perspectives distort and disguise the reality of chronic illness.

The first perspective views the chronically ill person as a failure. This is the patient who does not respond to the "miracle" of modern medicine, and somehow the lack of recovery is often perceived as the patient's fault. This attitude of blame accounts for some of the worst psychological abuses of patients by health practitioners and caretakers, an attitude typified by the too-frequently heard statement, "Stop complaining. You simply must adjust." Unfortunately, the sick person may also adopt this punishing attitude toward himself or herself. Sadly, the word "adjust" too often means "resign," "settle for less than a desirable existence," and "surrender." At its worst, "adjust" is just another way of saying "You are now a nonperson without the right to experience strong passions, desires, or fierce and unyielding hope." All the anger and blame inherent in this attitude is misdirected: the patient rather than the disease becomes the target.

The Pollyanna approach is typified by – and fueled by – personal stories or testimonials of complete recovery from extreme illness or disabling conditions. These stories tug at the heartstrings and catch the fancy of all who read them. Besides creating false hope by overplaying the likelihood of complete recovery, these stories consistently underplay the sadness and feelings of worthlessness that are part of the legacy of any physical or emotional trauma.

Sometimes, it is useful in social situations to present yourself as a Pollyanna. When meeting new people and situations, it may be an advantage for you to let others think you have mastered your disease. The anxiety of other people is reduced by not having to confront illness. The danger is that this Pollyanna image may create a barrier between you and the people who can offer real help.

The resignation viewpoint holds little hope; the Pollyanna viewpoint holds little reality.

The approach I propose took shape as my own understanding developed. My experience as a patient, observer, and psychotherapist has allowed me to see the many ways in which people creatively adapt and use their individual internal powers of *wholeness* (the sense of being emotionally intact) to reduce the destructive effects of severe physical limitations and accompanying depression, rage, and fear. The wellness approach I present stresses both the subjective experiences of loss and your responsibility for looking outward to reestablish quality in your life.

Central to wellness is the concept of adaptation – the flexible, creative use of resources to maximize your choices and experiences of mastery. This is the key to creating and sustaining a sense of inner tranquility in the face of difficult realities. There is no need to deny grim facts of existence or to pretend to others that all is well when inside there is little except torment. To be psychologically well while physically sick involves the belief that your personal worth transcends physical limitations; you need positive self-esteem for true adaptation. This belief in your self-worth rarely emerges until what you have lost and grieved for stands second in importance to precious moments of inner peace and joy.

Each stage in the progress toward wellness involves loss, grief, and acknowledgment of internal pain. During difficult times, emotional pain can engulf your life. All sense of time and proportion fade. The scope and intensity of the psychological pain fluctuates day to day. At times, it carries you closer to invaluable inner resources. At times, like a dangerous undertow, this pain drags you far from your recognizable self. It may seem that you have no reason for living or that you are living only to experience pain. Even so, the reason for living is life. The incentive for becoming psychologically well is the potential for the future.

Illness is an emotionally as well as physically depriving experience. It can do lasting harm by threatening a person's sense of well-being, competence, and feelings of productivity. At their worst, emotional reactions to illness may culminate in the feeling that life is meaningless. I do not share this belief; but I recognize how stress can make you feel this way.

Illness is a process, and like all processes it has different stages with different characteristics. We will discuss the stages below. The stages can occur in varying orders; often they are repeated. If a sick person lacks emotional support or a necessary feistiness, the process can stagnate, and one may be mired in one or another phase of the emotional transitions taking place. The emotional

process begun by illness is a highly varied and individual one. Not everyone gets bogged down. Not everyone experiences all the stages discussed in the following sections. The stages are not part of a once-through program, but are repeated as symptoms recur or losses come about.

The level of adaptation is an upward spiral in which coping mechanisms, learned one at a time, can be combined with strategies learned at other times to make each bout of illness less emotionally upheaving.

How people react to chronic illness depends on many conditions. Three deserve note. The first is the severity of the illness. The very sick must put all their energy into healing and may not have the luxury of energy left over for emotional growth.

The second is the social support available. If you are willing to ask for help and you have a wide support network, you'll have an easier time than if you are isolated.

The third condition is the preillness personality of the person. If you have always been pretty resilient, you are likely to have resilience in coping with the illness.

The emotional trauma of chronic physical illness is caused by loss of a valued level of functioning, such as the ability to drive or dance, for example. The chronically ill person not only suffers the loss of immediate competency but is deprived of an expectable future. No one's future is ever guaranteed, but most people become accustomed to looking at the odds; if I invest my energies in a particular direction, I can be reasonably certain I'll reach a desired goal in that direction. When illness intervenes, all past efforts may seem irrelevant – and in fact they may be.

In the face of such losses, to experience fear, anger, depression, and anxiety is normal. It would be abnormal to deny that your health and your life had changed for the worse. Serious emotional difficulties are more often the lot of people who do not acknowledge the emotional stress they feel and thereby bottle up depression or anxiety until these feelings are so powerful they break through their defenses. By the time an emotion becomes this powerful, it is much more difficult to survive its impact without severe scarring.

Is there anything that can help overcome the displacement and depression caused by physical loss and the loss of goals and dreams? I think the answer is an unqualified YES!

Goal-oriented striving, any experience of mastery, any outside acknowledgment of competence, a well-tuned sense of humor, any experience of joy, and the constant striving toward an inner state of tranquility are the aids that help overcome the displacement and depression of chronic physical illness.

These aids are of critical importance in the stages of the ongoing emotional process. I identify these stages as *crisis*, *isolation*, *anger*, *reconstruction*, *intermittent depression*, and *renewal*.

These are good summary categories for the whirl of emotions triggered by illness and we will take up each stage in turn, although in the course of an individual illness they may not always proceed in this order.

CRISIS

In the crisis stage, the patient is seriously ill and very frightened. Both psychologically and physically he or she has a decreased ability to respond to others. The sick person's energies are directed inward toward healing, and controlling panic. The patient is often too sick to even be frightened. Events are often confused. Time is distorted. Disorientation is common. At these times we fall back on our innate biological ability to heal. The support network, on the other hand, is feeling a highly stressful increase in anxiety, especially as it must carry the full responsibility for arranging for medical care, covering finances, and seeing that children's lives, if children are involved, can go on with a minimum of disruption. The family's anxiety can be energizing. The family may feel a need, sometimes an obligation, to be highly supportive of the patient.

By and large, everyone responds well in a crisis. Everyone knows the patient is terribly ill. And they respond. Unfortunately, those most affected by the patient's illness do not always receive the support and help they need at this time.

Friends sometimes respond by showering the sick person with cards, flowers, and get-well-soon wishes. Unfortunately, much of this is misdirected. The very ill person often cannot appreciate these signs of concern and affection. Patients often feel burdened by all the thank-you notes they cannot send. Friends can often do more by helping the family and other members of the support network to deal with the medical system, the incoming phone calls, and to give direct support when it becomes clear that the idea of "get well soon" has no relevance to chronic illness.

During the crisis stage almost all of the patient's energy and attention are focused on responding to the physical onslaught of the illness. Surviving is the primary concern.

In addition, the patient and the family must cope with the fear of an unknown and unknowable future. It is all too clear that the comfortable patterns of the past have been shattered. It is not clear at all what may lie ahead.

ISOLATION

In time, the acute nature of the illness may abate. But total recovery does not occur, and the illness persists. There is a dawning awareness of everyone's part that the situation has become a chronic one. There will be no full recovery. There is so much uncertainty about the future that the patient may not be able to sleep at night and may seem restless and distracted during the day. The lack of an expectable future constitutes a major assault on one's self-image.

The patient's anxiety often produces a stiffness or frozenness in dealings with others and oneself. There is a belief, usually partially justified, that no one can understand the devastation of the losses. Isolation most troubles patients who have been the most independent.

The family has often exhausted itself during the acute crisis stage. Family members may become aware that they are angry, fearful, and disgusted about the sick member's situation. Both patient and family members retreat into themselves and their thoughts, now haunted by the knowledge that life may never be the same.

Friends also tend to give out at this point – the idea of chronic illness is really terrifying to most people. After an initial burst of energy, some friends may find it too overwhelming a personal struggle to continue having contact with either patient or family. Some patients have been devastated by an apparent lack of concern shown by people for whom they care. I say apparent because often failure to contact the patient means that friends may care but don't know how to act.

This leads to a thorny question. How comfortable are you in asking for help? What does it mean to you to have to ask for help?

These questions begin to surface during the isolation stage, but actually they are part of everyday living for most chronically ill people. To feel really comfortable allowing others to help you is an art that must be learned and practiced. It is difficult to understand that relying on other people when it is necessary does not indicate weakness or failure. One of the emotional barriers to asking for help is a strong feeling of guilt about having a disease that makes one need help. During the isolation stage, patients look inward and experience many negative feelings about themselves.

In the isolation stage open communications are vital. Blame must not play a part. Talking about feelings is very important. Communication and sharing are ways to break the isolation.

ANGER

The sick person has been suffering severe upset, terror, anxiety, and helplessness. Add to this the sense of injustice, unfairness, and senselessness of being struck down by a disease, and the result may be a rage reaction of tremendous proportions. Often the target of this rage is the patient himself or herself. The ultimate, most dangerous, expression of this rage at self is suicide. The commonly experienced feelings of despair may result in contemplation of suicide.

There are two reasons why the patient targets himself or herself for these feelings of anger and despair. First, it is almost impossible to be furious with fate; there is no external opponent. In order to provide some meaning for what has happened, many people irrationally conclude they have bought disease on themselves by being faulty or wicked in some way. It is difficult to keep clear that it is the disease that introduced the disruption into one's life.

Another reason for suicidal thoughts is that illness breeds a sense of helplessness. The chronic disease cannot be wished away. The disabilities are there to struggle with every day, and the threat of a major recurrence or increase in symptoms may be a constant anxiety tucked away not far from consciousness. With the feeling that the underlying problem cannot be solved and the belief that it is the patient's fault, many patients suffer intense unhappiness. Sadly, the patient's feeling of self-blame is greatly reinforced by society. Often families are unable to help because they are angry at the patient. The changes in their life style are directly attributed to the patient and not to the patient's illness. Even supposedly neutral medical personnel may be furious with the patient for having a chronic condition they cannot cure. This anger directed at the patient from all sides is psychologically understandable but it is very destructive.

The flirtation with suicide, the patient's worst hazard of the anger stage, is a statement of the extent of one's rage with oneself and with those one cares about.

Another serious problem of the anger stage is the strain on the family. Families who fare better during this stage understand that the sick person is not the same entity as the disease and they see that the whole family is in this predicament together and are committed to coming out of it as well as possible. Family members need to devise ways to nurture and adequately support each other in order to cope with both the anxiety and the practical life changes accompanying chronic illness.

Anger is the stage most hazardous to your emotional well-being. It is also where most people get trapped. Fear and anger are disruptive emotions engendered by a sense of loss of control. Take back control in small steps. The basic reasons for the anger, in most cases cannot be avoided. It does no good to assign blame. The response must become task-oriented. "Today I will walk the length of my room, or call a friend, or answer one inquiry." Striving toward a goal, even in small doses, is an antidote to anger. Patients, family, friends, and helpers should all focus on the strengths that remain, on the accomplishments that can still be achieved. This basic rule is a key to dealing with anger.

RECONSTRUCTION

The sick person may now be feeling much stronger physically or may have had enough time to begin mastering new living skills. Important decisions or new social contacts may be in the picture. What is common is a growing sense of safety based on new competencies. Moods are happier and the difficulties seem a bit further away. The sick person is learning the possibilities and limits of the new competencies. Friends are selected on how well they react to the fact of illness. The family establishes new routines – or it dissolves.

What exactly has been reconstructed? Certainly it is not life like it was before. Instead, it is a reconstruction of the sense of oneself as a cohesive, intact entity. The reconstruction takes on many concrete aspects, such as the development of new skills, but the most important value is

emotional. When a customary pattern of living has been shattered by illness, the patient fears that he or she is longer recognizable as a whole being. It is the reemergence of a positive self-image that constitutes reconstruction.

Often people do well for a few weeks and then are devastated by some incident. But each experience with trusting and succeeding is a building block for the next step of reconstruction.

INTERMITTENT DEPRESSION

Now that everything is looking brighter, everyone is tempted to relax and may, therefore, be caught off guard when a significant depression recurs. The elation associated with new skills can give way to new feelings of despair as the patient recalls how much simpler it was to do routine things the old, preillness way. Nostalgia and grief may combine to produce sadness and discouragement.

Many people know exactly when they expect to hit these rough spots. Medical appointments and anniversaries are notable examples. Seeing a doctor, who confirms your intuition that your condition is not improving or is worse, often leads to depression. So may the third anniversary of having to give up the car, the first anniversary of a divorce, the time of the year the physical problems first occurred – the list is endless. It may be best to seek counseling during these difficult times as a way of shortening their duration and providing new understanding of what all the feelings of loss are attached to. New understanding brings new resilience; it does not make the losses go away.

Intermittent depressions seem to combine two feelings. One is the awareness of loss of function that occurs several times a day in the course of ordinary living. But clearly, an amputee does not become depressed each time there is a reminder of the inability to walk normally. There is a second element involved. If the awareness of loss arouses a distinct image of what life would be like if the amputation had not occurred, and if this fantasy has strong emotional meaning for the person, depression is very likely. This image of how you would be without the illness I call the *phantom psyche*.

The phantom psyche is usually not far from consciousness. It is the self-punishing mechanism whereby the chronically ill person continually erodes his or her own self of self-worth and competence. "If only I didn't have this arthritis [or whatever illness] I could still be mountain-climbing [or whatever activity]." "If only" statements are the bread and butter of the phantom psyche. They contain harsh judgments of worthlessness. In a happier mood, you might experience the same feeling of loss, but say to yourself, "I really miss mountain climbing, but at least I can take a walk today."

When the phantom stalks, the soul is uneasy. Doctors and friends often mistake the desperate pain of knowing one's hopeful fantasies will not be realized for self-pity. "Just stop feeling sorry

for yourself" so completely misses the point that it is tragic. It is very difficult to have a sense of self when you're depressed and are afraid that you'll never again be of value to yourself and others.

Self-esteem increases proportionately to successful experiences of independence and purpose, whether the success is remembering what time to take a certain medication or walking better after months of physical therapy. The phantom psyche – those unrealistic expectations you have for yourself – cannot compete with the heady gratification of hard-won success. If family, friends, and medical personnel can appreciate the triumph in being able to struggle, you feel even more triumphant. Well-wishers too often make the mistake of praising a sick person for progress without acknowledging how difficult is the ongoing battle against the inertia of chronic disease.

We all have periods when we feel overmatched and not up to the struggle. But as long as we pay attention to the struggle, we will get through the day. We flounder when we set unrealistic standards, or cannot grieve for what has been lost, or cannot start each day afresh. Depression can be tackled despite the physical complications that try to drag us down.

RENEWAL

The losses, and the sadness they cause, never go away entirely. There is a sense of lingering regret for all the capacities that have been lost. A person who has mastered the technique of using a wheelchair can feel very proud of this achievement and know full well that this device is essential for retaining an active life. But the person does not have to like it.

It is not necessary to like or to resign yourself to the compromises you need to make to get on with living. It is only necessary to acknowledge that changes in life style and skills have to be made. Acknowledging that your skills are different from your preillness days is not the same as "adjusting" to illness. There is no surrender involved, only growth – the creation of new options through new means.

The creation of renewal comes from the experiences that teach us not to waste the present on fearing the future.

The truly handicapped of the world are those who suffer from emotional limitations that make it impossible to use the capacities and controls they possess. If you have a chronic disease, you need not be emotionally handicapped if you continually strive to be able-hearted. Able-heartedness is within the grasp of all of us. I don't think of able-heartedness as a permanent, static state, however. Developing and maintaining this quality is a process that ebbs and flows, depending on how helpless you feel. Even if you feel in the grip of hopelessness, you are behaving in an able-hearted way by any expression of interest in another. Shared interest and compassion is what establishes meaning and purpose in life.

When you feel discouraged, you feel all alone – and there is some truth to this feeling. But in many important ways you are not alone. There are hundreds of people in your city who have similar feelings at times. If disturbing thoughts wake you in the night, know there are other struggling with their pain. No one can share your unique experience, but there is kinship and a strength among all of us who are no longer able-bodied.

There are some positive coping skills that are required by unavoidable health changes. These are summarized below.

Make Your Expectations Realistic

The most important aspect of making expectations realistic is the recognition that they are time-limited. "What can I do now on the basis of the way I feel at this moment?" If you have two minutes, what are you going to do? I counsel people to check with themselves to find out what they **want** to do. Illness can make you feel that you must surrender all goals, all wishes. But that is not necessary.

Make your expectations run like this. "Within the limits of my physical ability I will do whatever it is I want to do for as long as I can."

Approach Problems Actively

A second essential skill is an active approach to problems. What is an active approach? It consists of defining the problem and determining the outcome you want. It involves trying to ensure that any energy expended constitutes a step toward the solution. Rarely does it constitute the complete solution. The admission "I cannot do something" is often the first step in solving a problem realistically.

Define what you want and then use every ounce of creativity you possess to determine how you are going to make it happen. Creativity is *not* impaired by illness. When you define the problem you figure out how many facets there are to achieving some kind of resolution, and then you expect yourself to make only that part of the effort that is realistic. What this means is that you need a broader sense of community. There are going to be a number of things you cannot do alone. Your dreams do not have to change. How they are realized will probably change. The creative, flexible use of your energies and creativity to get as much satisfaction as possible is your mission.

Seek Appropriate Help

The next skill to learn is to ask for appropriate help. It is not a moral weakness to ask for assistance, but many can probably recognize the tendency to regard asking for help as shameful. It is a limitation if one does not know how to determine whether or not assistance makes sense. It is a limitation if one is harsh or angry with the helper. Asking for help can become a more and

more graceful skill. It is certainly not the first choice for people who would rather do everything themselves, but it should be your choice if you are going to pursue what you need and want – when you cannot do it alone.

If you have a hard time asking for help, consider what you would do if you were fully able-bodied and a friend of yours had your particular problem to solve. What would you do? Do you see yourself denying help as you gear others might deny you? Would you be upset if your friend asked for the specific help that was required? Chances are you would feel fine about helping out if you could. You would just do it. Try to be as kind to yourself as you would be to another when it comes to asking for help.

Handle Your Anger

The next skill involves learning how to become emotionally efficient and energy conscious. Energy is a tremendous problem for those with chronic illness. There is none to waste. Some of the most wasteful expenditures of energy are for resentment and anger. These emotions are not bad in themselves, but they do wear you out.

If you are angry, it helps to have some consciousness of what you are angry about, and whether you want to be angry about that. Sometimes you will want to be angry because that is the appropriate response. Sometimes you will want to be angry because it is more efficient to be openly angry than to deal with bitterness or other forms of calcified anger. The better you get at being direct about anger early, the more energy you save and the more efficient you are. Surprisingly, many people do not know how to recognize their own irritation or anger. If you are feeling irritated, it might be helpful to be assertive, even if in the short run you feel uncomfortable.

Participate

Another skill that is especially restorative for those with illness is to put positive energy back into the world. You can do this with family, friends, with self-help groups connected with your illness, or with community groups. Put your talents, your compassion, your knowledge, and your experience out there in a way that can benefit others. Be a good friend to yourself and don't overlook your finer qualities.

If asking for help is a skill you possess, then there is even more constructive energy available to invest in the world around you. Obviously, one of the things illness can do is to constrict your social world. Sometimes, this leads to the perception that there is nothing you can do for others. That is just flat-out wrong. If you have exhausted your own resources in looking for ways to participate, you can call organizations that are concerned with your illness, like the Arthritis Foundation or the National Multiple Sclerosis Society, as well as other national and local self-help

and research organizations. They can offer suggestions, and may have specific ways that you can help them. People volunteer because it feels good.

Live In The Present

Another skill, that is a challenge to learn, is to look neither too far backward or too far forward. If you are only looking backward, you are giving up on yourself emotionally. Your losses are major issues, but losses do not get people through one day at a time or one day after another. Losses are not a good reason for living. If you use all your emotional energy considering how things were before the illness and comparing it to how things are now, you are being very self-punishing. If you sense this going on, you need to be extremely aggressive about rejecting this.

Illness does not diminish one's humanity. Mobility and physical comfort decrease with illness. Fear and worry increase. But illness does not diminish humanity. Be humane to yourself. Avoid dwelling on how good things were in the past compared to now. Also avoid distant future fantasies. There is no way to know what will happen some years hence. And you know, there never has been a way to know the future. If you are not stuck in the past or tormented by distant future images of what should be, you have the opportunity to manage this day with awareness. Living in the moment with consciousness, patience, compassion, and appreciation for yourself and others lets you get on in a creative way, in spite of the pain of your losses.

Cherish The Good Times

The last skill I would commend to you is to pay attention to the positives. This can only be done if you have already mastered the skill of living fully in the present moment. You go through every twenty-four hours with enough of yourself available to the world that when something positive happens you let it in. There was a rainbow yesterday. There may have been an interesting interaction between you and the grocery clerk, or you had a close, warm exchange with someone you care about. These are the kind of positive moments I mean.

These are moments that need to be framed and stored to be used on days that are much harder. If we are in a quagmire of negative emotion, we can turn anything into proof that there are only painful things in the world. This final skill is learning how to hold onto the positives, to cherish them sufficiently that they do not drop out of your repertory of significant life events.

Once you notice the positives, how do you hold on to them? The best way is to slow down – to use relaxation, meditation, and your own internal capacity for joy to feel that moment inside. Let it resonate within. This allows your emotional commitment to be fully focused on the process of life. Be as emotionally able-hearted as possible, despite physical limitations.

What all these coping skills have in common is that they are daily necessities. You don't just get them down pat once and then forget about them. You need to use these skills frequently. Every

day is going to give you something different to try to manage. You need these well-practiced skills to succeed.

The circumstances you face may at times be miserable. Nothing can alter this reality. Trust that you will learn from each stage and from each cycle through the stages. Learn to trust others enough so that when the situation seems unbearably stressful, outside counseling and psychotherapy can be sought. Renewal cannot always be attained without help.

If these ideas have reached you at any level, you have already begun the process of renewal. You are adapting in the face of great difficulties. There is no right way to come through the ravages of unavoidable health changes. But I have tried to show you ways to remain an active agent in your own life.

You are not alone. None of us is alone. We may not know each other yet, but there are kindred spirits. A single treasured personal relationship makes the path bearable.

I wish you a safe and thoughtful journey on what is truly a road of hope. I travel it with you. You have a companion and you have hope.

To order a copy of After The Diagnosis, by Dr. LeMaistre, contact your local bookseller or bookselling web site. Or send \$15.95 to Alpine Guild, Inc. P.O. Box 4848, Dillon, CO 80435. The book will be promptly shipped to you