

Coping with Chronic Illness

This information was prepared to help patients and their families cope with chronic illness. It contains quotes from adult Clinical Center patients who face a variety of medical problems. Some of their reactions may echo your own feelings; others may not. Regardless of the differences, however, these comments may assist you, and those who care about you, to respond to your concerns.

All the patients contributing to this work overcame great challenges, which, at times, seemed insurmountable. Together with their families and caregivers, these patients learned to go on with their lives.

You can, too.

Part 1: Reactions to illness

Reactions to learning of one's chronic illness are varied, but they are always powerful. Emotions may range from shock to relief, and everything in between. Even when symptoms have been present for a long time, the diagnosis can be upsetting.

Feeling a spectrum of emotions

While shock may be the first reaction to learning your diagnosis, denial is also common, as are anger and grief over the loss of health. Some people become unconcerned about what goes on around them. Still others may sleep, cry, or withdraw to themselves. These reactions are normal.

"I went out dancing and had a great time with my friends. I came home and went to bed. The next morning I literally could not get out of bed. I was taken immediately to the hospital. No one knew what I had. I was losing weight, and my temperature was going up. The doctors performed exploratory surgery to find out what was wrong.

"Months later, we discovered that I had this chronic illness. I was extremely ill and my prognosis at that time didn't look very good. It was devastating. I just didn't know what was happening to my body. I was so sick and I didn't care about anything but surviving. It attacked my body so quickly. I kept thinking I'd wake up tomorrow and this would all be gone."

"I was devastated. I went into shock. I grieved. I thought about all the things I couldn't do. Perhaps I was frightened even more because I was familiar with the disease. Most people, when they are told they have this disease, have no idea of the progression. But my father had had it, and I knew what a crippling disease it really was. I knew what to expect and it really rocked me. I thought, 'If I can't be of use anymore, what's the point of living?'"

Denial

Refusing to accept the diagnosis right away may give you a chance to regroup. You may need the time to gather enough strength to confront what you are facing.

"I just didn't want to accept the fact that I wasn't going to get back to the way I was. I have a

lot of pride, and I didn't want this illness to be a reality. I had never been on this side of a disability.”

“I never thought it would be me. I blocked that.”

Confusion

“You go to the doctor, and even if he tries to explain what you have, it's hard to retain it all. In the first place he may not have much time to talk with you, or he may not really know a great deal about your disease. Even if he does, you cannot retain all the large words you're not familiar with. You go out of there thinking you know something, and by the time you get home, you can't repeat it.”

Fear

“In the periods early on, I was anxious regarding the natural history of the disease.”

“Sometimes I dread coming back to NIH because I dread what the tests will show.”

“Before I found out about my illness, I used to fantasize about the worst possible outcomes. These fantasies depressed me.”

Avoidance

Some avoid thinking of their illness. At times, this is a normal, healthy reaction.

“I really don't think much about it until I have to come in for treatment.”

Anger

“I used to be angry. Why am I like this? Why do I have to go in for surgeries? Why do I have to have physical therapy? The whys went on and on.”

“I used to think, 'If there is a God then why am I like this?' and 'Why do people have to suffer?' I've actually gained through the suffering! I can't say that it was an easy experience. I did a lot of crying, a lot of blaming, and spent a lot of time being angry at the world. I've learned that the hate I had in myself was not doing me any good. That's when I made the choice to change, to see what I could gain from my illness.”

Grief

“I used to cry myself to sleep. As I have learned to share my feelings with others, sleep comes more easily.”

Guilt

“My son was diagnosed with the illness also. That's tough for me. Passing it on to someone is pretty bad. I hope they'll have a treatment before his illness becomes more evident.”

Dealing with the unknown

Some chronic illnesses take people through periods of good health mixed with periods of sickness. Adjusting and readjusting to these changes may seem daunting.

“In five and a half years of illness, I’ve struggled with the question of how to live a ‘normal’ life and plan for a future while the possibility of sickness and death looms over me. I’ve decided it’s that sort of constant uncertainty that is the worst of it all.”

“It’s not easy dealing with the unknown. ”“For years I knew something was wrong...it came as a relief to give it a name. It wasn’t in my head! The fact that I fell a lot and couldn’t get up was not in my head! Any diagnosis is a relief because you know what you’ve got to fight. If people have proper diagnoses, they know which tiger to fight (as opposed to the whole jungle). Knowledge is power.”

Handling reactions from others

One of the most crippling things about chronic illness is the way some cultures shun the sick. In other cases, people’s own fears keep them from offering support. By standing up for yourself, regardless of these feelings, you can work with others towards better understanding.

“Some people don’t want to help. Maybe they feel that my illness will rub off on them. They don’t want to recognize that disease happens, and it can happen to them and their friends.”

“Whenever I see someone else with an illness, I say to myself, ‘Poor thing.’ Then I realize that other people are probably saying the same about me.”

Part 2: How to cope

The way you cope with your illness may have a lot to do with how you dealt with crises in the past. As you handled them, you gained strength, and you may have benefited from the support of others.

When dealing with chronic illness, you may find strengths you never thought you had. And while chronic illness may close the doors to some parts of your life, it may open others.

Patients coped with chronic illness in many ways. Acceptance of the condition is essential, as well as finding ways to feel more in control.

Building on old relationships and starting new ones are also important.

Acceptance

“For a long time it seemed to me that if I could just endure a little longer and be patient, I could resume my life. But it was one disease after another. It seemed as if I was taking one step forward and then two steps back- always an obstacle in my path to good health. Then, at last, it dawned on me that these obstacles were my life.”

“Having a chronic illness is a very emotional thing. You grieve, you feel sorrow. But you cannot stay there. You recognize that, yes, you’re justified for feeling that way, but to stay there would rob you of the years you’ve got. You can be useful, you can get things done, although not the same things that you did before. You still can do things and you still can enjoy plenty.”

Taking control

Chronic illness often requires you to release control of certain parts of your life. It is normal to feel angry because you no longer have as much self-mastery. But it is possible to find new ways to regain a feeling of control.

Control through knowledge

“I know about lab results and what my blood counts are supposed to be. I know when I’m supposed to get what medication. I know as much as I can, and if I don’t know, I ask. What others don’t know, we learn together.”

“I don’t like being sick, but I deal with what I’m able to deal with. I can’t change the fact that I have it, but I can see to it that I know as much as possible about my condition so I can take care of myself. I try to be very careful about taking my medicine accurately, eating the right kinds of food, exercising as much as I can, and getting plenty of sleep at night. The rest I leave in God’s hands and don’t worry about.”

“You never get over grief or pain. You recognize it but you move past it. Sometimes you get back into it. Then, you recognize it and you move past it again. If you dwell in it, you sink lower and lower, and all there is, is the pain. What helped me get past my grief and start coming up for air was the fact that I am curious about a lot of things. I wanted to know more about the disease.”

“I learned as much as I could. I got informed so I could make better decisions.”

“I sought out information so that I could be proactive about my illness. I’m curious. I like to know what’s being done to me and I like to know the results of the procedures.”

Control through planning

“I try to plan: I plan for my needs, I planned my estate, and I planned my will.”

Control through positive thinking

“I decided to find things I can do—things I am good at doing.”

“Always fight. Sometimes I take a deep breath, sometimes I take a time out, but I know that I’m going to continue just as long as I can. I just don’t give up. I think that people who are tenacious manage to rise above the disability better than others do. People need to look at what they can do, and be happy, because it could be a lot worse. A lot of them can still do something.”

“I use the theory ‘nothing lasts forever.’ This will be over soon. I’ll get through it and won’t have to come back to this moment again.”

“If I were to let go, I would feel like I failed in some way. I know a time will come to let go, but now is not that time. I’ve got to keep fighting.”

Control through problem solving

“I’ve learned to turn negatives into positives. For example, when I was told that I had lost my hearing due to side effects from the medication that was keeping me alive, I got hearing aids, a telephone for the hearing impaired, and closed-captioned TV.”

Benefiting from contact with others

Cooperation with the health care team

“Work with the medical team. If they recommend tests or procedures, be cooperative. Help them to find the answers for you and for them. They don’t draw blood just because they want to. They do it so they can help find the answers to your disease.”

“I hate the feeling of not being in control. When you’re a patient there’s only so much control you can have. I want all the control. Learning to relinquish some of that control is really hard. But the medical system is what’s keeping me going.”

Deepening personal relationships

“This illness has brought us closer together. My friend has shown me the power of his love by the way he has cared for me. I appreciate him immensely.”

“You cannot receive more than you give. It’s a rule of the universe. You can call it religion or whatever you want to call it. You can call it God; you can call it nature. You cannot receive more than you give.”

“I was going through so much that year that I had people tell me that if they were in my place, they would have committed suicide. But what would that have fixed? It would have only made the situation worse. Then I would have had four children left in the hands of a man who had just walked out because he couldn’t handle the situation. My children gave me strength.”

Support networks

People are often relieved to learn about others who have experienced what they have gone through. Support groups help, as do informal networks.

“I didn’t know what I had. I just got a lot of colds and just seemed to get sick real often. I used to wonder, ‘Is there anyone else in the world who has these problems? Am I the only one?’ Finally, after seeing many doctors, I came to the NIH and they had a name for what I was experiencing. I thought, ‘If there is a name for this and people study it, there must be other people who have it, too.’”

“I’ve never gone to a formal support group, but I believe everybody needs support. I find mine through sharing my concerns and greatest fears with my friends.”

“I think of NIH as my second home. When I come here I see friends and caregivers whom I consider a part of my extended family.”

“I found a support group back home. It meets two times a month at a local hospital. I find that being able to sit down with other people who deal with the exact things I do, really helps. I can’t keep it all inside. I know that saying, ‘You take it out on your gut.’ Well, I already have gut problems, so if I keep my feelings inside, it will only make things worse. In a support group I don’t feel self-conscious when I talk about my illness, because these people understand.”

“I have a few friends who don’t know what’s going on with me. Not everyone needs to know all the details of my life. Then I have friends with whom I share deep connections. They know that I’m not well and if I say I can’t do something, then I can’t do it and it’s OK.”

Being able to ask for help

Independence is highly valued in our culture. Those with chronic illnesses may face the challenge of learning how to ask for help, and being able to accept it.

“I used to hate it when others were always trying to help me. They all knew something was wrong, and they felt that they needed to help. I’ve learned to accept some help without having my pride get in the way. I say, ‘No, thank you’ to things I can do for myself, and I’ve learned to ask for help when I need it.”

“I’m learning how to be humble. I’ve really had to ask for help over and over again. This is the most difficult thing for me about having a chronic illness. Most people don’t want to ask for help. I don’t. I’ve been independent all my life. Now when I have to ask for help, it’s not easy. I hate it. So I started out trying to do it all myself. Then I realized, ‘Now wait a minute, this isn’t fair to other people. People get a lot out of giving.’ So I needed to find a way to let other people give.”

“I was afraid that I might not be able to live independently. Of course I would never admit this to anyone. But one day I decided I would try, and with the support of friends and family, I did it!”

Part 3: Relating to yourself

Self-assertion

“When I was in a wheelchair, I would go into a store with my daughter. I would put the product on the counter. I would put the money on the counter. I would hand it to the sales clerk. The sales clerk would give the change to my daughter and give her the bag. This happened over and over; it made me furious. At first I let it go. Then I learned to speak up very firmly. ‘That’s my money, give it to me, please.’ Now I consider it my responsibility to teach people to look at me, to interact with me.”

Accepting your physical changes

“It looked like I exchanged bodies with someone else along the way. The first time I saw myself in the mirror when I had lost so much weight and was having so many problems, I looked frail. My daughters were helping me to use the bathroom, and I didn’t even look like myself. A lot of things were so different. That experience has helped me look at myself in a new way. It has also helped me to be more attuned to my body so that I can report changes to my doctor.”

“In the beginning I used to hide my scars. I used to get upset and angry when I saw someone beautiful walk by. But now I’ve learned to accept myself for who I am. I’ve learned to see my positive qualities. I can look at myself in the mirror and see someone who is beautiful.”

“I have become more at peace with myself as the years have gone by.”

“I’ve learned that you can’t be vain with this illness.”

“I’ve never had a long-term relationship. Most of my friends are married and have children. I get sad about that. It’s hard, but I know there is someone out there who will accept me as I am. I didn’t even accept myself until a few years ago. I had to learn that it’s okay to have this illness. There’s so much more to me than this disease.”

Getting in tune with yourself

“I close the door and I meditate. It comes from inside, from my heart. From that which we have already been given. I take deep breaths and relax and allow this innerness to come out.”

“I’m doing all the things that are soul fulfilling. I do things that give me the most pleasure. I feel like I’ve gone back to basics. I’m in tune with myself.”

Expressing feelings

You may feel angry at your illness, your body, yourself, at health care providers, or family and friends. This is common and normal. It is a challenge to express these feelings in ways that don’t hurt those around you.

“I’ve struggled with anger in my life because I never want to hurt another person. I’m not a screamer, instead I play the piano.”

“Sometimes I protect myself mentally with an image of a shield on the outside. If I am really feeling overwhelmed, I do that many times, until I’m strong enough to open up again.”

“I think you have to allow yourself to have a pity party and then cut it out. You have to cry. You can’t be tough all the time. You can’t deny the feelings. They’re real but you don’t want to spend all your time crying. It just makes your eyes puffy after awhile, anyway.”

Just as expressing anger and pain helps, so does expressing positive emotions and doing pleasurable activities. Humor, faith, hope, and creativity all have great value in healing.

Humor

“If I live to be one of the old ladies at the quilting bee where they talk about their surgeries, boy will I be able to participate!”

Faith

“Just knowing I’m not alone helps. It’s just a feeling. Believe me, that feeling isn’t there all the time. I cried last night because I didn’t want to be here. There are the IV poles and the nurses, and I didn’t want to be here, but my faith helped me through.”

“Adversity is not the time to look at the negative. It’s a learning experience. Hold onto your faith, whatever it is. If you are rooted in faith you’ll be OK. It’s not the

end of the world. There are many possibilities. It may seem impossible, but every day is a new day of possibilities.”

“I tried to bargain with God. No matter how much I bargained, God wouldn’t listen, or at least that’s what I thought. But I see that my illness has given me new goals in life. Goals and dreams that I never would have imagined before. Maybe this is God’s answer to me.”

Hope

“Hope is born out of despair. You have to take risks. When you take risks, courage grows. That’s what I’ve had to do. I’ve relied on my faith. It speaks to my spirit, and it helps me to cope better.”

“I think we have to have a belief in something. It’s like a cushion to fall back on. You have to believe in something. You must have hope or I don’t think you can survive. People have to find out what they believe in to have hope.”

“This disease is not a death sentence. Doctors are doing research, and so there could be a cure. NIH is a place of hope for me.”

Helping yourself through activity

Creativity

“Since I’m away in the hospital a lot I don’t get to spend as much time with my sons as I’d like, so I write them letters. I tell them how I feel and that I love them. I give them advice and hope that if they ever have to

face something like this, they can learn from me.”

“When I am strong enough and have enough energy to do something, I make crafts. I need something to do with my hands, so I work on craft projects for as long as I can. This is my way of fighting the disease. No one can take this away from me.”

Pleasurable experiences

“I enjoy swimming when I’m in a large pool all by myself. I feel as though I’m in my own world. I can have full control of my body.”

“I like going into nature and taking pictures. Whether it’s of me in nature, or nature on its own. I feel that it is one way I can express myself.”

Distraction

“I pray a lot, and when the pain gets really bad, I pray for a distraction. One time I was lonely and in isolation at NIH. It was snowing and bitter cold outside and I was in a lot of pain. I just wanted the pain to go away. I knew the medication would take about 20 minutes to work, but I had to wait.

“I turned my head to the window and a pigeon landed; then another. I watched them and just thought how beautiful they were. But they were out in the cold. I was safe and warm. They were looking for food and my tray was coming soon. Nature distracted me and the pain went away.”

“There are times when I know I’m wounded and I need a day just to read something frivolous. Murder mysteries, for example. And I do it. Just relax. Cook if I feel like it; don’t if I don’t.”

Personal growth through adversity

Many patients find life meaningful despite chronic illness. They realize that the road towards personal growth is difficult, yet the journey is rewarding. The changes they face bring unexpected opportunities. Positive thinking plays a big part in being able to benefit from their experiences.

“Once in my life I had a beautiful painting of water. It showed where the edge of the water was coming up to the beach. As I saw out through the water into the very center of the picture, there was a calm area where the sun shone down on it. It was beautiful.

Before reaching the calm area, it was rough. From the point where I visually entered the water, the waves got rougher as I moved toward the center. That’s my analogy for life.

“Now I’m at a peaceful place, but there have been times when I felt as though I was barely treading water. It’s frustrating when I’m back in the turbulence. Sometimes it seems like my body is working against me. But I’ve been through it before, so I know I can do it again if I have to.”

“I’m a success story. I couldn’t walk at all and now I can. I can’t run, but I can walk. I accept who and what I am today.”

“As I work to provide others with knowledge about this disease, I’m getting better.”

“In order for me to cope well, I have to be a person willing to grow and work out a balance for my body, soul, and mind.”

“I believe that each day is not to be taken for granted. You have to make sure you tell people you love them because you don’t know where you’ll be tomorrow.”

“My life is not so bad. I wouldn’t wish it on anyone, but it’s not that bad. This illness is just one facet of my life. I’ve learned to love people, and people love me. Illness is not the main factor. I can’t have tunnel vision. I’ve been there before, but I can’t stay there for long.”

“I’ve been writing a journal and I would like someday to leave it for other patients who are experiencing what I’m going through. I’d like to help others.”

“I can never work again. I was in the Navy, and having to give up that uniform was one of the saddest things I’ve had to go through. I cried a lot. I miss it. I loved serving my country. It was a very emotional experience for me to give up my work. On the other hand, now I can spend more time with my family.”

“My granddaughter prayed, ‘God don’t let my grandmother die. Just please make her like she used to be so we can run and play.’ I can’t run and play anymore. That was heartbreaking to realize. My body has changed. We do other things now. Because of this illness, I actually think I am a better grandmother than I used to be.”

“When you have a disability, you dwell on what you can do, and not on what you can’t. That’s my gospel.”

“You have to have a good outlook, a good sense of humor, some curiosity. That combination can create good coping skills.”

“I just do the best I can today and I’ll deal with tomorrow, tomorrow. I just take what I’m given and deal with it. I sound like I have it all together, but I have my days and that’s OK.”

“I know a woman who is completely bedridden; she can’t even dial a phone. But she can punch a button that gives her the operator and she uses a wonderful speaker phone and she is the jolliest, happiest person I have ever talked to in my life. She calls people and people call her and she is still going, still giving of herself. All she has now is her voice, and she’s using it. She is a powerful person. When I think of her I think, ‘You better get out there and keep working, kid.’ There are so many people with chronic illnesses who are just amazing.”

“I appreciate the fact that I am alive since I’ve come so close to death. I want to do my best on a daily basis with other human beings. Life becomes so totally different. It’s so much more important how we treat other people. You have to figure out what the plan is for your life. I try to look for the beauty in everything. Even when it rains, I look for the rainbows.”

The Clinical Center Social Work Department wishes to thank the patients with chronic illnesses who gave their time to be interviewed for this booklet.

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