



I Have a Chronic Illness—I don't "know" what to do—No One Gave me the Textbook

We all have too many problems and too many choices. Often this is so overwhelming that we do not do anything for fear of making of the wrong choice. We decide to just live with our diseases and symptoms.

I know this, because I was born with a genetic chronic illness and have acquired a few more along the way. In fact, as I look back, I have never been what the rest of the world calls well. I, like many people, deal with pain, the vagaries of aging and a constant fight with the health care system. I like many people, I sometimes think it is better to do nothing than to engage in another stressful encounter or have yet another test or explain myself yet again to a new health professional. Having a chronic illness is hard work.

Let's start at the beginning. You are the same person today as you were yesterday. The only difference is that today you are a person living with diabetes, bipolar disorder, or arthritis. Naming your condition did not change you. It does not define you, but it does change the way you and the world might think about you. What chronic illness does, is add to the work of every day life.

A long time ago Anselm Strauss and Julie Corbin wrote a wonderful book about managing chronic illness*. After interviewing many people, they found three key management tasks. The first task is managing medical care, this includes taking medications, doing exercise, changing diet, managing devices etc. The second task (role management) and third task, emotional management, are often not acknowledged or are ignored.

Role management means how one does the things they need and like to do and still make necessary accommodation for the illness. We all know people with the same condition. One person continues to engage with life and is active in their roles as parent, worker, grandparent, bridge player, or baseball fan. The other person, largely retires from life, seldom sees friends and unfortunately often finds themselves sad and isolated. The difference in these two people is not the disease but how they manage the disease.

Emotional management, the third task, may be the hardest. Studies tell us that somewhere between one in five to one in three people with a chronic condition is also depressed. Almost everyone with a chronic condition is angry, frustrated, anxious or stressed. Unfortunately, emotions are not always visible, they are kept bottled up but seem to come out at very inopportune times. One is stressed by pain but gets mad at a friend.

I see people nodding their heads, just as I did when I first read this research. Thankfully, I was able to use this work, along with the lived experience of many many people to form our first Chronic Disease

Self-Management Program. It is hard to believe that this was more than 35 years ago. Since then more than a million people have taken part in self-management workshops. They have learned skills in medical management, role management and emotional management. More importantly, they use these skills and have demonstrated reductions in pain, disability, hemoglobin A1c. They are living happier and more fulfilling lives as well as reducing health care costs. These people come from every state, speak many languages, and represent many communities. I can promise that someone like you has benefited. The better news is that there are many programs to help people exercise, reduce falls and depression, and become better caregivers.

So, are any of these programs for you? I don't know. But I do know that if you "know" it will not help", it will not help. Sometimes "knowing" gets in the way. Just last week, I was served a new pasta dish. It looks like a common alfredo sauce and I was not much interested but tasted it. What a surprise! It was made with limoncello, a sweet lemon liquor and was wonderful! I will use this for my next dinner guests. My "knowing" was changed.

Some of you reading this work with people with difficult chronic conditions every day. You "know" about them, you hear their stories, or at least part of their stories. You are an expert. Some of you are living with a difficult disease and have used your experience to help others. You "know" what it is like.

There are many types of "knowing". Each has value in its own context, but each sometimes gets in the way. "Knowing," limits what we try, or encourage other people to try. Everyone knows that you do not put people with arthritis and diabetes in the same workshop and certainly not people with diabetes and Parkinson's Disease. If one happens to have a rare disease, there are more than 2000 of these, there is little disease specific education. Forty years ago, "knowing" meant that people with arthritis should not exercise and people with diabetes could not eat any sugar. We also "knew" that except for making the house a bit safer there was little that we could do about falling. Today we have evidence that people with different conditions can learn with and from each other and this also included people with rare diseases. All people, even those with arthritis should exercise. There are no prohibited foods for people with diabetes, moderation, especially in eating carbohydrates is the key and there are lots of ways of preventing falls.

"Knowing" is different than evidence. "Knowing" is what you believe or think, usually based on experience or faulty information. Some people "know" that vaccines are harmful and do not vaccinate their children. The result is that each year preventable disease rates and deaths rise.

Evidence is what we learn by testing what we "know" in a controlled setting and then carefully examining the results. Jenner noticed that people who got cow pox did not get small pox. He experimented by giving people, including himself, a small dose of cow pox and today small pox has been eliminated. In the 1800s people "knew" that cholera came through the air. John Snow observed that those who got cholera were drinking water from the Broad Street (London) pump. Short famous story, the handle was removed from the pump and the cholera epidemic ended. This provided the first evidence that cholera is spread by contaminated water. Thirty-five years ago, we "knew" that people with different long-term conditions could not learn self-management skills together. Many experiments later we have the evidence that most people benefit from non-disease specific education.

In sort form, this is the bottom line.

1. Having a chronic illness adds to the work of living.
2. There are many things that individuals can do to manage their disease and continue to live fulfilling lives.
3. “Knowing” sometime gets in the way of trying.
4. “Knowing” is different than evidence.

To find a free or inexpensive evidence-based program near you go to:

<http://www.eblcprograms.org/evidence-based/map-of-programs>

*Corbin, Juliet M., and Anselm Strauss. *Unending work and care: Managing chronic illness at home*. Jossey-Bass, 1988.