

Dealing with a Chronic Illness Diagnosis

Together, patients and their caregivers can play a role in coping with chronic disease to keep it from defining the individual.

By Meredith Whitmore



MAYBE THE DIAGNOSIS is primary immunodeficiency. Maybe it's multiple sclerosis (MS) or peripheral neuropathy. Whatever the chronic, life-changing illness is, the difficulty of dealing with medications, treatment, pain or even multiple surgeries and disability evokes an avalanche of emotions and questions in patients. Physicians, too, are affected because they must find and tailor ways to help their patients cope. The Centers for Disease Control and Prevention reports that in 2012, about half of all adults in the United States — 117 million people — had one or more chronic health conditions.¹ Considering that staggering statistic, developing coping skills for dealing with long-term illness is more crucial than ever.

How patients deal with their diagnosis depends largely on how they have dealt with various other stressors before they became sick. If, for example, they were previously able to successfully navigate troubles such as family turmoil, car accidents and other tense situations, the chances are more likely they will be reasonably adept at handling their new and often more limited lifestyle. But even the most “skilled” sufferer, faced with a

grinding, long-term condition, can be taxed in ways well beyond what they have been prepared to handle. As months or years wear on, disease can deteriorate even the strongest of psyches. According to Drs. Kathleen Franco and Tatiana Falcone, psychiatrists at the Cleveland Clinic, “Even generally high-functioning persons can regress in the face of life-threatening illness. Such regression can resemble the behavior of a dependent child or an angry adolescent.”² In other words, the best patients are likely to need help when dealing with a medical crisis. As such, physicians and other providers must teach coping strategies, and patients, in turn, must do the hard work of incorporating them into their treatment plans and lives. There are no quick fixes.

Typical Coping Patterns

For some patients and healthcare providers, simply having an overview of various types of personalities and how they typically respond to medical treatment/illness is helpful. In Table 1, Drs. Franco and Falcone highlight the patient personality types originally outlined in the text *Psychiatry and Medical Practice in*

Table 1. Patient Personality Types

Personality Type	Patients who...	Often feel...	Are helped by physicians who...
Dependent	Ask a lot of questions; make it hard for the doctor to end the conversation or leave the room	Afraid that physicians won't care for them or find them worthy	Offer regular, brief sessions; set tactful limits that reassure the patient
Obsessive	Are insistent; are detail-oriented	Angry when they can't control their illness, the medical staff and the schedule	Offer detailed explanations; provide choices whenever possible; try to use patient input collaboratively
Narcissistic	Are self-centered; criticize others; believe no one is qualified	Fearful, threatened and vulnerable	Avoid confrontation, but emphasize that they deserve the best care; keep them informed
Suffering victim	Always have symptoms and request much attention; might not follow recommendations	Suffering is their role; illness punishes them (and sometimes physicians) but hopes doctor will keep trying	Provide regular visits, no matter how varying the complaints; encourage them to “suffer” through treatments
Paranoid	Do not trust; refuse to participate in plans; threaten to sign out of the hospital against medical advice	They are being taken advantage of by others or purposefully neglected or harmed	Stay calm; don't argue; offer understanding of their position; make clear recommendations
Histrionic	Are flirtatious; want to call the doctor by his or her first name	They want to be special in the eyes of the physician; illness will invalidate them or make them unattractive	Encourage the patient to verbalize concerns; set boundaries for the relationship; remain courteous and objective
Schizoid	Are very lonely; tend to avoid medical care	Doctors are invading their privacy	Engage them in helping to make medical decisions

*a General Hospital.*³ Patients may see their own demeanors or attitudes in these descriptions and possibly gain more insight into their behavior. And, physicians may better understand how to work successfully with a variety of patients and their specific needs. “Recognition of the different patterns helps to inform caregiver responses that, if tailored appropriately, will be perceived as supportive rather than confrontational,” they note.

Patients’ reactions to their diagnosis also depend on how they view the illness itself. For example, if patients believe that the illness will end up taking their lives, their resistance to stress and ability to endure treatment will be notably hindered. If patients believe that, no matter what they do, they cannot improve their health, they are more likely to succumb to helplessness and worsen their illness. Understandably, healthcare providers who can help their patients learn as much as possible about their illness, reassuring, teaching and guiding them to a more positive outlook, can be very helpful.

HOW PATIENTS DEAL WITH THEIR DIAGNOSIS DEPENDS LARGELY ON HOW THEY HAVE DEALT WITH VARIOUS OTHER STRESSORS BEFORE THEY BECAME SICK.

Strategies to Succeed Mentally and Emotionally

According to Dr. Franco, the healthy “mental constructs,” or toolbox of strategies, required to deal with long-term illness can be honed, though it is a process requiring dedication. One such construct includes putting the illness in a different light. “Instead of saying, ‘Oh, my MS is going to get worse,’” she says, “the patient might say, ‘You know, nobody knows whether I’m going to have this course or that course of MS, and I am going to assume that I am going to get better. There are certain things that I can do to help myself. So I am going to choose to stay active and not wait for the illness to take over my body.’” In this way, she says, the patient develops proficiencies in dealing with fear and other negative emotions.

Many patients need coaching to develop such tactics. “Psychotherapy and cognitive behavioral therapy are especially helpful,” says Dr. Franco. “[Cognitive behavioral therapy] is when you recognize a distorted thought, and you understand that distorted thought is changing your mood. If you take that distorted thought out and put a more objective thought in, you can cope, whether it’s with arthritis, or MS or a cardiac condition. Believing that you can get better, and believing that some distorted thoughts you might have can be corrected, will help an individual tremendously. But patients have to practice that.”

While Dr. Franco says that working with a therapist is perhaps the best way to develop coping strategies, since they are specially trained in such areas, there are also less-involved ways to help oneself. “I use one particular book with my students, and it’s called *Feeling Good*,”⁴ she explains. “The author [Dr. David Burns] has a manual out that has the individual write in their interpretations, and they learn how to identify their own distorted thoughts. Through that, they learn how to be more objective and how to handle their own self-reflections. Or maybe to handle a difficult conversation with a person, or a lot of different things about when distorted thoughts might come in and what to do about them. That [book] is high on my list because it teaches people to believe that they can make things different.”

Another strategy Dr. Franco encourages is exercise. Regular exercise fights mood disorders, depression, anxiety and a host of other draining emotions, she says. The exercise doesn’t need to be exhausting to be beneficial. Even a walk or two around the block is something that can be helpful to one’s outlook and body. In addition, she says, a healthy diet is crucial, depending on what a patient’s nutritive needs are. One dietary aspect is certain, however: “A person who resorts to fast foods and carbohydrates can feel overwhelmed and be brought down [mentally and physically] as their blood sugars fluctuate. So a healthy, plant-based diet, with some protein, would be an excellent addition [to a person’s list of strategies].”

A Potential Step Backward

Sometimes, as an illness endures and perseverance subsides, it’s possible for some people to begin to conflate their condition with their identity. That is, they label themselves and their life according to their disease. While labels are helpful to identify problems, they do not need to define any person or situation. According to Dr. Franco, the suffering victim personality can be especially problematic in this regard. “Some patients can fall into



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self-pity,” she says. “[Their disease] becomes their identity. They can’t see anything else that’s worthwhile about themselves, except that someone might take pity on them. They want to be cared for. They want to be loved. They want to be appreciated for other things [than their illness], but they don’t know what those other things are anymore. Sometimes it takes either a therapist or a friend or someone else who gets them to take a look at other things. I’ve had patients who behaved that way, but who have been able to come out of it. They have been able to get themselves back to college and take classes or look for a career. But such recovery is hard work. And whenever such a patient makes a gesture of trying to escape that mentality, it’s important to praise them for trying.”

Dr. Franco also explains that to help such a patient, whether it’s a friend or loved one, a person must approach gently. “Some of them can hear and listen to what you say, and others may not be able to,” she explains. “If you have a good enough relationship with the person, and you believe that there’s more to them than their illness, help them to find or remember something they can do well, whether it’s music or drawing or teaching a child to read. There could be a million different things that can give them self-worth apart from the illness. When they focus on the illness, though, they often drive people away, but don’t understand why that’s happening. They become a martyr, and they intensify their efforts [to garner attention] because that’s what they’ve practiced — that’s what has brought them closer to people in the past. But they only have a plan A, so they have to learn other things about themselves that they can appreciate.”

Dr. Franco encourages friends and family members of struggling patients to reach out to the person. She suggests asking them to join an activity they would enjoy. It could be a walk in the park or a volunteer event at which they could help others — anything that the patient doesn’t normally do. Stretch them as far as they will allow in terms of pleasant experiences that are out of their usual routine.

Physicians can also help patients by determining what sources of emotional encouragement they already have and urging them to stay involved with these people or activities. Such sources of reassurance could include a church congregation, friends, family members or colleagues, or a hobby or event. “High social support of patients in heart failure reduced anxiety and depression in a nine-month longitudinal study,”⁵ say Drs. Franco and Falcone. “Social contact is associated with longer survival in women with breast cancer.”⁶ In addition, they say, it’s been demonstrated that “functional and social benefits for patients

with rheumatoid arthritis lasted up to five years after an intensive nine-day multidisciplinary program that included education, gym exercises, use of devices, counseling, dietetics and discussion of social assistance.”⁷

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Working to Implement a Plan Together

The role in helping a patient with chronic illness to cope differs but can be equally important for physicians, caregivers, friends or loved ones; they can help to devise and implement the strategies patients need to thrive in the face of difficulty. Patients trying to cope with their conditions need to remember that there is much more to them than their illness; they should not reduce their complexity and experiences to one thing that has the potential to negatively influence their life. A disease does not define an individual. Patients can control what is within their ability to control and learn how to recognize distorted thoughts and combat them with objectivity. And, they can let others help. ■

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