Steps to Open Communication

Communicating with family and friends about a chronic illness can be difficult, but it can be accomplished with some specific steps.

By Annaben Kazemi
At every stage of life, relationships with family and friends can be both joyful and challenging. Those who learn to communicate effectively can strengthen their own emotional health, as well as their connections to the important people in their lives. This is especially true for those diagnosed with a chronic illness or condition because these influential and critically important relationships impose additional tolls — the strain and stress of coping with a chronic illness. At times, patients may feel overwhelmed, guilty, resentful, angry, anxious and even depressed. And, those close to them often feel confused and must adjust to a drastic and unexpected change in daily life. But these varied and complex emotions are common, and there are some concrete steps patients can take to open communication with loved ones and lessen distress.

**The Benefits of Communication**

Having a chronic illness can be harder to handle than words can describe. Not only do patients have to cope with difficult and painful symptoms, but they also must live with the anxiety of an uncertain future. When it becomes all too easy to feel overwhelmed, hopeless and depressed, communication can fall by the wayside.

The good news is that improving communication with friends and family can increase quality of life. Creating a support system where honest communication and positive relationships are fostered enables bonding to occur. Numerous studies have shown that social support reduces the risk of depression and bolsters well-being, while the absence of social support has been linked with both the onset of depression and relapse. In fact, studies show that strengthening bonds with family and friends creates a safe place to express feelings — one in which desires and concerns can be shared, and the feelings of isolation, bleakness and depression are lessened. “When you’re facing a difficult situation, you can feel alienated and alone,” explains Sandra Reich, MEd, a cognitive behavioral therapist and clinical director of the Montreal Center for Anxiety and Depression. “Sharing the pain with someone else can help validate what you’re feeling.”

**Going from Crisis to Communication**

Everyone communicates in one way or another, but very few people have mastered the skill of truly effective communication. Honest communication takes both active listeners and authentic speakers to create a meaningful exchange. According to Dr. Patricia Tanner Nelson of the University of Delaware, active listening involves stopping what you are doing and focusing completely on what the other person is saying. This requires setting aside enough time, exercising patience and keeping an open mind.

By educating loved ones about their chronic illness, patients will feel more comfortable speaking with them about their condition and any limitations they are facing. But, it’s important to talk with loved ones in advance, rather than in the moment, warns Erika Lawrence, PhD, and associate professor of the Department of Psychology at the University of Iowa. She suggests several steps that patients can think about before approaching loved ones:

- Focus on only one specific topic or event.
- Limit each speaking turn to one or two sentences.
- Talk about how the patient thinks and feels (“I” statements), instead of attacking or blaming the other person (“you” statements).
- Do not ask the listener questions.
- Do not make statements about the listener’s character, honesty, etc. (avoid statements that make the listener defensive).
- Do not argue about whose “memory” is more accurate or about who is “right.” This will never resolve anything, and it usually makes things worse (it will result in the argument being repeated again and again).

Relationships must be mutually respectful and on equal footing, even when it seems that others “don’t get it.” Dr. Lawrence suggests that when it becomes difficult, everyone should try taking turns, with each person talking for one minute at a time. They should put all distractions aside.
and focus on understanding what the other person is saying, rather than preparing a defense. They also need to be conscious of the words they choose and their impact. “The relationship should be a back and forth,” adds Dr. Lawrence. “Sometimes relationships can get fixed into roles, making balanced, open communication difficult.”

**Ask for What Is Wanted and Needed**

Patients should talk to family and friends about their goals, and ask for their support. Dr. Lawrence recommends patients keep in mind that “the more specific patients are in asking for what they want, the more likely they are to get it.” Therefore, they should figure out what they need ahead of time and how family and friends can help them get it. They also need to be mindful of the efforts friends and family make, and they should express gratitude for their intent, even when the outcome isn’t what they hoped for.

Asking for what is wanted and needed can be scary and difficult — difficult because if it isn’t done correctly, it’s very likely it won’t result in the wanted response, and scary because even if it’s done correctly, the answer may still be no. But, it’s also very possible that the result will be better.
than what was imagined. Patients can get the conversation started about what they need and want by discussing events or activities that they used to enjoy or future events they want to be part of, such as a family reunion. Once family and friends understand their goals, they can work together toward achieving them.

Appointing an “ambassador” — someone they feel comfortable talking with and respect enough to heed their advice — can be helpful for patients. An ambassador can help patients communicate with everyone else, help manage their condition and act as a liaison between patients and healthcare providers, doctors or community service agencies.

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**Accept Limitations**

Sometimes spouses or kids will express anger and resentment about a patient’s illness or its effect on them. This is natural, and their dissatisfaction needs to be directed toward the illness rather than the patient. Patients can help by focusing on what they can do, rather than on their limitations. According to Dr. Lawrence, it’s important for patients to “try to understand where [others] are coming from, even if [they] disagree.”

Loved ones also may react strongly and not be sensitive, especially in times of stress. Patients should pay attention to how much their loved ones can hear. If they are too upset or emotional, they will not be able to take in what is being said. When this happens, it may be necessary to set aside a specific time in the future to continue the discussion, giving everyone a chance to step back. These limitations should be accepted as normal, but patients shouldn’t give up.

Along with having family and friends in their corner, patients can seek out support groups or professional help. Many patients find it helpful to turn to others outside their immediate circle of friends and family and connect with people who are facing comparable challenges. Support groups such as IG Living’s Facebook page or other online communities bring together people facing similar issues, whether those concern illness, relationship problems or major life changes. Members of support groups often share experiences and advice. It can be helpful just getting to talk with other people who are in the same situation. In addition, some patients who need help managing their condition or situation find counseling or other types of therapy beneficial. A good physician can recommend a therapist equipped to handle the complex challenges faced by patients with chronic illness.

**Maintaining a Fighting Spirit**

It takes tremendous courage, persistence, perseverance, determination and strength to maintain a fighting spirit in the face of so many challenges. Therefore, it is important for chronically ill patients to acknowledge themselves for these qualities. It is equally important for them to have compassion and forgiveness toward themselves and their loved ones when they hit a rough spot.

In the long run, continuing to work on communication with loved ones increases well-being. In a recent study, Brigham Young University professors Julianne Holt-Lunstad and Timothy Smith reported that social connections — friends, family, neighbors and colleagues — improve the odds of survival by 50 percent. Their study demonstrates the value of maintaining healthy, supportive relationships to develop resiliency and increase life span.

“We take relationships for granted as humans; we’re like fish that don’t notice the water,” says Smith. “That constant interaction is not only beneficial psychologically, but directly to our physical health.”

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**References**