

Finding Support with Chronic Illness

In addition to family and friends, patients can find support to help them deal with their illnesses from a variety of sources, including groups, providers and therapists.



By Cynthia Perry

PATIENTS WITH CHRONIC illnesses experience many emotions as they journey from diagnosis to finding specialists and choosing treatments to manage their symptoms, all while navigating the U.S. healthcare system. Oftentimes, this journey takes twists and turns if their conditions progress and additional diagnoses are made. As a result, patients often experience a variety of emotions such as anxiety, depression and fear, and many must adjust their work, goals and lives to accommodate very real limitations imposed by their illnesses.

But, finding support can help. A study by Concordia University that asked, “Do sick people get lonely?” revealed they often do as they get older, whether or not they are in a long-term

relationship. “The quality of our social ties plays a role when it comes to coping with the effects of serious disease in later life. And just having a partner around may not be enough,” says Meghan Barlow, PhD, the study’s first author. “Putting a halt to socializing only contributes to a downward spiral. The fact that loneliness can lead to further complications means that measures can be taken to prevent the effects from looping back around. Finding different ways to connect with other people also means you are less likely to blame yourself for being sick, and you can’t count on a partner to fill that gap.”¹

Further evidence of the importance of social support comes from a review of papers published in *Chronic Illness* that found

social networks, including friends and family, have a positive impact on patients' long-term coping with chronic illness. Social networks can help ease burdens and shape how patients view themselves and their illness.²

Fortunately, patients can look to a variety of sources for support along their journey in addition to family and friends. Support groups and groups focused around hobbies or interests can provide social and emotional support. Organized exercise groups appropriate for patients' medical needs can also provide a social outlet. And, patients can look to healthcare providers and trained therapists to provide important community resources.

Family

Family can be a wonderful source of support and encouragement. They are a logical first place to turn since they love the patient and want what's best for him or her. Family members can attend appointments, be medical advocates, ask questions of providers, suggest different ways of looking at things and be a shoulder to lean on.

Although partners and other family members may worry about what the future will hold for the patient, and how it may affect their lives together, they can learn to cope as a couple and family. This is especially true since chronic illness is an experience of continual unpredictability, with good days and bad days or good months and bad months. During rough patches, the healthy partner and other family members can be called on to add the patient's chores to their own. And, while this can add new stresses to a partnership and family unit, the following suggestions can help the family grow closer rather than apart:³

- *Acknowledge grief together.* Each partner will be affected differently by the illness, and each partner's feelings are valid. Open and honest communication about these feelings is key to mutual understanding and growth.

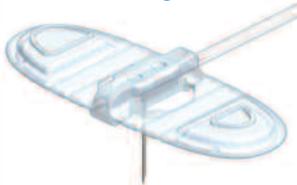
- *Solve problems together.* Chronic illness can bring physical, emotional and financial burdens to a couple. Sometimes patients look well even when they aren't, which can create misunderstanding and miscommunication in relationships. These problems can be

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approached as shared issues rather than something one or the other partner needs to solve on their own.

- *Appreciate the new normal.* As some activities and routines change out of necessity, the door can open to new ways of doing things as a couple. Even extended family can help the patient cope and adapt to his or her new normal. Family members can work together to monitor symptoms, identify obstacles to self-care and help the patient stick to medication, dietary and lifestyle regimens.⁴

Spreading requests for support for their needs across multiple people — family, friends and professionals — can strengthen all of the relationships in patients' lives.

Friends

Friends can be another excellent source of support. Some friends know just what to do and say and how to help. But, other friends may feel helpless and, not knowing what to say or do, may do nothing at all. If the patient tells friends exactly how they can help, it can ease anxieties for both parties. For instance, one friend could be asked to drive the patient to appointments, one might be asked to make a meal, another to run an errand, and perhaps another to entertain the patient's children when he or she isn't feeling well. Or the patient might just want someone to come and keep him or her company or find ways to help him or her laugh at the situation.

Also, group emails, a blog or a trusted friend can be a good way for the patient to keep family and friends apprised of their situation. This way everyone can feel informed without putting too much burden on the patient.

Community Groups

Churches and other community groups can also provide support. These groups may be able to provide rides to appointments, meals and childcare during acute phases of the patient's illness.

Organized exercise groups, with doctors' approval, can provide social outlets, as well as stress relief and overall health benefits.

If the patient retires early due to his or her medical condition, "active adult" groups could provide socialization and fill some of the time that used to be devoted to a career. These groups engage in a wide variety of activities such as travel, lectures, exercise, arts, card and board games, and attending concerts and shows. Although normally available to people "50 and better," some groups will make exceptions for membership.

Hobbies

Another place patients can look to forge new relationships is by finding a group for a hobby they like, or perhaps even starting a new hobby if physical limitations prevent them from participating in activities they used to enjoy. An added benefit of forming these new relationships is they will be grounded in shared interests rather than illness.

Patients can also lift their spirits by "losing" themselves in their hobby. They may even get to experience what author and psychologist Mihaly Csikszentmihalyi, PhD, calls "flow," which is "the sense of effortless action they feel in moments that stand out as the best in their lives." Dr. Csikszentmihalyi claims, "it is the full involvement of flow, rather than happiness, that makes for excellence in life."⁵

Support Groups

Support groups specific to patients' chronic conditions can be another tremendous resource. These groups can allow patients to share their personal experiences and hear from others who have been through similar events, helping them cope with their diagnosis and fight feelings of isolation. Patients can learn about community and other resources that might be available to them, and even learn about new technologies and treatments for their condition.⁶

Patients may even develop friendships with others in a support group. These new connections will be built on a unique understanding of what each is going through, and a unique ability to offer perspective and support.

Healthcare Providers

Patients shouldn't discount the assistance they can get from healthcare providers. Doctors and other healthcare providers can answer patients' questions about their condition and the expected course it will take. They can educate family members about patients' healthcare needs, discuss treatment options and develop a treatment plan in conjunction with patients and their families'

wishes. Having a plan in place may help to decrease the entire family's concerns.

Providers can also inform patients about how they can best care for themselves. They can also remove obstacles to treatment, insurance, disability coverage and other frustrations patients may encounter. Lastly, they can refer patients to community resources, including disease management programs, case managers and clinical trials.⁷

Trained Therapists

In some cases, trained therapists can aid patients in dealing with the changes in health, life goals, activities and relationships. Therapists can guide patients as they find new ways of viewing their circumstances and deal with coping while so many aspects of their lives change at once.

Therapists can also help patients decide how to handle relationships with their healthcare providers. For instance, if providers don't agree on a unified treatment plan, a therapist can help the patient decide how he or she wants to proceed. And, if a member of a patient's team isn't a good fit, a therapist can help that patient

find a new provider, thoughtfully determining the characteristics a patient might want to look for in a new provider.

Support Is Available

Patients with chronic illness have many people and groups they can rely on for support throughout their journey. Making specific requests for support can let people know how they can help. Spreading requests for support for their needs across multiple people — family, friends and professionals — can strengthen all of the relationships in patients' lives.

Changes in relationships and friendships may happen, and when they do, patients should show compassion and understanding. Avenues for starting new activities and building new relationships exist, and patients can explore these to have rich and rewarding lives in spite of their medical conditions.

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