

Support Groups

We thank Suzette G. Levy for writing this chapter.

Support groups are an invaluable tool to helping others and oneself deal with the consequences of being a patient with *dysautonomia*. There can never be enough talking and sharing thoughts, helping one another, learning, listening and hearing, in a support group. Taking the initiative to begin one and follow through is a major commitment, but with many rewards.

Chronic illnesses of course differ, but the social psychological effects on the patient, family, and caregivers are very similar. A chronic illness is forever. It changes lifestyles, personal relationships, goals, and vocational choices. Chronic illness is long-term and rarely curable, and so there is a baseline “constancy of illness.” The sense of health and vibrancy most people expect is no more.

The need to learn “coping techniques” from others becomes imperative. Patients with chronic illness need reliable guidance—understandable, clear, compassionate, and practical. In any chronic illness there are usually at least two people to care for—the patient and the caregiver. Including the caregiver, significant other, or family members is most important. All have needs and issues.

Conquering long-term problems is best not done alone. One of the best sources of help is a support group. Successful support groups can become an invaluable entity in assisting family and friends. Participants in support groups learn quickly from one another. Professional facilitators help accomplish even more.

What is a Support Group?

A support group is a regularly scheduled, informal gathering of people whose lives are directly affected by the caregiving needs of another. Members benefit from the peer acceptance and recognition of their common concerns and are grateful for the wisdom, insight, and humor of people in the same situation.

Assuming you understand your medical diagnosis, you can put your energy into learning how to cope through support groups – listening and becoming educated by others with the illness. Support groups are also a safe place to be heard and to listen and to understand symptoms and treatments. Support groups offer understanding on how to “reinvent yourself,” how to work with your healthcare team, how to communicate better with family and caregivers, and how to acquire effective strategies for daily living.

The support group may be in the best position to help patients with chronic illnesses, their thoughts and concerns regarding relationship issues, how to work with

their physicians, understanding the role of the caregiver and accepting the challenge of change.

Many physicians have come to recognize the value of caregiver and care recipient support groups. Many questions regarding daily living and what to expect are answered within the group. Today, physicians, social workers, rehabilitation specialists, neuropsychologists, and others refer many patients to a recognized support group. One is the NDRF Support and Outreach Program (“Program”).

Informal support groups generally are created by one or more individuals dealing with a care recipient with a common illness, or category (e.g., kids with special needs) that decide they need to reach out and to share with others, ultimately to help themselves. It doesn’t take special training, but it does take effort, dedication and some ingenuity. You will also find it to be one of the most rewarding things one can do.

Support groups offer opportunities to learn from one another and to share pain and joy. A support group can be a lifesaver as well as an ally, friend, and confidant.

If you wish to learn more about becoming a support group leader or member, contact sglevy@ndrf.org.

