## The Importance of Lymphedema Support Groups

In a support group, members provide each other with various forms of help, usually nonprofessional and non-material. They can be a crucial tool for individuals who share the common diagnosis of lymphedema to come together and share coping tips, experiences, news, and most importantly emotional support.

The help and information received in lymphedema support groups may take the form of providing and evaluating relevant information on treatment modalities, self-care, relating personal experiences, listening to and accepting others' experiences, providing sympathetic understanding, and establishing social networks.



While providing important emotional support, support groups are more than just a safety net for the patient. In fact, they can even improve the physical health and wellness of participants. Members of an established support group not only serve as educators for individuals newly affected by lymphedema, but also inform the public about lymphedema, engage in advocacy, or can serve as a clearing house for disseminating news of important advancements or therapies.

The primary goal of most groups is to ensure that no one affected by lymphedema ever has to feel alone again.

Most support groups are facilitated by individuals who have personal experience with lymphedema and became advocates for others. These groups may have regularly scheduled meetings, or exchange information via online forums.

There are also professionally operated support groups, which are facilitated by professionals who do not share the problem of the members, such as lymphedema therapists, social workers, psychologists, or members of the clergy. In these settings the facilitator controls discussions and provides other relevant information; such professionally operated groups are often found in hospitals or lymphedema treatment centers.

Many times we receive phone calls and messages from individuals asking about lymphedema support groups in their area. If we are unable to locate a support group for the inquiring individual, we generally refer them to the National Lymphedema Network (NLN), which has a listing of ongoing support groups in their quarterly publication *LymphLink* and a Support Group Locator search function for groups in the U.S. and links to international support groups on their

website.

The Support Group Locator can be accessed by clicking the "Support" tab on the top menu of this page.

Individuals can also list their support group with the NLN by submitting a <u>support group listing</u> <u>application</u>.

In order to increase access to support groups we urge you to list your support group with the NLN.

Other important resources include <u>StepUp-SpeakOut</u>, a support and advocacy group for individuals affected by lymphedema and <u>Lymphedema People</u>, a resource for people with lymphedema, created by people with lymphedema.