

Muscular Dystrophy Canada Support Groups

What is a Muscular Dystrophy Canada Support Group?

Muscular Dystrophy Canada support groups exist right across the country wherever people with various forms of neuromuscular disease, their families and friends, and any other **interested parties** get together for the purpose of **supporting** each other.

These small independent groups meet regularly face to face, or sometimes by teleconference.

Participants brainstorm about issues that others may have faced and look for solutions to their concerns.

What is the goal of a Support Group?

The goal of Muscular Dystrophy Canada Support Groups is to provide support to families through group interaction.

Support Group members have personal experience living with a neuromuscular disorder and are therefore a valuable resource to each other.

Members bring knowledge, skill and expertise coming from their own life-experience. They help others identify solutions by sharing strategies that have been helpful in their personal situation.

Our support group volunteers offer information about resources, tips on coping, and an "understanding ear" to people registered with Muscular Dystrophy Canada, family members or others who are looking for support.

Muscular Dystrophy Canada will assist families in accessing a support group wherever possible.

Who attends support group meetings?

Muscular Dystrophy Canada support groups are made up of people affected by neuromuscular disorders, their family and friends, health care professionals from our communities, Chapter members and occasionally Muscular Dystrophy Canada staff.

Support groups bring together people who want access to **support** and who are willing to share their life's experience.

Some groups also engage in advocacy issues that will ultimately promote social change.

What are the benefits of a support group?

Support comes in many forms as individual needs call it forth. Some people already have strong support systems in place through family and wider networks such as faith communities and their needs are minimal.

Other people are facing stresses such as financial difficulties or family problems, in addition to the day-to-day reality of life with a neuromuscular disorder. Difficulties can be intense at particular times, such as when the diagnosis is made or when symptoms seem to get suddenly worse.

This is a volunteer program where people help people. It offers those facing challenges the chance to talk to others who are experiencing similar issues.

Support Groups also provide people with an opportunity to meet socially in an informal setting.

What do I do now?

If you think you may be interested in participating, contact your Regional Services Director. Here is a list, by region, of Muscular Dystrophy Canada's Services Directors:

- *For Atlantic Canada:* Judy Spink, tel. 506-450-6322 or 1-888-647-6322 judy.spink@muscle.ca
- *For Quebec:* Pascale Rousseau, 514-393-3522 or 1-800-567-2236 pascale.rousseau@muscle.ca
- *For Ontario and Nunavut:* Margaret Otter, 416-488-2699 or 1-800-567-2873 marg.otter@muscle.ca
- *For Western Canada:* Maggie Kissel, 604-732-8799 or 1-800-661-9312 maggie.kissel@muscle.ca

How can I help Muscular Dystrophy Canada do its work?

Support groups are not fund-raising groups. However, Muscular Dystrophy Canada conducts year-round fund raising campaigns to support our diverse programs. If you can help financially, your gift will help the organization provide the dollars necessary to assist individuals living with neuromuscular disorders, and fund much-needed medical research and educational information. Please make a gift through our National office or any Regional or Community Muscular Dystrophy Canada office.

Who can participate?

Anyone who has been affected by a neuromuscular disorder may participate, whether or not he or she is registered with Muscular Dystrophy Canada. "Anyone" includes the person who has been diagnosed, a parent or spouse, a child, a sibling, a close friend, or a member of a Muscular Dystrophy Canada Chapter.

Who is responsible for the group?

From Muscular Dystrophy Canada's point of view, support groups are the responsibility of the Regional Director of Services. However, a member of the group will usually take a lead role in organizing the meetings, inviting people to attend, finding a location and so on. A group facilitator can help with the planning of the meeting as well as choosing topics for discussion. Successful groups develop their own internal patterns of leadership, with Muscular Dystrophy Canada resources as a back-up.

All Muscular Dystrophy Canada Information Sheets are available on our website: www.muscle.ca

Ce feuillet d'information est aussi disponible en français.

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