

DYSTONIA
MEDICAL
RESEARCH
FOUNDATION
CANADA



FONDATION DE
RECHERCHE
MÉDICALE SUR LA
DYSTONIE
CANADA

serving all dystonia-affected persons
désservant toutes personnes atteintes de dystonie

SUPPORT GROUP MANUAL

AUGUST 2026

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A: Introduction

Dear Support Group Leader,

Congratulations on your decision to become a part of a national network of people working to support those affected by dystonia. You are now part of the only organization dedicated to providing support to those with dystonia in Canada. We acknowledge your dedication and are ready to assist you in your efforts to represent the organization locally.

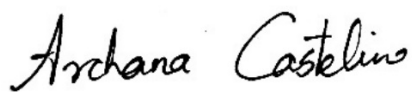
Support group leaders often must wear many hats. In addition to hosting meetings and responding to inquiries from patients, you may also have to work with the media to raise awareness or coordinate grassroots advocacy on a timely issue. **This manual was created to assist you with all aspects of running a local support group. Please refer to the sections as required.**

You will find that this manual is divided into broad sections which focus on the main areas of group leadership. This format was used to ensure that you have information on everything from planning a meeting to leading one of the meeting's discussions and beyond. Note that these are just guidelines. We recognize every group is unique so please use as per the needs of your group.

DMRF Canada will send you updated information as needed. The National Office staff is available as the primary contact for support group leaders, providing guidance on starting, maintaining, and strengthening your group. Remember to always take care of yourself first.

Thank you again, and please consider DMRF Canada a willing and helpful partner as you work to lead and grow your support group.

Sincerely,

A handwritten signature in black ink that reads "Archana Castelino". The script is cursive and fluid, with the first name "Archana" and last name "Castelino" clearly distinguishable.

Archana Castelino, National Director

ABOUT DYSTONIA MEDICAL RESEARCH FOUNDATION CANADA

Dystonia Medical Research Foundation (DMRF) Canada was founded in 1976 by Samuel and Frances Belzberg of Vancouver, after their daughter was diagnosed with generalized dystonia.

The mission of DMRF Canada is to advance research for more treatments and ultimately a cure; to promote awareness and education; and to support the needs and well-being of affected individuals and families. DMRF Canada is a registered non-profit Canadian charity governed by a volunteer [Board of Directors](#).

The Goals of the Foundation:

To advance research and ultimately find a cure for dystonia – DMRF Canada prides itself on a long history of supporting dystonia research. This research has led to a better understanding of dystonia, as well as breakthroughs in genetics and therapeutics.

DMRF Canada partners with the DMRF in the United States to fund the best world-wide research. Since 1976 this collaboration has funded over 400 grants awarding \$22 million in research funding. In addition, DMRF Canada partners with other organizations, including the Banting Foundation, Rare Diseases: Models & Mechanisms Network (RDMM), and the Dystonia Coalition to fund excellent dystonia research in Canada.

To build awareness of dystonia and the needs of dystonia patients – Promoting awareness of dystonia and educating the public about the condition is crucial. In addition to improving society's recognition and understanding of dystonia, increased awareness directly impacts our ability to advance research and identify people and families who need our help. Dystonia is unfamiliar to many people (even from within the medical community), despite the fact that it affects approximately 50,000 Canadians. An increased societal understanding of dystonia will also help to reduce the feelings of isolation that a dystonia patient may feel.

To support patient and family support groups and programs – Support groups empower individuals by providing them with a positive environment built on understanding which, in turn, helps them take greater responsibility for their own health. Support groups are key in simultaneously nurturing the needs of mind, body, and spirit. DMRF Canada assists with the establishment and development of support groups to ensure that dystonia-affected individuals across the country have access to this valuable resource. The Foundation also works with support groups to assist with regional events, such as educational symposiums and informational programs that will further serve the needs of dystonia patients in the community.

THE ROLE OF LOCAL SUPPORT GROUPS

Coping with a chronic illness can take anyone outside of their comfort zone. Pre-diagnosis can be frightening and uncertain, and the loss of health or independence can be frustrating and stressful. Serious personal issues can present as patients struggle through changes in self-image and self-esteem as a result of loss of independence and/or quality of life.

Peer support can help dystonia patients recover and thrive. By sharing knowledge and feelings about their experience, dystonia patients can learn from each other and take comfort in knowing that they are not facing an uncertain future alone. Support groups can help alleviate feelings of depression and promote a healthy mental attitude and better physical outcomes.

Support groups offer patients, family members, and friends a venue for discussing and validating their changing needs and feelings. Foundation resources and the experiences of members offer companionship and lessen feelings of loneliness and isolation. The support group also serves as a trusted resource for accurate research-based information. This is critical, as some media and online sources offer easy access to inaccurate or misleading information from unqualified or unchecked sources.

As an individual's needs change, so will their participation and interest in the support group and what it offers. It is important that the support group remains flexible and welcoming so that all people from the community can attend, share, and engage in the ways in which they are most comfortable.

While the support group can be many different things to different people, **it should not be considered an alternative to appropriate medical treatments or therapies.** The support group is a resource to address the needs of mind, body, and spirit, but it cannot be an alternative to a structured treatment plan prescribed by a medical professional.

The key function of the group is connection and information, and this can go beyond holding a regular meeting. Electronic communications and technology make it easier than ever for the group to stay in contact or for you to correspond with group members about upcoming events and activities. Your support group can be a valuable resource for all dystonia-affected individuals in your area. Visit section D5 for the role description.

B: DMRF CANADA POLICIES AND GUIDELINES

The following policies and guidelines provide details on what is expected of DMRF Canada support group leaders and what you can expect from the Foundation. Please review this information. If you have questions, please do not hesitate to contact the DMRF Canada office.

Once you have carefully reviewed these policies, please complete the authorization form and submit it to the DMRF Canada office by email or mail.

1: CODE OF CONDUCT

Our goal is to foster an environment and culture of professional and courteous service for all DMRF Canada volunteers, members, stakeholders, and employees. The Volunteer Code of Conduct describes volunteer responsibilities and the potential consequences of one's conduct during the term of service. Volunteers are accountable for their personal and professional conduct as per the terms of this policy. This applies to all DMRF Canada volunteers except the DMRF Canada Board, which has its own code of conduct.

All volunteers have the right to a respectful and safe environment while volunteering/working for DMRF Canada, free from harassment, violence, or prejudice. The Foundation expects all volunteers to maintain a level of personal conduct that will reflect positively on themselves and the reputation of the Foundation.

DMRF Canada volunteers will always abide by and conform to the following code of conduct and principles.

Inclusion

DMRF Canada asks that all support groups be open and welcoming to people with all forms of dystonia. It may be that there will be subgroups with different interests (example: groups composed of individuals with blepharospasm or spasmodic dysphonia or torticollis, or generalized dystonia), and specific sessions on topics of interest to different groups; but the policy of the Foundation is to always be inclusive and never discriminatory. Our aim is to serve all dystonia-affected persons and their families. Furthermore, DMRF Canada support groups must prohibit discrimination against people attending meetings on the basis of race, color, religion, gender, national origin, disability, age, sexual orientation, marital status, or any other basis prohibited by law. This extends to respecting others' beliefs and ensuring everyone feels accepted and welcomed into the dystonia support group.

Confidentiality

Confidentiality must be maintained for all support groups, and we ask that all support group meetings and associated communications be conducted in a manner that protects the privacy and confidentiality of your members. Groups should discuss the need for confidentiality and assume this as a policy in all its activities. This means that any information that may identify a group member cannot be released outside the group. Because privacy may be a concern of many participants, this policy should be stated as one of the ground rules (along with time for speaking and other rules) at the beginning of every meeting. A good rule of thumb is: you can repeat what you said during a meeting, but do not repeat what others said or how they reacted to your comments. In other words, “What you see and hear at a meeting, leave at the meeting.”

Furthermore, if a news release about a group activity includes pictures, videos, or names, a news/video release permission form should be signed by the group members who will be identified. If pictures are taken or members from the media attend a meeting, support group members must be advised beforehand about what is happening and why so they can decide whether to participate.

No volunteer shall share, copy, reproduce, transmit, divulge, or otherwise disclose any Confidential Information related to the affairs of DMRF Canada, unless required by law or with expressed permission from the National Director. Any questions as to whether certain information qualifies as Confidential information, shall be referred to the National Director.

Upon completion of a term of service, retiring volunteers must ensure all confidential documents, personal information, and/or other property is transferred to their successor or the DMRF Canada office. As with in-person support group meetings, website and social media pages must maintain the confidential nature of the support group.

- Refrain from posting other member’s comments or concerns discussed during a meeting. All information shared at meetings must be kept confidential.
- Obtain written permission from guest speakers and lecturers before recording, filming, or posting information regarding topics discussed or presented-on during support group meetings and events.
- When taking pictures, respect the privacy of support group members and attendees at meetings and support group related events, such as lunches, educational symposiums, or awareness events.
 - Inform group members of your intention to post pictures online before photographing and respect their privacy if they choose not to be in photos.
 - Before taking a picture at a support group meeting or related event, give attendees the opportunity to opt out of participation.
 - When in doubt, obtain written consent before posting online.

- If you are photographing or recording any content which includes children to be used on any support group related website or social media page, you must obtain signed permission from a legal guardian, and specify where on the Internet the content will be posted/used. Note, consent is implied if you are posting content of your own children.

Responsiveness and Accessibility:

One of the primary responsibilities of a support group leader is to be responsive to those in need of support. Leaders may decide that they need to take a temporary break from group leadership due to burn out, health issues, family emergencies, and so on.

DMRF Canada understands that leading a support group can be a challenging task, and that support group leaders often have to manage many of their own personal challenges in addition to those of leading a support group. **The Foundation recommends identifying someone who can help you manage the support group, such as a co-leader or a volunteer who is able to help with meeting administration and support.** Managing the group with another person can alleviate some of your responsibilities and allow the group to remain active even if you need to take a break. If you decide to take a step back from managing your support group, we ask that you please inform the National Office of your concerns as soon as possible so that we can best support you. DMRF Canada understands that self-care comes first.

Integrity and Respect

Each volunteer must act in good faith with honesty, dignity, and integrity. They shall conduct the business affairs of DMRF Canada with due diligence and reasonable competence and shall take no action that could bring DMRF Canada into disrepute.

Volunteers must also contribute to an environment of respect, cooperation, and collegiality. They must treat peers, DMRF Canada community members, staff, other persons, and stakeholders with courtesy, allow them to express their views, and respect differing opinions. Where volunteers disagree on an issue, this disagreement should be resolved with a high standard of civility and respect.

Volunteers shall not take undue advantage of other volunteers, DMRF Canada staff, services, equipment, resources, or property for personal or third-party gain. Volunteers must refrain from publicly representing that their view is that of DMRF Canada as a whole unless authorized to do so, and to take care in ensuring that their view is not misinterpreted as such.

Alcohol, Drug, and Substance Abuse

The Foundation is committed to fostering a safe and healthy work environment. Recognizing the potential negative effects of alcohol, drugs (prescribed or not), or organic substances (i.e., marijuana or homeopathic products), intoxication while volunteering will not be tolerated and will result in action required under the circumstance. Volunteers are cautioned to use good judgment when consuming the products listed above. It is the volunteer's responsibility to know when the use of the above-mentioned substances

- Might impair their ability;
- Might endanger the safety of others; or
- Is inconsistent with their intended or medically-prescribed purpose.

Conflicts of Interest

Each volunteer must obey the law and act in the best interests of DMRF Canada and not for personal or third-party gain or financial enrichment. Volunteers shall not use their position to promote their personal, professional, or business interests; nor use their association with DMRF Canada for personal financial gain. If you have any questions about identifying conflicts, please contact the National Office. When encountering a potential conflict of interest, volunteers must disclose the conflict to the National Office and, remove themselves from all discussions as required.

Escalation Procedures/Management of Non-compliance with this Policy

Depending on the severity of the infraction, measures imposed by DMRF Canada Board of Directors and/or National Director will apply.

2: AUTHORIZATION AND AGREEMENT TO BE A SUPPORT GROUP LEADER

DMRF Canada Agrees to:

1. Help new support group leaders get acquainted with their role by providing an overview of the Foundation's history, organizational structure, and a brief update of the Foundation's current activities and connect them with a mentor if required.
2. Provide technical assistance and act in an advisory role in all aspects of operating the support group.
3. Supply relevant materials for authorized support group use at no charge.
4. Provide regular updates to the support group leader regarding current DMRF Canada programming, including: research grants and contracts, awareness efforts, support programs, advocacy efforts and other activities that may be of interest to support group members.
5. Provide assistance with securing speakers and topics for meetings, when appropriate.
6. Assist in the promotion of meetings/activities of the group via DMRF Canada marketing channels.
7. Confer the use of its logo to the support group for communication and marketing purposes.
8. Respond to all requests for assistance, provide meeting notices as requested, and post details on upcoming meeting information on DMRF Canada digital platforms on a timely basis.
9. Assist with group fund raising efforts, including but not limited to providing gift acknowledgments/tax receipts, tracking gifts, providing indirect support for approved events, and providing materials for approved events/activities.
10. Celebrate support group activities via DMRF Canada channels, including the Dystonia Canada Report, and the DMRF Canada website as appropriate.

As a DMRF Canada Support Group Leader, I Agree to:

1. Be open and welcoming to all persons affected by all forms of dystonia.
2. Ensure meetings maintain confidentiality. I agree to remind participants that confidentiality is a critical component of the group dynamic.
3. Maintain the privacy of support group members and guest speakers in online spaces by obtaining verbal or written permission before posting pictures, videos, or audio recordings.
4. Not discriminate against people attending meetings based on race, color, religion, gender, national origin, disability, age, sexual orientation, marital status, or any other basis prohibited by law.

5. Ensure the dissemination of accurate dystonia information and will only distribute DMRF Canada reviewed and approved educational materials.
6. Provide relevant information and programming to all group members, leveraging DMRF Canada resources whenever possible. The group may decide to ask for contributions to cover the operating costs of the support group, but it is understood – contributions are not required.
7. Never provide medical advice relating to diagnosis, treatments, or alternative therapies and to remind other group members to refrain from providing medical advice as well.
8. Never endorse institutions (such as hospitals), individuals (such as physicians) or products / treatment methods.
9. Recognize that the DMRF Canada logo is the property of the Foundation. The support group shall have the right to use the logo as long as it remains an authorized support group and the logo use is authorized by the National Office.
10. Comply with DMRF Canada Support Group Website & Social Media Guidelines (Section C-3) and provide relevant links to the National Office (if the group has an online presence, including a website or social media page).
11. Respond appropriately and promptly to calls and emails from the public asking for information on the group, local dystonia resources and meetings, or forward these requests to DMRF Canada.
12. Respond appropriately and promptly to requests for information (including membership lists and financial data) from DMRF Canada. Note that if DMRF Canada has reached out to a support group leader 3 or more times using the contact details provided within a 30-day period and have not received a response, the group will be considered inactive.
13. Will comply with all accounting and fundraising guidelines in the event of any local events/fundraisers, including but not limited to informing DMRF Canada office of their intent, providing names of donors to the National Office so tax receipts can be produced, providing a complete accounting of the event for audit purposes and forwarding the proceeds to the National Office within 30 days from the event or activity.
14. Provide DMRF Canada the name and contact details for the key contact person (with their expressed permission), if this person is different from the support group leader.
15. Promptly inform DMRF Canada of any changes in contact information, such as phone numbers, mailing and email addresses.
16. Comply with the policies and Code of Conduct of the Foundation and comply with all applicable laws.

I, _____, the undersigned, acting as the Support Group Leader for the Group to be known as:

_____,
(Name of the Group)

understand that the contact information provided will be made available to the public through DMRF Canada website and support group meeting promotions. I understand that if I am deemed to be unreachable within a 30-day period my contact information will be removed from DMRF Canada website, and the group will be considered inactive until I have renewed contact with the National Office. I understand that the support group shall conform to all regulations and policies of DMRF Canada, and that the Board of Directors of the Foundation, upon notice, reserves the right to alter the terms of this agreement and maintains the right to cancel authorization to operate the support group for any reason deemed by the Board to be sufficient. The parties agree to be bound by the agreement.

Support Group Leader Signature: _____ Date: _____

DMRF Canada National Director: _____ Date: _____

Contact Information:

The contact information you provide below will be made available on DMRF Canada website and will be listed on support group meeting promotions made through DMRF Canada, including email, mail and Facebook.

Name:

City: _____ Province: _____

Phone: _____ Email: _____

C: ORGANIZING A SUPPORT GROUP

1: HOW TO ORGANIZE A DYSTONIA SUPPORT GROUP

RECRUITING MEMBERS

It will be important to work with others who share your desire to form a support group. This will help establish a core of leadership for the support group which is necessary for the support group to be able to grow and thrive. Please consider enlisting the support of friends, family, and medical professionals as you work to establish this core group. You can also work to raise local or regional awareness to try and attract other highly motivated individuals who can assist you with forming this core group.

FINDING LIKE MINDED PEOPLE

Enlist the cooperation and assistance of neurologists, movement disorder specialists, other healthcare providers and their staff. The physicians will know of others who are interested in sharing common feelings and experiences related to the condition. Names of patients are confidential so this initial process may take time for the physician to ask others of their interest, but people will eventually respond.

DMRF Canada is another resource for finding the names of helpful contact persons. These are people who have consented to be contacted for regarding dystonia-related calls and inquiries. They may know of other persons in your geographic area who wish to be part of the group. The Foundation is happy to help with meeting promotion by reaching out to individuals and organizations in your area to announce the establishment of a new local support group as well as upcoming meetings and events and can develop and mail out a targeted list for outreach on your behalf. Dystonia patients across the country receive DMRF Canada's e-news and mailing updates. Reaching out to the individuals in your area through direct mail, emails, and social media can greatly increase interest and participation in support group activities.

DEFINING THE PURPOSE OF THE SUPPORT GROUP

After learning who shares your interests in having a support group, the members of the organizing group will want to talk about the reasons why they want to start a support group, such as:

- Supporting one another, offering companionship, and guiding one another in learning to cope with lost health and life-altering impacts of dystonia.

- Engaging with medical professionals for guidance regarding dystonia - and to receive information about treatments or therapies.
- Learning what medical advances are being made and how you as a group can contribute to the medical research efforts through fundraising and other activities.
- Keeping up to date on laws, regulations, and policies that impact the dystonia community and working to address these issues through participation in coordinated advocacy activities.
- Increasing awareness about dystonia in the medical and lay communities.

HOST AN INITIAL MEETING FOR THE ORGANIZING GROUP

If you can identify other interested individuals and helpful healthcare providers or other community members, consider inviting this core group to a planning meeting. These individuals can provide valuable input and perspective for creating a support group and making sure it caters to all dystonia patients. They may even be interested in helping run the meetings and share the work or assisting with regular administrative tasks. As the discussion moves forward and addresses topics like when and where to meet, it is important to remember that you will not be able to please everyone, but you should always be open and willing to try working with everyone to collaboratively identify the best courses of action.

INITIAL MEETING OBJECTIVES

Some critical topics should be discussed at this initial meeting and some important issues should be addressed to ensure that the group moves forward, including:

- What should the structure of the group be?
- What tasks are group members willing to take on?
- What responsibilities would group members like?
- What needs should we focus on addressing?
- What community resources are available to us?
- What experiences, expertise, and skills can group members apply to critical areas like raising awareness and recruiting additional members?
- What should the time, place, program, etc., be for your first official, widely announced DMRF Canada support group meeting?

TIPS FOR SUPPORT GROUP LEADERS

To follow are a few general tips that can assist you with many aspects of support group leadership:

- Never provide medical advice or counsel members of the group.
- Continually remind members that all conversations and discussions are to be kept confidential.

- Whenever possible, contact new participants and work to make sure they feel comfortable within the group.
- Always speak in a loud, clear voice.
- Be patient.

2: SUPPORT PROVIDED BY DMRF CANADA

PROMOTION

DMRF Canada Calendar Of Events

This online calendar would include all the details for your support group meeting, including date and time, location, and support group leader contact information. This may also include specifics such as guest speaker information/biography, parking and transportation directions, etc.

E-mail Blasts

DMRF Canada will include your meeting information in [E-newsletters](#) as upcoming events.

Social Media

DMRF Canada may post meeting information-on their social media pages, including Facebook, Instagram, and Twitter.

MATERIALS

The Foundation has a wealth of information for patients with all types of dystonia brochures, pamphlets, and videos. These and a sampling of our materials are all available by visiting: www.dystoniacanada.org. They are also available by contacting the DMRF Canada National Office. (For a full list of our current materials, please see section G.)

If the support group has an upcoming event or meeting planned, please let the Foundation know well in advance of the meeting so they can send you any relevant materials.

PERSONNEL/ASSISTANCE

The Foundation can assist with giving telephone advice and encouragement. Support group leaders may be provided leadership coaching, if required, to assist with the formation of a new support group or to re-engage their group.

3: SUPPORT GROUP WEBPAGE & SOCIAL MEDIA GUIDELINES

DMRF Canada support group leaders are empowered representatives of the organization, and the Foundation strives to provide resources to help them serve their members. DMRF Canada support groups are NOT required to maintain a webpage or social media page (such as Facebook), but for those that do we offer the following guidelines.

PURPOSE

The purpose of the webpage or social media page should be to:

- Promote support group meetings and activities
- Serve as a local resource to share information such as DMRF Canada research updates, events, and advocacy and awareness activities
- Refer users to the information on DMRF Canada website (www.dystoniacanada.org) for questions on treatment, research, diagnosis, and resources
- Stay in-touch with support group members between meetings
- Attract new members to continue building local support communities

CONTENT

Web page and social media content should adhere to all DMRF Canada policies outlined in the *Support Group Agreement*.

- Clearly state the name of the support group and the group's affiliation with DMRF Canada, incorporating DMRF Canada logo where possible.
- Content included on a support group website or social media page may include:
 - Contact information for the support group
 - Dates and details of upcoming meetings and events
 - News from DMRF Canada website, social media pages, and e-blast announcements
 - A link to DMRF Canada website: www.dystoniacanada.org and online support forums: www.dystoniacanada.org/support
- Photos from support group meetings and activities (refer to the Confidentiality section of this manual).
- Keep in mind that dystonia support groups cannot provide medical advice relating to diagnosis, treatments, or alternative therapies. Groups must not endorse medical institutions (such as hospitals), individuals (such as physicians), or products.
- DMRF Canada support groups and leaders should avoid disparaging or promoting certain therapies and/or treatments based on personal experiences or circumstances. It is always best to encourage members to consult with their doctor with questions regarding treatment, products, methods, or techniques.

4: LEADING A DYSTONIA SUPPORT GROUP

LEADING THE GROUP

Leading a support group can be a demanding task. Support group leaders are expected to be knowledgeable, good listeners, good organizers, non-judgmental, and capable of managing difficult personalities in addition to managing the group. Most importantly, an effective leader is aware of their limitations. Do not hesitate to ask others for help or work to delegate responsibility amongst interested individuals. You may find that a team approach that plays to multiple group members' strengths is the best way to lead the organization.

Most support groups are informal. The leader is responsible for orderly, pleasant meetings, encouraging others to participate, and recognizing that people come and go as their interests and needs are met. The leader makes attendees comfortable with flexible membership requirements and uses an "open door" policy for members and their families.

IDEAS FOR MEETING LOCATIONS AND TIME

It is common for group leaders to enlist the assistance of a neurologist and/or his/her staff members and host meetings in conference room of a hospital, or other public building thus ensure accessible entrances and washroom facilities thereby avoiding any liability insurance which private establishments will require. You may also wish to investigate using spaces available in universities, colleges, libraries and banks.

Generally, meetings are best on a Saturday or Sunday afternoon when driving is relatively light, and families and/or friends can easily attend with the dystonia-affected person. Some dystonia support groups choose to meet weekday evenings, finding their members and speakers like that time. Every group is different, and it is important to check-in with members to find the right day, time and month that works for the most people.

MANAGEMENT OF THE SUPPORT GROUP

To ensure the success of the support group, it is important that all group members feel accepted as equals. Each person has his or her own unique experiences and his or her own way of dealing with issues. One person is not necessarily better or worse at handling his or her problem than another person.

It is also important to promote contact between established and new members of the group. A person who has extensive experience at successfully dealing with a particular problem can reassure a newcomer that the issue can be managed and will be able to give pointers. In this regard, it may be a good idea to have a welcoming session for new members before the official meeting begins. Sharing experiences also reminds the long-standing members of why they

originally joined the group. Most importantly, this kind of sharing helps people feel good about themselves and about the group. Some established groups have a “buddy system” to encourage communications. The strictly observed rule about confidentiality will encourage members to be more open than they would otherwise be.

There is usually an expectation that the support group leader be knowledgeable about the various types of dystonia. Keeping up to date on articles and media attention to areas like dystonia research, treatment options, and advocacy activities, can be very helpful. You may want to consider asking group members to discuss or provide on a regular basis any new dystonia information they have come across. This information may help you answer questions or identify a good program topic for an upcoming meeting.

FREQUENTLY ASKED QUESTIONS

You receive a call from a person who has just been diagnosed with dystonia. The caller has many questions – how do you respond?

- “*Am I receiving the correct treatment?*” It’s important to support the caller. Dystonia is a complicated disorder and what works for one individual may not work for another. Instead of giving advice, tell a story about yourself or a friend. *It is important to* encourage them to speak with their doctor if they are concerned about their treatment.
- “*What doctor should I see?*” Tell them that it is important that they find a doctor who will listen to them and with whom they trust and feel comfortable. The Foundation maintains a list on their web site of neurologists and other healthcare professionals who specialize in movement disorders. Refer to section H. The Foundation can provide assistance over the telephone for anyone looking for a physician in their area.
- “*Will this get any worse?*” Give them hope—they need to allow time to pass after the initial diagnosis is made. Tell them with proper medication it may improve. It’s very unpredictable and all medications work differently on different people. Also, tell them this is a question they should ask their doctor and encourage them to talk with their doctor.
- “*Where did it come from?*” Respond that it’s a disorder from the part of the brain called the basil ganglia which is responsible for movement. It may affect one or many parts of their bodies. The cause is not yet known.
- “*Will it be passed onto my children?*” Let them know that it may be passed on if they have a genetic form. Suggest they seek genetic counseling or contact DMRF Canada as we have helpful information in this area.

- “*What medications should I take?*” Finding the right medications is a trial-and-error situation. To find the right one and develop a treatment plan, you must work with your doctor.
- “*Life is changing, and it isn’t fair.*” Reassure them it may take time for balance to return to their life. Suggest they join a support group to foster a better understanding of dystonia and to learn coping techniques. Remind them that they are strong enough to work through this and that it is very possible to live well with dystonia.

IF A MEMBER IS IN CRISIS

It is important to note that at some point you may have a support group member who is going through a particularly difficult time. Feelings of anxiety and depression are not uncommon in the dystonia community, and as a support group leader you may find yourself in a situation where a support group member or individual from the community is in need of professional help. If this situation arises, know that DMRF Canada is here to support you. The role of a support group leader is to offer peer support – you are not expected to fill the role of a mental health professional.

For resources and more information to help navigate these potential challenges, please see Mental Health information and helplines and professional support services in section E.

5: FACILITATING A MEETING

The major challenge of support group meetings is making sure they satisfy the needs and expectations of group participants. Having multiple members of the group act in different roles during a meeting can be helpful in meeting this challenge. For example, someone could greet new members and introduce them to the group. Feedback materials, such as comment cards and suggestion sheets, can provide timely information on the thoughts of support group members.

Staying organized is a great way to make sure meetings run smoothly. Beginning your preparations for a meeting well in advance is a key to success. Furthermore, arriving early the day of the meeting and utilizing the meeting checklists in this manual can help ensure that no detail is overlooked.

You may want to have general dystonia material available at your meeting or information specific to the topic of your meeting. DMRF Canada has a wide range of literature, pamphlets, and informative materials that are available to you through the National Office.

(For a full list of materials, see section G)

TIPS FOR EFFECTIVE MEETINGS

- Make the atmosphere friendly, cooperative, and pleasant; help new members easily fit into the discussion and the activities.
- Encourage all members to participate and communicate, not just a few. Give everyone an opportunity to speak and try to keep discussion to a topic that is relevant for most.
- Encourage the group to use the abilities of all members rather than relying on a few.
- Provide an environment where members feel safe speaking out; neither ideas nor people should ever be ridiculed or belittled. Individuals or situations that negatively affect this safe space should be addressed quickly and sensitively.
- Keep members well informed and up to date.
- Remember that decision-making is carried out in a consensus-building manner.
- Remind attendees that all discussions are kept confidential.
- Ensure that group members who are not medical professionals do not provide medical advice or counsel to others.
- Schedule the meetings on a regular set date so group members can maintain a consistent calendar.

FACILITATING A DISCUSSION

Keeping the discussion on track can be a necessary and complicated task for a support group leader. You continually have to balance priorities like maintaining a focused discussion with making sure everyone gets to participate. It is also important to remember that not everyone will know how to appropriately participate in a support group discussion, and you may have to steer the conversation through some strong personalities.

Developing ground rules can help ensure a structured environment where group members feel comfortable attending and sharing. Rules can be drafted by the support group leader with input from group members and then posted at every meeting. Before a discussion, new members should be made aware of the rules, and the option of opening any of the rules for modification should always be available to group members. Below are some sample ground rules:

- What is said and discussed during support group meetings is confidential.
- Participants will refrain from judging one another or making disparaging comments.
- No interrupting—everyone will patiently listen to the views of all support group members.
- Participants will not pressure one another or make anyone feel compelled to participate.

Ensuring Participation - Discussion is greatly affected by the number of people in the group. The best size for personal discussion is between 6 and 10 people. Too few people limit the diversity of experiences while too many may mean that not everyone gets the opportunity to speak.

If your group is large, or wishes to break up into specific dystonia groups, there could be smaller groups for discussion which get back together for activities the whole group is interested in. Having “reporters” of the individual smaller sessions relaying information back to the whole group affords the opportunity for more people to be involved.

You may experience individuals who monopolize or take the conversation into uncomfortable areas. We have all come across individuals who attempt to dominate a conversation, refuse to participate, or are perpetually negative, and the support group setting will be no different. Anticipate these situations and have some strategies ready to immediately mitigate them and move the conversation along in a manner that the entire group will be comfortable with. Be aware of not monopolizing the discussion yourself, especially if the group is quiet or unresponsive. Meetings will progress as needed by the participants.

Responsibilities – While support group members are participating in a group discussion, it is important that the support group leader is in tune with when to move the discussion along.

6: SUGGESTED PROGRAMS

Suggested Time Frame: 1.5 - 2 hours including a Q&A

Overview of Dystonia

Synopsis:

Many dystonia patients have general medical questions and require additional background information on the condition. Learning about dystonia and recent advancements in our understanding of the condition can lead to better management of symptoms and improved quality of life and self awareness.

Recommended Speakers:

Neurologists; Physicians who administer Botulinum Toxin; Movement Disorder Specialists

Purpose:

- To answer questions of a medical nature.
- To provide information concerning the origins of dystonia, what is known, what is not known.
- To promote understanding of the genetic and nongenetic factors.
- To review current research and discuss the state of the science.
- To understand how a Dystonia Clinic and/or a Movement Disorder Clinic operates.
- To explain the process by which dystonia is diagnosed.
- To better understand dystonia treatment options.
- To provide group members with the opportunity to ask questions.

Physical Therapy

Synopsis:

Exercise and physical therapy are important to everyone who wishes to maintain an active lifestyle, but dystonia can be physically disabling and can make even simple activities more difficult and riskier. Posture assistance, safe exercises, and strategies for avoiding fatigue can help dystonia patients better manage their physical activities.

Recommended Speakers:

Certified Physiotherapists

Purpose:

- To improve independent function and address the treatment of pain, as well as provide advice on exercise and posture.

- To share information about short-term relief (moisture, heat, ice, etc.).
- To offer guidelines on exercise and posture.
- To suggest safety and mobility devices.

Occupational Therapy for Dystonia Patients

Synopsis:

Occupational therapy can be an effective non-drug therapy for dystonia patients. Learning useful or innovative techniques for staying active can be an empowering experience as well as one that helps dystonia patients achieve greater awareness and control over their bodies.

Recommended Speakers:

Certified Occupational Therapists

Purpose:

- To promote, maintain, and restore task related proficiency, performance, health, and emotional well being.
- To offer guidelines to control fatigue and maintain good posture, and to maintain good nutrition.
- To assist patients in the choice of medical equipment and materials, as well as adaptive equipment.

Speech Therapy

Synopsis:

Learning strategies and conversation techniques to communicate more effectively can educate and empower dystonia patients. Tips regarding diet, chewing and swallowing, and nutrition are also viewed as valuable by many dystonia patients.

Recommended Speakers:

Certified Speech-Language Pathologists

Purpose:

- To improve communication, individualized therapy programs can help develop specific techniques. Speech therapy may be more effective in combination with other specific therapies such as medications. (If speech is severely impaired, a communication aid may be required.)
- To make speech intelligible.
- To help improve chewing and swallowing.

- To recommend diets which ensure proper nutrition.

Psycho-Social Aspects

Synopsis:

Many dystonia patients are interested in advice concerning adjusting to lifestyle changes and managing associated stress. Dystonia patients may also be interested in counseling services or other available coping resources.

Recommended Speakers:

Social Workers; Counselors; Psychotherapists; Psychologists; Psychiatrists; Quality of Life Specialists. *In each instance, ask about certifications and qualifications.*

Purpose:

- To validate and normalize the reactions persons with dystonia and their families experience.
- To use the group process to recognize, identify, and develop coping strategies.
- To utilize the expertise of professionals in improving quality of life for the dystonia patient and their family.
- To enhance the self-confidence of the individual participants in their ability to cope actively and constructively with issues which confront persons with dystonia and their families.

Community Resources

Synopsis:

Dystonia patients may have questions or be interested in additional information about the local, provincial, and federal resources which are available to them. In addition, there may be some questions about helpful local services, such as policies or programs available within the community or local hospitals.

Recommended Speakers:

Social Workers; Social Security Specialists; Government Representatives; Insurance and/or Legal Specialists. *In each instance, ask about certifications and qualifications.*

Purpose:

- To educate dystonia patients and their families about availability and accessibility of community resources.
- To receive the latest information on federal and state assistance.

- To make known what entitlements or financial assistance may be available.
- To ease anxieties and discomforts which may accompany the effect of having dystonia.

Nutrition/Well-Being

Synopsis:

A proper diet can boost energy levels and feelings of personal satisfaction for anyone. Furthermore, adequate nutrition can aid dystonia patients in controlling their weight, even as physical ability is reduced, and avoid the complicated health issues that arise with significant weight gain.

Recommended Speakers:

Certified Dietitians; Certified Nutritionists; Physicians who specialize in weight problems

Purpose:

- To educate dystonia patients and their families about the importance of diet.
- To alert patients to possible allergic reactions and the effects of chemical reactions with medication.
- To dispel misconceptions.
- To understand how foods affect us.

Caregiver's Meeting

Synopsis:

Many individuals are impacted by dystonia due to the constant support and aid they provide for a loved one who has the condition. These dystonia-affected individuals have their own unique issues and perspectives to discuss and share.

Recommended Speakers:

If this is an occasional caregivers-only meeting, a social worker is usually an appropriate facilitator.

Purpose:

- To give caregiver's the opportunity to share feelings with one another.
- To help caregivers cope more effectively with dystonia.
- To be emotionally supportive in relation to the disorder.
- To provide a safe place for caregivers to vent their feelings.
- To encourage self-care for the caregiver.

Back-up Programs

Purpose:

Unforeseen events can occur at the last minute to disrupt a planned support group meeting. Speakers can cancel without any notice or programs may be missing an overlooked component. Since many individuals look forward to and rely on these meetings, and since there may not be time to provide sufficient notice, an alternative meeting may need to take place instead. Below are some ideas which you may want to have prepared as possible back-ups to a scheduled event.

1. Show a video. You can always visit the DMRF Canada YouTube channel for a collection of videos that can be shared.
2. Group Exchange (to elicit a positive response by discussing a topic and then returning as a whole, reporting your findings).

Examples:

- How to build a community event
- Sharing of personal stories
- How to write a news story
- How to avoid burnout as a caregiver
- How to be sensitive to family needs

7: MEETING CHECKLISTS - EXAMPLES

PRE-MEETING CHECKLIST

Speaker/Program Decided. (6 weeks prior to meeting)

- _____ Speaker invited and confirmed well before meeting.
- _____ Speaker's A/V needs confirmed.
- _____ Speaker's introduction prepared.
- _____ Notify DMRF Canada if help is needed for sending out meeting announcements.

Preliminary Communications Completed. (4 weeks prior to meeting)

- _____ Flyers/notices sent out to group members.
- _____ Social media and digital communications used to raise awareness more broadly.
- _____ Press releases sent out to local media (if required).

Materials Obtained. (2 weeks prior to meeting)

- _____ Brochures received from Foundation (if needed).
- _____ Posters, displays, informational literature, advertising, exhibits ready.
- _____ Agenda drafted and available.
- _____ Reminder call to individual(s) responsible for refreshments.

Surroundings Prepared. (1 hour prior to meeting)

- _____ Refreshments available.
- _____ Sign-in sheet and nametags available
- _____ Lighting, temperature, seating, parking, coat racks, etc. taken care of.

MEETING CHECKLIST

_____ Placard designating the meeting room and directional signs to meeting room.

_____ Front desk aware of meeting location (if applicable).

_____ Host to welcome and introduce guests as they arrive.

_____ Start meeting on time and finish on time in accordance with agenda.

_____ Ensure there is time for Q and A after presentation(s).

_____ Ground rules for meeting established and communicated.

_____ Encourage all to participate and reach out to new members.

_____ Delegate responsibilities for the next meeting through discussion.

_____ Announce when and where the next meeting will be held.

_____ Remind everyone to add their contact information to the sign-in sheet.
(Please see sample sign-in sheet)

_____ Prepare a summary immediately following the meeting or take notes.

POST-MEETING FOLLOW-UP

- _____ Evaluate the meeting regarding location, timing, convenience, speaker, discussion, and identify what went well and what needed work.
- _____ Send out thank you e-mail to speakers.
- _____ Call/contact new members or first-time meeting attendees to get their feedback.
- _____ Consider and address outstanding organizational issues that have been highlighted at meetings and identify solutions to persistent issues that continually arise, such as a logistical problem or inconvenience with the meeting space.
- _____ Keep searching for new members and interesting ideas, themes, and speakers.
- _____ Evaluate which group members showed up and think about ways to attract new members.
- _____ Send out follow-up information through the DMRF Canada network.
- _____ Identify upcoming birthdays as an opportunity to personally reach out to members and use other opportunities to stay in touch with the group.
- _____ Track or report the number of meeting attendees to DMRF Canada office

This can be managed by the support group leader, co-leader, or a responsible member of the group to assist with delegating and sharing responsibility.

Consider having an annual meeting review with group members to ensure that the schedule, format, and programs are supported by the group. Refrain from getting discouraged if the group dwindles in size. It is very important to continue with meetings. Some participants may need to know the group will last before they wish to commit more time and energy.

D: MOVING YOUR DMRF CANADA SUPPORT GROUP FORWARD

1: MAINTAINING MOMENTUM

Support groups tend to go through a process where participants grow increasingly accustomed to one another and begin to participate more. From a leadership perspective, it is important to make sure no one dominates early discussions and that possible personality conflicts are immediately resolved. Moving forward, it will be important to ensure that strong personalities have a role in the organization which suits their interests. Establishing a leadership core by assigning tasks to group members can ensure they stay involved and help the support group grow.

Leadership – There are different styles of leadership which are effective in different situations. For example, an assertive leader might be required to get a group moving on a problem, but that personality may be less effective when encouraging compromise. The support group is stronger when it realizes that no single person possesses all leadership skills such as facilitating, organizing, motivating, planning, and delegating. Different members can therefore perform different leadership roles and share in the responsibilities of the group.

Publicity – You are providing an important service to the community, and you should work to publicize it. Getting the word out about meetings will ensure robust participation and a steady stream of new participants. Widely disseminating meeting notices and public service announcements through local newspapers, community bulletin boards, radio stations, and relevant newsletters is an excellent way to raise the profile of your support group.

Group Development – Support groups rely on cooperation among members. All groups have needs that must be met if the group is to stay lively and effective. One need is to get its job done work towards its purpose. Other needs are being met when members get the meeting started, arrange for speakers, help keep the meeting moving, give information, or summarize events. Typically, though, a support group is more focused on the social and emotional needs of its members to ensure that members are compromising, adding humor when appropriate, participating openly, and receiving encouragement and validation.

Structure – Support groups are usually quite informal. Generally, the organizer is designated as the leader. It may be that you, as the organizer, or your group would feel more comfortable with rotating responsibilities. Sometimes the need for structure can be met through a system of rotating responsibilities among various group members. A system of rotation helps keep members involved with group activities and is also a way that members learn more.

Informal groups are often better at meeting emotional and physical needs while more formally structured groups are often better at accomplishing specific tasks. It is important to add more structure as the group's needs progress and, ultimately, strike the appropriate balance between a formal organization and one that is unstructured.

Each support group should cultivate a core group to implement Foundation goals as well as to offer personal comfort and medical education for members and families. As the group becomes more established these individuals who want to take on a larger role in the group could be responsible for certain tasks. Such responsibilities might include:

Awareness/Public Education:

To publicize success stories, make contact with media outlets, and distribute news items-- particularly during Dystonia Awareness Week.

Development:

To monitor the group's changing needs and identify opportunities to improve the group or advance its goals.

Children's Education:

To reassure families that there are treatments and to aid them in obtaining education rights and put them in touch with other parents.

Advocacy:

To disseminate grassroots information from the Foundation which informs dystonia-affected persons about legislative efforts of interest to the patient community.

Medical Education:

To distribute educational brochures and materials to physicians and hospitals so they will refer patients and their families to the Foundation and local support groups.

Fundraising:

If the support group decides to undertake fundraising activities, these individuals should interface with the Foundation and work collaboratively on fundraising events.

Keeping People Involved – The effectiveness of any group depends partly on how people feel about being members of the group. It also depends on how they feel about taking part in its activities. One meeting may be warm, informal, and exciting, while the next may seem formal

and relatively quiet. This “climate” depends on who is present, what the activities are, and on the behavior of the facilitator.

The physical surroundings are important; attention to details such as room temperature, comfortable chairs, and quiet surroundings makes a difference. Seating arrangements are also important. Arranging chairs in a circle will make it more likely that all members will see each other and participate, while classroom style seating would be appropriate for a particular speaker.

The support group leader’s mood and personality also greatly contribute to the setting. A leader who is cheerful, approachable, and enthusiastic will encourage others to act in a similar, productive manner.

2: MAINTAINING SELF-CARE

Maintaining self-care is paramount for every support group leader. While you are providing support to others, DMRF Canada encourages you to remember to take care of yourself first. If you are starting to feel overwhelmed or burnt out with running the support group, the Foundation has some suggestions that may help:

Delegate Responsibilities:

While it is ideal to find a co-leader, there is not always someone available who is willing to divide the responsibilities of running a group. This does not mean that you must do everything yourself. Call on your support group members to share in the responsibilities of running a group and give them smaller, more manageable tasks that can offer you some relief but will not overwhelm them.

Create a list of things that need to be done (whether it be getting snacks and refreshments, helping with set-up, sending out the newsletter, maintaining a group Facebook page, etc.) and ask for volunteers to sign-up. Asking others to be involved in running the group will not only help you as the leader, it will also serve to build-up a community of support and ensure that members are invested in the group and its activities.

Find Volunteers:

If you are having trouble finding support group members to step up and take on some of the responsibilities of running the group, try contacting volunteer organizations or people who are retired and ask for help. Give volunteers specific tasks and ask what they would like to do.

Set Boundaries:

Support group leaders not only give their time, but also much of their energy, in being a support and resource for others. Fielding calls and inquiries from support group members and the general public can become draining. It is important to set boundaries and maintain a balance in supporting others and yourself.

While support group leaders are expected to be responsive to outreach from the public and DMRF Canada, you are not expected to be available 24/7. Set limits on when you receive calls and respond to emails. Having a separate email address can help you maintain your privacy and ensure that you do not feel as if you are constantly “on-call”.

It is also important to remember that you are not responsible for the wellbeing of your support group members. You are not a medical professional or a mental health professional and you may sometimes need to remind others of that. As a volunteer who truly cares about others, it can be difficult to say “no”. Take care of yourself first: understand that setting boundaries will

help you to continue being a successful support group leader. Refer to section E for useful tips on *'How to say no with empathy and kindness'*.

Build Your Personal Support Network:

While you take on the task of being a support and resource for others, you should also make sure that you have your own network of support. Building and maintaining relationships with family, friends, neighbors, and other DMRF Canada support group leaders is essential for self-care.

Take a Break:

If you ever need to take a break from leading the support group, you should do so. Self-care is important for every leader and will always come first. Let DMRF Canada know that you need to take some time away from the group and know that you can always return when you feel ready and refreshed.

DMRF Canada is here to support you and help you navigate leading a support group. If you are feeling overwhelmed, please do not hesitate to reach out to the Foundation and share your concerns and frustrations.

3: EXPANDING ACTIVITIES

Once your support group has grown and established itself, you may want to consider taking on additional activities beyond hosting a meeting. At this point, it is likely additional members will have taken an interest in being involved in planning and executing the support groups activities. These individuals and the support group itself may want to discuss ways in which the group can move into new areas and expand its role in the future. Two opportunities which will engage and empower support group members and raise the profile of the support group in the community are:

- (1) help advance the dystonia community's legislative agenda by becoming advocates; and
- (2) help directly support critical research and education initiatives by fundraising.

Advocacy – As legislative issues emerge; the Foundation will send through information on how your support group and its members can make an impact. You may want to consider sharing this information with your support group, discussing its importance, and encouraging politically minded members to become patient advocates. Please note that the Foundation avoids partisan issues, wedge issues, or controversial issues.

DMRF Canada is available to answer any questions on legislative issues your support group might have, as well as to provide you with any additional advocacy or legislative information if you contact the National Office.

Setting an Annual Agenda – As you set the calendar for the upcoming year, you strive for an interesting and varied collection of meetings and programs that will stimulate attendance. Below are some tips to on how to plan meetings: frequency, location, day/time, etc.

- Have comment cards available at all meetings and events so that you can easily identify the programs and activities that support group members are interested in.
- Select a core group that will set the agenda. Note holidays and sporting events because you don't want your meetings to compete with special occasions.
- Decide where to meet and try to keep that location consistent for one year.
- Pick topics that reach out to the total group and decide which speakers you want to invite. Topics do not have to be medically related. One group shared a successful meeting where a policeman spoke to the group about personal safety.
- Plan seasonal and social events like a lunch out, a picnic in the park, a holiday party, or activities celebrating Dystonia Awareness Month.
- When planning, think about your members—do they come for education, support, or both? Also think of weather conditions and if there are any limitations for your members. You may want to refrain from a January meeting if the winter is typically harsh and creates travel problems.

Fundraising – DMRF Canada is available to provide support, guidance, and assistance with any fundraising activities. See the fundraising guidelines and agreement in section F of this document for more information.

DMRF Canada relies on financial contributions and funds raised by individuals and groups to continually support the community through advancing research, producing helpful educational materials, hosting informative events, and other approved activities.

Support groups are not expected to raise funds for research, but it can be a meaningful group activity. All funds raised will be directed back to support the mission of the Foundation. A reminder, to ensure donor privacy and stewardship, all funds and associated administration should be delivered to the Foundation within 30 days of the fund-raising event. The National Office must be informed of any planned fundraising activities well in advance.

Reasonable expenses depending on the event are allowable for: printing, duplicating, postage, decorations, entertainment, unusual telephone tolls and/or faxes. (In-kind donations by local businesses and/or member underwriting can minimize these expenses.)

If clerical help is needed for events, temporary hourly pay can be deducted from the gross receipts. The foundation can not authorize salaried positions or payments to persons except in the Foundation office.

4: PARTICIPATING IN FOUNDATION ACTIVITIES

Freedom to Move for Dystonia – A hybrid (virtual and in-person) fundraising and awareness event held across Canada in June, with volunteer-led in person activities in different cities. This event brings dystonia patients and families together from across the country to raise funds and support people with dystonia. Your support group may want to consider hosting a gathering like a picnic or a walk event.

Dystonia Awareness Month – September is Dystonia Awareness Month. DMRF Canada and affiliated support groups use this opportunity to raise awareness of the issues affecting the dystonia community.

Dystonia Symposium – The Foundation may host Symposium events – these are usually multi-day events that cover a number of areas and brings dystonia patients and families together from across the country.

Your support group may want to consider raising awareness of this event or help by sending interested members.

5: ROLE DESCRIPTION - DMRF CANADA SUPPORT GROUP LEADER

Dystonia Medical Research Foundation (DMRF) Canada aims to provide support for the thousands of individuals who are affected by dystonia in Canada through the establishment and management of local support groups. Volunteer support group leaders help us to achieve this goal.

Support group leaders work with DMRF Canada to:

- Increase awareness of the condition and DMRF Canada in their local community.
- Provide an opportunity for persons affected by dystonia to meet others similarly affected.
- Offer relevant, valid, and reliable sources of educational information.
- Expand fundraising potential.
- Develop and enhance a relationship between DMRF Canada and the local community.

Location:

All volunteering is based within your local community or online. This could include the organization of regular (quarterly/semi-annual/annual) meetings or gatherings where individuals with dystonia can come together – either virtually or in person - to talk about their experiences, discuss challenges and successes, share stories and meet others with dystonia. It could also include the organization of other events, fundraisers, or any other opportunities that would allow an opportunity to raise the profile of dystonia and the DMRF Canada.

Key Responsibilities:

- Respond to patient support queries – over the phone and by email.
- Maintain an active support group with at least one meeting taking place each year and keeping DMRF Canada informed about meetings dates, times and locations.
- Connect with local movement disorder clinics/dystonia treaters to ensure they are aware of - and referring patients to the local support group or DMRF Canada for resources and support.
- Build relationships with local physicians, health care professionals, government and community representatives, in order to increase dystonia awareness and group membership.
- Circulate dystonia and DMRF Canada literature to support group members, health care providers, and others as needed.
- Act as a local dystonia and DMRF Canada ambassador for their community. Promote the Support Group within their network.
- Leverage DMRF Canada to ask for support in raising awareness of upcoming events as needed.
- Provide feedback to DMRF Canada about the needs of the group, including additional support and training requirements.

- Participate in DMRF Canada led training programs on opportunities and responsibilities of DMRF Canada Group Leaders via Webinar/conference (when required).

Length of Appointment /Time Commitment:

- Minimum commitment of one year.

Qualifications and Characteristics:

- Strong leadership skills;
- Strong organizational skills;
- Passionate about making a difference in the lives of others affected by dystonia;
- Comfortable speaking with individuals about their dystonia experience;
- General understanding of the various forms of dystonia;
- Flexibility, ability and interest in meeting with others in person or over the phone;
- Ability to understand and comply with DMRF Canada policies as described in the support group manual;
- Possesses good judgement, and an ability to maintain privacy and confidentiality.

Note: You do not need to have dystonia in order to be considered for this position.

Interested parties should email info@dystoniacanada.org

E: MENTAL HEALTH

1: MANAGING A QUERY FROM A PERSON IN CRISIS

Sometimes individuals who contact support group leaders may be experiencing an unexpected personal or social setback, and feel overwhelmed emotionally, leading to difficulty regulating an appropriate response.

According to Centers for Disease Control and Prevention USA, *Crisis is an acute emotional upset; it is manifested in an inability to cope emotionally, cognitively, behaviorally, or to solve problems as usual*. DMRF Canada staff and volunteers are not professionals trained to engage in crisis intervention. Support group leaders must encourage a person who is showing signs of declining mental well-being or experiencing a crisis to reach out to supports or connect the person to crisis support if needed.

The first step when you receive a call from someone in a crisis is to direct them to the helplines outlined in section E3. Below are some helpful resources to help leaders in directing such persons in need. If you don't feel capable of providing this support, please contact the National Office.

1: HELPFUL LINKS FOR COMMUNICATION STRATEGIES

- A. Reducing mental health stigma: Reference Guide to Safer Language:
www.mhfa.ca/en/safer-language-reference-guide
- B. Informational guide on how to talk to youth who are at risk of suicide:
www.suicideinfo.ca/resource/youthatrisk/
- C. A more detailed and fulsome guide courtesy of the Canadian National Suicide Prevention Lifeline: www.suicideprevention.ca/im-having-thoughts-of-suicide/
- D. A Guide on Helping Others courtesy of Canadian Mental Health Association:
www.cmha.ca/find-help/helping-others/
- E. Assisting Members in Crisis - Support group leader Webinar:
www.dystoniacanada.org/resourcesforleaders
- F. From Awareness to Empowerment: Navigating Mental Health with a Neurological Condition www.dystoniacanada.org/dystonia-information-sessions

2: GENERAL TIPS FOR SUPPORTIVE LISTENING & COMMUNICATION

If you believe one of your members needs professional help, you can engage the person in conversation and offer resources. Here are some general tips for communicating clearly and compassionately:

- ☐ Encourage the person to talk with their healthcare provider, therapist, or other qualified professionals. Offer suggestions and contact information from your Resource List.
- ☐ Encourage the person to seek support from a family member or friend.
- ☐ Ask questions to show you care and are concerned and seek clarification about what they are telling you.
- ☐ Be patient, even when the person may not be communicating well, is repetitive, or is speaking more slowly and less clearly than usual – be prepared for periods of silence.
- ☐ Be careful not to give unhelpful advice such as “cheer up” or “pull yourself together.”
- ☐ Be careful to not minimize a person’s experiences or feelings with comments such as “put a smile on your face” or “be positive” or “everyone has problems, not just you.”
- ☐ Pauses and silences are ok. Keep conversation going with prompts such as “I see” and “ah.”
- ☐ Resist the urge to “fix” the person or solve their problems. You can offer support and resources to help them.
- ☐ Do not be critical or express frustration.

IMPORTANT: If you believe a person is *actively suicidal or at immediate risk (i.e., they are planning to engage in self-harm and have access to materials, such as pills, firearms, etc.)* give the person a contact that is always available, for example call **911**, a crisis helpline, a friend or family member who is available to help, a physician, or a mental health professional. For example, offer the person the Talk Suicide Canada Helpline (**1-833-456-4566**). The helpline is also available to anyone who needs information and resources to help someone else.

Adapted from: Mental Health First Aid™ USA

3: GUIDE FOR MANAGING CONVERSATIONS WITH MEMBERS IN CRISIS.

Adapted from the American Foundation for Suicide Prevention, "If Someone Tells You They're Thinking About Suicide: A #RealConvo Guide"

Let them know you're listening

- Reassure them you hear what they're saying, and that you're taking them seriously.
- "I'm so glad you're telling me about how much has been going on, and how you're feeling. Thank you for sharing this with me."

Show your support

- In your own way, make sure they know you're there with them, and that you care.

What can you say if they tell you they're thinking about killing themselves?

Stay calm – just because someone is having thoughts of suicide, it doesn't mean they're in immediate danger. Take the time to calmly listen to what they have to say and ask some follow-up questions.

- "How often are you having these thoughts?"
- "When it gets really bad, what do you do?"
- "What scares you about these thoughts?"
- "What do you need to do to feel safe?"

Reassure them that help is [available](#), and that these feelings are a signal that it's time to talk to a mental health professional.

- "The fact that you're having these thoughts tells me something significant is going on for you right now. The good news is, help is out there. I want to help you get connected to resources that can help."

How to suggest they could benefit from professional help

It is helpful to have this supportive conversation – but you're not a mental health professional. If the person you care about has told you they're thinking of suicide, it's a warning sign that they should speak with a mental health professional. Here's how you can broach the subject.

- “I hear you that you’re struggling, and I think it would really be helpful for you to talk to someone who can help you get through this.”
- “It is normal to need help sometimes.”
- “You know, therapy isn’t just for serious, ‘clinical’ problems’. It can help many of us process challenges we’re facing – and we all face serious stuff sometimes.”
- “I really think talking to someone can help you gain some perspective and keep things from getting worse.”
- “You’re in good company: the highest-performing executives and elite athletes lean on mental health professionals to hone their performance. Reaching out for professional guidance and therapy is a strong thing to do, and it can make all the difference.”

Help them connect

Sometimes making that first moment of contact to professional help can be the hardest. Offer to help them connect in whatever way you’re comfortable with.

If they’re concerned about privacy

If the person is worried about others finding out that they’re getting treatment, reassure them that:

- “Mental health treatment actually has even greater confidentiality safeguards than physical health treatment.”
- “Most people realize that mental health is an extremely important, valid part of health in general – and we all have various kinds of health issues. People who get support for their mental health are seen as strong, smart and proactive.”

If they ask you not to tell anyone, validate their concerns regarding privacy. Respect this boundary and provide resources they can pursue. If you are worried that they are at imminent risk (i.e., about to kill themselves), you can let them know that you cannot keep this private and will call for help.

What if they refuse?

Not everyone is ready right away. If someone you know is struggling refuses your suggestion of professional help (and if they aren’t in immediate danger, i.e., that they are not presently self-

harming or about to), be patient and don't push too hard. Respect their right to privacy and dignity.

- “It’s okay that it doesn’t sound like you’re ready yet. I really hope you’ll think about it. Just let me know if you change your mind, and I can help you connect with someone.”
- “I know you’re going through a lot, and I really believe it can make a big difference for your life, and your health. Just consider it for later and know I’m here to help.”
- “If you’re not ready to go in and meet with someone in person, you could call [Talk Suicide Canada](#) at [1-833-456-4566](tel:1-833-456-4566), or if you don’t feel like speaking, text the [Crisis Text Line](#) at 45645. They can tell you more about what it might be like to work with a doctor, counselor or therapist.”

When the conversation is winding down...

End the conversation by validating their current experience, expressing appreciation for their vulnerability with you, and ensuring them that you are still there to provide support, while encouraging them to seek professional help as needed.

*** If they’re in immediate danger**

- Stay with them
- Call 911
- Call for help if lethal means (i.e., a firearm) are present
- Call [Talk Suicide Canada: 1-833-456-4566](#)
- Text 45645 to text with a trained crisis counselor from the Talk Suicide Canada for free

2: SELF CARE AND COMPASSIONATE COMMUNICATION

Compiled by Karen K. Ross, PhD, DMRF (USA) Board Member

How to say no with empathy and kindness:

1. I am sorry I cannot do this for you.
2. No, I am sorry.
3. No, that won't be possible.
4. I understand that you are having a difficult time.
5. What you are asking of me is beyond my scope of expertise.
6. I would like to help you in this, but I can't. However, I have a list of referrals for you.
7. What do you think would help you at this point?
8. I am not a therapist, but I can refer you to some that I know others have used.
9. Yes, I know you have been to therapists before and I wish I could help you, but it is not my role as a support group leader to be a therapist.
10. I would like us to find some ways to work on this issue together.
11. I am not available for calls in the evening and on weekends.
12. Let's find another time to sit down and talk about this, right now I have other things I need to do.
13. I understand you don't like your doctors, but I am not a professional and I cannot help you in this area.
14. I understand you are feeling depressed, please discuss this in detail with your neurologist.

Setting limits and boundaries:

- ☐ Setting boundaries means knowing what you are responsible for and what you are not.
- ☐ You are not responsible for another person's feelings, mental health, well-being or life.
- ☐ You are responsible for your feelings, your mental health and your well-being.
- ☐ Setting limits and boundaries with members has a big payoff; you continue to build your own self-esteem and feel more empowered. Always take care of your own well-being first.

3: HELPLINES AND PROFESSIONAL SUPPORT SERVICES

Always remember when the focus is on suicide, if someone is already injured or there is immediate danger, contacting emergency services is necessary. Otherwise, there are helplines and professional support services available to help someone thinking about suicide.

National Resources

- Befrienders Worldwide
www.befrienders.org
- Talk Suicide Canada
1.833.456.4566
www.talksuicide.ca
- Crisis Text Line Canada
Text CONNECT to 686868
www.crisistextline.ca
- Emergency Services
911
- Canadian Mental Health Association (CAMH)
Website: www.cmha.ca
E-mail: info@cmha.ca

For a listing of Mental Health Organizations and Support by Province visit
www.dystoniacanada.org/mental-health-resources

Other Resources

Once your member has been connected to a crisis expert, there may be other resources that you can share with them as well. Select from the categories below for suggestions of where to find help to support various concerns.

- **Addictions and Substance Abuse**
Gamblers Anonymous www.gamblersanonymous.org

Substance Use Service Directory
www.canada.ca/en/health-canada/services/substance-use/get-help/get-help-problematic-substance-use.html

- **Culture**

An elder in your community
First Nations and Inuit Hope for Wellness Help Line
1-855-242-3310 www.hopeforwellness.ca

National Indian Residential School Crisis Line 1-866-925-4419

- **Family Information Line**

North America: 1-800-866-4546;
International: 00-800-771-17722 (24/7)

- **LGBTIQ + Community**

Trans Lifeline 877-330-6366
<https://www.translifeline.org>

- **Finances**

Credit Counselling Information
www.canada.ca/en/financial-consumer-agency/services/debt/debt-help.html

Credit Counselling Canada
1-866-398-5999 www.creditcounsellingcanada.ca

- **Military & Veterans**

Military chaplain
VAC Assistance Service (For veterans, former RCMP members, and family members)
1-800-268-7708 (24/7) www.veterans.gc.ca

Canadian Forces Member Assistance Program
1-800-268-7708 (24/7)

Wounded Warriors
1-888-706-4808 <https://woundedwarriors.ca>

- **Mental Health**

Mental health professional (e.g. counselor, psychologist, psychiatrist)
Family doctor
Community mental health service

- **Relationships**

Relationship counselor

F: RESOURCES FOR SUPPORT GROUP MEETINGS

PATIENT CARD



I would appreciate having more information about dystonia and being placed on the mailing list to receive the Dystonia Canada Reports.

Name: _____

Address: _____

City: _____ State: _____ Zip: _____

Phone: _____ E-mail: _____

Referred by (physician's name): _____

Hospital (if any): _____

Form of Dystonia: _____

_____ I would like to find out about a dystonia support group in my area.

_____ I would like to be contacted by the support group in my area.

Comments:

Return completed forms to the National Office:
Dystonia Medical Research Foundation (DMRF) Canada
PO Box 1009 STN Toronto DOM
Toronto, ON M5K 1P2

DMRF CANADA FUNDRAISING GUIDELINES AGREEMENT



Thank you for your interest in raising money for dystonia-specific research. The following guidelines have been developed as a tool to assist you with your project and clarify the assistance that the Foundation staff and volunteers can provide for you.

_____ agree(s) to:
(Name of individual or support group)

1. Comply with and be bound by the policies and standards of DMRF Canada and comply with all applicable Federal and Provincial laws.
2. Work with the staff of the DMRF Canada to create and adhere to an agreed upon event budget and an event plan.
3. Comply with all accounting and fundraising guidelines in the event of any local events/fundraisers, including but not limited to informing DMRF Canada office of their intent, providing names of donors to the National Office so tax receipts can be produced, providing a complete accounting of the event for audit purposes and forwarding the proceeds to the National Office within 30 days from the event or activity.
4. Submit a detailed financial accounting of the event, including bank statements, gross income, net income, expenses, and any in-kind donations.
5. Advertise clearly on all materials related to the fundraiser that all proceeds are raised on behalf of the DMRF Canada and proceeds will be applied to medical research and support programs.
6. On all advertising materials, DMRF Canada contact information and charitable registration number should be clearly identified. Please provide the Foundation with copies of all materials used to advertise the event in advance; and
7. Maintain regular contact with the staff at the Foundation on progress of the event.

I/We understand that:

1. Support groups are not incorporated separately and are volunteer units of the Foundation. Groups may charge dues to cover operating expenses (costs of mailings and incidental expenses), informing the Foundation in advance. Funds raised for

research should be recorded separately and sent to the Foundation. The Foundation will issue receipts to the individual donors for contributions received.

2. Reasonable expenses (depending on the event) are allowable for such items as printing and duplicating, postage, decorations, entertainment, unusual telephone tolls, faxes, and/or e-mails. (In-kind donations by local businesses and/or member underwriting can minimize these expenses).
3. Donations forwarded to the Foundation will be issued tax receipts according to generally accepted policies.

Support Group Name:

Name: _____

Address: _____

Phone: _____

E-mail: _____

I, the undersigned, acting for the individual or group holding the fundraiser, understands that such individual(s) shall conform to all regulations and policies of the Foundation and that the Board of Directors, upon notice, reserve the right to alter the terms of the Agreement and maintains the right to cancel authorization to operate the fundraiser for any reason deemed by the Board of Directors to be sufficient. The parties agree to be bound by this agreement.

Signed: _____

Date: _____

DMRF Canada authorization to operate a fundraiser on behalf of the Foundation:

Signed: _____

Title: _____

Date: _____

Campaign Name: _____

Campaign Date: _____

SUPPORT GROUP MEETING FUND REQUEST FORM



Support Group Event and Activity Form

DMRF Canada encourages events that will allow for a guest speaker and provide an opportunity for patients to meet and interact – in person or virtually.

PLEASE NOTE: All funding for planned events or meetings must be requested and approved by DMRF Canada in advance of the events taking place.

To apply for funding for an event or support group meeting, please fill out the following information. *Please ensure you have allowed sufficient time to properly plan the event and encourage attendance:*

1. Date and time of the Event:

- ## 2. Topic and Format of the Event:

3. Amount you wish to apply for: _____

4. Please provide a breakdown of expenses:

[illegible]

5. How many people are you anticipating will attend this event – either in person or virtually:

6. How are you planning on marketing this event?

7. What additional support do you require from DMRF Canada?

8. What are you hoping to achieve by hosting this event?

After the event, you will be required to report back on attendance, feedback/summary on the special event, new member count, and key takeaways.

Thank you for all you do to support the patient community.

SUPPORT GROUP POSTER TEMPLATE



Join the <City Name> Dystonia Support Group

Received a dystonia diagnosis and don't know what's next?

- **Experienced a change in your situation with dystonia?**
- **Living with dystonia?**

Dystonia Medical Research Foundation Canada **<City Name>** Support Group holds active and informative meetings, which include both community members and guest speakers.

People with dystonia, as well as their loved ones, benefit from being a part of a community through local support groups across Canada. Connect with others who have been impacted by dystonia near you. Join your local dystonia support group today.

For information on joining the <City Name> Area Dystonia Support Group, contact:

Name: XYZ

Phone: 012 345 6789

Email: XYZ@abc.com

www.dystoniacanada.org/cityname



/DMRFC



@dystonia_canada



DMRF Canada

(Support group webpage QR code would be provided)

SAMPLE SPEAKER RELEASE FORM



I hereby authorize and release Dystonia Medical Research Foundation Canada and the _____ [name of support group] to photograph and video/audio record my presentation. I also grant DMRF Canada permission to use, edit, digitize, transmit, and display the video or audio or other presentation materials of my participation as well as to use my name, voice, photograph, likeness, biographic information, and ancillary material in connection with such video or audio.

I understand these images/recordings may be used in awareness, educational, and promotional materials, electronic or in print, produced or endorsed by DMRF Canada.

Name _____

Please Print	First Name	Middle Initial	Last Name
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Phone: _____

E-mail address: _____

Signature:

NOTICE OF FILMING AND PHOTOGRAPHY



NOTICE OF FILMING AND PHOTOGRAPHY

Date:

Dystonia Information Session featuring

Name:

Title:

Organization:

This event/session will be recorded/broadcasted for a broader audience. This is notice that you are participating in an event/session where photography, audio, and video recording will occur.

By participating in the event/session today, whether electronically, by phone or in person, you consent to photography, audio recording, video recording and its/their release, publication, exhibition, or reproduction to be used for news, web casts, promotional purposes, telecasts, inclusion on websites, social media, or any other purpose by DMRF Canada and its affiliates and representatives. Images, photos and/or videos may be used to promote similar DMRF Canada events in the future, highlight the event and exhibit the capabilities of DMRF Canada. You release DMRF Canada, its officers, employees and volunteers, and each and all persons involved from any liability connected with the taking, recording, digitizing, or publication and use of interviews, photographs, computer images, video and/or or sound recordings.

By entering the event/session today, whether electronically, by phone or in person, you waive all rights you may have to any claims for payment or royalties in connection with any use, exhibition, streaming, web casting, televising, or other publication of these materials, regardless of the purpose or sponsoring of such use, exhibiting, broadcasting, web casting, or other publication irrespective of whether a fee for admission or sponsorship is charged. You also waive any right to inspect or approve any photo, video, or audio recording taken by DMRF Canada or the person or entity designated to do so by DMRF Canada.

You have been fully informed of your consent, waiver of liability, and release before participating in the event/session.

MEETING AGENDA (SAMPLE)

Toronto Support Group An Overview of Dystonia

Saturday, January 10, 2023
1:00 PM
Johnson Memorial Medical Center
123 Main Street
Any Town, Toronto, A1A 1A1

12:45	Check In
1:00 PM	Welcoming Remarks and Facilitator Introduction
1:05 PM	Group Announcements DMRF Canada and Dystonia News Personal News
1:15 PM	Participant Introductions New Attendee Introductions
1:20 PM	Introduction of Speaker and Topic
2:00 PM	Question and Answer Session
2:15 PM	Sharing Time Comments about the Program
2:45 PM	Closing Remarks Topic of Next Meeting Next Meeting Date and Time Other Outstanding Items
2:55 PM	Refreshments and Social Time

SIGN-IN SHEET

Date: _____ Time: _____

Program: _____

NAME	ATTENDED BEFORE?	PHONE	E-MAIL

COMMENT CARD/SUGGESTION SHEET

The members of this dystonia support group welcome you. Please feel free to share any comments or suggestions with us. Your thoughts and feedback help this support group grow and better serve the needs of its members.

Areas of Interest (Speakers/Topics, etc.):

Areas of Concern (Issues/Potential Problems, etc.):

General Comments/Suggestions:

Please list the names and contact information for anyone you think may be interested in this support group:

Your relationship with Dystonia (required)

Patient_____ Relative_____ Friend_____ Other _____

Your contact information is (*optional*):

Name:

Address:

Phone:

E-mail:

SUPPORT GROUP MEMBER QUESTIONNAIRE



DMRF Canada Support Group Member Questionnaire

This questionnaire is administered by Support Group Leaders of DMRF Canada to better assess the needs and opinions of its members. All responses are anonymous. Thank you for your time in taking this survey. Your leaders greatly appreciate your feedback!

1. What do you look for in a support group? (You can select more than one)

- ☐ Discussion and sharing
 - ☐ Research updates and new information
 - ☐ Activities
 - ☐ A strong community
 - ☐ Guest speakers
 - ☐ Social activities
 - ☐ People who understand what I'm going through
 - ☐ To better understand my loved one's disorder
 - ☐ Community or fundraising activities and events
 - ☐ Other (please specify)
-

2. Where would you like to have support group meetings? (You can select more than one)

- ☐ Hospital/Medical Center
- ☐ Public Park
- ☐ Restaurant
- ☐ Community Center
- ☐ Library
- ☐ Current meeting venue
- ☐ Someplace else (please specify)

3. How often would you like to have meetings?

- ☐ Twice a year

- ☐ Three times a year
- ☐ Four times a year
- ☐ Every other month
- ☐ Every month
- ☐ Other (please specify)

4. In general, what do you think are the best months to have support group meetings? When are you most likely to be available?

5. What would be the best day to have meetings?

6. When would be the best time to have meetings?

- ☐ Mornings
- ☐ Afternoons
- ☐ Evenings
- ☐ Other (please specify)

7. For you, how important is it to have food/refreshments available at support group meetings?

- ☐ Very important
- ☐ Somewhat important
- ☐ Hardly important
- ☐ Does not matter

8. What topics would you like to explore at future support group meetings?

9. Which guest speakers would you be most interested in having your leader invite to support group meetings? (You can select more than one)

- ☐ Neurologists
- ☐ Physical Therapists
- ☐ Occupational Therapists
- ☐ Alternative Therapists
- ☐ Psychologists
- ☐ ENT Specialists
- ☐ Other (please specify)

10. Would you be interested in remote participation for support group meetings?

- ☐ Yes, I can do video conferencing
- ☐ Yes, I can do telephone conferencing
- ☐ No, I'm not interested
- ☐ Other (please specify)

11. What, if anything, hinders you from regularly attending support group meetings? (You can select more than one)

- ☐ Transportation
- ☐ Access and/or cost of parking
- ☐ Scheduling conflicts
- ☐ Dystonia or other health issues
- ☐ Meeting location
- ☐ Meeting day and/or time
- ☐ Not interested in meeting topics
- ☐ Negative experience at a previous meeting
- ☐ I don't feel the need to go to meetings at this time
- ☐ N/A
- ☐ Other (please specify)

12. What is the best way to inform you about upcoming meetings and events? (You can select more than one)

- ☐ Phone
- ☐ Email
- ☐ Mail
- ☐ Facebook
- ☐ Other (please specify)

13. Additional Comments?

G: DYSTONIA MATERIALS AND RESOURCES

DMRF Canada is here to support you. We have a wide variety of printed materials and online resources at your disposal.

PRINTED MATERIALS

Dystonia Brochures

- Blepharospasm Dystonia Brochure (Cranial or Meige's)
- Cervical dystonia (Spasmodic Torticollis) Brochure
- Deep Brain Stimulation Brochure
- Dystonia of the Hand Brochure
- Focal Hand Dystonia (Writers Cramp)
- Functional (Psychogenic) Dystonia Brochure
- Generalized Dystonia Brochure
- Laryngeal Dystonia (Spasmodic Dysphonia) Brochure
- 'What Is Dystonia?' Brochure

Dystonia Fact Sheets

- Tips for Self-care
- Fact sheets on non-motor symptoms, including topics like dystonia and social anxiety and sleep.

Others

- Going Forward Patient Package
- 'Never Look Down' Picture book to help your child's friends and peers understand dystonia
- 'Real Patients Real Answers' Dystonia Canada Survey Report
- Dystonia Canada Report (Newsletters)
- 40 years Research Report
- What is Dystonia? / Dystonia Support Group Wallet Cards
- 'Do you have Dystonia?' Posters
- 'Going Forward' Posters

Additional brochures and factsheets can be found online.

www.dystoniacanada.org/dystonia-information-materials

ONLINE RESOURCES

DMRF Canada Website:

www.dystoniacanada.org/

Support Groups:

www.dystoniacanada.org/support.

Webpage of Resources for Support Group Leaders (Private Link):

www.dystoniacanada.org/resourcesforleaders

Social Media:

www.dystoniacanada.org/social-media

Dystonia Information Materials:

www.dystoniacanada.org/dystonia-information-materials

Dystonia Information Sessions:

www.dystoniacanada.org/dystonia-information-sessions

YouTube:

www.youtube.com/@dystonia_canada

Online Support Forums:

The internet can be a valuable resource for persons with dystonia and there are many forums and websites that are available 24/7; however, the DMRF Canada advises that all medical advice or recommendations are thoroughly discussed with your medical health care team before you proceed.

DMRF Canada website features numerous online support forums. To see the list, please visit:

www.dystoniacanada.org/online-support

Patient and Family Run Online Dystonia Groups:

Find online support for parents of children and teens who have dystonia, as well as the children and teens who are affected by the disorder. Please visit:

www.dystoniacanada.org/resources-for-teens

www.dystoniacanada.org/support-for-caregivers

DYSTONIA TREATER LISTS AND GUIDES

Treater Lists:

You can visit this link to find dystonia treaters by location – www.dystoniacanada.org/support

Federal Resource Guide:

Federal financial support - www.dystoniacanada.org/financialsupport/federal.

Information On Assistive Devices:

Assistive technology for dystonia – www.dystoniacanada.org/assistivetechology.

Neurotoxin Injectors Lists:

Ontario List – www.dystoniacanada.org/neurotoxin-injectors-ontario

Quebec List - www.dystoniacanada.org/neurotoxine-injecteurs-quebec

If you require printed versions of these lists, please contact the National Office.

H: APPENDICES

APPENDIX 1: SUPPORT GROUP GUIDELINES: ROLES AND EXPECTATIONS

DMRF Canada Support Advisory Group, August 2024. Revised August 2026.

Scope: These guidelines apply specifically to DMRF Canada support group meetings. Speaker education sessions are governed by separate guidelines and may have different requirements regarding recording, sharing, and distribution of content.

Participants:

- Respect: The behaviour and responses of all in the meeting is one of respect and empathy. This includes recognition and respectful response to individual social, emotional, physical, spiritual and intellectual boundaries.
- Time: Attending on time and ensuring that they are capable and available physically and emotionally to participate. All participants will have an opportunity to share their experiences in a timely manner. Monopolizing the conversation for any reason will be redirected (this includes promotion of products or services).

If a participant does not want to participate and share, they can pass on their turn without judgment. However, it is important for all in the group to be introduced to each other.

- Confidentiality: This meeting is a private, supportive space for people living with dystonia and their caregivers to connect, share experiences, and access relevant information.

Anyone outside this group must disclose their affiliation and purpose for attending to the support group leader before the meeting.

Everything shared in the support group meeting is confidential. This means that it stays within the group. The exception is in the case of abuse, crime or physical harm. This will be reported to the appropriate authority.

- Identity Verification: To help protect the privacy and safety of everyone attending, all participants are required to identify themselves when joining the meeting. Individuals who cannot be identified may not be admitted or may be removed from the meeting.
- No Recording or Capture of Content:
 - Recording or capturing any part of the meeting, including but not limited to audio, video, screen recordings, screenshots, photography, live streaming, is strictly prohibited.
 - The use of AI tools to record, transcribe, summarize or analyze the meeting is not permitted.

Meeting content cannot be shared, distributed, published, or posted to third parties or on any platform, including but not limited to social media, websites, messaging platforms, or other public or private channels. Participants who do not comply with these requirements may be removed from the meeting and may be prohibited from attending future DMRF Canada events.

The Group Leader Role:

As well as adherence to the guidelines mentioned above, the group leader will:

Welcome the participants, share any news or updates, provide time for introductions as well as the opportunity for

each participant to share or pass. Leaders facilitate and keep the meeting moving along and on time. They end the meeting on a positive note and follow up on anything that may have come out of the meeting.

By entering the meeting, you acknowledge that you have read and accepted the terms above.

APPENDIX 2: SUPPORT GROUP MEETING PROCEDURES FOR LEADERS

Before the Meeting – Registration

Require all participants to register in advance for virtual meetings. For in-person meetings, leaders must maintain a sign-in sheet for all attendees.

The following information must be collected through the online registration or sign-in sheet:

- a. Full name
 - b. City/Province
 - c. Email
 - d. Phone (for in-person meetings)
 - e. Connection to dystonia: Living with dystonia / Supporter / Other
 - f. Purpose for attending: Personal support / Supporting someone / Other
 - g. If Other, please specify
 - h. Agree to meeting rules: Yes / No
 - i. Signature/ Initials (for in-person meetings)
2. For virtual meetings, enable the 'Waiting Room'.
 3. Disable participant recording permissions.
 4. Restrict screen sharing to the Host and designated presenter(s).
 5. At the beginning of each meeting, make available to participants the *Support Group Guidelines: Roles and Expectations*. For in-person meetings, print and display the guidelines at the meeting venue. For virtual meetings, share them on screen as a reminder at every meeting.

At the Start of the Meeting - Participant Identity Verification

- Verify the identity of all participants before beginning the meeting.
 - For virtual meetings, admit participants from the Waiting Room individually, as appropriate, and confirm their identity against the registration information.
 - Begin the meeting only after participants have been verified.
- If a participant cannot or will not identify themselves, deny entry or remove them from the meeting to protect the privacy and confidentiality of all participants.

During the Meeting - Responding to a Potential Privacy Breach

If you believe a participant is recording, using AI transcription, taking screenshots, or otherwise capturing meeting content without permission:

1. Remind the participant that recording, AI transcription, and other unauthorized capture of meeting content are prohibited, and ask them to stop immediately.
2. If the participant refuses or continues, remove them from the meeting.

Report the incident to DMRF Canada staff as soon as possible. Include the participant's details, if known, the date of the meeting, and a brief factual description of what occurred.



DYSTONIA MEDICAL RESEARCH FOUNDATION CANADA

PO BOX 1009 STN TORONTO DOM
TORONTO, ON M5K 1P2

PHONE: (416) 488-6974
TOLL FREE: (800) 361-8061
E-MAIL: INFO@DYSTONIANCANADA.ORG

WWW.DYSTONIANCANADA.ORG

AUGUST 2026

Adapted from DMRF (USA) Support Group Manual 2018.

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