

Caring for Someone with Dystonia

The participation and support of family members and friends is critical for the successful care of people living with dystonia. However, supporting someone with a disorder like dystonia can take a toll on the main caregiver too, and family members as well.

A caregiver's duties can include:

- Providing support and encouragement;
- Providing prescribed medications and pain relief;
- Helping manage symptoms and side effects;
- Coordinating medical appointments and treatments;
- Assisting with meals and personal needs;
- Helping with household chores;
- Handling medical paperwork, including insurance;
- And more.

Despite the challenges, caring for someone suffering from dystonia is a very fulfilling role benefitting you and your loved ones in many ways. Caring for your loved one with dystonia can greatly improve their quality of life, demonstrate how committed you are to providing as much help and support as you can, and provide an opportunity for you to develop a stronger, closer relationship.

Going beyond duties

- Remain open to a patient's feelings and opinions;
- Accept a patient's limitations;
- Include a patient in activities they enjoy and look for ways to encourage involvement;
- Learn how to provide proper physical care;
- Make time to chat about your own needs and what would work best for both of you;
- Celebrate achievements in discovering and putting in place what works for all;
- Connect with other caregivers affected by dystonia in your community.

Taking care of yourself

Remember that as a caregiver, your health and well-being are as important as those of your loved one. DMRF Canada support groups are open to caregivers too. If you are caring for a family member or friend with dystonia, take care of yourself as well. Get help from family, friends and professionals. If you are in a family setting, divide up chores and schedules in ways that spread the load, don't overburden, and provide a sense of teamwork. Contact DMRF Canada at info@dystoniacanada.org for information on local support groups or to find out about the resources that are available for caregivers.

We provide educational workshops, conferences, seminars, activities, printed resources and supportive services. You can find a list of recommended printed resources/books on our website and special articles available online at: www.dystoniacanada.org/support.

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Some Golden Rules of Caregiving:

1. **Identify yourself as a caregiver.** A caregiver is anyone who provides unpaid care for someone who is ill, frail or disabled. People caring for a family member do not always define themselves as caregivers. But the fact is you are also a caregiver!
2. **Know your right to benefits.** The person you care for may be entitled to a number of different benefits (please refer to the following sections for details on tax benefits).
3. **If you feel you need help, ask.** Caring can be hard work, stressful and isolating, so many caregivers need their own support. This can come from a friend or relative but also from a fellow caregiver, support group or an online connection. Please contact us at info@dystoniacanada.org. We'll see what we can do to provide you with appropriate contacts.
4. **Tell your doctor.** Your personal physician ought to offer caregivers regular health checks and may be more flexible on appointments. They may also refer you to additional support where necessary.
5. **Take breaks.** Caring can be a full-time job. Take a respite break to relax and recharge your batteries. Options such as a few days' residential care for a patient may apply if you are a principal caregiver. Daytime or night-time sitting services, day care centres and support with holidays might be available.
6. **Eat well.** Caring can be time-consuming. You may form a habit of not eating properly or frequently. It is important that you look after yourself, not least because you need your strength and health in order to be available to help.
7. **Get adequate sleep.** Sleep is vital for health. You will quickly start to feel the effects if you are not getting enough. If the sleep pattern of a patient is too disturbed to allow you to get enough sleep, you may need to request night-time help as part of your assessment of needs.
8. **Get a hobby.** It is not possible for anyone to spend 100% of their time 'on the job'. You need other activities to maintain a balanced life. If necessary, you can ask for respite support to enable you to do this.
9. **Engage your patient's participation.** Keep in mind that dystonia patients need to be independent too. Involved them in helping out if and when they can. Give them time, space and routines to accomplish things on their own, at their own pace. This in turn will give you time for yourself.
10. **Always make time for you.**

Please visit www.dystoniacanada.org/caregivers for additional details on the resources available for caregivers.