

mitochondrial disease charter

mitocanada

Canadians living with mitochondrial disease face significant care challenges. Access to the highest standard of care varies widely from person to person, province to province, and between urban and rural areas. The Mitochondrial Disease Charter has been created to empower Canadians with mitochondrial disease and their caregivers and to provide governments with a standard of care so they can ensure that Canadians living with mitochondrial disease enjoy the same level of support wherever they live in Canada.

This Charter acknowledges the role the individual plays in negotiating their complex care journey from diagnosis to treatment. It has been compiled by the MitoCanada Foundation in consultation with patients, families and caregivers. It is based on similar documents created by other chronic disease organizations.

This Mitochondrial Disease Charter is not a legal document; rather it is a set of rights and responsibilities intended to improve knowledge and ultimately the quality of life for the growing numbers of Canadians diagnosed with mitochondrial disease.

WHEREAS the Canada Health Act guarantees Canadians the right to publicly administered; comprehensive; universally accessible high-quality healthcare;

Canadians living with mitochondrial disease have the right to:

- be treated with respect, dignity and without discrimination
- timely diagnosis followed by education and advice from an inter-professional team that may include primary care
- a provider, developmental pediatrician, neurologist, metabolic specialist, genetic counsellor, nurse, pharmacist, physiotherapist, dietitian, neuropsychiatrist, kinesiologist, occupational therapist, and speech and language pathologist
- affordable and timely access to:
 - prescribed medications used to treat symptoms including but not limited to anti-convulsants, muscle relaxants, Botox® and supplements including creatine monohydrate, vitamins C and E, alpha lipoic acid, co-enzyme Q10, riboflavin, thiamine, L-carnitine and L-arginine
 - devices, supplies and services including physical, occupational, respiratory, speech and massage therapy
 - exercise training and,
 - overall high quality care regardless of income or location
- psychological, spiritual and emotional support (psychosocial services) and related information for patients, families and caregivers, including specialized services of psychologists, social workers and system navigators
- appropriate and seamless transitional care that recognizes the progression of the disease and,
- optimum standards of care and best practices across the care continuum including prevention, screening, diagnosis, treatment, support, management and palliative care

Care providers have the right to:

- ongoing training and tools needed to provide high quality mitochondrial disease care.
- work in well-coordinated teams, either at the same location or virtually where support from specialists who provide care can be obtained within a reasonable time.

Canadians living with mitochondrial disease, and their advocates, have the responsibility to:

- self-manage to the best of their abilities and personal circumstances including a healthy diet, exercise, following care plans and attending appointments
- be honest and open with care providers about their current state of health so that the most suitable care plans can be created and,
- actively seek out education, information and support to live well with mitochondrial disease.

Care providers have the responsibility to:

- treat people with mitochondrial disease and their advocates as full partners in their own care
- learn and apply up-to-date evidenced-based clinical practice guidelines when caring for people with mitochondrial disease
- diagnose people living with mitochondrial disease as early as possible and,
- help people with mitochondrial disease and their caregivers navigate the health care system.

Workplaces, schools, pre-schools, and daycares have the responsibility to:

- ensure staff and peers have basic information about mitochondrial disease and protect against discrimination.

Governments have the responsibility to:

- support mitochondrial disease research and innovation, including the timely dissemination of knowledge
- adopt strategies, policies and plans for prevention, diagnosis, and treatment of mitochondrial disease and its complications
- collect data on prevalence, incidence and the burden of mitochondrial disease, including costs and complications, and to regularly measure progress towards improved health outcomes and,
- ensure fair access to mitochondrial disease care, education, treatments, and supplies to all Canadians, no matter what their income or where they live.

The MitoCanada Foundation has the responsibility to:

- advocate for people living with mitochondrial disease
- raise public awareness about mitochondrial disease
- work to make available in the public domain reliable information about mitochondrial disease and,
- partner with others to improve the planning, provision and quality of care.

