

Patient and Caregiver Resources

This compilation of resources has been developed directly by members of the Topic Expert Group.

ME/CFS Patient and Caregiver Resources

Source	Link	Description
Making Sense of your Symptoms to Support Diagnosis and Treatments		
<p>Bateman Horne Centre A centre dedicated to the diagnosis and care of patients with ME/CFS, FM & Long COVID</p>	<p>https://batemanhornecentre.org/education/me-cfs/</p>	<p>Extensive resources including 6 part video series on <i>Getting the Right Diagnosis</i>. Info on PEM, Orthostatic Intolerance, MCAS. ME/CFS Guidebook includes a crash survival guide, health, information and medication sheets, pre-visit forms for patients.</p>
<p>The Management of ME/CFS Two publications from the Institut national d'excellence en santé et en services sociaux (INESSS) an independent organization promoting clinical excellence that reports to Québec's Minister of Health and Social Services</p>	<p>https://www.inesss.qc.ca/fileadmin/doc/INESSS/Rapports/Usage_optimal/2023_EM_Fatigue_chronique_Outil_ANG_VF.pdf</p> <p>https://www.inesss.qc.ca/fileadmin/doc/INESSS/Rapports/Usage_optimal/2023_EM_Fatigue_chronique_Aide_memoire_ANG_VF.pdf</p>	<p>ME/CFS Management Support Tool for primary care physicians, pharmacists and nurses and also very useful to patients and carers. *English and French versions available.</p> <p>Aide-Memoire - Support for People with ME/CFS *English and French versions available.</p>
<p>Centers for Disease Control and Prevention (CDC) ME/CFS homepage Information on possible causes, symptoms, treatments, living</p>	<p>https://www.cdc.gov/me-cfs/resources/patient-toolkit.html</p>	<p>Information to support diagnosis, treatment, and additional educational resources.</p>

<p>with ME/CFS. Information for both patients and healthcare providers.</p>		
<p>#MEAction A U.S. based non-profit organization with international reach that advocates locally for more government funding to support ME patients and provides tools for patients and clinicians.</p>	<p>https://www.meaction.net/learn/what-is-me/</p>	<p>A description of ME including prevalence, symptoms, diagnosis and treatment.</p>
	<p>https://www.meaction.net/resource/pacing-and-management-guide/</p>	<p>Guides and tools for pacing and self-management strategies for diseases where PEM is a feature (for adult, pediatric and clinician). Links to two of the tools provided below.</p>
	<p>https://www.meaction.net/wp-content/uploads/2021/02/Pacing-and-Management-Guide-for-ME_CFS-9.pdf</p>	<p>Pacing and Management guide for ME/CFS</p>
	<p>https://www.meaction.net/wp-content/uploads/2023/02/Pacing-Guide-Clinicians.FINAL2_.pdf</p>	<p>Clinician’s Pacing and Management Guide for ME/CFS and Long COVID. An 8-page referenced guide developed jointly by #ME Action and Patient-Led Research Collaborative</p>
<p>Royal College of Occupational Therapists (UK) Provides information to help manage your energy levels</p>	<p>https://www.rcot.co.uk/conserving-energy</p>	<p>A guide that helps people with fatiguing illnesses find ways to conserve energy and go about daily tasks such as bathing, grooming, dressing, cooking, shopping, laundry and housework.</p>
<p>Stanford University ME/CFS PEM Avoidance Toolkit</p>	<p>https://www.omf.ngo/wp-content/uploads/2018/03/PEM-Avoidance-Toolkit-2018.pdf</p>	<p>Toolkit designed to help patients build crash avoidance plans, monitor triggers, and understand symptoms.</p>

<p>Environmental Health Clinic, Women’s College Hospital, Toronto An Ontario-wide provincial resource/clinic for patients who meet the criteria for ME/CFS, FM or ES/MCS.</p>	<p>https://www.womenscollegethospita.ca/care-programs/environmental-health-clinic/</p>	<p>Assesses patients and supports primary care clinicians in Ontario determining whether their patients meet criteria for ME/CFS, FM or ES/MCS and provides recommendations for management to be carried out by the patient’s primary care provider. Requires a referral from a primary care clinician. Lengthy wait list.</p>
<p>Workwell Foundation Organization focused on the functional aspects of ME/CFS, long COVID, and other fatigue-related illnesses to facilitate an understanding of the biological basis for fatigue and post-exertional malaise (PEM).</p>	<p>https://workwellfoundation.org/resources/#conted</p>	<p>Education materials, podcasts and presentations on PEM, heart rate monitoring, energy saving tips, and disability testing information.</p>
<p>Power Over Pain Portal Women’s College Hospital, Toronto</p>	<p>https://poweroverpain.ca/</p>	<p>A first-in-Canada virtual chronic pain management portal providing information and resources about pain and pain management.</p>
<p>Provincial Health Services Authority Myalgic Encephalomyelitis or Chronic Fatigue Syndrome and Risk of Post Exertional Malaise from Functional Capacity Evaluations</p>	<p>http://www.bcwomens.ca/Specialized-Services-Site/Documents/Complex%20Chronic%20Diseases%20%28CCDP%29/CCDP%20ME%20CFS%20PEM%20and%20FCE%20Jan%202024.pdf</p>	<p>Describes the concern with Functional Capacity Evaluations and PEM.</p>
<p>The Interdisciplinary Canadian Collaborative Myalgic Encephalomyelitis (ICanCME)</p>	<p>https://www.icancme.ca/</p>	<p>ICanCME works to advance the understanding of ME by initiating, supporting and</p>

<p>Research Network A national research network of clinicians, researchers and patient partners funded by the Canadian Institutes of Health Research (CIHR).</p>		<p>sustaining innovative and collaborative research in Canada and internationally. Membership is free.</p>
<p>Disability and Accommodation Resources</p>		
<p>Benefits Wayfinder A simple, easy to use, plain language tool that helps people on low and modest incomes find and track benefits they could get.</p>	<p>https://benefitswayfinder.org/</p>	<p>Information and resources from federal, provincial, and territorial governments, updated on an ongoing basis as new information becomes available.</p> <p>Individuals can use the tool on their own or with the support of an agency staff person.</p>
<p>Unity Health, Toronto Toronto healthcare network comprising three hospitals providing services across the whole spectrum of care.</p> <p>A video from the Outpatient Post-COVID clinic on possible sources of income when sick or disabled.</p>	<p>https://www.youtube.com/watch?v=dQGKRO-J3G4&t=9s</p>	<p>A review of possible sources of income (CPPD, Ontario Works, OPD) and their application processes (for Long Covid patients but much is applicable to ME/CFS).</p>
<p>211 Ontario Ontario helpline for social services, programs and community support.</p>	<p>https://211ontario.ca/</p>	<p>A free confidential service that helps connect Ontarians to potential social and community support. It can be searched using various topics e.g., disabilities.</p>
<p>National ME/FM Action Network Canadian charitable organization dedicated to to ME/CFS and FM through</p>	<p>http://www.mefmaction.com/images/stories/CPP/CPGuide-2020.pdf</p>	<p>Canada Pension Plan Disability – Application and Appeals Guide for Canadians with ME and/or Fibromyalgia, 2020 edition</p>

support, advocacy, education and research		
<p>Workwell Foundation Organization focused on the functional aspects of ME/CFS, long COVID, and other fatigue-related illnesses to facilitate an understanding of the biological basis for fatigue and post-exertional malaise (PEM).</p>	<p>https://workwellfoundation.org/testing-for-disability/</p>	<p>Information on obtaining disability testing for individuals with disabling fatigue who are unable to work.</p>
More Helpful Information – Articles and Publications		
<p>Task Force on Environmental Health (TFEH) The TFEH was an Ontario Ministry of Health and Long-Term Care appointed committee (composed of doctors, researchers and people with lived experience) tasked with providing advice on how to overcome gaps in knowledge, care and attitudes related to ME/CFS, FM and ES/MCS.</p>	<p>https://files.ontario.ca/moh-task-force-on-environmental-health-report-dec-2018-en-2023-03-09.pdf</p>	<p>The Task Force on Environmental Health's final report produced in December 2018 was Care Now: An Action Plan to Improve Care for people with Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS), Fibromyalgia (FM) and Environmental Sensitivities/Multiple Chemical Sensitivity (ES/MCS). The report proposed a system of care for people living with these conditions.</p>
<p>World ME Alliance An alliance of organizations from around the world sharing information on Myalgic Encephalomyelitis (including from Canada, Millions Missing Canada and AQEM - Association québécoise de l'encéphalomyélite myalgique)</p>	<p>https://worldmealliance.org/wp-content/uploads/2023/04/Myalgic-Encephalomyelitis-ME-FactSheet.pdf</p> <p>https://worldmealliance.org/wp-content/uploads/2023/04/</p>	<p>Myalgic Encephalomyelitis (ME) Factsheet – a concise two-page handout available in a number of different languages (including English and French)</p>

	Myalgic-Encephalomyelitis- ME-FactSheet-Francais.pdf	
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