

Resource Guide for people with ALS

This document provides information on various resources available to people with ALS at the community, provincial and federal levels. The available resources are divided into categories according to the type of service or assistance available. A brief introduction to each resource is provided and supplemented by links to the Website of the organization as well as a contact phone number, where relevant.

This document is by no means a comprehensive listing of resources and is meant to act as a preliminary guide for people with ALS, as well as staff and volunteers associated with client services. The list of resources mentioned will be updated regularly and the revised version will be available on our Website under the links section.

Disclaimer:

The materials and Web sites referenced and/or linked from this document are provided for information purposes only. The linked sites are not under ALS Society of Ontario's control, and ALS Society of Ontario does not assume any responsibility or liability for any communication or materials available at such linked sites. Any reference to a commercial or non-commercial product, process, service or company is not an endorsement or recommendation by the ALS Society of Ontario, nor a guarantee of the reliability of the information or product.

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Information on ALS

The website of the *ALS Society of Ontario* includes information about ALS and services provided by the society, publications as well as useful links. Information on ALS clinics in Ontario and services provided by them is also available on the website.

www.alsont.ca

1-866-611-8545

The website of *ALS Canada* includes a section devoted to ALS research. News and updates on research trials is published on the website. Publications on ALS are available for download from the website at no cost.

www.als.ca

1-800-267-4257

The *ALS Association* website contains news on ALS research as well as useful links.

<http://www.alsa.org/>

International Alliance of ALS/MND Associations on the Internet

<http://alsmndalliance.org>

International Organizations, Motor Neuron Disease Association (UK) [http:](http://www.mndassociation.org)

[//www.mndassociation.org](http://www.mndassociation.org)

The website of *ALS Therapy Development Foundation*, a nonprofit biotechnology company, contains references to the latest in ALS research. Apart from the searchable database on ongoing studies, ASLTFDF offers a regular newsletter on research updates which is delivered by email. [http: /](http://www.als.net)

[/www.als.net](http://www.als.net)



Financial and legal support

Canada Pension Plan (CPP) disability benefit is available to people with disabilities if they are below 65 years of age and meet the eligibility criteria which include making regular contributions to the CPP. The CPP disability benefit is made up of two parts: the first is a flat rate amount and the second depends upon the amount and length of CPP contributions made by the applicant. Disability benefits are greater than retirement benefits available under the CPP. While disability benefits are not payable after age 65, the recipient can apply for Old Age Security pension which is payable from age 65.

<http://www.hrsdc.gc.ca/en/gateways/individuals/cluster/category/db.shtml> 1-800-277-9914

The *Ontario Disability Support Program (ODSP)* provides financial assistance and other benefits to eligible people with disabilities. Apart from accommodation and basic living expenses, cost of prescription drugs and dental care may also be covered. Employment support is also available for people with disabilities who want to continue working. Although eligibility criteria, particularly the income criteria, may disqualify some people from income support, it may be possible to apply for extended health benefit under ODSP.

Contact the local ODSP office or the Ministry of Community and Social Services at 1-888-789-4199 for more details or visit their website at:

http://www.cfcs.gov.on.ca/mcss/english/pillars/social/questions/odsp/about_odsp.htm

People with disabilities can avail of *Disability Tax Credit (DTC)* under Canada Revenue Agency regulations. The DTC reduces the amount of income tax that a person with disability, or their supporting person, might otherwise have to pay. In addition, some medical and attendant care expenses can also be claimed in your tax return. For more details, speak to your tax consultant or call 1-800-959-8281 to speak to a volunteer who can assist you. You can also refer to the Canada Revenue Agency website: <http://www.cra-arc.gc.ca/tax/individuals/segments/disabilities/menu-e.html>

Community Legal clinics are available in 79 communities across the province to provide legal advice and representation to clients who have specific problems including employment insurance matters.

<http://www.legalaid.on.ca/en/area.asp>

1-800-668-8258

Through the *Ontario Drug Benefit Program*, the Ministry of Health and Long-Term Care covers most of the cost of prescription drug products listed in the Ontario Drug Benefit (ODB) Formulary. Ontario residents living in a long-term care facility or receiving professional support from the CCAC's are eligible for this benefit. In exceptional circumstances, a request for special coverage of a non-listed drug product not normally covered under the ODB program can be made. This process is known as Section 8 mechanism and at present,



covers Rilutek (Riluzole), the approved drug for ALS. However, this drug must be prescribed by approved specialists before Section 8 approval can be obtained. For more information, check with your Neurologist or contact the program at:
http://www.health.gov.on.ca/english/public/program/drugs/drugs_mn.html 1-866-811-9893

The *Trillium Drug Program* provides assistance to people who have high drug costs in relation to their income. The program covers prescription drug products (included in the ODB formulary) as well as limited nutritional products. Only applicants with valid Ontario Health Insurance (OHIP) can apply for this program. The program has a deductible that is based on income and family size. Each year starting August 1, the applicant must pay their drug costs up to their deductible level before they can start getting assistance for drug coverage. Application kits are available at your local pharmacy store or you can call the Ministry INFOLine at 1-800-268-1154
<http://www.health.gov.on.ca/english/public/pub/drugs/trillium.html>



Assistive Devices

The *Assistive Devices Program (ADP)* under the Ministry of Health and Long-Term Care extends financial assistance to Ontario residents with long-term physical disabilities to obtain assistive devices by paying up to 75% of the cost. This assistance is extended for a wide variety of equipment — relevant categories for people with ALS being mobility aids, communication devices and respiratory equipment. The ADP program is the primary source of funding assistance for most people with ALS for these devices. This program can be accessed through an ADP authorized medical professional.

http://www.health.gov.on.ca/english/public/program/adp/adp_mn.html 1-800-268-1154

Ontario March of Dimes provides limited financial assistance for people with physical disabilities to buy equipment. At some locations, they also provide equipment on a low-cost rental basis for short term or long term use. For their Assistive Devices Program, you can call their toll-free number: 1-866-765-7237. <http://www.dimes.on.ca/programs/access.asp?sect=access>

The March of Dimes also operates the *Home and Vehicle Modification Program* with funding from the Ontario Ministry of Community, Family and Children's Services. Under this program financial assistance may be available towards the cost of home or vehicle modifications for residents of Ontario up to a maximum of \$15,000. Toll-free number: 1-877-369-4867, extn. 222. http://www.dimes.on.ca/programs/access_hvmp.asp?sect=access

The DesignAbility® Program matches volunteers skilled in woodworking, metalworking, plastic molding/shaping, electronics and engineering with consumers, to meet the need for unique designs and customized solutions for people with disabilities. Volunteers help build one-of-a-kind products, or adapt existing devices, to the needs of individuals with physical disabilities. These volunteers work in a group and one-on-one with consumers to develop simple solutions to help make their lives easier. http://www.dimes.on.ca/programs/access_designability.asp?sect=access

The purpose of the *Tetra Society* is to recruit skilled volunteer engineers and technicians to create assistive devices for people with disabilities similar to the DesignAbility program. <http://www.tetrasociety.org> 1-877-688-8762

The *Residential Rehabilitation Assistance Program (RRAP)* offered by the Canadian Mortgage Housing Corporation provides offers financial assistance to Persons with Disabilities to undertake accessibility work to modify dwellings occupied or intended for occupancy by low-income persons with disabilities. Assistance is in the form of a forgivable loan. You can contact the Canada Mortgage and Housing Corporation at 1-800-704-6488 for more details or visit their website at: <http://www.cmhc-schl.gc.ca/en/co/prfinas/>



The *Ventilator Equipment Pool (VEP)* provides home ventilators as well as bi-level support machines (BiPAP) on loan at no cost. Operated by Kingston General Hospital, this facility is funded by the Assistive Devices Program (ADP) of the Ministry of Health and Long Term Care. While their website is still under development, especially useful is the section on application process (under FAQ's), product information as well as downloadable versions of user manuals for equipment. www.vep.ca 1-800-633-8977

The website of *Communication Independence for Neurologically Impaired (CINI)* provides information and links for communication products for people with ALS. Information on software and hardware products is available with links to the manufacturers. Particularly useful is the glossary of terms associated with communication devices. Please note that the contact number mentioned is for their office in Albertson, NY. <http://www.cini.org/> (516) 465-1629

DisabilityResources.org is a meta-site containing information and links to websites serving the disability community. It includes thousands of disability resources on the Internet, annotated and alphabetically arranged by subject for easy access.

World-renown astrophysicist, *Stephen Hawking*, was diagnosed with ALS in 1963. He is a long-time user of augmentative communication devices. You can read about his experience with these devices at the following link. <http://www.hawking.org.uk/disable/dindex.html>

The *Accessibility Directorate of Ontario* was established under the Ontarians with Disabilities Act, 2001 (ODA) to manage the implementation of the ODA and to support and review the progress of organizations with legal obligations under the ODA. These organizations include the Government of Ontario and all of its ministries, municipalities, hospitals, school boards, colleges, universities and public transportation organizations. The website contains useful links to disability resources.

http://www.mcass.gov.on.ca/mcass/english/pillars/accessibilityOntario/what/about_ado.htm

The *Accessibility Directory* was created by the Ontario March of Dimes with funding from the Ontario Government as an online one-stop resource for people with disabilities. The directory can be searched or browsed through a list of categories. <http://www.accessibilitydirectory.ca/> 1-800-263-3463



Home care and community support

Community Care Access Centres (CCAC) act as nodal agencies for providing access to Ontario's long-term care system. These 42 centres across the province assess and arrange for in-home services as well as manage admissions to long-term care facilities in their area. Services coordinated through the CCAC include nursing, physiotherapy, occupational therapy, speech-language therapy, dietician services, social work, personal support and homemaking. These services are available for eligible Ontario residents. For more information, you can contact your local CCAC or the Ministry of Health and Long Term Care INFOLine at 1-877-234-4343 or visit the websites given below. http://www.health.gov.on.ca/english/public/contact/ccac/ccac_mn.html

The Ontario Association of the CCAC's also provides an online searchable tool for locating CCAC offices.

<http://www.oaccac.on.ca/index.php>

This Ministry of Health and Long-Term Care website provides information about *Long-Term Care* facilities in Ontario — types of accommodation available, services provided and costs of long term care in an institutional setting. This website also allows you to search for a long term care facility in your community using the facility locator.

http://www.health.gov.on.ca/english/public/program/ltc/15_facilities.html 1-800-268-1154

The *Direct Funding* program allows adults with disabilities to manage attendant care on their own by giving them a fixed amount of money every month for this service. The recipient will be responsible for managing a budget, hiring and supervising his/her own attendants. Attendant services covered under this program refers to support provided by another person for routine activities of daily living, such as transferring, showering, dressing or undressing up to a maximum of 6 hours a day (182.5 hours/month). Although this program has run out of funding, people with ALS are encouraged to apply in case a vacancy opens up. The program maintains a waiting list for this purpose. This program is administered by the Centre for Independent Living in Toronto, although all Independent Living Centres across Ontario will assist people interested in applying. <http://www.cilt.ca> 1-800-354-9950



Caregiver resources

As of January 4, 2004, new *Compassionate Care* benefits are now available under the Employment Insurance (EI) program. Under this program benefits (up to a maximum of 6 weeks) are payable to caregivers who have to take off from work to provide care and support to a gravely ill family member. Contact the local HRDC office or visit the following website for more details.

http://www.hrsdc.gc.ca/en/ei/types/compassionate_care.shtml

Hospices across Ontario provide a variety of services covering emotional and bereavement support as well as respite care. The *Hospice Association of Ontario* is the provincial association for hospices in Ontario. This website provides a list of hospices across Ontario, information on services provided by them as well as contact details and/or links to their websites. <http://www.hospice.on.ca/> 1-800-349-3111

This website provides useful links, online publications and resources for caregivers. Particularly useful are the resources mentioned under Resource Centre.

<http://www.clickintocaregivers.com/indexcndservice.htm>

The website of Caregiver Network provides links and resources for caregivers.

<http://www.caregiver.on.ca>

