

# **Speech and Swallowing**

Ataxia can affect communication and/or swallowing.

The most common communication difficulty is called *dysarthria* – this means voice quality, clarity, naturalness and intelligibility is altered. Cognitive changes can also impact language processing and communication.

Difficulty swallowing is a common symptom of ataxia as the disease progresses. Swallowing difficulty is called *dysphagia* – this is when the muscles involved in swallowing food and drink are uncoordinated.

Dietitians can give you information about food and nutrition that can help.

## **Community Resources**

### **For Speech Therapy**

**Bonnie Bereskin**, Speech Language Pathologist familiar with neurological conditions and can help with swallowing and voice improvement. Phone: 416 633 2164 Email: <u>bbereskin@hotmail.com</u>

**The Ontario Association of Speech-Language Pathologists & Audiologists (OSLA)** Find a Speech Language Pathologist <u>https://www.osla.on.ca/</u>

### **For Dietician Services**

Telehealth Ontario: 1-866-797-0000. You can talk to a registered Dietitian on the phone.

#### The Four Villages Community Health Centre (Free) www.4villageschc.ca

#### Dieticians of Canada Find a Dietitian www.dietitians.ca

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## **Speech Therapy Resources**

### Apps

#### LSVT Global LOUD

Understand how to improve speech, voice and communication through training/treating healthy vocal loudness. LSVT LOUD uses clinically-proven methods for **improving** communication and movement in individuals with neurological conditions.

#### Loud and Clear Speech

Over a four-week period in 15 to 20-minute sessions, this app aims to help strengthen voice volume.

### Books

<u>LSVT LOUD Homework Helper! DVD by Cynthia M. Fox PhD, CCC-</u> <u>SLP Amazon.ca</u> This DVD takes you through voice and speech exercises based

Vocal practice videos

upon LSVT LOUD speech therapy.

#### SPEAK OUT! Practice Videos (parkinsonvoiceproject.org)

SPEAK OUT! Practice videos guide you through daily exercises with Speech Language Pathologists.

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# Patient Education

Speed Exercises for people wink and other neurological disorders











# **Mental Health**

Living well includes being healthy in mind, body and soul. A health condition can sometimes affect you and your family emotionally and spiritually. Seeking help for emotional and spiritual as well as physical concerns can be an important part of living well and is a coping strategy for patients and their families.

Psychological and emotional states can affect your physical condition. Chronic stress and anxiety have a physical component, which can affect your body's natural healing process.

## **Community Mental Health Resources**

Psychotherapy is provided by psychotherapists, psychologists, social workers, nurses, psychiatrists, general practitioners (GP) and occupational therapists.

Treatment from psychiatrists or GP's is free, it is covered by OHIP. Other mental health professionals such as psychologists, social workers and psychotherapists may be free if they work in hospitals, clinics, agencies, or employees assistance programs. IF they work in a private practice, you will have to pay. Your private health insurance plan may cover some or all of the cost.

**Medical Psychotherapy Association Canada** Find a GP that provides psychotherapy - <u>https://www.mdpac.ca/</u>

**The Center for Addition and Mental Health (camh)** Information on how to access psychotherapy - <u>www.camh.ca/-/media/files/community-resource-</u> <u>sheets/psychotherapy-resources-camh-pdf</u>

Talk to your doctor about mental health concerns. They can refer you to an appropriate mental health professional.

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## **Mental Health Resources**

### Websites

Wellness Together Canada Mental Health & Substance Use Support https://ca.portal.gs/about/

Centre for Addiction and Mental Health (camh) Mental Health 101 <u>www.camh.ca/en/health-info/mental-health-101</u>

## Apps

### іСВТ

iCBT is Internet-based Cognitive Behavioral Therapy. Combining a personalized therapist-guided program with digital tools and exercises.

#### TeleCBT

Canadian online counselling service that specializes in the use CBT. OHIP covered. Register at <u>https://telecbt.ca</u>

#### **Smiling Mind**

This mindfulness app was designed by educators and psychologists to make mindfulness practice easy, light, and enjoyable.

#### ACTCompanion

This app teaches you to use Acceptance and Commitment Therapy skills, like mindfulness, acceptance, and acting on what matters to you most. It also provides guided mindfulness meditation.

### Books

#### Mind Over Mood, Second Edition: Change How You Feel by Changing the Way You Think. By Dennis Greenberger

Simple yet powerful steps to overcome emotional distress and feel happier, calmer, and more confident. Effective forms of psychotherapy with step-by-step plans to help with depression, anxiety, anger, guilt, and shame.

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Abiliti**CBT** 

TeleCBT

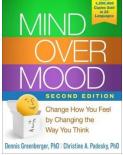
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with Dr Russ Harri





# **Occupational Therapy**

Occupational Therapy (OT) can help you develop or restore the skills you need to live independently and maintain your quality of life in areas like self-care, work, and leisure. Occupational therapists provide support, help you adapt, and can help you find new activities and roles that you enjoy and find value in.

Adaptive devices, such as weighted utensils, weighted pens, dictaphones, walkers or canes, can help you maintain your independence. There are many everyday options that may help depending on your needs - food choppers, travel mugs, and trolleys to name a few. Pay attention to potential safety hazards, make sure you have non-slip rugs or no rugs at all, good lighting, a shower chair, and grab bars can help.

Fatigue can be a problem. Take regular rest breaks, prioritize activities, pace yourself, and maintain a healthy lifestyle.

Regular exercise, physiotherapy, and speech therapy can also help, as well as having organized work and home areas.

## **Community Occupational Therapy Resources:**

#### Local Health Integration Networks (LHIN) (free)

Phone: 310-2222 (no area code needed) Toll-Free: 1 888 470-2222 LHIN provides home and community services support for people of all ages who need care in their home, at school or in the community.

In addition to occupational therapy, LHIN can help with nursing care, physiotherapy, home healthcare supplies, speech language therapy, social work, and healthy eating.

#### **Ontario Society of Occupational Therapists (OSOT)**

Information on how to access private OT services - www.otontario.ca/find-an-ot/

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# Physiotherapy

Physiotherapy at an early stage of the disease can help establish strategies to maintain balance, coordination, and posture.

Exercise is important. Regular exercise, yoga, and pilates can help maintain strength, flexibility and balance. Swimming and hydrotherapy can also help. The social benefits of group activities such as exercise can be very rewarding.

## **Community Physiotherapy Providers**

#### **Ontario Physiotherapy Association**

<u>https://opa.on.ca</u> You can contact them and ask for a physiotherapist who works with patients who have Ataxia.

#### **College of Physiotherapists of Ontario**

<u>https://www.collegept.org/patients/Accessing-Government-FundedPhysiotherapy</u> They can help you find a physiotherapist covered by OHIP.

#### The Local Health Integration Networks (LHIN) (free)

Phone: 310-2222 (no area code needed) Toll-Free: 1 888 470-2222 LHIN provides home and community services support for people of all ages who need care in their home, at school or in the community.

# Search online for "neuro physiotherapy" or "neurorehab" to find a clinic in your area that specializes in neurological disorders.

One Step Ahead Mobility - https://www.onestepaheadmobility.com/ Balance Physiotherapy - https://www.balancephysiotherapy.com/ Propel Physiotherapy - https://www.propelphysiotherapy.com Neurocore Physiotherapy - https://www.neurocorephysiotherapy.com Concept Physiotherapy - https://www.conceptphysio.com

\*If you have private insurance, you might be covered for several sessions. Check with your insurance provider to see if physiotherapy is covered under your plan.

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## **Exercise Resources for Ataxia**

**11 Exercises for Ataxia patients** www.ataxia.org/11-exercises-for-ataxia-patients/

Benefits of physical activity and exercises for Cerebellar Ataxia patients Cerebellar Ataxia Exercises – YouTube

Physiotherapy for patients with Ataxia Coordinative-physiotherapy-for-patients-with-Ataxia.docx.pdf

Therapies for Ataxia

### Apps

#### ParticipACTION

Fitness and exercise app designed to get Canadians moving and to reward them with prizes. Everything in the app is research-based, rooted in behaviour change science. FREE

#### Strava

Track your fitness activity. Record your walk, map a cycling route and set goals for yourself. FREE

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## Support Resources you may find helpful

### Information

National Ataxia Foundation (NAF) Phone: (763) 553-0020 www.ataxia.org Information about symptoms, treatments and causes can be found here: www.ataxia.org/what-is-ataxia/ Follow them on Facebook: www.facebook.com/ataxiafoundation/

#### Ataxia Canada

Phone: 1-(855)-321-8684 www.lacaf.org Information about symptoms and the different types of Ataxia's can be found under the "Ataxias" drop down menu.

#### SCASource

<u>www.scasource.net</u> This is a website dedicated to research on SCAs and related ataxias. Information about types of Ataxias: <u>www.scasource.net/what-is-ataxia/</u> Follow them on twitter: <u>www.twitter.com/SCAsource</u>

## **Support Groups**

#### Hope for Ataxia

www.hopeforataxia.org This is a global support group. To sign up for a meeting: www.hopeforataxia.org/gasg/

#### Living with Ataxia

www.livingwithataxia.org

This is an online supportive place to connect with others. Discussions on symptoms, treatment, strategies and support, and research.

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### Additional resources you may find helpful

#### **Broadway for Ataxia**

www.broadwayforataxia.org Enriching the lives of people with Ataxias through theatrical arts.

#### **BC Brain Wellness Program**

www.bcbrainwellness.ca BC Brain wellness programs are not specific to Ataxia but may be helpful, most have a virtual option.

## Research

#### Coordination of Rare Diseases at Sanford (CoRDS)

https://research.sanfordhealth.org/rare-disease-registry Phone: 1-(605)-312-6300 CoRDS is a registry for rare diseases.

#### ClinicalTrials.gov

www.clinicaltrials.gov ClinicalTrials.gov is an international database of clinical research studies. You can search for studies by disease/condition and location.

\*Learn about clinical studies, what they are, how to participate, and how participants are protected here: <a href="http://www.clinicaltrials.gov/ct2/about-studies/learn">www.clinicaltrials.gov/ct2/about-studies/learn</a>

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# **Patient Education**

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