

# Introduction

The McGill University Health Centre (MUHC) ALS Clinic is found at the Montreal Neurological Hospital (MNH).

*Clinics are held on Mondays only.*

The purpose of the ALS Clinic is to provide you with specialized care that is designed to meet your needs. In order to do this a team will care for you. This team includes you, your close friends and family, and many health care professionals from the hospital. Other specialists will be contacted if needed. Your team will work to:

- Identify your needs and make a care plan for you.
- Involve your family in this plan if it is appropriate for you.
- Manage your symptoms.
- Give you opportunities to join clinical trials.
- Involve other health care professionals from the community.
- Give you care at all stages of your illness.

**Amyotrophic Lateral Sclerosis (ALS)** is also known as Lou Gehrig's Disease or Motor Neuron Disease. It is a progressive neurological disorder. That is, it gets more serious over time. ALS destroys motor neurons. These are cells that send messages from the brain to voluntary muscles. Walking, talking, breathing, swallowing, chewing and moving your arms all use voluntary muscles. In most cases, your senses, your ability to think, eye muscles and the heart, bowel and bladder are not affected. Sexual function is not affected. ALS is not contagious.

About 3000 Canadians currently live with ALS. Most people with ALS are between the ages of 40-60, but ALS can occur in younger and older people as well. The most common form of ALS occurs for no obvious reason. About 5-10% of people may have an inherited form of ALS. There is no known cure for ALS but researchers are working to learn more about this disease. Researchers believe that ALS is caused by many events occurring in the body. With more research, better treatment for ALS will one day be available.

## Your Team

As a patient at the MUHC, a team of dedicated health care professionals will care for you. Each member of the team has a different background and specialty. Your team may include doctors, nurses, a physiotherapist, an occupational therapist, a speech language pathologist, a social worker, a respiratory therapist, a dietitian, a neuropsychologist and a spiritual care counselor. Other specialists may be contacted if needed. Before and after each visit to the clinic, your team will discuss your case and agree on any changes that need to be made to your treatment. Your team is available by phone outside of the clinic hours.



## Administrative Agent

The administrative agent will assist you with scheduling your clinic appointments and tests. She will also help you to make appointments with other consultants that the doctor may want you to see. She will help by coordinating the many different forms and paperwork that may be required. You may, for example, need forms to get certain medication. You may need letters for your employer, your insurance provider or for other health care professionals involved in your care. In between clinic visits, the administrative agent is a resource person available to you and can be reached at (514)-398-5262.

NAME: \_\_\_\_\_ TEL: \_\_\_\_\_

## **Clinical Nurse Specialist (CNS)**

The clinical nurse specialist (CNS) is there to provide care and information to you and your family. She will give you information about treatments, medications and how to manage your symptoms. She will meet with you and your family to talk about concerns or problems. The CNS will work with other team members to give you information about community resources. This will help to make sure that you continue to receive proper care once you return home. Between your visits to the clinic, you may call her by telephone to answer any questions that you have. The CNS will help you and your family throughout your illness.

NAME: \_\_\_\_\_ TEL: \_\_\_\_\_

## **Social Worker**

The social worker will help you and your family cope with your illness. The social worker will see you in the clinic. It is also possible for the social worker to visit you in the hospital if you are admitted. You may have many concerns because of changes in your life such as money troubles, losing your independence, or problems with friends and family. You may also be very worried about the future. She can talk with you and your family to help you make informed decisions. She can give you information about organizations and government agencies, and she will be able to help you with government forms.. The social worker will also help you get ready to leave the hospital. She will continue to help you and your family throughout your illness.

NAME: \_\_\_\_\_ TEL: \_\_\_\_\_

## Respiratory Therapist (RT)

During your visit to the clinic you will meet the respiratory therapist. She will do a test that will measure your ability to take a big breath and exhale quickly. She will also ask questions concerning your breathing. At each visit you will be asked to do a breathing test and with this information the doctor will suggest a different way of improving your breathing. She will help you with:

- coughing techniques
- deep breathing exercises
- any questions regarding your breathing problems
- some teaching about the disadvantages of smoking
- sometimes the use of equipment to help support breathing is also talked about
- her goal is to provide the appropriate care for each and every patient

NAME: \_\_\_\_\_ TEL: \_\_\_\_\_

## Occupational Therapist (OT)

The occupational therapist (OT) will help you to be better able to complete and enjoy your daily activities. The OT will ask you questions about what you do everyday at work, at home and in your leisure. The OT will help you to continue these activities for as long as possible. The OT might help you to:

- Learn about how to save your energy.
- Use assistive devices, splints, and compensatory techniques.
- Get access to special government programs for parking, driving, handicapped transport, or home modification, and wheelchairs.



- Get access to rehabilitation programs.

The OT will contact other therapists that may be involved in your care. The OT is also responsible for helping people who have problems swallowing. The therapist will give you information on techniques to help you eat safely and make suggestions about foods to eat. During your illness, the OT will change the interventions provided to help you have a better quality of life with ALS.

NAME: \_\_\_\_\_ TEL: \_\_\_\_\_

## **Dietitian**

The dietitian plays an important role in your care. You will need to make changes in your eating habits because of ALS. This can make it difficult to maintain good nutrition. The dietitian will check to see if you are eating and drinking enough of the right kinds of foods. She will give you and your family advice to make sure that your nutritional needs are being met. This advice might include:

- Good food and drink choices
- Foods with the right texture (e.g.: solids and liquids)
- Proper food preparation
- Changes in the size of meals
- Changes in the number of meals each day
- Nutritional supplements (eg: Ensure Plus)
- Foods that are easy to eat and swallow
- Ways to save your energy
- Other feeding methods if needed

NAME: \_\_\_\_\_ TEL: \_\_\_\_\_

## Speech-Language Pathologist

The speech-language pathologist will look at how you are speaking throughout the course of the disease. Testing will check the strength, movement and coordination of the muscles that help you to speak.

The speech-language pathologist will give you strategies to help you communicate as well as you can. She may also recommend the use of communication aids such typing devices, computers or voice amplifiers. If necessary, she may refer you to other community resources for more specialized communication aids.



NAME: \_\_\_\_\_ TEL: \_\_\_\_\_

## Neurologist

The neurologist is a doctor who is trained to care for people with diseases of the nervous system. The neurologists in the ALS Program are specialists in treating this disease. They are able to tell the difference between this disease and the many other diseases of the nervous system with similar symptoms. The neurologist will also give you medications, tests and special equipment to help you with your illness.

NAME: \_\_\_\_\_ TEL: \_\_\_\_\_

## Spiritual Care Counselor

The spiritual care counselor will provide emotional and spiritual support to you and your family. For many people, illness can change the way that they see themselves and the world. You may have questions about your beliefs and values. You may be asking important questions about what is happening to you and what your illness will mean to your friends and family. Talking to the spiritual care counselor can help you find inner strength to live with ALS.

NAME: \_\_\_\_\_ TEL: \_\_\_\_\_

## Physiotherapist (PT)

The role of the physiotherapist is to assist you in maintaining your mobility as much as possible. If you notice any difficulties walking, the physiotherapist may recommend mobility aids - like a cane, a walker, or braces – to improve you safety and independence. She may also assess if you would benefit from an exercise program. If appropriate, the goals would be to:



- Maintain or improve flexibility
- Prevent discomfort which can be caused by fatigue or postural problems
- Optimize respiratory status

Along with other team members, the physiotherapist may refer you for community services if needed.

NAME: \_\_\_\_\_ TEL: \_\_\_\_\_

## **Location of the Clinic**

The McGill University Health Centre (MUHC) ALS Clinic is located at the Montreal Neurological Hospital (MNH). Clinics are held on Mondays only. You may call the clinic from 8am to 4pm, Monday to Friday.

**Location:** ALS Program  
Montreal Neurological Hospital  
2nd floor, Room 201  
3801 University Street  
Montreal, Quebec H3A 2B4  
**Tel: (514) 398-5262**

## The Clinic Visit – What to Bring



- Family members are encouraged to come with you to the clinic.
- Please bring all the medications you are taking to the clinic.
- It is a good idea to come prepared with a list of questions for your neurologist. This will help you to remember your questions at the time of the clinic visit.

Questions to ask your doctor include:

- ⊙ *What are the treatments available?*
- ⊙ *What are the benefits and/or the possible side effects?*
- ⊙ *How will the treatments affect my normal activities?*
- ⊙ *Would a clinical trial (research study) be appropriate for me? Can you help me find one?*

## The Clinic Visit

- Your visit at the ALS Clinic may take up to half a day.
- On your first visit, the doctor will do a full assessment and medical history.
- During your visit, other tests (like an Electromyography – EMG or Magnetic Resonance Image – MRI) may be scheduled. These tests are done to give the doctor more information about your condition.
- It is possible that you will meet other team members during your visit, including the physiotherapist or occupational therapist, the clinical nurse specialist, the respiratory therapist, the fellow and/or other team members.

# How Can I get to the ALS Clinic?

## By Car

By Decarie autoroute and from the South shore follow the signs “Montréal – Centre Ville – Autoroute Ville Marie” and exit at University Street. Continue North on University Street. Parking for a fee is available on site. Entrances are located on University Street.

## Parking

Parking near the hospital is limited.  
Limited metered parking is available on University Street.



## By Metro

The nearest metro station is McGill on the green line, which is located at the corner of University Street and de Maisonneuve Boulevard. The McGill metro will allow you to get out on University Street. If you decide to take the metro, there is a 10-15 minute walk up a hill to get to the hospital. If you have difficulty walking, you may want to take a taxi up the hill. You could also get off at the Atwater or Sherbrooke metro stations and take bus #144.



## By Bus



- **From the east**, get off at the Sherbrooke metro and take the #144 which will take you to the corner of Pine Avenue and University Street without having to cross a busy intersection. **From the west**, take the #144 at the Atwater metro.
- #107 at Pine Avenue and Doctor Penfield Street. For the most direct route, contact the STM (Société des Transports de Montréal)
- **Tel:** (514) 288-6287 (A-U-T-O-B-U-S)
- **Web site:** [www.stm.info](http://www.stm.info)

## Handicapped Access



Handicapped entrances are north of the main entrance on University Street, or through the ambulance entrance at the rear of the hospital.

Washrooms that are accessible with a wheelchair are located on the 1<sup>st</sup> floor in room 186 and at the clinic on the 2<sup>nd</sup> floor, where there is a raised toilet.

## **Information about *InfoNEURO***

The Neuro-Patient Resource Centre of the Montreal Neurological Institute and Hospital will help you by providing the following services:

- Books, pamphlets and articles about your condition
- Research on your questions by a medical librarian
- Community resources
- Computers with internet access for your needs

**All our services are free and confidential**

***We invite patients and their families to come and visit us!***

**Location:** Montreal Neurological Hospital (room 354)  
3801 University Street, Montreal, H3A 2B4

**Tel:** (514) 398-5358

**Email:** [infoeuro@muhc.mcgill.ca](mailto:infoeuro@muhc.mcgill.ca)

**<http://www.infoeuro.mcgill.ca>**

## **Resources in the Community**

ALS Society of Quebec: <http://www.sla-quebec.ca>

ALS Society of Canada: <http://www.als.ca>

ALS Association (USA): <http://alsa.org>

### **Disclaimer Information**

Important. Materials provided by the Resource Centre are for educational purposes only, they are not intended to replace the advice or instruction of a professional healthcare practitioner, or to substitute for medical care.



