PASSPORT

Amyotrophic Lateral Sclerosis (ALS)

This is a valuable personal document.
Please respect its confidential nature.
If found, please return to:

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1 Introduction

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

The Amyotrophic Lateral Sclerosis ALS Clinic is a specialized team made up of health care professionals who will provide you with expertise and care through all stages of your illness. The MNH ALS team includes neurologists, an administrative agent, a clinical nurse specialist, a respiratory therapist, a social worker, an occupational therapist, a physiotherapist, a speech language pathologist, spiritual care counselor, a dietician, researchers and an orthotist (see glossary). The 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 health problems
- Help maintain your ability to do daily activities on your own
- Involve other health care professionals from the community

The Passport

This passport will help guide you through your care experience. It can help you manage your appointments and various meetings with the many health care professionals from both the hospital and the community. You can use the passport to record information and keep track of your clinic visits.

Remember to take this passport with you when you go to hospital, to the doctor's office, the CLSC or the emergency room. Show the passport to your care providers; they may be interested in the information it contains.

Don't hesitate to share your concerns, questions, or comments with your health care providers.

Thank you.

2 Acknowledgements

This booklet was created by the ALS Team of the Montreal Neurological Hospital and community partners.

The MUHC Oncology Passport was used as a model for the creation of this booklet.

Funding has been graciously provided by the MUHC Patient Education Grant and the Neuro Patient Resource Centre.

We wish to thank the ALS Society of Quebec for its ongoing collaboration and support.

Always contact your health care professional if you have any questions concerning your care.

Authors:
Elizabeth Robertson and Mia Lanno

Editor:
Eileen Beany Peterson

Collaborators:
Dr. Angela Genge
Ms. Toni Vitale
Ms. Ritsa Argyriou
Ms. Dolores Bertone
Mr. Robert Lambert
Ms. Marie-France Lanoie
Ms. Carmela Maloney
Ms. Lana Kim McGeary
Ms. Doreen Shalla
Ms. Valentine Weber
Ms. Carla Di Gironimo

3 Personal Information

To be completed by you

Name: _____

Address: _____

City: _____ **Postal Code:** _____

Telephone number(s): _____

E-mail address: _____

Emergency contact name/telephone number(s): _____

_____

Important Telephone Numbers

To be completed by you and a member of the health care team

ALS Clinic:_____

24/7 service *(you must be registered with your CLSC)*_____

_____

Your pharmacy name/telephone number:_____

Other:_____

4 ~ CLSC and Community Teams

To be completed by you and the appropriate health care team member

Name of CLSC to which you belong: _____

Address: _____

Telephone number: _____

Fax number: _____

CLSC nurse: (name) _____

Telephone number: _____

CLSC occupational therapist (name): _____

Telephone number: _____

CLSC Social worker (name): _____

Telephone number: _____

CLSC – other health care professional: _____

Telephone number: _____

Home Ventilation Program

Name of therapist: _____

Contact number: _____

Other Health Care Partners

(i.e. Constance Lethbridge Rehab Center, Centre de Readaptation Lucie Bruneau, Interval, Le Bouclier, ALS Society, etc.)

Name/profession: _____

Center: _____

Telephone number: _____

Name/profession: _____

Center: _____

Telephone number: _____

Name/profession: _____

Center: _____

Telephone number: _____

Name/profession: _____

Center: _____

Telephone number: _____

5 ALS Team

Montreal Neurological Hospital

This team is made up of several health care professionals, whose roles are described in our "Information for Patients and their Families" booklet.

The members of the ALS team are available to you during your clinic appointment, depending on your needs.

PROFESSION	NAME	TEL #	E-MAIL
Neurologist **Director, ALS Program**	Dr. Angela Genge	514-398-5262	
Neurologist			
Administrative Agent			
Respiratory Therapist			
Clinical Nurse Specialist			
Nutritionist			
Occupational Therapist			
Physiotherapist			
Social Worker			
Speech Language Pathologist			
Spiritual Care Professional			

6 ~ My Background Health Care Information

To be completed by you and a member of the health care team

Name/profession: _____

Diagnosis: _____

Allergies: _____

_____

_____

Past medical history/other health problems: _____

_____

_____

- ☐ Heart condition: _____
- ☐ High blood pressure: _____
- ☐ Respiratory problem: _____
- ☐ Diabetes: _____
- ☐ Arthritis: _____
- ☐ Cancer: _____
- ☐ Other: _____
- ☐ Surgery: _____

Medication(s):

Please indicate any **natural products, vitamins or other substances** that you consume, even occasionally. Certain substances may react with medications.

DATE	PRODUCT	REASON

7 ~ Additional Information

To be completed by you and a member of your health care team

	DISCUSSED (date)	ACCEPTED (date)	REFUSED (date)	NOTES
Member of ALS Society				
CLSC file				
PAD (programme adaptation à domicile)				
Rehab services : PAT ☐ OT ☐ PT ☐				
Personal response system (i.e. Lifeline)				
Do you drive? Yes ☐ No ☐ Manual ☐ Automatic ☐				
Parking sticker				
Driving evaluation/ adaptation				
Adapted transport				
PEG*				

**see glossary*

Additional information *(cont'd)*

	DISCUSSED (date)	ACCEPTED (date)	REFUSED (date)	NOTES
BiPAP*				
Oxygen				
Home Ventilation				
Communication Aids				
MOBILITY AIDS cane				
walker				
manual wheelchair				
motorized wheelchair				
scooter*				
POSITIONING & ORTHOTICS* Headmaster™ collar*				
resting hand splint*				
foot drop splint*				
ankle-foot orthosis*				

8 ~ Clinic Visits

This is a brief summary of your clinic visit to monitor things like weight changes, pain, stress level etc. This will be completed by a member of the ALS team. More detailed information can be found in the different health care professional sections (p. 15-58).

DATE	WEIGHT	NOTES

Clinic visits *(cont'd)*

DATE	WEIGHT	NOTES

9 Clinic Visits by Health Care Professional

To be completed by the Doctor

DATE	**DOCTOR – COMMENTS**

To be completed by the Doctor

DATE	**DOCTOR – COMMENTS**

To be completed by the Doctor

DATE	**DOCTOR – COMMENTS**

To be completed by the Doctor

DATE	**DOCTOR – COMMENTS**

To be completed by the Doctor

DATE	**DOCTOR – COMMENTS**

To be completed by the Doctor

DATE	**DOCTOR – COMMENTS**

To be completed by the Clinical Nurse Specialist

DATE	**CLINICAL NURSE SPECIALIST** – NOTES

To be completed by the Clinical Nurse Specialist

DATE	**CLINICAL NURSE SPECIALIST** – NOTES

To be completed by the Clinical Nurse Specialist

DATE	**CLINICAL NURSE SPECIALIST** – NOTES

To be completed by the Clinical Nurse Specialist

DATE	**CLINICAL NURSE SPECIALIST** – NOTES

To be completed by the Clinical Nurse Specialist

DATE	**CLINICAL NURSE SPECIALIST** – NOTES

To be completed by the Clinical Nurse Specialist

DATE	**CLINICAL NURSE SPECIALIST** – NOTES

To be completed by the Nutritionist

DATE	**NUTRITIONIST** – NOTES

To be completed by the Nutritionist

DATE	**NUTRITIONIST** – NOTES

To be completed by the Occupational Therapist

DATE	**OCCUPATIONAL THERAPIST** – NOTES

To be completed by the Occupational Therapist

DATE	**OCCUPATIONAL THERAPIST** – NOTES

To be completed by the Occupational Therapist

DATE	**OCCUPATIONAL THERAPIST** – NOTES

To be completed by the Occupational Therapist

DATE	**OCCUPATIONAL THERAPIST** – NOTES

To be completed by the Occupational Therapist

DATE	**OCCUPATIONAL THERAPIST** – NOTES

To be completed by the Occupational Therapist

DATE	**OCCUPATIONAL THERAPIST** – NOTES

To be completed by the Physiotherapist

DATE	**PHYSIOTHERAPIST** – NOTES

To be completed by the Physiotherapist

DATE	**PHYSIOTHERAPIST** – NOTES

To be completed by the Physiotherapist

DATE	**PHYSIOTHERAPIST** – NOTES

To be completed by the Physiotherapist

DATE	**PHYSIOTHERAPIST** – NOTES

To be completed by the Respiratory Therapist

RESPIRATORY THERAPIST – NOTES							
Study: Date Started:				Breath Augmentation* ☐ Date Started: Bipap: ☐ Date Started:			
DATE	WEIGHT	FVC/ FEV_1*	SVC*	SOB/OE*	SAO_2*	IPAP* EPAP*	NOTES

**see glossary*

To be completed by the Respiratory Therapist

DATE	WEIGHT	FVC/ FEV_1*	SVC*	SOB/OE*	SAO_2*	IPAP* EPAP*	NOTES

To be completed by the Respiratory Therapist

DATE	WEIGHT	FVC/ FEV_1*	SVC*	SOB/OE*	SAO_2*	IPAP* EPAP*	NOTES

To be completed by the Respiratory Therapist

DATE	WEIGHT	FVC/ FEV_1*	SVC*	SOB/OE*	SAO_2*	IPAP* EPAP*	NOTES

To be completed by the Respiratory Therapist

DATE	WEIGHT	FVC/ FEV_1*	SVC*	SOB/OE*	SAO_2*	IPAP* EPAP*	NOTES

To be completed by the Respiratory Therapist

DATE	WEIGHT	FVC/ FEV_1*	SVC*	SOB/OE*	SAO_2*	IPAP* EPAP*	NOTES

To be completed by the Social Worker

DATE	**SOCIAL WORKER** – NOTES

To be completed by the Social Worker

DATE	**SOCIAL WORKER** – NOTES

To be completed by the Social Worker

DATE	**SOCIAL WORKER – NOTES**

To be completed by the Social Worker

DATE	**SOCIAL WORKER** – NOTES

To be completed by the Speech Language Pathologist

DATE	**SPEECH LANGUAGE PATHOLOGIST** – NOTES

To be completed by the Speech Language Pathologist

DATE	**SPEECH LANGUAGE PATHOLOGIST** – NOTES

To be completed by the Spiritual Care Professional

DATE	**SPIRITUAL CARE PROFESSIONAL** – NOTES

To be completed by the Spiritual Care Professional

DATE	**SPIRITUAL CARE PROFESSIONAL** – NOTES

To be completed by the Spiritual Care Professional

DATE	**SPIRITUAL CARE PROFESSIONAL** – NOTES

To be completed by the Spiritual Care Professional

DATE	**SPIRITUAL CARE PROFESSIONAL** – NOTES

COMMUNITY PARTNERS

To be completed by your Community Partners who have information to relay to the MNH ALS team (i.e. CLSC or rehab professionals, or the ALS Society)

DATE	ORGANIZATION	NOTES

COMMUNITY PARTNERS *cont'd*

DATE	ORGANIZATION	NOTES

COMMUNITY PARTNERS *cont'd*

DATE	ORGANIZATION	NOTES

COMMUNITY PARTNERS *cont'd*

DATE	ORGANIZATION	NOTES

10 ~ Health Problems

The following is a general list of health problems that may arise. If you have one or more of them, **it is important that you notify your contact person as soon as possible :**

Name : _____

Tel. no. _____

Please do not hesitate to call if you are worried about any other changes in your health, like problems getting worse or new problems arising.

Please note that this is only a guide. Remember that you are the best person to know how you are feeling. Trust your feelings. Do not stay at home and allow problems to worsen and perhaps get serious.

If you have any of the following health problems, but are unable to reach a health care provider, you should go to the emergency room.

HEALTH PROBLEM	REPORT TO YOUR CONTACT PERSON if you have……	GO TO THE HOSPITAL EMERGENCY ROOM if you have……
Pain	• New pain • More intense pain • Usual pain that is not relieved by current medication	Extreme pain
Breathing Changes	• Trouble breathing or you are more often out of breath • Trouble breathing when coughing • Trouble breathing when doing daily activities • Trouble breathing after effort	• Sudden trouble breathing with or without chest pain • Trouble breathing with fever of more than 38.3°C (or 101°F) • Trouble breathing with more mucous and feelings of general
Constipation	• Had no bowel movements for 3 days • Constipation that does not improve with prescribed medication • Stomach ache or cramping • Swollen or bloated stomach • No passing of gas	Had no bowel movements for 3 days and any of the following: • extreme pain, or • nausea and/or vomiting, or • bloated stomach, or • no passing of gas
Falls	Fallen: • Inform the CLSC or call the CLSC emergency number as a home visit may be required	Fallen and have any of the following: • hit your head • had a loss of consciousness • bleeding • severe pain **Call 911 and go to the hospital**

HEALTH PROBLEM	REPORT TO YOUR CONTACT PERSON if you have……	GO TO THE HOSPITAL EMERGENCY ROOM if you have……
Walking	• Changes in your usual way of walking • Changes in your balance	Fallen (please see falls section above)
Fatigue (tiredness)	Changes in your level of energy	Extreme, sudden fatigue (tiredness) with chest pain, heart palpitations (uneven or fast heart beat), or both
Sleep	Been sleeping more or less than usual	
Saliva	• Changes in the amount of saliva and are constantly wiping your mouth • Noticed more coughing when you swallow saliva	
Eating	Noticed: • Changes in your ability to feed yourself, or • Loss of appetite for more than three days, or • Feel too tired to chew food, or • Weight loss	

HEALTH PROBLEM	REPORT TO YOUR CONTACT PERSON if you have……	GO TO THE HOSPITAL EMERGENCY ROOM if you have……
Difficulty swallowing	• Been coughing during or after swallowing liquid or solid • Voice changes after you swallow (a gurgling, wet sounding voice) • Lost your appetite • Lost weight	• A high fever (>38.3°C or 101°F) and a change in your breathing • A choking episode with trouble breathing, **CALL 911**
Speech difficulties	• Changes in your voice when you speak (your voice is softer or sounds rougher) • Changes in the way you speak (voice is slurred, your speech is slower, you are mumbling)	

Once again, this is a guide. You may experience other health problems that are not addressed here. If you are concerned, call your contact person or go to the nearest emergency room.

11 ~ Questions and/or Notes:

Please feel free to use this section to prepare questions in advance for the team or to write down notes during clinic visits. You might want to discuss topics such as pain, fatigue (tiredness), trouble breathing, anxiety, insomnia, cramping, nausea, vomiting, diarrhea, constipation, loss of appetite, coughing and/or choking etc).

Questions and/or notes *(cont'd)*:

Questions and/or notes *(cont'd)*:

12 ~ GLOSSARY

Adapted Transport
This is a specially-designed bus that you may be able to take if you are unable to use the regular bus and metro system. Your Occupational Therapist at either the ALS clinic or the CLSC can give you more information.

AFO – Ankle/Foot Orthosis
This is a device that is used to support your ankle and foot to help you with walking. Your Physiotherapist will give you more information.

Amyotrophic Lateral Sclerosis (ALS)
Is also known as Lou Gehrig's Disease or Motor Neuron Disease. It is a progressive neurological disorder. Your Doctor and Nurse can give you more information.

BiPAP – Bilevel Positive Airway Pressure
This is a machine that helps you breathe more easily. Your Respiratory Therapist and Nurse will give you more information.

Breath Augmentation
This method of breathing may be recommended to you by your Doctor or Respiratory Therapist.

Headmaster Collar
This is a neck brace with a chin support to help hold up your head if your neck is weak. Your Occupational Therapist can give you more information.

Constipation
Constipation means having a bowel movement less than three times per week. Your Doctor and Nurse can give you more information about how to manage constipation.

Cramping
Painful spasms. Your Doctor and Nurse can give you more information.

Diarrhea
Diarrhea means having loose, watery bowel movements three or more times per day. Your Doctor and Nurse can give you more information.

Epap – Expiratory Positive Airway Pressure
This is one of the settings on the bipap machine. Your Respiratory Therapist and Nurse can give your more information.

FVC – Forced Vital Capacity
These are some of the tests we perform to measure your breathing. Your Nurse and Respiratory Therapist can give you more information.

Insomnia
Being unable to sleep or having difficulty staying asleep. Your Doctor and Nurse can give you more information.

Ipap – Inspiratory Positive Airway Pressure
This is one of the settings on the bipap machine. Your Respiratory Therapist and Nurse will give you more information

Orthosis (or Orthoses)
This is a device that is used to give support to your body. An orthosis is often called a splint or brace. Your Physiotherapist and/or Occupational Therapist can give you more information.

Orthotist

A health care professional who provides orthoses to help you function better. He/she might provide a device to help support your neck, or hands, or feet, in order to ease movement and help prevent pain. The orthotist may also provide you with equipment, like a cane or walker to help prevent falls. The orthotist is consulted by your Occupational Therapist or Physiotherapist.

PAD - *Programme adaptation à domicile*

This is a government program that helps pay for changes to your living environment. Your Occupational Therapist and Speech Language Pathologist can give you more information.

PAT – *Programme d'aide technique*

This is a government program that can lend you equipment and technical aids, like a voice amplifier and provide computer adaptations. Your Occupational Therapist and Speech Language Pathologist can give you more information.

PEG

This is a procedure that places a tube into the stomach. It may be used for feeding if you are having difficulty swallowing. Your Doctor or Nurse can give you more information.

Personal Response System

This is a device that is worn, either as a bracelet or a necklace, that lets you call for help any time of the day or night. Your Occupational Therapist or Social Worker can give your more information.

PNAVD – National Program for Home Ventilatory Assistance

This is a program offering care and equipment for those using breathing equipment (such as BiPAP). Your Nurse and Respiratory Therapist can give you more information.

Four-Wheeled Walker (*Déambulateur*)

This is a folding walking aid that has 4 wheels, handles that adjust with brakes, a seat and a back rest. Your Physiotherapist can give you more information.

SaO_2

This test measures the amount of oxygen in your blood, by placing a clip on your finger. Your Nurse and Respiratory Therapist can give you more information.

Scooter

A 3- or 4- wheeled motorized vehicle. Your Occupational Therapist can give you more information.

Splint

A device made out of plastic or foam. A footdrop splint is a plastic device with a sheepskin insert that is worn on your lower leg while in bed to keep your ankle in a comfortable position. A resting hand splint can either be made of foam or plastic, is custom-moulded, and it supports your hand and wrist. Its purpose again is to maintain your comfort. Your Occupational Therapist can give you more information.

SVC – Slow Vital Capacity

A test performed to measure your breathing. Your Respiratory Therapist can give you more information.

Vomiting

Throwing up

Rollator Walker (R/W)

This is a walking aid that folds. It comes with two front wheels and "skis" or gliders in the back. It is possible to add accessories like a basket, etc. Your Physiotherapist can give you more information.

13 ~ Patient Satisfaction Questionnaire

Please leave in Patient Satisfaction Questionnaire box at secretary's desk

Please answer the following questions to help us improve the ALS passport.

1. Overall, you found the ALS passport helpful.

   Yes ☐ No ☐

2. The passport has made it easy for me to communicate with the ALS team, the CSLC and other health care professionals in the community

   Yes ☐ No ☐

3. The information is presented in a way that is easy to follow.

   Yes ☐ No ☐

4. It is easy to write in the passport, find the information and read it.

   Yes ☐ No ☐

5. The passport contains enough information

   Yes ☐ No ☐

   If no, what information do you think is missing?

   _____

   _____

   _____

   _____

6. What section was ***most*** helpful? Why?

_____

_____

_____

7. What section was ***least*** helpful? Why not?

_____

_____

_____

8. General comments & suggestions:

_____

_____

_____

_____

_____

_____

Thank-you!