

Living Your Best Life With ALS

A Guide To Help You On The ALS Journey



SOCIETY • SOCIÉTÉ
NB • NS

YOU ARE NOT ALONE

ABOUT THE ALS SOCIETY OF NEW BRUNSWICK AND NOVA SCOTIA

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 www.facebook.com/ALSNBNS

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**Please contact us today to enroll to receive our services or just
talk to someone who will listen and understand.**

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***The ALS Society of New Brunswick and Nova Scotia is able to provide services
free of charge to people living with ALS and their families. This is possible
because of the amazing generosity of our donors, supporters and volunteers.
The ALS Society of New Brunswick and Nova Scotia is a non-profit organization
not funded by any level of government.***

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INTRODUCTION

This guide has been created by the ALS Society of New Brunswick and Nova Scotia as a tool to help New Brunswickers and Nova Scotians living with ALS and their families. The Society is a non-profit organization committed to providing much needed support to people living with ALS and helping to alleviate some of the burdens that comes with an ALS diagnosis.

“I’ve Been Diagnosed with ALS”

You may have ALS, but ALS doesn’t have you. *You are so much more than a disease.*

The ALS Society of New Brunswick and Nova Scotia is here for you and your family:

- YOU ARE NOT ALONE!
- We are here to help you and your family navigate through a confusing and difficult disease with dignity and purpose.
- We will help you manage your health and live your best life in the face of your ALS diagnosis.
- We have the information and resources you need to get the most from your life.



“And so I began living my new life. Looking back, there are three words that summarize my new journey. The first is ACCEPTANCE. I knew that how I handled this was important to pave the way for this new road ahead. I made up a motto for myself and shared it with others, what I have, what I am and what I want. I have faith and hope, I am optimistic and I will find joy every day. I had to repeat it to myself several times during each day until I began to believe it myself. I looked for joy- ‘unexpected happiness’ and began to find it in the most unexpected places.”

-Judy Starritt

ABOUT THE ALS SOCIETY OF NEW BRUNSWICK AND NOVA SCOTIA

Mission

ALS Society of New Brunswick and Nova Scotia is the life-affirming ALS advocate established to help patients and their families navigate through a difficult disease with dignity and purpose.

Vision

People living with ALS and their families are able to live their best life possible in the face of an ALS diagnosis.

Values

Advocacy

ALS Society of New Brunswick and Nova Scotia is a strong voice for ALS care, policies, research and personal empowerment. Those living with ALS are people first, patients second.

Knowledge

ALS Society of New Brunswick and Nova Scotia draws upon the competence, skills and knowledge of ALS experts including researchers, healthcare providers, and most importantly, people living with ALS and their families.

Time

To help people and their families living with ALS make every moment matter.

Inclusion

ALS Society of New Brunswick and Nova Scotia encourages people living with ALS and their families to be integrated and connected.

Choice

ALS Society of New Brunswick and Nova Scotia empowers people living with ALS and their families to be powerful and independent decision makers for their own best life.

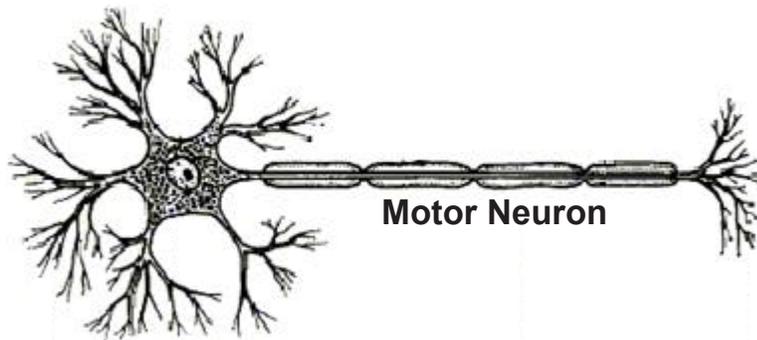
WHAT IS ALS?

ALS is also known as...

- Amyotrophic Lateral Sclerosis (ALS).
- Motor Neuron Disease (MND).
- Lou Gehrig's Disease (after the famous baseball player).

What Is ALS?

- ALS destroys the motor neurons which are an important link in the nervous system. Motor neurons send messages to your voluntary muscles (those muscles you control like your arms, hands, legs) as opposed to involuntary muscles like your heart.
- In 90% of cases, ALS occurs randomly in the general population. This is known as sporadic ALS.
- In 5% to 10% of cases, the disease is inherited. This is known as familial ALS.
- Out of every 100,000 people, 6 to 8 will be diagnosed with ALS.
- ALS does not affect your five senses – sight, hearing, taste, smell, and touch.
- ALS is not contagious.
- Although ALS is most common in people over 40, people can get ALS at any age. The ALS Society of New Brunswick and Nova Scotia have clients from 24 to 91 years of age.



Symptoms and Signs

- Tripping, dropping things, slurred or “thick” speech.
- Muscle cramping, weakened reflexes.
- Difficulty swallowing.
- Shortness of breath at rest.
- Decreased muscle tone.

WHAT IS ALS?

How Long Will I Live with ALS?

- Every case of ALS progresses differently. No one can predict how long you will live, not even your medical team.
- Most people will have a life span of 2 to 5 years. There have been people in Nova Scotia and New Brunswick that have lived more than 10 years.
- The most important tools you have are your family support, your positive spirit, and if you are up to the challenge, your knowledge about the disease and willingness to accept nutritional, breathing, and other types of intervention and assistance with equipment.
- ALS Society of New Brunswick and Nova Scotia is a positive group of caring people that want to help you live your best life as long as you can.



Connie, living with ALS, with her grand-nephews.

WHAT CAUSES ALS?

In ALS, the nerve cells that control the movement of your muscles gradually die, so your muscles progressively weaken and begin to waste away. ALS is recognized as having multiple interacting causes.

Researchers are studying several possible causes of ALS, including:

- Gene mutation. Various genetic mutations can lead to inherited ALS, which appears nearly identical to the non-inherited form.
- Chemical imbalance. People with ALS generally have higher than normal levels of glutamate, a chemical messenger in the brain, around the nerve cells in their spinal fluid. Too much glutamate is known to be toxic to some nerve cells.
- Disorganized immune response. Sometimes a person's immune system begins attacking some of his or her body's own normal cells, which may lead to the death of nerve cells.
- Protein mishandling. Mishandled proteins within the nerve cells may lead to a gradual accumulation of abnormal forms of these proteins in the cells, eventually causing the nerve cells to die.

Source: MayoClinic.org



Dr. Victor Rafuse, PhD
Director of Brain Repair Centre & ALS Researcher
Department of Medical Neuroscience, Dalhousie University
ALS Society of New Brunswick & Nova Scotia Board Member

RESEARCH IN THE MARITIMES

Dr. Victor Rafuse - Dalhousie

Light activated therapy in regenerating the motor neuron – hopes to collaborate with UBC researcher working on nano particles. Stem cell based compounds. Motor Neuron survival and function. How can we keep the motor neuron healthy?

Dr. Turgay Akay - Dalhousie, from Columbia

Changes to the spinal cord early on in ALS – hoping to find treatment to slow progression.

Dr. Ying Change - Dalhousie, from Salk Institute

Looking at applying Chinese traditional medicine in an ALS mouse model that have been effective in other neurological diseases.

Dr. Jim Fawcett - Dalhousie, from University of Toronto

Comparing proteins in healthy and ALS motor neurons – looking for a pharma solution. Looking at different genetic forms of ALS, studying the motor neuron mutations and why they lead to ALS, do they share a similar pathway.

Dr. Jong Kim - Dalhousie

Studying air quality and disease which could be paired with research being done in New Brunswick with Dr. Colleen O`Connell studying clusters of ALS in mining towns.

Dr. Pier Morin - University of Moncton

Diagnostic test for ALS.

Dr. Alier Marrerro - University of Moncton

Atlantic Institute. Clusters of ALS. Genetic mutations.

Dr. Colleen O`Connell - Stan Cassidy Centre

Studying clusters of ALS in mining towns. Conducting Pimozide Trial. Use of Cannabis.

TREATMENTS & DRUGS

There is no treatment (yet) that will slow progression of the disease. However, there are treatments, strategies and equipment to make you as comfortable as possible and aid in breathing, mobility, and communication.

Canadian ALS Researchers have a goal of making ALS treatable, not terminal by 2024.

Your multi-disciplinary team at the ALS Clinic will be of great assistance helping you make decisions about interventions and equipment.

ALS Clinic Contact Information:

New Brunswick

The Stan Cassidy Centre for Rehabilitation

Fredericton, New Brunswick

 506-447-4082

Nova Scotia

Capital District Health Authority – Queen Elizabeth II Health Sciences Centre

Halifax, Nova Scotia

 902-473-5565

AFTER THE DIAGNOSIS - COPING WITH ALS

Give It Time and Patience

A diagnosis of a terminal illness like ALS takes time to process both for the person diagnosed and for family and friends. Every person will process the information differently. Patience and space to process the information is required on the part of all family members and friends. Be kind to yourself and allow yourself to experience and go through the process of denial, anger, sadness and grief.

It's perfectly normal to grieve. Just don't unpack your bags and live there. Cry, scream it out, write it down, do what you have to. Then, refocus your energy to living your best life as well as you can, as long as you can. And remember, ALS Society of New Brunswick and Nova Scotia is here to help you. YOU ARE NOT ALONE.

ALS Does Not Define You

ALS is part of your life - but not all of it. You are still the same person you always were. Fight for that person.

Maintain Positivity and Hope

You're a normal human being and you're not going to be able to be positive and hopeful every day. But practicing and focusing on what is still good in your life, choosing a positive thought over a negative one, putting a smile on your face even when you don't feel like it can change your day (and the day of your family and caregivers) around for the better.

The Gift of Sharing

Share your diagnosis as early as you are ready to with family, friends, and children. Don't deny yourself the gift of support and love and don't deny those who love you the gift of caring for you in the ways they are able.

AFTER THE DIAGNOSIS - COPING WITH ALS

Darrell's Story

Darrell Cottam LIVED with ALS. Darrell worked in sales when he was diagnosed with ALS. Once Darrell lost his voice, he was no longer able to work in sales. So what did he do? He returned to a lost love - photography. He spent many days at Nova Scotia's beautiful beaches and parks, giving him a purpose and bringing him peace.



Darrell's beautiful work hangs in the office of ALS Society of New Brunswick and Nova Scotia and can be viewed/ordered at www.easternlight.net. Proceeds support our Equipment Loan Program.



AFTER THE DIAGNOSIS - COPING WITH ALS

Maintain a normal routine. Okay, a ‘new’ normal routine.

If weekly family dinners were at your house, keep hosting them as long as possible. Maybe the menu is less complicated, maybe you ask for help preparing food, maybe you sit back and let others bring the food. Ask for help maintaining as normal a routine as possible. People want to help – you give them a gift by letting them know what help is useful. Remember, you would do the same thing for any family member or friend if the situation were reversed.

A New Perspective

It is an unfortunate fact that you have a shortened life span. That fact must be acknowledged and grieved. However, many people with ALS find that it is helpful not to focus on the timeline, but to embrace each day and each moment. Take time to develop deeper relationships and explore your spiritual awareness.

Be Pro-Active and Knowledgeable

Familiarize yourself about the disease progression, the treatment and equipment available to reduce symptoms and make you more comfortable. Ignoring manageable problems or delaying intervention can make a difficult situation worse for both you and your loved ones caring for you.

Seek Help from Professionals

Seeking help (therapy or counseling) can offer a great deal of comfort and hope. Counseling and therapy sessions can be a safe place for you and/or your family to express fears, to learn how to cope with anxiety, to adapt to huge changes, and to deal with grief. Please refer to our Living the Gift Program under Programs and Services for more information.

Goals

Setting some goals can assist you in making decisions about your medical treatment and how you wish to live your life. Be sure to consult with your Continuing Care Coordinator, Palliative Care, ALS Clinic or family physician about your medical directives.

AFTER THE DIAGNOSIS - COPING WITH ALS

Mike's Story

Mike set a goal of living until his daughters graduated from high school. This helped him make decisions about medical interventions, when to accept assistive equipment and other help. Mike achieved his goal and lived with ALS for 12 years.



Kathleen's Story

Kathleen was diagnosed with ALS in her mid 40's. Kathleen decided to use her life to raise awareness about ALS. Her family, friends, and community rallied around her and helped her build a float which she rode in the Apple Blossom, Halifax Natal Day, Gay Pride and many other community parades over the course of 3 summers. Kathleen is seen here hand painting the float with the assistance of a Hoyer Lift loaned to her by the ALS Society of New Brunswick and Nova Scotia



AFTER THE DIAGNOSIS - COPING WITH ALS

Plan Ahead – The Difficult Decisions

You and your family have a lot of decisions to make and plans to develop. This means you will have hard conversations and face end of life issues. Making these decisions early on allows you to be in control of your life and care. It gives your family members and health care team direction when they understand and know your goals. It reduces stress as your level of care increases. Once the hard decisions and paperwork are out of the way, you can move on with living your best life for as long as you can. And remember this, you can change your mind at any time. Interventions people thought they may not want at the beginning of their journey may change as treatments develop and as you gain strength and confidence about your ability to cope.

Friends, Family, Children and Co-Workers – Breaking the News, Communication, Supporting Each Other

Most people have the potential to have a great support system of family, friends, and co-workers. While they will not experience the physical symptoms of ALS with you; they are sharing the emotional ups and downs, the worries, the fears. Ultimately, you are in control of your care and disease management. The emotional and physical well-being of your support system will play a big part in your own ability to cope. Both are interconnected. Both rely on good communication, emotional support, give and take, shared decision making.

The Value of Connection and Experience

Sometimes people delay joining a support group or meet and talk with someone else with ALS because they don't want to know what is ahead. It can be difficult seeing what is down the road, but it can also be very helpful. For example, some people with ALS may make decisions about future treatment without a full understanding of the implications of the treatment. Some people will say, when it's time for a feeding tube, I don't want to live anymore. And then they meet someone with a feeding tube that is doing very well and still engaged in life. Meeting someone living with ALS can be a great support and help you make the best decision for you. At ALS Society of New Brunswick and Nova Scotia, we have witnessed amazing friendships amongst our ALS families. Remember, it is not only the person with ALS that needs support but spouses, caregivers, and children.

AFTER THE DIAGNOSIS - COPING WITH ALS

The Value of Connection and Experience - Maritime Online Support Group

The Maritime Online Support Group meets every second Tuesday every month. This is a great way to connect with others in New Brunswick and Nova Scotia who are going through the same struggles. This is a great way to gather information and provide and receive support from one another. For more information, please contact your ALS Champion, Terri Cooper.

Let's face it – time is precious.

Be open and direct with your support system in expressing your needs, wishes, fears, and emotions. In return, receive their expressions of the same without judgement.

Just like it takes a village to raise a child; it will take a team of family members, friends, and health care workers to care for you. Encourage your team members to take care of themselves physically and emotionally. Encourage your family to be realistic in the way they can help you and ask them to do things that are in their comfort level.

Use humour to diffuse difficult situations. Laughter really is the best medicine.

An ALS diagnosis can be especially difficult for children of parents living with the disease. What is more difficult for those children however is when they are not kept informed at an age appropriate level. What children imagine is usually worse than the reality.

What is important for children is their daily routine. Being able to keep a routine for them will offer safety and security. Keep them informed of changes in the routine daily. Mom is taking Dad for a check-up today so Grandma will be here when you come from school. Next week, Dad is getting a wheelchair to help him get around. Dad can't use his voice anymore, but he still hears and understands you.

While it is important not to overwhelm children, they can be involved in planning family activities and helping out at an age appropriate level. This helps them understand that family members support one another, that they can cope in difficult situations and be okay.

At some point depending on their age, children will need to know that ALS is progressing, that their loved one is going to die and how that will impact their life. It will be important to assure them that they will always be taken care of; that although you may get sad when they ask these questions, they can still ask them; that for a time you will be sad together but that you will get happy together too.

YOUR HEALTHCARE TEAM

Occupational Therapist (OT)

Occupational Therapists help people who, through disease or injury, must adapt to how they perform everyday tasks – everything from mobility to personal care. Occupational therapists will help you perform your daily functional tasks safely and efficiently. After conducting an assessment and talking to you, occupational therapists will be the members of your health care team that will most often recommend assistive devices and medical equipment.



Physical Therapist (PT)

A Physical Therapist has training in movement and function and can help you when you are experiencing difficulties with things like balance, walking, sitting and standing. Physical Therapists also prescribe equipment and assistive devices. They may also teach you exercises for things like stretching and strategies for energy conservation.

Physiatrist

A Physiatrist is a medical doctor who treats patients with temporary or permanent impairments due to injury or conditions such as ALS. Their training focuses on the nerves, muscles, and bones – parts of the anatomy which affect mobility and physical function.

Respirologist

A doctor who will take care of your respiratory system (breathing).

YOUR HEALTHCARE TEAM

Dietician

A Dietician is an important member of your health care team, helping you with your nutrition needs, advice on food preparation, and food swallowing safety.

Speech Language Pathologist (SLP)

A Speech Language Pathologist will help you with strategies and recommend assistive devices to cope with speaking.

Neurologist

A neurologist is a specialist in disease of the nervous system. Neurologists experience in the diagnosis and care of ALS patients can work with you to rule out other conditions, and provide you with specialized care.

Your ALS Clinic

Regular attendance at your ALS Clinic is invaluable. Your first few visits may seem overwhelming as you will see many different professionals from an occupational therapist to a dietician and more. The value comes from a multi-disciplinary team of specialists that are experienced in working with people with ALS. They can also confer with one another on the day you attend the clinic to adjust your care plan. In order to be seen at ALS Clinic, a definitive ALS diagnosis must be given and you must be referred to the Clinic.



PALLIATIVE CARE

Often, our PALS (people living with ALS) and their families do not wish to access the services of Palliative Care because of the connection of the word with imminent end of life. This is not always the case. Palliative care services are broad in scope and will support your family in the goal of helping you live your best life as long as you can.

Palliative care is an approach to care for people who are living with a life-threatening illness, no matter how old they are. The focus of care is on achieving comfort and ensuring respect for the person with a terminal diagnosis and maximizing quality of life for the patient, family and loved ones.

Palliative care addresses different aspects of end-of-life care by:

- Managing pain and other symptoms.
- Providing social, psychological, cultural, emotional, spiritual and practical support.
- Supporting caregivers.
- Providing support for bereavement.

Many people think that palliative care is only provided in the last weeks and months of life, when curative treatments are no longer available. A palliative approach to care can help people early in their illness. It can start at diagnosis, when treatments are taking place and there may still be many months and years left to live.

Palliative care is not necessarily provided by a team that only becomes involved at the end of your life. It is ideally provided by the people who know patients the most, working together with experts when they are needed.

How do I access services?

Family physicians and frontline care providers, including care coordinators, nurses, pharmacists, social workers, and spiritual care providers, all play a role in providing palliative care.

These providers can access support from a palliative care team who specialize in complex care planning and symptom management. Their support can complement the care that patients receive from their primary care provider and other members of the care team, but is not meant to replace it.

Please see the 'Contact List' at the end of this manual for contact palliative care contact information.

MEDICAL MANAGEMENT

To date, there is no cure for ALS or treatments/drugs that slow progression more than three months. However, the influx of research funding due to the 2014 Ice Bucket Challenge has accelerated research greatly, and it is anticipated that ALS will become a treatable, not fatal, disease in the not-too-distant future.

There are a number of treatment strategies and equipment that will help you conserve energy and live a better quality of life for a longer period of time.

Early adaptation and adoption of intervention and treatment is helpful in the medical management of ALS and will make your days and your family's days a little easier.

The following is only a very brief introduction to the medical management of ALS and is designed to let you know what kind of help is available and to point you in the right direction to obtain more information.

Medication

The drug riluzole (Rilutek) is the only approved medication that, in some people, may slow the disease progression, perhaps by reducing levels of a chemical messenger in the brain (glutamate) that's often present in higher levels in people with ALS. Riluzole may cause side effects such as dizziness, gastrointestinal conditions and liver function changes.

Your doctor may also prescribe medications to provide relief from other symptoms, including: muscle cramps and spasms, spasticity, constipation, fatigue, excessive salivation, excessive phlegm, pain, depression, sleep problems, and uncontrolled outbursts of laughing or crying.

MEDICAL MANAGEMENT

In the last few years, ALS research has accelerated and we are starting to see new drugs and therapies become available for people with ALS. The Society is not in a position to endorse new drugs and treatments. We are not medical professionals. The Society shares information with our PALS and their families asking you to consider the information in consultation with your healthcare team and by reading as much as you can (make sure you consider the reliability of the resource).

It is important to consider that disease progression in every person is different and new treatments that work in some may not work in others. It is important to consider and acknowledge the risk you are taking in seeking new drug treatment waiting approval (in terms of safety and effectiveness) by Health Canada. There are also financial and emotional aspects to seeking new treatment that you will need to think about with your family.

Edaravone

In the last few years, ALS research has accelerated and we are starting to see new drugs and therapies become available for people with ALS. The Society is not in a position to endorse new drugs and treatments. We are not medical professionals. The Society shares information with our PALS and their families asking you to consider the information in consultation with your healthcare team and by reading as much as you can (make sure you consider the reliability of the resource).

It is important to consider that disease progression in every person is different and new treatments that work in some may not work in others. It is important to consider and acknowledge the risk you are taking in seeking new drug treatment waiting approval (in terms of safety and effectiveness) by Health Canada. There are also financial and emotional aspects to seeking new treatment that you will need to think about with your family.

An ALS family in Nova Scotia is the first family in Canada to receive Edaravone, a drug that is not available in our country to date. Edaravone has not yet been approved for the treatment of ALS by Health Canada.

This is the story of the Bishop family and their suggested steps based on their experience in receiving the drug Edaravone. Please note that the ALS Society of New Brunswick and Nova Scotia does not fund medication and cannot financially assist with obtaining this drug. (The ALS Society has not verified this information.)

MEDICAL MANAGEMENT

Edaravone Continued...

1. Prior to receiving the medication and with Edaravone being an IV medication, meet with your healthcare practitioner and institution as to what is required for administration and someone (example the local hospital) will administer the medication once acquired.
2. Contact Dr. Hiide Yoshino, Yoshino Internal Medicine Neurology Clinic, Ichikawa, Japan. His email address is yoshino-iin@silk.ocn.ne.jp. He has done more work with Edaravone than any other neurologist and he was involved in the clinical trials which were used for the approval of treatment of ALS in Japan, South Korea and the USA.
3. Provide your present status: diagnosis report, a 2nd opinion diagnosis if available, most recent lung capacity results and present mobility. He will discuss your results and discuss release of the medication. Other information will be required such as name, date of birth, address, copy of letter diagnosis 'ALS' or 'MND' with signature MD (other medical records are not required), and your current health condition (Can you walk? Can you eat and dress yourself? Drinking? Speaking? Eating?).
4. If Dr Yoshino approves release of the medication, contact Satoshi Obara at obarasatoshi@yahoo.co.jp. Upon receiving a bank transfer from yourself or a family member, he will purchase the medication from Dr. Yoshino, package it, courier it to your home and charge a small fee. Today, the cost is 298600 Japanese yen.

Due to changing of exchange rates, the Canadian dollar amount will keep changing. Always check the price with Mr. Obara as medication pricing or courier services may change. He will supply banking information to use for transferring the funds. Allow a week between Mr. Obara receiving the funds and receiving the medication via courier in Canada. Due to the increasing demand for the medicine, they are limiting the amount they can send on each order to 120 ampoules (12 boxes x 10 ampoules per box).

5. Mr. Obara when couriating the medication, will include a letter from Dr. Yoshino for Canada Customs explaining the contents of the package.

6. As to Health Canada, as long as the following is used, there is no documentation required from Health Canada. The main criteria to keep in mind is a 90 day treatment supply is allowed under the Personal Importation Regulations of Health Canada.

MEDICAL MANAGEMENT

Edaravone Continued...

7. Edaravone is currently not authorized for sale in Canada and as such, it has not been assessed by Health Canada for safety, quality and efficacy and has not been issued market authorization in Canada. It is also not currently listed on Health Canada's Prescription Drug List (PDL) nor identified as a controlled substance under the Controlled Drugs and Substances Act (CDSA).

Non PDL/non-CDSA drugs may be imported into Canada for personal use in accordance with the following conditions:

- Individuals may be permitted to import a single course of treatment or a 90-day supply based on the directions for use, whichever is less, of a non-PDL/non-CDSA drug
- The drug must be shipped/carried in one of the following: Hospital or pharmacy dispensed packaging, original retail packaging or have the original label affixed to it which clearly indicates what the health product is and what it contains

Health Canada works closely with the Canada Border Services Agency (CBSA) to verify that imported health products meet the requirements of the Food and Drugs Act and its Regulations. The CBSA can refer shipments of health products to Health Canada to undergo an admissibility determination in order for Health Canada to make a recommendation for refusal or release to the CBSA. Not all shipments are referred to Health Canada by the CBSA. Product admissibility decisions at the border are based on the available information at the time of import.

Individuals importing Edaravone in person should have documentation to support the personal import which may include a letter from the doctor indicating the personal use of the specific medication for the individual or for someone under their care (accompanying evidence of the importers relationship with the patient should be available). Couriers may also be used to import a personal quantity of Edaravone. These shipments may also be set aside by CBSA for Health Canada to inspect and thus it is important that the products be clear as to their contents, quantity, use instructions and destination so that an admissibility determination can be readily made based on personal import considerations noted above.

Importers must be careful to ensure that any storage, packaging requirements that may be applicable to the safe transport of the drug are followed. The manufacturer should be contacted where these conditions are unknown.

As Edaravone is currently not classified in Canada, it is important prior to importing the drug in future to confirm that its status has not changed and that it has not been added to the PDL or CDSA which have specific regulatory requirements in place.

MEDICAL MANAGEMENT

Breathing

In ALS your breathing muscles and diaphragm weaken and breathing becomes difficult. At some point breathing difficulty will drain your energy that you want to preserve for other things. When this happens, you can choose to introduce some preventative measures. You will experience symptoms such as the inability to cough, difficulty having enough breath to speak long sentences, daytime headache, and overall tiredness. It is time to consider what is known as non-invasive ventilation. Some testing is involved and a bi-pap machine may be recommended. A bi-pap is a portable machine (the size of a shoe box) and comes with a tube and a mask. With a prescription, they are available for loan at no cost to you from the ALS Society of New Brunswick and Nova Scotia.

Speaking and Swallowing (Choking) /Nutritional Support

At some point you may have to consider being fed through a feeding tube. Naturally, most people find this a difficult decision and believe it means that the end is near. At the ALS Society of New Brunswick and Nova Scotia, we have witnessed many people who chose this route in order to meet their goals – i.e. living longer to be with children and other family. You can still be completely mobile with a feeding tube; you can still eat your favourite things if you choose occasionally and under advice from your medical team. The care is very manageable and not as unpleasant as some might imagine. Maintaining your weight with ALS is very important to help increase length of life. As well you may opt to have the feeding tube surgery while you are still able to eat and before your breathing is compromised. Your speech language pathologist and dietician will help you with these problems, recommending therapies, food preparation, assistive communication devices (available for loan with a prescription from the ALS Society of New Brunswick and Nova Scotia).

Being able to communicate with your spouse, family, friends and health care providers is extremely important. Losing the ability to communicate with your voice is challenging and emotionally taxing both for the person with ALS and all those they need to communicate with. Patience is the key word here for everyone. Be open to discuss adaptations for communicating. Don't lose hope. There are a variety of options and technology to help you communicate. It is important to work with a speech language pathologist to discuss a range of strategies.

MEDICAL MANAGEMENT

Choking

Choking is something that everyone with ALS worries about. Please worry no further. It is a myth that you will die by choking. Choking is a manageable symptom that your healthcare team will provide strategies for you to reduce the risk.

Saliva Build Up

When tongue and throat muscles weaken in ALS, you may have difficulty expelling excess saliva and phlegm. This is the time to see a physiotherapist or a respirologist who will help you with strategies for assistive equipment such as a suctioning or cough assist machine. With a prescription, you can loan these devices from the ALS Society of New Brunswick and Nova Scotia.

Mobility

Everyday activities such as getting in and out of bed, walking, and taking a shower may be difficult as ALS progresses. It can be difficult to have medical equipment such as a patient lift, hospital bed, assistive devices in the bathroom, and a wheelchair all of a sudden appear in your home. However, they are important for your comfort, the prevention of falls and injury and will help you live as independently as possible. The decision about when to obtain equipment (available on loan at no cost with a prescription) is one that you should make with your family and occupational therapist. When making the decision to access equipment, you may also wish to consider the physicality involved of your caregiver in lifting you, helping you move, etc.

MEDICAL MANAGEMENT

End of Life – Physician Assisted Death

This is not an easy topic for sure, but one that needs to be discussed with professionals (legal, finance, healthcare team) and your loved ones to ensure that people understand your wishes and why you made the decisions that you did. It helps your family carry out your wishes even when they may be uncomfortable with them.

A good online resource can be found at www.advancecareplanning.ca/home.aspx

You can revisit your decisions a couple of times a year. As you progress with the disease you might change your mind about certain things – getting a feeding tube or ventilation assistance, etc.

Make sure that your loved ones know where you keep your advance care plan and provide your medical team with a copy.

Physician assisted death was legalized in Canada in June 2015.

ALS Society of New Brunswick and Nova Scotia believes that there is a life of quality to be had of varying degrees for most people after an ALS diagnosis. The ALS Society of New Brunswick and Nova Scotia will do everything possible to help someone diagnosed with ALS and their family to achieve quality of life. The Society will continue to advocate for strong palliative and end of life care for people living with ALS.

ALS Society of New Brunswick and Nova Scotia also recognizes that quality of life can only be determined by the person living with ALS. We commit to supporting those choosing physician assisted death with information on the law, the process, and emotional support.

Physicians are asked to contact the office of the Nova Scotia Health Authority Vice President of Medicine at 902-491-5892.

ALS SOCIETY OF NEW BRUNSWICK AND NOVA SCOTIA EQUIPMENT LOANS PROGRAM

Equipment Loans Program

The ALS Society of New Brunswick and Nova Scotia operates an Equipment Loans Program that is designed to help people cope with the daily challenges of decreasing mobility and independence and to help families cope with the financial challenges of ALS. The Society tries to provide equipment that is cost prohibitive for most families. This includes mobility equipment, basic communication devices, respiratory equipment, and bath assist equipment. Equipment will be recommended to you by your occupational or physical therapist. Prior to purchasing any equipment, please talk to your ALS Champion.

Our goal is to keep people living with ALS comfortable, safe, breathing, communicative, and mobile.

This is a recycled equipment loan program. Our equipment serves more than one person and is used several times. It is cleaned and sanitized between uses and maintained by professionals when required. We obtain equipment by purchasing new pieces when funding allows, by assisting with co-payment of insurance deductibles, and in-kind donations.

ALS Champion

- Your ALS Champion will work closely with your health care team to provide various types of assistive and mobility equipment as they are required.
- We loan out equipment regardless of financial situations and there are no rental fees to access the equipment loan program.
- There may be some minor set up and fees to adjust the equipment to fit your personal needs.
- The equipment is delivered to your home free of charge.

ALS SOCIETY OF NEW BRUNSWICK AND NOVA SCOTIA EQUIPMENT LOANS PROGRAM

You need to do two things to access our the Equipment Loans Program

1. Complete a brief enrollment form and submit it to tcooper@alsnbns.ca. The enrollment form can be found on our website alsnbns.ca.
2. Have a member of your healthcare team fax or email a prescription for the piece of equipment you require. Visit our website to download the form at www.alsnbns.ca

Please feel free to contact ALS Champion Terri Cooper tcooper@alsnbns.ca or Dianne Blanchard at dblanchard@alsnbns.ca. They can assist you with your equipment needs and answer questions or concerns you may have.

Smoking Policy

Due to sanitation issues, health and safety, we need to protect our equipment loan program in order to serve our clients currently living with ALS. Our equipment services more than one person and used several times. It is cleaned and sanitized between uses and maintained by professionals when required.

In order to keep our recycled equipment program operational and sustainable, the ALS Society has implemented a new policy regarding smoking. This policy will become effective immediately and effects clients and family members currently smoking within the home.

There will be a \$75.00 non-refundable fee per material item for people currently smoking within the home. The deposit will be required before equipment is delivered to the home.

This fee will be used to cover the cost of a new cover for the equipment, specialized cleaning, and the shorter life span of equipment used in homes where smoking occurs. This decision was made so we can continue do the most good for the most people and expand the life span of our equipment. Thank you for your understanding.

Because the ALS Society of New Brunswick and Nova Scotia is a non-profit and we rely entirely on fundraising and donations, we are unfortunately unable to purchase new equipment for specific clients and may not be able to provide the newest or most expensive equipment. We commit ourselves to providing you with the best we have with the resources and equipment we have available.

ALS SOCIETY OF NEW BRUNSWICK AND NOVA SCOTIA EQUIPMENT LOANS PROGRAM

Other Resources for Equipment

Canadian Red Cross

For more than 50 years the Canadian Red Cross has been offering Health Equipment Loan Programs. The Nova Scotia Region of the Canadian Red Cross includes eight full-time Service Centres located in Amherst, Antigonish, Bridgewater, metro Halifax (Burnside), Kentville, Sydney, Truro and Yarmouth. Through the HELP program the Red Cross provides more than 50,000 pieces of health equipment to Atlantic Canadians every year, ranging from crutches and canes to specialized equipment such as wheelchairs. In Nova Scotia, the Red Cross also provides hospital beds for recovery or palliative care at home for individuals determined to be eligible after an assessment by care coordinators with the provincial Department of Health.

Other programs under the Community Health umbrella continue to flourish. Home Support Services are provided to clients in Nova Scotia and New Brunswick.

Easter Seals – Nova Scotia

Easter Seals Nova Scotia's programs and services are directed to real needs in our communities: to help children, teens, and adults with physical disabilities to become more active, build independence and confidence, and gain access to equipment and information.

Wheelchair Recycling Program

In partnership with the Nova Scotia Department of Community Services, uninsured Nova Scotians aged 64 years or younger who meet the program criteria may obtain a wheelchair based on a medial prescription from a health care professional.

Contact Tamara Purcell, Wheelchair Program Assistant

☎ 902-453-6000, ext. 229

☎ 1-866-554-4527 (toll free)

✉ wheelchairs@easterseals.ns.ca

Visit the website to download an application form www.easterseals.ns.ca

ALS SOCIETY OF NEW BRUNSWICK AND NOVA SCOTIA EQUIPMENT LOANS PROGRAM

Veterans Affairs Benefits

Veterans living with ALS will now be able to obtain the help and support they need and deserve, faster than ever before. These veterans will now be able to receive disability benefits, treatments and home care support services which are greatly needed by veterans and their families affected by ALS. For example, they will now be eligible for adapted wheelchairs, medical resources, housekeeping services and more.

Given the wide variety of benefits and services that may be available, you are encouraged to contact Veterans Affairs Canada.

 1-866-522-2122

 www.veterans.gc.ca/eng/contact

 information@vac-acc.gc.ca

Most of the time, the ALS Society of New Brunswick and Nova Scotia will be able to assist you with the loan of equipment. Other agencies are listed here should there be a wait list or should there be pieces of equipment the ALS Society of New Brunswick and Nova Scotia does not provide. Our Equipment Loans Program is on a first come, first serve basis.

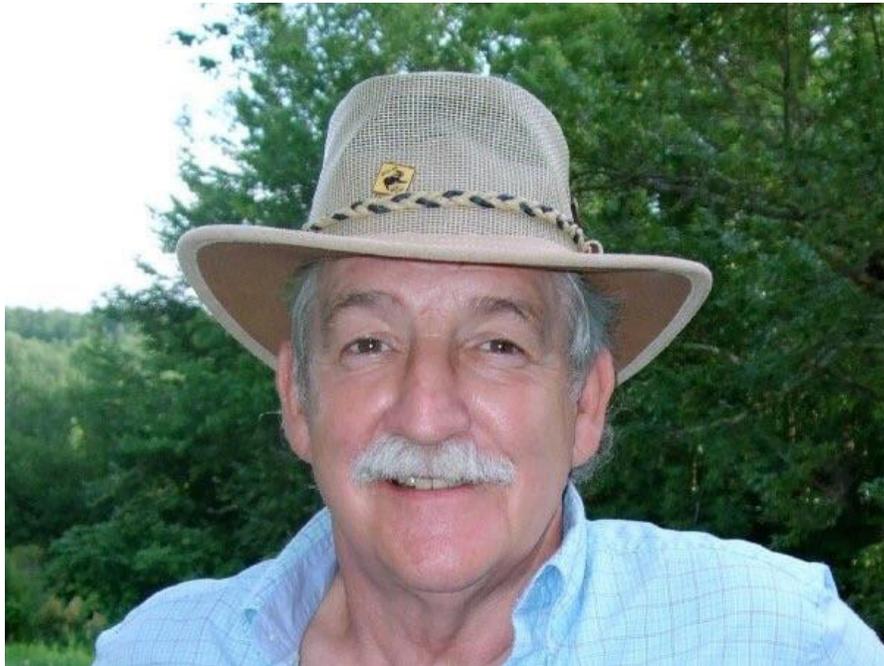
LIVING THE GIFT PSYCHOLOGY SUPPORT PROGRAM

Nova Scotia

The Living the Gift Psychology Support Program is named after the late Charles Bower who lived with ALS and wrote a blog called Living the Gift. Charlie embraced life as it came to him and believed that life was a gift no matter the challenge.

With the help of the Association of Psychologists in Nova Scotia, the ALS Society of New Brunswick and Nova Scotia is pleased to refer people and their families living with ALS to a psychologist for help with coping with a terminal disease and other related issues. The help may be for the person living with ALS, for children or other immediate family members.

Please contact your ALS Champion for further information.



New Brunswick

New Brunswickers living with ALS can access psychological services through the Stan Cassidy Centre. People wishing to access these services must be registered with the Stan Cassidy Centre and have a referral.

For more information please contact the Stan Cassidy Centre at 506-447-4082.

TRAVEL

Traveling offers many exciting opportunities; a chance to meet with family and friends, see new places and experience different cultures. It also requires that you leave your daily routine and comfort zone. If you have difficulty getting around, traveling brings additional challenges. People with ALS should consult with their physician before making travel plans.

As of January 11, 2009 Canadian passenger airlines must provide one complimentary companion ticket for people with disabilities who must be accompanied by an attendant/caregiver. Applicable taxes must be paid. A doctors note is required. Contact your airline or Via Rail for more information.

OTHER RESOURCES

Society of Deaf and Hard of Hearing – Nova Scotia

The Society for the Deaf and Hard of Hearing Society has in the past loaned TTY systems to PALS unable to use their voice and has indicated that they will continue to do so should their client's needs be met.

A TTY system allows the user to place a phone call and then communicate through written text, rather than spoken communication. Systems include a telephone handset that is attached to a keyboard; each key makes a specific tone that can be read by the handset. The handset communicates those tones to a receiver on the other end of the line, and the receiver interprets the tones and generates a line of text.

Obviously, when someone places a call with a TTY system, they need to be certain that the recipient also has one. If the recipient has no TTY receiver, he or she will pick up the phone and hear a series of tones. In a situation where someone with a system needs to call someone without one, or vice versa, a telephone relay service is used. The relay service can read typed messages to callers who can hear, and turn spoken messages into text for deaf and hard of hearing callers.

Sydney

56 Nepean Street 117

Sydney, NS, B1P 6A8

☎ 902-564-0003 (voice/video phone/fax)

✉ cbdeaf@ns.sympatico.ca

Halifax

1657 Barrington Street

Halifax, NS, B3J 2A1

☎ 902-422-7130 (voice/videophone/tty)

☎ 902-564-0486 (TTY)

902-492-3864 (fax)

☎ 1-888-770-8555 (toll free)

☎ 1-800-516-5551 (toll free)

www.sdhns.org

✉ sdhns@ns.sympatico.ca

OTHER RESOURCES

South-East Deaf and Hard of Hearing Services and the Saint John Deaf and Hard of Hearing Service – New Brunswick

South-East Deaf and Hard of Hearing Services, Moncton and the Saint John Deaf and Hard of Hearing Services service most of New Brunswick. They have TTY systems for PALS unable to use their voice.

A TTY system allows the user to place a phone call and then communicate through written text, rather than spoken communication. Systems include a telephone handset that is attached to a keyboard; each key makes a specific tone that can be read by the handset. The handset communicates those tones to a receiver on the other end of the line, and the receiver interprets the tones and generates a line of text.

Obviously, when someone places a call with a TTY system, they need to be certain that the recipient also has one. If the recipient has no TTY receiver, he or she will pick up the phone and hear a series of tones. In a situation where someone with a system needs to call someone without one, or vice versa, a telephone relay service is used. The relay service can read typed messages to callers who can hear, and turn spoken messages into text for deaf and hard of hearing callers.

Short term loans are available while your purchase is on order. There are subsidies available for those who qualify. Please contact your social worker for guidance.

South-East Deaf and Hard of Hearing Services Inc.

1690 West Main Street
Moncton, NB E1E 1G9

✉ seds@nb.aibn.com

☎ 506-859-6101

Saint John Deaf and Hard of Hearing Services

324 Duke Street West
Saint John, NB E2M 1V2

✉ sjdhhs@nb.sympatico.ca

☎ 506-633-0599

OTHER RESOURCES

Meals on Wheels - Saint John

-  506-658-1888
-  mealsonwheels@nb.aibn.com
-  www.mealsonwheelssj.ca

Meals on Wheels - Sussex

-  506-433-5886
-  WeCare@redcross.ca

Meals on Wheels - Fredericton

-  506-458-9482
-  info@frederictonmealsonwheels.ca
-  www.frederictonmealsonwheels.ca

Ability New Brunswick

Ability New Brunswick's mission is to empower the independence and full community participation of persons who have a spinal cord injury or mobility disability by providing innovative services and developing progressive public policy.

-  www.abilitynb.ca
-  506-462-9555 or 1-866-462-9555 (Fredericton)
-  506-858-0311 (Moncton)
-  info@abilitynb.ca

OTHER RESOURCES

Canadian Pension Disability Plan – New Brunswick and Nova Scotia

The Canada Pension Plan (CPP) disability benefit is a monthly payment. It is available to people who contributed recently to the Canada Pension Plan while they worked, and then became unable to work at any job on a regular basis because of a disability. The primary purpose is to replace a portion of employment earnings for people who recently paid into the CPP. There are also benefits for children if at least one parent qualifies for the CPP disability benefit.

A CPP disability benefit is not approved on the basis of which disability or disease you have, but on how the medical condition and its treatment affects your ability to work at any job on a regular basis. Please visit the website for more information and forms.

 www.servicecanada.gc.ca

Caregiver Benefit Program – New Brunswick and Nova Scotia

The Caregiver Benefit Program, formerly known as the Caregiver Allowance, recognizes the important role of caregivers in their efforts to assist loved ones and friends.

The program is targeted at low income care recipients who have a high level of disability or impairment as determined by a home care assessment. If the caregiver and the care recipient both qualify for the program, the caregiver will receive the Caregiver Benefit of \$400 per month.

Please visit the link to review eligibility checklist:

 www.servicecanada.gc.ca

OTHER RESOURCES

Housing Assistance for Persons with Disabilities- New Brunswick

For homeowners in need of disabled accessible modifications assistance is in the form of a forgivable loan up to a maximum of \$10,000. Additional assistance may be available in the form of a repayable loan based on a household's ability to repay.

Landlords are eligible for a forgivable loan for disabled modifications to a maximum of \$10,000.

The maximum forgivable loan for the creation of a secondary/garden suite or an extension to an existing dwelling is \$24,000. The applicant is required to produce equity or provide proof of other sources of financing to cover the cost of creating a secondary/garden suite or an extension which exceed the maximum forgivable loan available. The housing response to an applicant's particular situation is based on the needs of the applicant(s) and the most cost effective solution to address his/her current housing situation.

For more information and New Brunswick regional contact numbers visit:

 www.gnb.ca/services

Disabled Residential Rehabilitation Assistance Program for Homeowners – Nova Scotia

The Residential Rehabilitation Assistance Program (RRAP) for Persons with Disabilities offers financial assistance to homeowners to undertake accessibility work to modify dwellings occupied or intended for occupancy by persons with disabilities. Funding is provided jointly by the Government of Canada (75%) and the Province of Nova Scotia (25%).

 www.housing.novascotia.ca

OTHER RESOURCES

Hyperalimentation Program – New Brunswick

This program assists clients of the Social Services department with coverage for feeding supplies and formulas which are not covered by NB Medicare or private health insurance plans. This program is available to:

- Clients of the department and their dependents
- Individuals who have special health needs and who qualify for assisted health care under Section 4.4 of the Family Income Security Act and Regulations

There is no cost to eligible clients for entitled hyperalimentation supplies. Eligible services are paid monthly, but quantities and frequencies are monitored. Please contact your social worker for more details on this program.

 www.gnb.ca/services

Car Insurance – New Brunswick and Nova Scotia

Because of the ALS diagnosis you may want to speak to your physician and insurance provider to make sure that you still have good hand and foot control to operate a motor vehicle safely.

Taxes – New Brunswick and Nova Scotia

The disability tax credit is a non-refundable credit for eligible individuals. It reduces income tax payable on your income tax return. Eligibility is outlined on form TT2201 which is available on the Revenue Canada website. The application must be completed and signed by your doctor. It is advised that you send your application in prior to tax season to avoid delays. Visit the Revenue Canada website at:

 www.cra-arc.gc.ca/disability

OTHER RESOURCES

Insurance Coverage – New Brunswick and Nova Scotia

For those who have been diagnosed with ALS and continue to work, one of the things to consider is when and what to tell your employer. This is a personal decision depending on you and your employment situation. In light of a diagnosis of ALS, you may wish to consider exploring any extended healthcare benefits you might be eligible for. It is important to consider your current needs in addition to what may be required in the future, as there may be limits to what is provided. Consultation with your healthcare team is recommended while investigating these resources. This can be done before telling your employer you have ALS.

Some questions you should ask yourself before making the decision to leave work are:

- Do you have access to benefits? (short & long term disability, banked sick time, EI benefits and CPP disability benefits.)
- Do you enjoy work and does this change your quality of life if you left to work?
- Are you still able to carry out your work duties safely?
- Do you still have the energy to continue working?

It is recommended that you do not sign any termination papers without consulting Human Resources to see if you are eligible for a severance package. Contact your insurance provider to see what coverage you have available.

Here is a list of questions for your insurance provider:

- Is there an annual deductible?
- Is there a cap on my medical coverage? If so, is it yearly or a maximum amount?
- Does my plan cover prescription drugs and if so are there any drugs that would not be covered? (example: Riluzole).
- Does my insurance cover pre-existing conditions?
- Does my plan cover durable medical equipment? Ask specifically what the coverage is for wheelchairs.
- Is there pre-authorization or quotes required?
- Does my plan cover Home Health Coverage and if so how do I access this service?
- Is there a specific Home Health Supplier I must use and if so, can you provide me with a list of contacts?
- Is there a maximum amount that is covered yearly and if so, what is the limit?
- Does my medical plan cover the cost of feeding tube supplies and formula?

All questions would apply to Group Medical Coverage. However, you will want to contact your provider exact coverage, loss of wages and deductible

OTHER RESOURCES

Parking Permits – New Brunswick

The Province of New Brunswick issues parking placards and permits for persons with disabilities to promote designated parking spaces for persons with disabilities. The intent of this program is to limit eligibility for the parking permit and placard for person(s) having a disability to those situations where the person has a significant degree of mobility impairment or other health problems, such that the person would have difficulty walking unassisted more than 50 metres in outdoor weather conditions. The placard and parking permit may be obtained upon application at Service New Brunswick Centres throughout the Province without charge. Applications must be signed by one of the following; a physician, occupational therapist, nurse practitioner or physiotherapist.

🌐 www.gnb.ca/services or google 'parking permits New Brunswick' and click on the second link for a PDF application form.

New Brunswick Accessible Vehicle Tax Refund

Tangible Personal Property Tax and Provincial Vehicle Tax - the Minister may authorize a credit of tax paid on a specially equipped vehicle (either the 8% component of the Harmonized Sales Tax (HST) if the supply was made by a registrant, or the 13% Provincial Vehicle Tax (PVT) in the case of a private sale).

☎ 1-800-669-7070
☎ 506-444-3000
✉ pcd-cpmph@gnb.ca

The Community Volunteer Income Tax Program (CVITP)

The CVITP is a collaboration between community organizations and the Canada Revenue Agency. These organizations host free tax preparation clinics and arrange for volunteers to prepare income tax and benefit returns for eligible individuals for taxpayers with modest incomes.

☎ 1-800-959-8281
🌐 www.cra-arc.gc.ca/volunteer

OTHER RESOURCES

The ALS Patient Registry/ CNDR Registry - New Brunswick and Nova Scotia

As of June 2011, a new national registry for patients with neuromuscular disease– the Canadian Neuromuscular Disease Registry (CNDR)– will help patients connect with researchers to participate in clinical research that will benefit patients by offering possible new therapies, treatments and understanding of their disease.

“This is a tremendous opportunity for patients, healthcare professionals, and researchers, to connect and improve research into neuromuscular diseases across Canada” says Dr. Lawrence Korngut, the National Principal Investigator from the University of Calgary’s Faculty of Medicine, and a member of the Hotchkiss Brain Institute.

The CNDR is a Canada-wide database of patients who have been diagnosed with a neuromuscular disease. The term “neuromuscular disease” refers to a group of more than 40 diseases that affect how muscles and nerves work. ALS is the most prominent of these diseases in adults, and Duchenne muscular dystrophy (DMD) is the most common pediatric muscular dystrophy.

The Canadian Neuromuscular Disease Registry (CNDR) includes 17 clinics across Canada located in Vancouver, Calgary, Edmonton, Ottawa, Toronto, London, Kingston, Montreal and Halifax.

Why Participate?

The Registry is the only means by which valid national epidemiologic data about ALS can be obtained.

Patients with neuromuscular disease will benefit from this new national registry. Shelagh Mikulak has ALS and joined the registry because it gives her hope that “with the information available to researchers there will be a significant increase in the number of studies leading to discovering the cause, treatment and cure of ALS”.

Finding treatments for neuromuscular diseases has been challenging, as patients are scattered across the country. This registry will allow doctors and researchers to look at medical data from large groups of patients helping them to find better ways to manage each disease.

OTHER RESOURCES

The ALS Patient Registry/ CNDR Registry - New Brunswick and Nova Scotia Continued

All patients, both adults and children, across Canada who have been diagnosed with a neuromuscular disease are able to join the registry. Patients living outside the cities with affiliated clinics, or those not currently seeing a neuromuscular specialist, can register by contacting the CNDR National Office at the University of Calgary. The CNDR is supported by the ALS Society of Canada, Jesse's Journey and the Marigold Foundation.

 1-877-401-4494
 www.cndr.org

Telehealth – New Brunswick

The New Brunswick Telehealth Network (NBTHN) is a video conferencing communications network that connects healthcare focused facilities across New Brunswick. The NBTHN uses video-conferencing technologies to improve access to health services for patients, families and healthcare professionals.

Patients from across New Brunswick can meet face-to-face with health care professionals located anywhere on the network, without leaving their home communities. This saves patients the time, stress and expense associated with travel. Barriers to health care access including travel costs or inclement weather are removed.

Please check the link for a list, by region, of facilities and programs offering this service:

 www.horizonnb.ca

OTHER RESOURCES

Tele-Health - Nova Scotia

The Nova Scotia Tele-health Network (NSTHN) is a video conferencing communications network that connects healthcare focused facilities across Nova Scotia. The NSTHN uses video-conferencing technologies to improve access to health services for patients, families and healthcare professionals.

Patients from across Nova Scotia can meet face-to-face with health care professionals located anywhere on the network, without leaving their home communities. This saves patients the time, stress and expense associated with travel. Barriers to health care access including travel costs or inclement weather are removed.

The Tele-health is available to our ALS clients. If you would like to be seen via tele-health in your community, instead of travelling to Halifax, please contact Melanie Ellerker at the ALS Clinic to make arrangements.

 902-473-1245

ALTERNATIVE HEALTH

Massage Therapy

ALS involves the degeneration of motor neurons but not sensory ones, and the client is fully aware of the changes occurring in his or her body. This combination of factors makes massage a great choice for many ALS clients because sensation is intact and the client can communicate about how the massage feels and what is needed. Gentle massage techniques are traditionally used on our ALS clients to help relieve stress, help with relaxation and comfort. This is a great therapy to help with joint stiffness and tightness in the muscles.

Remember to always use a licensed massage therapist for treatment and notify your therapist of any changes to your condition.

Remember, please consult your medical insurance provider for coverage information!

Acupuncture

The medical definition of Acupuncture is one of the main forms of treatment in traditional Chinese medicine. It involves the use of sharp, thin needles that are inserted in the body at very specific points that are manipulated by the hands or by electrical stimulation. This process is believed to adjust and alter the body's energy flow into healthier patterns, and is used to treat a wide variety of illnesses and health conditions. When not delivered properly, acupuncture can cause serious adverse effects.

You will require a referral from a physician and it is always a good idea to check the credentials of your therapist. Please contact the Maritime Association of Registered Acupuncturists for more information.

 www.mara-atl.ca

Be sure to communicate to your healthcare team about all alternative therapies you currently use.

CONTACT LIST

Hospital Listings – New Brunswick

New Brunswick's health services are delivered via two health authorities: Horizon Health Network and Réseau de santé Vitalité. These health authorities deliver health care services to residents and are responsible for all hospitals, community health services, mental health services and public health programs in their districts.

Horizon Health Network

506-623-5500

www.horizonnb.ca

Réseau De Santé Vitalité

506-544-2133

www.vitalitenb.ca

Chaleur Regional Hospital	506-544-3000
Campbellton Regional Hospital	506-789-5000
Charlotte County Hospital, St. Stephen	506-465-4444
Dr. Everett Chalmers Hospital, Fredericton	506-452-5400
Dr. Georges L. Dumont Hospital	506-862-4000
Edmundston Regional Hospital	506-739-2200
Grand Falls General Hospital	506-473-7555
Grand Manan Hospital	506-662-4060
Hotel-Dieu St-Joseph, Saint Quentin	506-235-2300
Hotel-Dieu of Saint-Joseph, Perth-Andover	506-273-7100
L'Enfant-Jesus Hospital, Caraquet	506-726-2100
Miramichi Regional Hospital	506-623-3000
Moncton General Hospital	506-857-5111
Oromocto Public Hospital	506-357-4700
Restigouche Hospital, Campbellton	506-789-7000
Sackville Memorial Hosp.(secondary care)	506-364-4100
Saint John Regional Hospital	506-648-6000
St. Joseph's Hospital, Saint John	506-632-5595
Stella-Maris-de-Kent Hospital	506-743-7800
Sussex Health Centre	506-432-3100
Tracadie-Sheila Hospital	506-394-3000
Upper River Valley Hospital, Waterville	506-375-5900

CONTACT LIST

Hospital Listings – Nova Scotia

Nova Scotia's health services are delivered in nine district health authorities. These health authorities deliver health care services to residents and are responsible for all hospitals, community health services, mental health services and public health programs.

Annapolis Valley Health Authority	902 678-7381
Cape Breton Health Authority	902-567-8000
Buchannon Memorial Community Health Centre	902-336-2200
Cape Breton Regional Hospital	902-567-8000
Glace Bay Health Care Facility	902-849-5511
Harbourview Hospital	902-736-2831
Inverness Consolidated Memorial Hospital	902-258-2100
New Waterford Consolidated	902-862-6411
Northside General Hospital	902-794-8521
Sacred Heart Community Health	902-224-1500
Taigh Na Mara	902-842-3900
Victoria County Memorial Hospital	902-295-2112
Halifax Infirmary/Victoria General Sites	902-473-2700
Cobequid Community Health Centre	902-869-6100
Dartmouth General Hospital	902-465-8300
East Coast Forensic Hospital	902-460-7300
Eastern Shore Memorial Hospital	902-885-2555
Hants Community Hospital	902-792-2000
Musquodoboit Valley Memorial Hospital	902-384-2220
The Nova Scotia Hospital	902-464-3111
Twin Oaks Memorial Hospital	902-889-2200
Colchester East Hants Health Authority	902-893-5554
Lillian Fraser Memorial Hospital	902-657-2382
Cumberland Health Authority	902-661-1090
St. Martha's Regional Hospital	902-867-4500
Pictou County Health Authority	902-752-7600
Fishermans Memorial	902-634-8801
Queens General	902-354-3436
Shore Regional	902-543-4603
Yarmouth Regional Hospital	902-742-3541
RoseWay Hospital	902-875-3011
Digby General Hospital	902-245-2501

CONTACT LIST

Community Occupational Therapy & Physiotherapy Contacts – New Brunswick

CBI Health Centre, Moncton 506-853-5144
pt Health Clinics, Rothesay, Moncton, Fredericton & Riverview 1-888-998-4779

Community Occupational Therapy & Physiotherapy Contacts – Nova Scotia

South Shore Regional 902-527-2215
Queens General Hospital 902-354-3575
Yarmouth Regional 902-742-3542, ext. 137
Digby General 902-245-2502, ext. 3257
Roseway Hospital 902-875-4144, ext. 204
Valley Regional 902-679-2770
Soldier's Memorial 902-825-3411, ext. 358
Colchester Regional 902-893-5520
Cumberland Regional Health Centre - Physio 902-667-5400, ext. 6102
Cumberland Regional Health Centre - Occupational 902-667-5400, ext. 6418
Pictou County Health Authority 902-755-7498
Antigonish Mall Business Centre 902-867-4745
Cape Breton Regional 902-567-7747
Halifax (Joseph Howe Drive) 902-487-0622

You can self-refer to access the services of an occupational therapist or physiotherapist.

CONTACT LIST

Point Pleasant Lodge – Nova Scotia

Point Pleasant Lodge is a privately owned and operated, not-for-profit specialty hotel, providing 100 guest rooms exclusively for people undertaking medical related travel in the Halifax area. This includes people who may be visiting patients in hospital or have appointments with doctors, dentists, ophthalmologists, etc.

Point Pleasant Lodge provides accommodations at reasonable rates, considerably less than hotel rates, because they understand the financial burdens associated with medical related travel.

 www.pointpleasantlodge.com
 902-421-1599

Extramural Program – New Brunswick

In-home care is offered in New Brunswick through the services of the New Brunswick Extramural program. Services are accessed through your Occupational Therapist. You can also contact your ALS Champion, Terri Cooper, for more information.

 www.horizonnb.ca/facilities-and-services.aspx

Private Home Care Agencies – New Brunswick

Kings County Home Care Services Ltd.

 506-433-5536 Sussex
 506-847-5295 Rothesay

We Care

 1-866-729-3227

CONTACT LIST

Private Home Care Agencies – New Brunswick

Integrity Home Health Services

- ☎ 506-383-1273 Moncton
- ☎ 506-454-1273 Fredericton
- ☎ 506-657-1273 Saint John

Bayshore Health Care

- ☎ 1-877-289-3997

The New Brunswick Home Support Association offers an agency search by your area:

🌐 www.nbhsa.ca

Helping Hand

Helping Hand is based in the Saint John and Moncton areas, with service also available in Nova Scotia. They offer various services charged by an hourly rate. These services include light housekeeping, personal care, yard work and foot care, to name just a few. All staff are certified for their position, and there are RNs and LPNs on staff too.

- ☎ 506-639-5879

Victorian Order of Nurses (VON)

VON offers more than 75 different home care, personal support, and community services to enhance each client's quality of life by providing them with the personal assistance and the support needed to make them comfortable in their own home.

🌐 www.von.ca

CONTACT LIST

Nursing Homes – Nova Scotia

A variety of agencies and services are available in many communities. Some are privately owned and operated for profit (proprietary), others are affiliated with hospitals, and some are private non-profit agencies. Be sure to speak with your Continuing Care Coordinator regarding placements on waitlist. There is currently 8 months to a year wait list for placement.

Should a nursing home or some type of other assisted living facility become necessary please know that this is not the end of the road of you. Consider instead that it is a place to continue to live as long as you can as well as you can. Many of our PALS in nursing homes continue their outside social activities, use their computer to stay in touch with family and friends, and still stay in control of their medical decisions. Your ALS Champion is happy to visit your chosen residence to help staff understand the special needs of someone living with ALS. Any equipment on loan from ALS Society of New Brunswick and Nova Scotia is available to you in a nursing home as well.

LifeLine

Just over 30 years ago, Lifeline became the first personal response and support service in Canada dedicated to helping seniors, the physically challenged, and patients with medical conditions live confidently and safely at home. Lifeline Programs are based in hospitals, community agencies, and senior living facilities. They are the backbone of our service network and ensure outstanding service delivery coast-to-coast. Please visit the website for further information: LifeLine

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 www.lifeline.ca

CONTACT LIST

MedicAlert Foundation Canada

In a moment of crisis, paramedics, police and other emergency responders need to know your medical needs quickly. That information is critical when every second counts.

“As a subscriber to one of our service plans, you’ll have the certainty of knowing that your MedicAlert ID will speak for you when you can’t speak for yourself.” -MedicAlert

 www.medicalert.ca

Hospice – New Brunswick

The New Brunswick Hospice Palliative Care Association

 www.nbhpcaspnb.ca

Canadian Virtual Hospice

 www.virtualhospice.ca

Residential Hospices

Bobby’s Hope House at Hospice Greater Saint John

Atlantic Canada’s first residential hospice is equipped with 10 private bedrooms, four family bedrooms, living rooms, kitchens, a dining room, playroom, onsite chapel, and garden. Pain and symptom management and 24 hour care is delivered by a team of doctors, nurses, staff and volunteers.

385 Dufferin Row, Saint John, NB, E2M 2J9

 506-653-2995

 info@hospicesj.ca

 www.hospicesj.ca

CONTACT LIST

Local Palliative Care Programs

Hospice Fredericton

Fredericton, NB

☎ 506-472-8185

✉ support@hospicefredericton.ca

Hospice Greater Moncton

Moncton, NB

☎ 506-383-2404

✉ info@hospicegm.ca

Hospice Greater Saint John, Inc.

Saint John, NB

☎ 506-632-5593

✉ info@hospicesj.ca

Hospice of Charlotte

St. Stephen, NB

☎ 506-465-0800

✉ director.hospice@nb.aibn.com

Hospice Sussex

Sussex, NB

☎ 506-432-5001

🌐 www.hospicesussex.ca

Miramichi Regional Health Authority - Palliative Care

Miramichi, NB

☎ 506-623-3000

CONTACT LIST

The Moncton Hospital Palliative Care Program

Moncton, NB

 506-857-5111

 www.horizonnb.ca

Sackville Memorial Hospital Palliative Care Program

Sackville, NB

 506-364-4154

 educonsack@nb.aibn.com

South-East Hospice Sud-Est Inc.

Shediac, NB

 506-533-9100

 crcfb@nbnet.nb.ca

Tantramar Hospice Palliative Care Organization

Sackville, NB

 506 364-8813

 www.thpco.ca

In Nova Scotia, palliative care is accessed through your Continuing Care Coordinator.

Nova Scotia Hospice Palliative Care Association

 902-818-9139

 www.nshpca.ca

SOURCES

www.alsclinic.pitt.edu/patients/pt_ot_therapy.php
www.massgeneral.org/als/patienteducation/physicaltherapy.aspx
www.todaysdietitian.com/newarchives/tdoct2007pg84.shtml
www.aan.com/Guidelines/Home/GetGuidelineContent/373
www.alsn.mda.org/news/als-experts-keep-weight
www.als.ca