

ALS SOCIETY OF NEW BRUNSWICK AND NOVA SCOTIA



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“And so I began living my new life. One of the words that summarize my new journey 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

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 come with an ALS diagnosis.

The ALS Society of New Brunswick and Nova Scotia is partially funded by the Governments of Nova Scotia and New Brunswick. We rely heavily on the support from our donors. With extreme appreciation and gratitude, thank you to our donors who make it possible for the ALS Society to continue providing supports and services to people living with ALS and their families.

ALS Society of New Brunswick and Nova Scotia is NOT affiliated with ALS Canada.

ALS Canada is an organization based in Ontario. ALS Canada takes care of families with ALS in Ontario and funds national ALS research and federal advocacy. ALS Canada does not provide funding to any of the provincial ALS Societies. The ALS Society of New Brunswick and Nova Scotia does not receive any benefits, funding or other support from ALS Canada.



ALS Society of New Brunswick and Nova Scotia
LOGO



ALS Canada
LOGO

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 Healthcare providers, researchers, 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 with their communities.

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.

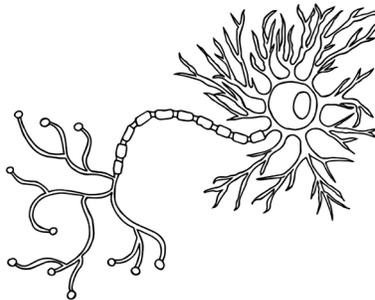
AMYOTROPHIC LATERAL SCLEROSIS (ALS)

ALS is also known as...

- Amyotrophic Lateral Sclerosis (ALS)
- Motor Neuron Disease (MND)* (MND is the umbrella term, ALS is just one type of MND)
- Lou Gehrig's Disease (Baseball player Lou Gehrig passed away from ALS)

What Is ALS?

- ALS is a neurological condition in which the motor neurons die. Motor neurons send messages to your voluntary muscles (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 has seen 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

AMYOTROPHIC LATERAL SCLEROSIS (ALS)

Life Expectancy

- 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 and others who have not
- 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

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: www.mayoclinic.org

COPING WITH AN ALS DIAGNOSIS

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 approach 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 stages 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 will go a long way towards helping you live your best life.

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.

COPING WITH AN ALS DIAGNOSIS

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 help you, or to 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 yourself more comfortable. Ignoring manageable problems or delaying interventions can make a difficult situation worse for both you and your loved ones.

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 on our website (www.alsnbns.ca) 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 Coordinator, ALS Clinic staff or your physician about your medical directives.

COPING WITH AN ALS DIAGNOSIS

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, 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 team 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 and 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 and both rely on good communication, emotional support, give and take, and shared decision making.

The Value of Connection and Experience

Sometimes people delay joining a support group or the opportunity to 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.

COPING WITH AN ALS DIAGNOSIS

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 they are comfortable with.

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. He still likes hugs! Even if he can't hug you back, the feeling of your touch is very comforting.

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 be happy together again too.

HEALTH CARE TEAM

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.

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, including ALS. Their training includes focus on the nerves, muscles, and bones – parts of the anatomy which affect mobility and physical function. They also work extensively with patients who have suffered traumatic brain injury.

Respirologist

A doctor who takes care of your respiratory system. They will be able to provide insight in regards to breathing equipment such as a Bi-Pap machine.

HEALTH CARE 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. Dieticians will also consult on feeding tubes.

Speech Language Pathologist (SLP)

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

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 made and you must be referred to the Clinic.

PALLIATIVE CARE

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. 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.

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 may be broad in scope and will support your family in the goal of helping you live your best life as long as you can.

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 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) 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.

Edaravone is the generic name for a drug that is marketed as Radicava and sometimes Radicut. Manufactured by the Mitsubishi Tanabe Pharma Corporation, it has been used in Japan since 2001 as a treatment for stroke. Radicava may slow disease progression by 33% in selected subgroups of ALS patients. Clinical trials testing Radicava as a treatment for ALS have been taking place in Japan since 2006 and in recent years the drug was approved in Japan and South Korea for treating ALS. In October 2018, Health Canada approved Radicava as a treatment for ALS – the first in more than 20 years, and only the second ALS drug to be approved in Canada.

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

Breathing

In ALS your breathing muscles and diaphragm weaken and breathing becomes difficult. 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). With a prescription, they are available for loan at no cost to you from the ALS Society of New Brunswick and Nova Scotia. A mask, humidification chamber and tubing can be purchased through a sleep clinic or vendor when the bi-pap is set up to your specifications.

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 to 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 maintain 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 issues, recommending therapies, food preparation, and 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 for all those with when they want to communicate. 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 unlikely that you will die by choking. Choking is a manageable symptom and your healthcare team will provide strategies for you to reduce the risk.

Excess Saliva

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 borrow these devices from the ALS Society of New Brunswick and Nova Scotia at no charge. Masks and set-up fees are the responsibility of the client.

Mobility

Everyday activities such as getting in and out of bed, walking, and taking a shower may become difficult as ALS progresses. It can be hard 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 for your caregiver in lifting you, helping you move, etc.

MEDICAL MANAGEMENT

End of Life – Medical Assistant In Dying (MAiD)

ALS Society of New Brunswick and Nova Scotia believes that there is quality of life 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.

This is not an easy topic for sure, but one that needs to be discussed with professionals (legal, financial, healthcare team) and your loved ones to ensure that everyone 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. 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.

Nova Scotians who are seeking information about MAiD can discuss this with their primary care provider or a specialist. They may also contact the Nova Scotia Health Authority MAiD Care Coordination Office, toll free at 1-833-903-6243, or 902-491-5892 within the Halifax region. The Office email address is: maid@nshealth.ca.

New Brunswickers who are seeking information about MAiD can discuss this with their health care provider. If you do not have a health care provider or prefer not to discuss medical assistance in dying with that health care provider, contact the Horizon Patient Representative Office by phone at 1-844-225-0220.

EQUIPMENT LOAN PROGRAM

Equipment Loan Program

The ALS Society of New Brunswick and Nova Scotia operates an Equipment Loan 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. Our goal is to keep people living with ALS comfortable, safe, breathing, communicative, and mobile.

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 Terri Cooper.

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.

- The ALS Society works 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
- The equipment is delivered to your home free of charge and picked up when no longer needed at no cost to the family

Accessing the Equipment Loan Program:

1. Complete a brief enrollment form (online or phone/email) and submit it to Terri Cooper at tcooper@alsnbns.ca or Katharine Cowan at kcowan@alsnbns.ca. To access our services, you must have a definitive or probable ALS diagnosis from your diagnosing neurologist or physiatrist.
2. Have a member of your healthcare team fax or email a prescription for the piece of equipment you require.

OTHER EQUIPMENT RESOURCES

In addition to the ALS Society of New Brunswick and Nova Scotia's Equipment Loan Program, clients can access services:

Canadian Red Cross

For more than 50 years the Canadian Red Cross has been offering Health Equipment Loan Programs. The Canadian Red Cross operates in both New Brunswick and Nova Scotia. 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.

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 medical prescription from a health care professional.

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. Veterans receive disability benefits, treatments and home care support services which are greatly needed by veterans and their families affected by ALS. For example, they are eligible for adapted wheelchairs, medical resources, housekeeping services and more. Those who've served in the military are approximately twice as likely to develop ALS as those who have not served.

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 when traveling within Canada. Applicable taxes must be paid. A doctor's note is required.

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

902-564-0003 Voice/TTY or cbdeaf@ns.sympatico.ca

Halifax and Mainland

902-422-7130 Voice/TTY or sdhhs@ns.sympatico.ca

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. Short term loans are available while your purchase is on order. There are subsidies available for those who qualify.

South-East Deaf and Hard of Hearing Services

506-859-6101 or seeds@nb.aibn.com

Saint John Deaf and Hard of Hearing Services

506-633-0599 or sjdhs@nb.sympatico.ca

OTHER RESOURCES

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) or 506-858-0311 (Moncton)

info@abilitynb.ca

Canadian Pension Disability Plan – New Brunswick and Nova Scotia

The Canada Pension Plan (CPP) disability benefit is a monthly payment, 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. A doctor's note will be required.

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 can be obtained 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.

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 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

INSURANCE

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 of which you might be eligible. 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 to 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 would it change your quality of life if you left 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?

PARKING AND TAXES

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. The placard and parking permit may be obtained, without charge, upon application at Service New Brunswick centres throughout the Province. Applications must be signed by one of the following: a physician, occupational therapist, nurse practitioner or physiotherapist.

Parking Permits - Nova Scotia

Licence plates or Identification Permits are available for vehicles regularly used for the transportation of persons with disabilities. These plates and permits authorize parking in any space designated for persons with disabilities. Application for Accessible Parking Identification Permits requires the certification by a qualified medical practitioner -- No fee required. (Doctor may charge fee, but no fee for permit).

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 or 506-444-3000 or 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 or www.cra-arc.gc.ca/volunteer

CNDR REGISTRY

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.

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.

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 or www.cndr.org

TELEHEALTH

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

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 at 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 at www.mara-atl.ca.

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 under one health authority and four zones. 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

Extramural Program – New Brunswick

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

Medavie BlueCross - Nova Scotia

In-home care is offered in Nova Scotia through the services of the Meadvie BlueCross program. Services are accessed through your Occupational Therapist. You can also contact Terri Cooper for more information.

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