



Live As Well As You Can

Live As Long as You Can

We Will Help You!

(506) 206-7727 Phone

www.alsnbns.ca

rmacnally@alsnbns.ca

About Us

The ALS Society has been serving people living with ALS (PALS) and their caregivers (CALs) for over 25 years. Our founding members – Brian Smith and Maureen Hope – realized that people living with ALS needed practical information and assistance accessing expensive equipment required to maintain independence and mobility. The Society is a non-profit organization and is not funded by any level of government. We appreciate and recognize all those who support our work financially.

We are governed by a volunteer Board of Directors, supported by a small staff. All are dedicated and passionate about helping PALS live as well as they can, as long as they can.

Although our office and equipment warehouse is based in Dartmouth, we serve all of New Brunswick and Nova Scotia.

The First Steps

If you are reading this you have either been diagnosed with ALS or are in the process of being tested for ALS. Understandably, you are feeling shocked, overwhelmed, and full of anxiety.

There are three things you need to know right away:

1. You still have **life ahead** of you – yes, there are challenges that will need to be faced and overcome but there is still joy and love and beauty in life.
2. You may have ALS but **ALS doesn't have you**. You can do amazing things!
3. It is important to work with your medical team, your family, friends, and the ALS Society of New Brunswick and Nova Scotia to maintain your independence, to keep up with volunteer work, to travel, to do many of the day-to-day things you do now.

There is one thing you need to do today:

1. Complete the attached registration form.

By completing this registration form you can access the services of the ALS Society. There is no charge at any time for the services of the ALS Society.

Over the next few weeks:

Knowledge is power and will help you and your family cope with stress and ultimately the changes you will need to deal with. The ALS Advisor, the ALS Manual, and the ALS Society of Canada are all great sources of information.

Awesome Advisory: Some people will want to know every single fact as fast as they can absorb it. Others will want to take things more slowly. You know yourself better than anyone else. Do what feels best for you.

ALS Society of New Brunswick and Nova Scotia: www.alsnbns.ca

ALS Society of Canada: www.als.ca

Client Services Manager for NB – Rachel MacNally

(506) 206-7727

rmacnally@alsnbns.ca

We're on



Facebook – ALS Society of New Brunswick and Nova Scotia

<https://www.facebook.com/ALSNBNS?fref=ts>

Awesome Advisory: Contact the ALS Society of New Brunswick and Nova Scotia for information about accessing health care, for the Equipment Loan Program and for general guidance and support. Visit the ALS Canada website to download fact sheets and other disease and research information.

The ALS Advisor

Our hope is that the ALS Advisor will be a practical resource, helping our PALS and their families access all the health, homecare, and other services they will need in the coming months and years.

Throughout the Advisor you will see Awesome Advisories (helpful hints that our PALS have learned along the way) and Stories of Hope (real people that have lived or are living with ALS).

The ALS Advisor is updated annually. Should you have any suggestions for the content, please contact our Client Services Manager, Rachel MacNally at rmacnally@alsnbns.ca - Thank you.

Our Values

- We value the lives of those living with ALS
- We believe that every individual should be able to maintain their day-to-day quality of life while living with ALS
- We value education and awareness of ALS.
- We believe that furthering the advancement of research will lead to a cure for ALS .
- We believe in financial accountability and transparency.

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Equipment Loans

- **ALS Society of New Brunswick and Nova Scotia Equipment Loans Program**

The Equipment Loan Program is designed to help people cope with the daily challenges of living with ALS, by access to an Equipment Loan Program.

The ALS Society of NB-NS is a non-profit organization entirely funded by the generous donations of the people of New Brunswick and Nova Scotia.

There are no charges for any services offered by the Society including the Equipment Loan Program. The Society does not conduct needs testing because of the financial challenge of loss of employment; often for both the person living with ALS and their family members/caregivers.

There is a wide variety of equipment available for people living with ALS and there are many options to help people remain comfortable, safe, communicating and mobile. The options to keep someone living well with ALS range from very basic equipment to high end, high tech options. An example might be communication equipment which can range from a homemade letter board to a \$20,000 communication device. **ALS NB-NS's goal is to be able to provide a basic level of service/equipment for every person diagnosed with ALS in our provinces.** That means that every person living with ALS can breathe, is mobile, can communicate, is safe. From time to time because of donations the Society is in a position to offer enhanced services or equipment.

The equipment loan pool consists of: mobility equipment (manual and power tilt wheelchairs, walkers, scooters), basic communication devices, respiratory equipment, bath assist equipment, hospital beds.

This is a recycled equipment loan program. That is, 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 donations.

We loan the equipment out free of charge with no needs testing. Sometimes, however some auxiliary, one person use accessories/services will need to be paid by the person to whom it is loaned. For example; if you require a bi-pap machine (for breathing) you will be required to pay for the mask and for the professional vendor that will be required to teach you how to use the machine and to do set the levels. This may cost a few hundred dollars which can be difficult

during this time but having the bi-pap machine loaned free of charge will save someone living with ALS approximately \$5,000. Sometimes it is necessary when you receive a power tilt wheelchair to have a vendor come to your home to modify the chair specifically for your body and program the speed and other features to your individual needs. This may also cost about \$200. A typical power tilt-wheelchair is usually valued between \$12,000 and \$30,000. To aid the Society in helping as many people as possible, we ask that as much as possible the charges described above are paid by person/family to whom the equipment is loaned. However, when it is absolutely not possible, the ALS Society will on a case by case basis consider taking care of these fees when the budget is available to do so.

As our organization grows and as awareness grows, we will be able to expand our equipment loan inventory and the services we provide.

With the progression of ALS, your equipment needs will change. We encourage you to keep your appointments with your healthcare team as much as possible so that you can be assessed regularly and that upcoming equipment needs can be ordered for you in a timely manner.

The Society does not loan out equipment for trial as it is cost prohibitive to do so. To deliver a power tilt wheelchair for example may cost up to \$600 in administration, labour, and delivery costs. We encourage you to talk to your health care team member and prepare yourself emotionally to accept the equipment before it is delivered. This helps us keep the cost of our loan program at a level where we can help as many people as possible.

Solid, open, and honest communication between a person living with ALS and their family members/caregivers is essential. Sometimes, the person living with ALS may not be ready to accept for example – a new wheelchair. The caregiver and healthcare team member may be encouraging the use of a wheelchair. The caregiver may need some relief from assisting with mobility. The healthcare professional may know that you will do better if you accept a wheelchair. All members of your team need to communicate well and respect the needs and expertise of each other. This will ensure that you have the right pieces of equipment at the right time and reduce the stress of all involved.

Except in the case of breathing equipment which is delivered within 24 hours if at all possible, requests for other pieces of equipment are processed on a first come, first serve basis. The turnaround time for equipment is 2 – 6 weeks to allow for proper sanitation, regular maintenance, and inventory control.

It is helpful when you require one piece of equipment to have a conversation with your team about other equipment that may be required in the near future. This practice also assists in keeping our costs low.

The ALS Society of NB-NS makes every effort to deliver the equipment as prescribed by your healthcare team. We cannot guarantee the exact manufacturer and model as requested is delivered but we try to fill the prescription as close as possible to your needs. For example, we might substitute one brand of wheelchair for another but we will attempt as much as possible to meet the measurement and accessory requirements.

Other Organizations

- **Canadian Red Cross**

For more than 50 years the Canadian Red Cross has been offering health equipment through their Equipment Loans Program. The New Brunswick Region of the Canadian Red Cross includes fourteen service centres located in Fredericton, Grand Falls, Richibucto, Atholville, Bathurst, Campbellton, Edmundston, Miramichi, Moncton, Sackville, Saint John, Sussex, Tracadie-Sheila, and Woodstock.

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. Home Support Services are provided to clients in New Brunswick. Community support services provide a wide range of daily services such as Meals on Wheels and transportation to older adults, vulnerable people, and their caregivers. Community support initiatives are unique community offerings to support seniors, so use the link below for contact information in your region.

For further information:

<http://www.redcross.ca/who-we-are/about-the-canadian-red-cross> (general information)

<http://www.redcross.ca/where-we-work/in-canada/new-brunswick> (NB services by region)

Awesome Advisory: Most of the time, the ALS Society 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 does not provide.

- **South-East Deaf and Hard of Hearing Services** and the **Saint John Deaf and Hard of Hearing Service**

South-East Deaf and Hard of Hearing Services, Moncton (506-859-6101), and the Saint John Deaf and Hard of Hearing Services (506-633-0599) 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
seeds@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

- **Easter Seals**

Easter Seals New Brunswick'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. By filling the gaps not covered by other services, Easter Seals NB Personal Services Program is a great offering to its clients." Your OT can help you access their services.

Visit <http://www.easterseals.nb.ca/index.php/en/home> for more information

- **Meals on Wheels**

Meals on Wheels of Fredericton is an independent, non-profit organization dedicated to providing nutritious meals and social support for members of our community who have difficulty preparing meals for themselves. (506) 458-9482

<http://www.frederictonmealsonwheels.ca> (Meals On Wheels, Fredericton)

<http://www.nbinfo.ca/bresults.asp?SubjID=1352> (Meals On Wheels, NB)

- **Ability NB**

Our 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. Fredericton (506) 462-9555 Moncton (506) 858-0311

<http://www.abilitynb.ca/wp/>

- **Veterans Affairs Benefits**

If you are a veteran living with ALS you are also entitled to have equipment funded through their benefit program. Please see page 12 for further information.

Stories of Hope – Mike Watson



A Family Man Speaks for Veterans – Mike Watson and his family were not defined by ALS.

For reasons not yet understood, veterans experience a higher incidence of ALS, but until October 2010 were not awarded medical benefits as a result of service. Mike Watson lived with ALS for 12 years and indeed when he passed away, it was from another medical condition. His family - wife Brenda and teenage daughters Kim and Michelle – traveled the Maritime provinces and to Ottawa to advocate for others living with ALS. Kim personally told the Prime Minister what it was like to have a parent with ALS. Mike was an integral part of a team that helped veterans with ALS receive benefits in 2010. To date, over 70 veterans and their families have received benefits.

Financial Assistance

- **Canadian Pension Disability Plan**

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 affect your ability to work at any job on a regular basis. Please visit the website for more information and forms.

<http://www.servicecanada.gc.ca/eng/isp/cpp/applicant.shtml#>

- **Caregiver Benefit Program**

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:

<http://www.servicecanada.gc.ca/eng/lifeevents/caregiver.shtml>

- **Housing Assistance for Persons with Disabilities**

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 info and New Brunswick regional contact numbers visit:

http://www2.gnb.ca/content/gnb/en/services/services_renderer.19576.html

- **Hyperalimentation Program**

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.

http://www2.gnb.ca/content/gnb/en/services/services_renderer.8055.Health_Services_Hyperalimentation_Program_.html

- **Insurance Coverage**

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 that would be missing if you were unable 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. Be sure to have all

of the specific information about your insurance plan in front of you while calling.

Here is a list of questions:

- 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 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

Car Insurance

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.

- **Parking Permits**

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. Follow the link to download the application:

<http://app.infoaa.7700.gnb.ca/gnb/pub/EServices/ListServiceDetails.asp?ServiceID1=14197&ReportType1=All>

- **Taxes**

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:

<http://www.cra-arc.gc.ca/disability/>

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

<http://www.gnb.ca/0048/pcsd/directoriesforpersons/directoryofservices/Finance-e.asp>

- **Veteran's 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 VAC, toll-free at 1-866-522-2122; visit one of the District Offices across the country; contact the Royal Canadian Legion (http://legion.ca/ServiceBureau/overview_e.cfm), or any other Veterans' organization for further information and assistance.

Do I qualify? <http://www.veterans.gc.ca/eng/services/health/treatment-benefits>

Veteran's Affairs Canada Contact info & forms <http://www.veterans.gc.ca/eng/contact>

Health Care

- **The ALS Clinic**

Four times a month, a specialty clinic for persons diagnosed with ALS is held at the Stan Cassidy Centre for Rehabilitation: two with Dr. Worley and two with Dr. O'Connell. Representatives from Neurology, Physiatry, Respiriology, Nutrition Services, Occupational Therapy, Physiotherapy and Speech Language Pathology are all present in the clinic to provide clients with any advice and assistance they require. Your ALS New Brunswick coordinator is also present and available at each clinic to meet with clients at their request.

To access this clinic, persons with a diagnosis of ALS must be referred by their physician to one of the Neurologists or Physiatrists who specialize in the care of persons with ALS, and work in the specialty clinic.

Further information about this clinic can be obtained by contacting the ALS Society's (NB) office at 506-206-7727.

With a doctor's referral, ALS clients may also access psychological services at the Stan Cassidy Centre. For a referral form, please contact the Stan Cassidy Centre, or email Rachel MacNally at rmacnally@alsnbns.ca

- **The ALS Patient Registry - CNDR Registry**

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.

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 at 1-877-401-4494.

The CNDR is supported by the ALS Society of Canada, Jesse's Journey and the Marigold Foundation. For more information about the registry please visit <http://www.cndr.org>

- **Self-Referrals**

If you are in need of immediate assistance for any services, you can contact your family doctor for referral. You can also self-refer to certain services such as Physiotherapy, Occupational Therapy and

local dieticians. Referrals are required for Respiriology testing and, can be obtained through the family doctor.

- **Telehealth**

The New Brunswick Telehealth Network (NBTHN) is a video conferencing communications network that connects healthcare focused facilities across New Brunswick. The NBTHN uses videoconferencing 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:

<http://en.horizonnb.ca/home/facilities-and-services/services/support-and-therapy/telehealth.aspx>

- **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. You can contact the Association of New Brunswick Massage Therapists (ANBMT) for further information. Please call (506) 452-6972, or visit <http://www.anbmt.ca/anbmt/>

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 at <http://www.mara-atl.ca> for more information.

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

- **Community Occupational Therapy & Physiotherapy Contacts**

CBI Health Centre (Moncton) 1 (506) 853-5144

pt Health Clinics: 1 (888) 998-4779
<http://www.pthealth.ca/new-brunswick-physiotherapy.php>
Rothesay, Moncton, Fredericton and Riverview

Awesome Advisory: You can self-refer to access the services of an occupational or physiotherapist.

- **Hospital Listings**

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

Fax: 506-623-5533

<http://en.horizonnb.ca/home.aspx>

Fredericton Area 506-452-5400

Miramichi Area 506-623-3000

Moncton Area 506-857-5111

Saint John Area 506-648-6000

Upper River Valley Area 506-375-5900

Réseau de santé Vitalité 506-544-2133

Fax: 506-544-2145

<http://www.vitalitenb.ca>

Chaleur Regional Hospital, Bathurst	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, Moncton	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 Hosp, Sainte-Anne-de-Kent	506-743-7800
Sussex Health Centre	506-432-3100
Tracadie-Sheila Hospital	506-394-3000
Upper River Valley Hospital, Waterville	506-375-5900

Home Care & Living Independently

- **Extramural Program**

In-home care is offered in New Brunswick through the services of the New Brunswick Extra Mural program. Services are accessed through your OT. You can also contact your ALS Client Services manager Rachel MacNally @ 506-206-7727 for more information, or visit the link below.

Website: <http://en.horizonnb.ca/home/facilities-and-services/services.aspx?type=extra>

- **Private Home Care Agencies**

Kings County Home Care Services Ltd., Sussex (506) 433-5536 and Rothesay (506) 847-5295

We Care 1-866-729-3227

Integrity Home Health Services, Moncton (506) 383-1273, Fredericton (506) 454-1273, and Saint John (506) 657-1273

Bayshore Health Care 1-877-289-3997

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

<http://nbhsa.ca/english/home-care-agencies>

- **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. Please call 506-639-5879 for further information.

- **The Red Cross**

The Canadian Red Cross provides in-home community services to help individuals live as independently as possible. <http://www.redcross.ca/in-your-community/new-brunswick>

- **Victorian Order of Nurses**

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.

<http://www.von.ca/locations/Default.aspx?Provid=4#List>

- **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:

http://www.lifeline.ca/content/english/medical_alert_service/how_lifeline_works/why_choose

Stories of Hope – Darrell Cottam

Changing Life Perspectives and Careers – The first thing Darrell Cottam lost when he was diagnosed was his speech. As a result he could no longer work in the sales field. Darrell turned this challenge around when he and his wife Deana formed a new business based on

Darrell's previous hobby and passion – photography. This photo of Darrell (taking photos himself) was taken in August 2012.

Darrell also formed a support group for PALS and was actively involved with the ALS Society in an advisory capacity and active fundraising leader. www.easternlight.ca

- **Nursing Homes**

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. Social Development offers a listing of licensed nursing homes in New Brunswick: http://www2.gnb.ca/content/gnb/en/departments/social_development/nursinghomes.html

Awesome Advisory: Should a nursing home or other type of assisted living arrangement become necessary, please know that this is not the end of the road for 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 living 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. Staff from ALS NB-NS are happy to make an appointment to visit your chosen residence to help them understand the special needs of someone living with ALS. Any equipment on loan from the ALS Society is available to you in a nursing home as well.

- **Palliative Care/Hospice 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 nearing death 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

Some other services are also offered. For example, Hospice Fredericton, servicing Fredericton and Oromocto, offers a caregiver support program to offer relief to those caring for loved ones in the home.

For information relevant to New Brunswick, please follow the link below:

http://www.virtualhospice.ca/en_US/Main+Site+Navigation/Home/Support/Resources/Programs+and+Services/Provincial/New+Brunswick.aspx#MapAnchor (virtualhospice.ca)

Awesome Advisory: Words are so powerful. Often, our PALS 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. Please know that this is not always the case. Palliative care services are broad in scope and will support your family in their goal of helping you live your best life as long as you can.

- **Other resources**

Patterson Medical offers for sale many helpful items for daily living assistance:

<http://www.pattersonmedical.com>

Manual of equipment:

http://www.alsa.org/assets/pdfs/ot_manual_2006_1.pdf

Assistance for voting:

<http://www1.gnb.ca/elections/en/faq/faq-e.asp?CATEGORYID=6&TYPE=2>

NB Community Mental Health Resources:

<https://www.gnb.ca/0055/contacts-e.asp>

River Valley Health Patient Advocate offers help navigating issues in the healthcare system:

[Kathleen Snow 506-447-4426](mailto:Kathleen.Snow@506-447-4426)

Vehicle Retrofit Program - This program is designed to increase the mobility of persons with a disability residing in the province of New Brunswick by providing financial assistance towards the cost of supplying and installing eligible retrofitting and accessibility features for vehicles:

[http://www2.gnb.ca/content/gnb/en/departments/dti/services/services_renderer.7715.Vehicle_Retrofit_Program_\(Persons_with_Disabilities\).html](http://www2.gnb.ca/content/gnb/en/departments/dti/services/services_renderer.7715.Vehicle_Retrofit_Program_(Persons_with_Disabilities).html)

Services For People With Disabilities

http://www.faslink.org/Disability_Guide_ENG.pdf

Social Media Networks

- **Lotsa Helping Hands**

Harness the Power of Community to Help Others in Need

Lotsa Helping Hands is a free web-based service that brings together caregivers and volunteers through online Communities that help organize daily life during times of medical crisis or caregiver exhaustion. Caregivers benefit from the gifts of much needed help, emotional support, and peace of mind, while volunteers find meaning in giving back to those in need.

From our Help Calendar to Well Wishes Wall, learn more about using Lotsa Helping Hands: Please visit the website for further information: <http://lotsahelpinghands.com/who-we-help/>

Transportation

- **Saint John Transit HandiBus**

The Saint John Transit Commission currently has 5 HandiBuses on the road plus 1 bus for backup. These buses are operated by Independence Plus, Inc., a non-profit charitable organization. Please consult the link below for availability and service.

Information page:

<http://www.saintjohn.ca/en/home/cityhall/transportation/transit/services/accessibility/handibus.aspx>

- **Fredericton Transit Dial-a-Bus**

Dial-A-Bus is Operated by Fredericton Transit to provide a specialized transportation service to the mobility impaired residents of the City. Registration is required for Dial-A-Bus use. This can be accomplished through contact with Easter Seals New Brunswick (Tel: 506-458-8739). Please consult the link below for availability and service.

Information page: <http://www.fredericton.ca/en/transportation/DialABus.asp>

- **Codiac Transpo Moncton Accessible Transit**

Accessible Transit is a bus-stop to bus-stop service servicing Moncton, Dieppe and Riverview. Door to door service is not offered.

<http://www.codiactranspo.ca/Assets/Codiac/Accessible+Transit.pdf?method=1>

Travel

- **Travel Tips**

- All airlines will transport a wheelchair (manual and power) for no charge.
- Check in at the airport when traveling in a wheelchair is required 3 hours prior to departure.
- If traveling on an aircraft with a power wheelchair the patient must declare the battery type on their chair at the time of reservation.
- Certain aircrafts have extendable restroom walls that allow for a caregiver to assist easier (i.e. 747 and larger) .
- The baggage tag that is affixed to the wheelchair needs to indicate where the patient would like it to be held for them once they reach their destination (ex. at the gate or at Special Baggage).

- The patient can stay in their own wheelchair until they reach the gate for comfort.
- Patients must make sure that a special transport chair is going to be on board if they require it during the flight.
- Flight attendants are not required to assist a patient in and out of the restroom.
- Patients can request special seating with removable arms and closest to the bulkhead portion of the plane.
- As of January 11th, 2009 Canadian passenger airlines must provide a complimentary companion ticket for People Living with Disabilities who must be accompanied by an attendant/caregiver. A doctor's note is required. Contact the airlines for details and booking. **For more information go to www.cta.gc.ca**
- Via Rail and Greyhound offer the same companion ticket courtesy. For more information visit: VIA RAIL <http://www.viarail.ca/en/travel-info/special-needs/accessibility> GREYHOUND <https://www.greyhound.ca/en/ticketsandtravel/AccessibleTravel.aspx>
- All prescription medications must be in their original packaging with clear labels or they may be confiscated at security.
- Always check for updated restrictions with the airline prior to flying.
- <http://www.accesstotravel.gc.ca> provides information on accessible transportation across Canada.

If your wheelchair gets damaged in transport by the airline, you MUST file a damage report at the time of the incident. DO NOT leave the airport without doing this first.

- **Healthy Meal Alternatives**

The Frozen Favorites Healthy Meal Program offers delicious and nutritious frozen meals prepared by a registered dietitian. This program provides healthy food choices for people who live alone, renal, pureed and diabetic special diets, chronically ill, those recovering from surgery or chemotherapy or simply for active people on the go! Delivery of meals to your home is available. Please contact your local VON to find out more about this program.

Meals on Wheels- There is no age restriction for receiving Meals on Wheels. Our clients may be elderly or disabled individuals or those recovering from illness, surgery or injury. Meals on Wheels clients cover a wide spectrum of ages and needs. They may require our services for a short time only, or for a longer term. What they all share is the desire for regular healthy and nutritious meals. Please contact your local Meals On Wheels for more information.

Costco Pharmacy- What makes Costco Pharmacy special is people: the people who work for us, and the **people** we serve. We know that in order to serve you well, we need very knowledgeable, highly skilled people, and enough of them. So when you come in to Costco Pharmacy, you will be coming in to a team of pharmacists, technicians, and pharmacy assistants dedicated to your health

care. Costco Pharmacy can order in feeding tube formula such as Iso Source , Resource at a lower cost. The formula has to be purchased by the case and rate between 1.39 – 2.89 per tetra pack. Please multi this by 24 to indicate case pricing.

Stories of Hope – Kathleen Oikle



Putting Others Before Herself – When Kathleen Oikle was diagnosed with ALS she decided to use her life to raise awareness about ALS. Her family, friends, and community rallied around her, helping her build a float which she rode on in the Apple Blossom, Halifax Natal Day, Gay Pride and many other community parades this. Kathleen is seen here hand painting the float with the assistance of a Hoyer Lift loaned to her





AMYOTROPHIC LATERAL SCLEROSIS SOCIETY OF NEW BRUNSWICK & NOVA SCOTIA

Client Registration Form (Confidential)

Client Information

Surname:		<input type="radio"/> Mr. <input type="radio"/> Ms. <input type="radio"/> Mrs. <input type="radio"/> Dr.	
First Name:		Sex: <input type="radio"/> Male <input type="radio"/> Female	
Middle Name:		Date of Birth (M/D/Y)	
Address:			
City:		Business #:	
Province:	Postal Code:	Home #:	
Email:		Cell #:	
Primary Alternate Contact Person			
<input type="radio"/> Spouse <input type="radio"/> Partner <input type="radio"/> Parent		<input type="radio"/> Son <input type="radio"/> Daughter	
Surname:		First Name:	
Address:			
City:		Business #:	
Province:	Postal Code:	Home #:	
Email:		Cell # :	
Secondary Alternate Contact Person			
<input type="radio"/> Spouse <input type="radio"/> Partner <input type="radio"/> Parent		<input type="radio"/> Son <input type="radio"/> Daughter <input type="radio"/> Other	
Surname:		First Name:	
Address:			
City:		Business #:	

Province:	Postal Code:	Home # :
Email:		
Additional Information Please list children or other dependents living at home and their ages so that we may provide appropriate support:		



AMYOTROPHIC LATERAL SCLEROSIS SOCIETY OF NEW BRUNSWICK & NOVA SCOTIA
Client Registration Form (Confidential)

Have you served in the Military or are you a Veteran?	<input type="radio"/> Yes	<input type="radio"/> No
Have you received a copy of " A Manual for People Living With ALS"	<input type="radio"/> Yes	<input type="radio"/> No
If not, would you like to receive a copy now?	<input type="radio"/> Yes	<input type="radio"/> No

Medical Information	
Family Physician:	
Address:	Postal Code:
Telephone #:	Fax #:
Neurologist:	Date of Diagnosis:
Address:	Postal Code:
Other Medical Conditions/Concerns:	
Have you been to ALS Clinic?	<input type="radio"/> Yes <input type="radio"/> No
Would you like ALS NS to send your physician information on the care of people living with ALS?	<input type="radio"/> Yes <input type="radio"/> No

Insurance Coverage	
Do you or your spouse have Extended Health Benefit?	<input type="radio"/> Yes <input type="radio"/> No

Name of Health Care Provider:

Employment History Information	
Status of Employment:	<input type="radio"/> Working <input type="radio"/> Retired <input type="radio"/> Medical Leave
Employer:	



AMYOTROPHIC LATERAL SCLEROSIS SOCIETY OF NEW BRUNSWICK & NOVA SCOTIA

Client Registration Form (Confidential)

Spouse/Partner-Status of Employment	<input type="radio"/> Working <input type="radio"/> Retired <input type="radio"/> Medical Leave
Employer	

Confidentiality Statement

The ALS Society of NS Respects your privacy and adheres to all legislative requirements with respect to protection of privacy. The ALS Society of NS does not rent, sell or trade contact lists. Personal information is used only to deliver services, inform you of Society activities including programs, services, special events, funding needs, volunteer and donor opportunities. If you wish to be removed from any ALS Society lists please contact the office by phone or email.

Permission to Share Information to Provide Services

The ALS Society staff work closely with the ALS Clinic, Capital Health, Nursing Home/Home Care Agencies, Social Workers, family physicians, occupational and physical therapists to coordinate the best possible care. It is sometimes helpful to be able to share information with these organizations. The ability to advocate for you can reduce waiting times for equipment and services. Please indicate your permission for the ALS Society to discuss your case file when working on your behalf.

Permission Granted

Permission Not Granted

Signature _____

CARE FOR TODAY/HOPE FOR TOMORROW