

Caring for the Caregiver

You Are Not Alone!

Your parent, spouse, sibling, or friend has been diagnosed with ALS and you will be the principal caregiver.

- ALS NB & NS is here to help you support your family member/friend to navigate through a confusing and difficult disease with dignity and purpose.
- We are also here to help you take care of yourself.

What to Expect

 **ALS affects the whole family, not just the person diagnosed.**

Everyone handles an ALS diagnosis *differently*. Allow yourself the time and space to grieve in *your own way*. It is normal to feel a full range of emotions which can sometimes feel like a rollercoaster. This is a difficult time as your loved one will be going through their own feelings around their diagnosis too. You may want to be strong for your loved one, but it is a good idea not to try and ‘handle’ it all alone.

Preparing to Become a Caregiver

Chances are, you are not going to have a lot of time to prepare to become a caregiver. It’s like becoming a parent for the first time – it’s learning on the job. Just as it is important as a new parent not to lose your identity, social life, and relationships; **it will be important to remember that you have an identity outside that of caregiver and ALS.** It will be a balance between caring for your loved one and remembering and fostering your relationship to the person with ALS – you are still a daughter, or a sibling or a spouse. The person you are caring for is still the same person they were before their diagnosis.

Contact Your ALS Champion

Your ALS Champion is a great source of advice and a shoulder to lean on. Oftentimes the person diagnosed is not ready to accept that they have ALS. By reaching out to the Society you can get the support you need and learn about the disease and our resources. You will then be prepared as your loved one moves through the process of denial, anger, and acceptance. All contact is private and confidential.

Call today – 902-454-3636 or 1-866-625-7257

Find Your Person – You will need one person in your life with whom you are going to be able to confidentially express yourself fully and know that you and your loved one will not be judged, and from whom you will not receive unsolicited advice. Someone you can laugh with, cry with, have hard conversations with. A person who will distract you from your caregiving responsibilities.

ALS NB & NS Manual – ALS NB & NS provides a manual with an overview as to what the person with ALS and their caregiver can expect and the treatments and equipment that can help. The manual is not exhaustive and should be used as a guide to direct you in seeking the right medical professional and equipment at the right time.

Keep a Normal Routine and Encourage Your Loved One to do the same

Easy to say we know, but how? Gently and consistently encourage your loved one to focus on the *living* with ALS. It's okay to grieve losses of function, just don't allow yourself or loved one to unpack your bags and stay there. If the person with ALS can adopt and practice the habit of not concentrating on what they can't do but instead turn the thought around and concentrate on what they still can do, they will be more emotionally healthy and able to cope. A very wise man and friend once said to a staff member "I'm grateful for everything this disease has taught me and the friendships I've made. It's allowed me to enjoy each day with a completely new perspective. I don't take a day for granted." Family outings should be continued as much as possible. Sure, they will require more flexibility and planning, but going to cheer at the kids' hockey games may still be possible for a while. One of our PALS decided to have a friend lay a garden path to accommodate his wheelchair so that he could continue his morning coffee and nature watch at the end of his garden by the woods.

Help Your Loved One With Communication

It is a good idea to be open with friends and family so that they may understand your situation and be well-informed as to how they may help. It is also important to respect the wishes of your loved one and their own timing of sharing the news with family and friends. Everyone is different; everyone has their own ideas of privacy. For some, the messages from well-wishers will be an encouragement; for others it will be overwhelming. Respecting their wishes means asking permission before sharing their news and agreeing on what news will be shared with whom. A helpful hint may be agreeing with family and friends that you will send them an email once a week or so to keep them updated. This will keep everyone informed without the daily interruption of texts, emails, and phone calls to add to your daily care routine. You can also use the weekly communication to ask for help, being specific about the task, date, and time required.

Communication is Between Caregiver and Loved One

This is a shared experience for you and the person you are caring for. As the disease progresses, communication will become difficult and patience will be required to ensure your loved one's needs are being met. To help someone, you need to know what they need help with and how they wish to receive that help. It is also important to talk about what your needs as a caregiver are. Is there care you would rather have a professional do (example personal hygiene for Mom or Dad)? Is there a weekly activity you would still like to participate in and who would be acceptable to your loved one to take your place during that time? Encourage visitors to talk directly to your loved one. They are still the same person and can answer for themselves how they are feeling/doing, etc.

As the disease progresses it will be important to have "difficult conversations". You may wish to read some articles and books together or separately and then discuss things like how your loved one wants to live the rest of their life. Ask them (depending on their openness with the topic) how they want to die. Ask them what worries them, what goals you can help them fulfill, what they would like to talk about. Your local palliative care professional or spiritual advisor can be a great resource to help you facilitate this conversation.

Laughter Really is the Best Medicine

Humour really can make a difficult situation a whole lot better and easier to cope with. Often, friends and family get so serious that they miss out on these lighter moments. Creating an atmosphere that is a balance of reality coupled with love and laughter will make coping easier and leave you with very special memories. We had a special person with ALS who once undecorated the Christmas tree while his family was out and replaced the ornaments with empty feeding tube formula boxes!

Balancing Responsibilities

Chances are, being the primary caregiver of a loved one with ALS is not the only responsibility you have. You may have a spouse, children, and work to think about. It will be important to have a conversation with your employer regarding your new situation. Many employers are compassionate, and are aware of the juggling of responsibilities that some employees have to do. Workplaces today are becoming more family-friendly with organizational policies such as flexible work arrangements, family leave, employee assistance programs and educational opportunities.

Taking care of someone with ALS may be quite long term and you will need to still take care of yourself and other people depending on you. Children are still growing up and need the security of having you home at dinner, tucking them in at night, etc. Dedicate time to your children daily and spend time with your spouse. Remember, you need to protect and nurture

the relationships of children and spouses who will be there when your loved one with ALS is gone.

Solicit the help you need to be able to keep the balance in your life.

More Balance

False Hope vs. Informed Positivity

Don't downplay the situation or create false hope as this denies your loved one the chance to process what is happening and talk about it. For example, ALS research is in a better position and moving faster than it ever has, but we are still a long time away from a cure. We must be realistic in what new discoveries mean for those already living with ALS. However, taking advantage of early intervention for treatment and assistive equipment will help keep your loved one in the best shape possible for potential new treatments to slow progression. Think about AIDS in the 80's when it was always terminal. Now, people with AIDS are living for extended periods fairly well. The goal of scientists in Canada is to make ALS treatable, not terminal by 2024.

Help your loved one discern what they read on the internet and social media sites. Some information is excellent and can be applied to living well and caring for someone with ALS. As with all things, some information is not balanced and does not tell the entire story. Be especially careful about research information. Is it published in a reputable scientific journal? Is the source well known – e.g. The Mayo Clinic or Sunnybrook Hospital in Toronto, the Stan Cassidy Centre in New Brunswick, The Brain Repair Centre in Halifax; or do you not recognize the name of the institute?

Dreams and Wishes

Creating a wish list of things to experience or accomplish is a great way to focus on the living! Encouraging your loved one to think about things they would like to do, and offering to help make them a reality is a wonderful way to show support and help your loved one live life to the fullest. One family in our ALS community took their first ever vacation outside of Canada brought about by exploring their dreams in the face of ALS. In fact, many of our families choose to travel, and we can share some great travel tips with you. However, living life to the fullest means something different for everyone. It may mean creating lots of social interaction, or deep conversations with only one or two close friends, a family reunion, or immersion in art, or time in nature.

Sharing the Load

Each family member will have their own way of helping and supporting. For some, they are more comfortable helping with the practical, everyday things, and for others it will be the company and conversation. As a primary caregiver, consider keeping a list of things you need help with; that way when someone asks how they can help, you can give them a task from the list.

The Power of Human Contact

Often people don't want to touch those who look ill, but people crave human contact. Some people are comfortable asking for a hug, but for those who aren't or who can no longer speak, it is okay to offer a hug or ask if you can hold their hand.

Self-care and Support

While caring for a loved one, it is important to remember to also care for yourself! "Caregivers are strong and courageous individuals who play an important and invaluable role in our society."

Caregivers are those family members and friends providing care, assistance and support to another. Often, they have many other responsibilities, and it does not take long before stress sets in. For this reason, it is essential that caregivers take the time to make sure they are also taking care of themselves.

The task of caring for another will be demanding physically, mentally and emotionally, so it will be important to make sure that you have a network of friends, family and organizations around you for your own support. This will help you to remain as strong and capable as possible. You will need to recognize when you are feeling overwhelmed and to ask for help. Some signs of caregiver stress are feelings of anger, anxiety, and/or depression; social withdrawal; exhaustion and sleeplessness; and health problems.

When You Lose Your Loved One

Allow yourself to grieve before you attempt to heal. The healing process is difficult and never ends, but don't ignore your feelings. Allow yourself to grieve the loss, to cry and be angry and work through the emotions. Make time for grief. If you don't, it will come back to bite you at some point – the stress of losing a loved one can quickly deplete you physically, mentally and emotionally. Everyone heals at different times and in different ways. Be gentle with yourself and know that there is no 'best' way. "You are Stronger than You think" – A staff member of ALS NB & NS had the opportunity to speak with one family after the loss of their loved-one and they explained their journey like this. The grieving process is like a roller coaster, full of ups and

downs, highs and lows. Like many roller coasters, the ride tends to be rougher in the beginning, the lows may be deeper and longer. As time goes by, it does get easier. Your loved one will always be with you in spirit, you will always miss them, but you will return to functioning well daily and experiencing the good things in life.

Links:

Nova Scotia

<http://caregiversns.org/>

New Brunswick

http://www2.gnb.ca/content/gnb/en/departments/social_development/seniors/content/caregivers_guide.html

Hospice Fredericton (NB) offers volunteer hours to provide respite to caregivers for a few hours a week. For more information, visit:

<http://hospicefredericton.ca/about-us>

For both provinces:

The ALS Society of NB & NS holds support groups in both provinces. For more information, please visit the event section of our website.

Guides:

The MDA ALS Caregiver's Guide:

https://www.mda.org/sites/default/files/publications/ALS_Caregiver's_Guide_P-531.pdf

Self-Care for Caregivers Guide from the Public Health Agency of Canada:

http://www.phac-aspc.gc.ca/publicat/oes-bsu-02/pdf/self-care-caregivers_e.pdf

<http://www.prevention.com/print/health/supporting-someone-terminal-illness>

Resources - Financial

The **federal family caregiver tax credit** allows family caregivers taking care of an ill family member to claim an enhanced caregiver amount for a dependant under one of the existing dependency-related tax credits. For more information visit:
<http://www.cra-arc.gc.ca/familycaregiver/>

The **federal infirm dependent tax credit** provides tax relief to individuals providing support to an infirm relative residing in a separate residence. For more information visit:
<http://www.cra-arc.gc.ca/tx/ndvds/tpcs/ncm-tx/rtrn/cmpltng/ddctns/Ins300-350/306/menu-eng.html>

Compassionate care benefits are Employment Insurance (EI) benefits paid to individuals who are away from work temporarily to provide care or support to a family member who is gravely ill and who has a significant risk of death within 26 weeks (six months). A maximum of six weeks of compassionate care benefits may be paid to eligible people. For more information visit:
<https://www.canada.ca/en/services/benefits/ei/ei-compassionate.html>

Nova Scotia

The *Nova Scotia caregiver benefit* targets low income care recipients and caregivers. If eligible, caregivers receive \$400 per month. This financial support is key for the self-care and support of family caregivers.
<http://novascotia.ca/dhw/ccs/caregiver-benefit.asp>

New Brunswick

To assist low-income seniors in New Brunswick, the government offers an annual benefit to qualifying applicants, this low income seniors benefit offers an annual benefit of \$400 to eligible seniors. Where both spouses receive the GIS and reside in the same household, only one \$400.00 benefit will be granted. However, where spouses live separately (for example, one residing in a nursing home), both will be eligible for the benefit. For more information visit:
<http://www2.gnb.ca/content/gnb/en/departments/finance/promo/seniors.html>