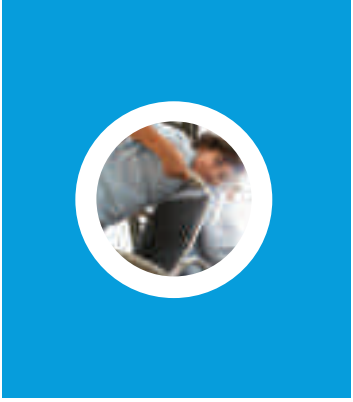

Talking With Your Patient's Children About

ALS

A Primer For Health Professionals

ALS SLA

ALS

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Introduction

This booklet is designed for health care professionals to reinforce the importance of considering family dynamics in the care and management of an ALS patient, and in particular how to help young children understand the diagnosis and management of their parent's illness. Content in the booklet may also apply to working with grandchildren.

Health care professionals on interdisciplinary care teams who routinely interface with patients with ALS can benefit from reading this booklet, but it is also aimed at other health care providers who become involved with ALS patients in their family practice or through homecare service delivery. If you are in need of additional information about ALS, a fact page and a list of other ALS resources are included at the end of this booklet.

Amyotrophic Lateral Sclerosis (ALS) and the Family

Diagnosis

Receiving a diagnosis of any life threatening disease is traumatic for a family. Plans and expectations are suddenly turned upside down. Family members generally experience waves of strong emotions — shock, bewilderment, anger, denial, sadness, guilt, fear and withdrawal. The emotional experience will be different for each person in the family. It is likely that they will only absorb information about ALS and how to manage it gradually, and will need to revisit early decisions about the management and care of the parent with ALS.

Client centred decision making

A parent with ALS experiences a spiraling process of loss. It is vital for their emotional well-being and sense of self that they remain central in the decision-making about their care. Care needs should be negotiated and prioritized with them and the rest of the family.

A potential complicating factor in client-centred care is the potential for cognitive dysfunction in ALS. Although ALS was traditionally viewed as not being accompanied by cognitive change, there is substantial evidence showing that a very small proportion of patients will meet the criteria for frank frontotemporal dementia, and perhaps as

many as 50% or more without dementia will be mildly to moderately affected primarily in the area of executive function. These functions include organization and planning of behaviour, mental flexibility, task completion, attention, following rules, appropriate inhibitions, abstract thinking, and verbal fluency. Depending on the nature and severity of one's cognitive impact there may be difficulties understanding, accepting, and following care plans.

In many cases, family caregivers are not aware this may be part of the disease and subtle changes may be overlooked given the magnitude of physical care involved in ALS, and when changes in speech occur. It is advised that ALS patients have access to neuropsychological assessments to ensure best provision of care.

Management

Health professionals can help a family talk through their feelings and the issues the disease raises. Sometimes additional counselling may be needed and may range over a wide area including emotional, psychological, social and financial concerns.

There is no "formula" for managing the physical aspects of ALS. Each family's way of coping emotionally will be different. As a health professional you need to recognize and work within these unique dynamics and support requirements. It is important to avoid making judgments about the way a family copes; it can undermine trust and block communication. You may find it useful to talk with other health professionals and ALS teams about their experiences to compare approaches and strategies.

central person for liaison between the family and the ALS team. Refer families to the "Coping with ALS" section in the ALS Society of Canada publication, *A Manual for People Living with ALS*, for descriptions of each professional discipline as well as a business card holder page to store contact information. Patients can obtain a personal copy of the *Manual* by registering with their Provincial ALS Society. If you currently do not have a working relationship with the Society in your province, please see pertinent contact information in the resources section of this booklet.

Managing changes

Over time, changes of roles within the family may intensify existing family dynamics. There will be many layers of change and loss as the parent with ALS becomes less able to do things with his or her children and requires more help, forcing the caregiver parent or a child to take on more roles. Families are likely to confront the loss of normalcy and privacy and may need to manage the reactions of close relatives and friends. These changes can bring people closer together as they discover previously untapped personal strengths and begin to work as a team. They can also put pressure on relationships, especially if there are cognitive or behavioral changes.

Familial ALS

The inherited form of ALS known as Familial ALS (FALS) brings parents the added concern of knowing the impact living with ALS has had on relatives. They are likely to be concerned that it will be passed on to their children. Information about genetic counselling should be explored with these families.

Supporting a "caregiver" parent

The parent providing primary care is likely to have less time to spend with the children and may be feeling exhausted, anxious, stressed, depressed, helpless, hopeless and fearful. Accurate information about ALS and its progression at the right time is important in helping them be prepared and able to plan ahead.

"The important thing is to make sure families know they can have access to whatever information is required, when it is needed. They simply need to know that it is OK to ask, and that someone will help them find what they need." (Counsellor)

Many caregiver parents experience emotional and physical "burnout" and become resentful and ambivalent about the caring role. They may describe this process as feeling "numb." Caregiver parents need to be aware of respite care available to give them some time to recharge their energy. Stress caused by the potential loss of one or both incomes may require professional assistance. It can be helpful to explore financial issues as early as possible. Some parents rely heavily on their children for emotional and practical support and this can be hard on the children. In single parent households a child may have to become the primary caregiver. They will need special support and encouragement from health professionals.

Talking with children about ALS

"Opening up" a conversation with the children about a parent's diagnosis can be one of the hardest things parents have to face. Patients may ask their ALS health team's advice about when and what they should tell the children. They may also ask their primary care doctor to assist if it is more convenient to take their children to a local appointment should the ALS clinic not be located nearby.

Make it routine to ask patients about how their children are coping with their illness. This question encourages parents to think about the impact ALS might be having on their children and the importance of addressing the mental health needs of their children.

Counsellors suggest it is better to tell children as soon as possible after a diagnosis has been made. Even very young children can detect when parents are unhappy and anxious. They may start worrying that what is troubling their parents might be their fault, something bad that they have thought, said or done.

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Of course, parents need some time to understand ALS and come to terms with their own reactions and grief before preparing to talk to their children.

"The parent needs to have a certain level of psychological comfort in talking about ALS. Poor communication is often about 'where the parent is at' in coming to terms with the disease as well as established family patterns of communication and emotional expression". (Psychologist)

Their desire to protect the children – and even themselves – from the distress of facing the full implications of ALS is understandable.

"ALS is often rapid and involves losses at every level. Explanations to children can be even more complex and challenging." (Social worker – Palliative care)

However, the rapid progression of ALS can mean there is limited time to prepare the children. Parents need to know that it is alright if they don't get it quite right the first time they talk with their children. Children understand when they feel loved and included, even if a message is unclear. Being "included" can also help to develop their sense of trust and self esteem.

Parents don't need to know all the answers – they simply need to convey to children that all questions are acceptable and they will help the children to find information.

Information should be given gradually and clearly at a level and pace appropriate to a child's intellectual and emotional maturity. The health

care team may be able to support the parents in talking through the issues, and even rehearsing how to tell the children. Be open to the idea should a patient want to bring their child(ren) to a clinic visit. Some children may need that level of inclusion and the opportunity to ask care providers questions about ALS directly.

"Parents should always be the decision maker in terms of timing of information, amount of information and who provides this information. Our experience has been that parents are happy to accept guidance but want to be the ones involved in telling their children the 'hard news'."
(Social worker – Palliative care)

Parents can become the "comforters" rather than the bearers of bad news if health professionals, such as the neurologist, ALS nurse coordinator, psychologist, social worker or family doctor, explain the diagnosis to the children in the context of a family meeting. Discussion can begin by exploring what the children already know about their parent's health problems. Questions from the children should be encouraged to clear up any misunderstandings.

Children's responses to ALS

Parents may be challenged by their children's reactions to ALS. These might include "acting out," withdrawal, regression, aggression, disturbed eating and sleeping patterns, difficulty with concentration and poor performance at school. Tensions within the family can also be increased when siblings react very differently. Some may want to keep close to their parents; others may want to stay away from home. Effective communication between family members can help reduce the long term impact that living with ALS can have on young and adolescent children.

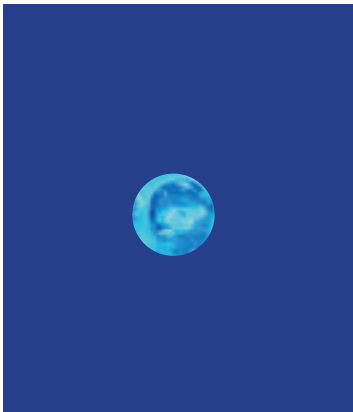
Young children

Children under four are too young to understand a parent's serious illness. However, they have a "magical" way of thinking, and can wonder

- Do you have any questions about ALS?
- ALS can happen to anyone and there is nothing you said, thought, or did to your parent to make this happen.
- Give your parents lots of love and hugs because you can't "catch" ALS like a flu bug.
- ALS may change the way your mommy/daddy gets around (or speaks, etc.) but it doesn't change how much your mommy and daddy love you—you are still going to be loved and taken care of by them.

Pre-teens & teenagers

Older children's emotional and physical maturity and experience of the family's dynamics strongly influence the way they react to living with ALS. Adolescents already face many changes as they shed their identity as a child, and orientate strongly towards their peer group. Emotionally, most young people are on a roller coaster ride with dramatic ups and downs of mood. They may have mixed feelings about their parent's condition, perhaps feeling deep sadness but also resentment about how their life has suddenly changed. Changes in what their parent with ALS can do, and in family routines, can cause confusion. Teenagers are also likely to have concerns about their own health and worry about their caregiver parent and how the family will cope emotionally and financially. Some older children and adolescents find getting involved in ALS awareness and fundraising helps them feel empowered which is can be a very positive coping strategy. Some children get overly involved



in care at home, so this is an area that should be discussed with patients to avoid inappropriate dependence on a young person.

They may feel lonely because ALS has marked them as "different" from their peers. Some will be reluctant to bring friends home because of embarrassment about their parent's disability. Some teenagers may even "act out" and reject the parent with ALS. Subsequent feelings of guilt can complicate the situation as they struggle with their conflicting reactions, such as anger, regression, "shutting off," sadness, guilt, and isolation. At times their emotions may feel out of control. Young adults may adopt a very grown-up attitude to their parent's condition and its effect on the family, but this could be hiding a lot of emotional turmoil. Encourage patients to take time to regularly "check-in" with their older children and if there are concerns about their mental health and coping to ask about counselling resources.

"I just remember being very sad, but determined to try to be a strong person, and not be seen to let it affect me." (Young person)

Validation of the full spectrum of feelings is important. Young people need to be reassured that it is OK to react and feel the way they do.

Older children have a strong need to be communicated with in an honest, open manner. Just like with younger children, it is important to take cues as to how much information they are ready to know. Some will want to know everything, and others will not. To foster an environment of openness and trust, it is critical that parents let their children know they can freely ask questions and not to worry that asking certain questions will upset them. However, it would be helpful to let children know they can talk to their parent's health care professionals to ask questions should they prefer not to ask their parents out of fear and worry about their reactions.

Example phrasing to consider:

- How much do you know about ALS? Do you have any questions you'd like me to answer right now?

- Finding out your parent has ALS must be really tough. I'm sure there are a lot of thoughts going through your head right now, but I want you to know you can contact us whenever you have any questions.
- I know ALS is going to change some things for you. How you feel about that?
- Even though ALS will change things your parent can do, let's talk about what they still can do right now and how we can help them remain independent.
- Do you have some ideas about what you could do to help your parent(s) at home? Maybe we can discuss some things that you could talk to your parents about doing.

Children and home visits

When a parent is diagnosed with ALS, the child's home may not seem like the safe and secure place it used to be. Changes such as home modifications and the introduction of medical equipment can be unsettling and confronting for children. The arrival of the health care professionals can add another level of uncertainty and confusion as the range and frequency of visitors can seem overwhelming.

"As I was at school most of the time I didn't really have any contact with the people who came and talked to us at home. I was often getting home and there were people I didn't know leaving. I didn't really have any information apart from what my mom told me."

It can be helpful to reduce the mystery about what is happening and who people are by including children, especially older children, in therapy, counselling, and care planning sessions. Teenagers in particular are likely to feel more in control if they understand and are prepared for the changes involved in the progression of their parent's ALS. They may want to know the reasons for decisions about their parent's care and be included

Practical strategies for supporting young people

Although the time health care professionals might have with the children may be limited, it is very valuable when people outside the family encourage and validate young people. Whether you interface with your patients' children in the home setting, medical office, or during an interdisciplinary ALS clinic visit, there are several support strategies you can use.

Experienced health professionals' suggestions include:

- Make a special connection with the children by knowing their names, ages and interests.
- Provide opportunities for them to ask questions about their parent's care and answer honestly, taking into account their language level and familiarity with medical terms.
- Invite older children, with parents' permission, to attend therapy, care planning and counselling sessions. If they do attend, check their understanding of the situation and clarify any confusions or misunderstandings.
- When arranging home visits, be sensitive to family routines such as school pick-up time. Joint home visits can help to reduce disruptions to home life.

- Encourage open communication within the family. Suggest ways parents can keep communication strong.
- Encourage parents to help the children create a balance between helping and sharing activities with their parent with ALS, and keeping up their own interests and friendships.
- Be aware of any cultural and religious/spiritual attitudes likely to influence the way the family communicates and manages living with ALS. Consider seeking the family's permission to involve interpreters, ethnic support organizations and pastoral care workers.
- Encourage parents to keep in contact with the school so they are aware of any difficulties or behavioural changes the children may be experiencing at home, in school or with their friends.
- Help the parents talk through their concerns if there are serious changes in a child's behaviour.
- Explain the value of personal counselling. Children may prefer to talk to a person not directly involved in supporting their parents.

Information for health care professionals less familiar with ALS

Amyotrophic lateral sclerosis (ALS), sometimes called Lou Gehrig's Disease, or motor neuron disease in some regions of the world, is a progressive fatal neuromuscular disease. It is characterized by the degeneration of upper and lower motor neurons in the brain and spinal cord. Degeneration leads to progressive weakness, wasting, and paralysis of all muscles involved in mobility, swallowing, speaking, and breathing. The region of the body where the onset of symptoms may occur can vary from person to person. Onset may begin in nerves associated with muscles of the upper or lower limbs, the throat, or upper chest area. ALS does not usually involve the loss of sensory, bowel, bladder, and sexual function. In perhaps as many as 50% or more cases, cognitive

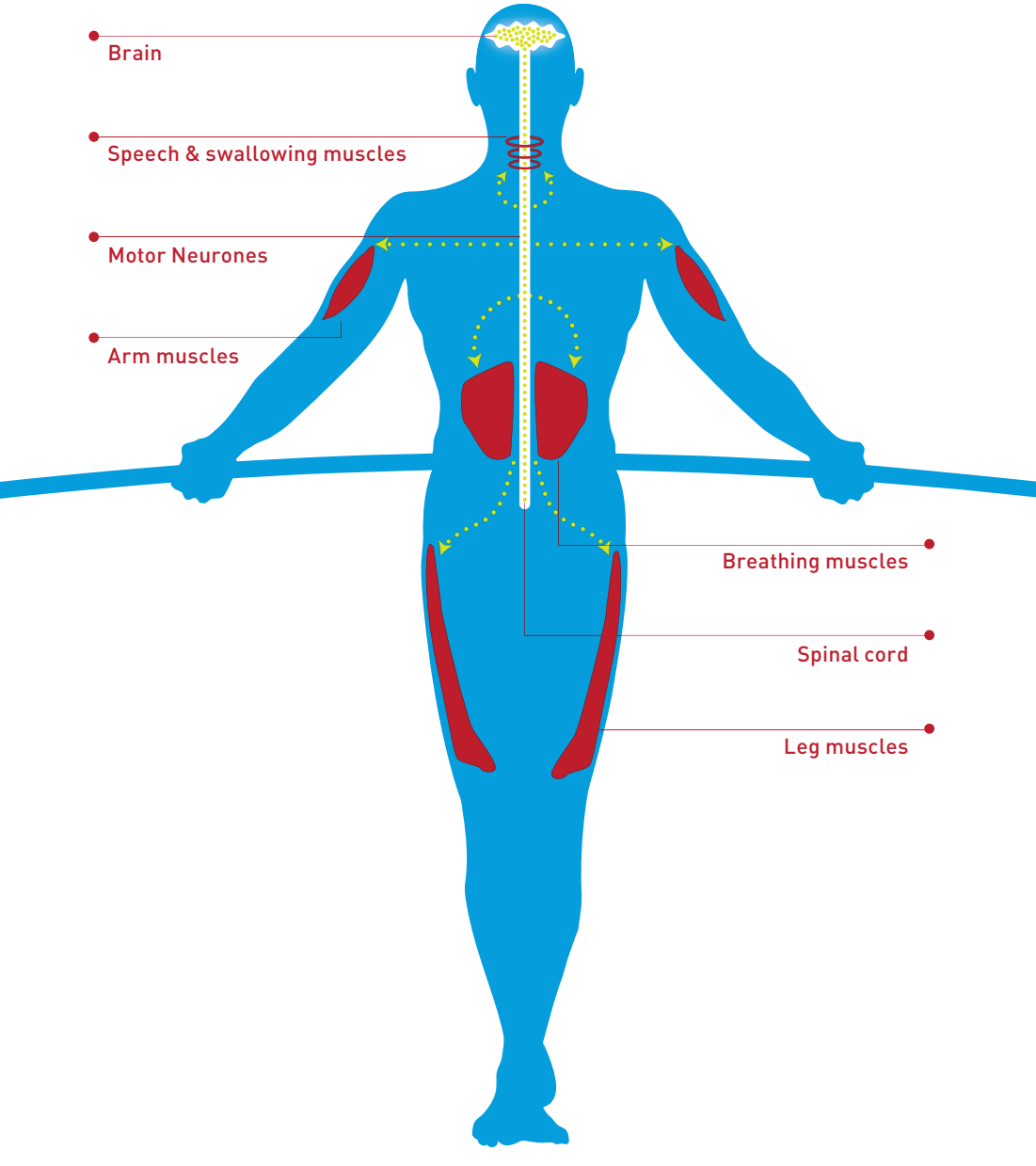
abilities may be mildly to moderately affected such as executive function or subtle changes in personality and behavior. Dementia meeting the criteria for frontotemporal lobe dementia (FTD) may occur in a very small proportion of cases. People with ALS are usually very aware of what is happening and must cope with each stage of progression.

The patterns of weakness and rate of progression varies from person to person, however people with ALS are likely to face rapidly increasing levels of disability.

Some general facts include:

- Approximately 2500-3000 Canadians are living with ALS at any given time (prevalence)
- The number of new cases each year (incidence rate) is 2/100,000
- The number of people who die each year with ALS (mortality rate) is also 2/100,000
- The cause is unknown
- There is no treatment to date that slows progression and prolongs life significantly
- ALS typically strikes most people between the ages of 40 and 70, but people as young as teenagers and those in their 90's have been diagnosed with ALS
- Eighty percent of those diagnosed live for two to five years after diagnosis; 20% live past five years, and only 10% live 10 years or longer
- In 90% of cases it strikes people with no family history of ALS
- A person with ALS is best supported by a coordinated health care team that can assist with symptom management and adaptive technology to remain as independent and comfortable as possible for as long as possible

Motor Neurons in our Brains & Spinal Cord carry messages to muscles in different parts of our body



ADDITIONAL RESOURCES

To understand ALS from a child's or teen's perspective, visit www.als411.ca, to access sites developed by the ALS Society of Canada for children and teens.

PRINT RESOURCES FOR YOUR PATIENTS' CHILDREN

When Someone Special has ALS— A Booklet for Children, a resource published by the ALS Society of Canada and part of the als411 series. It can be downloaded from www.als411.ca, or ordered through your Provincial ALS Society.

When Your Parent Has ALS— A Booklet for Teens, a resource published by the ALS Society of Canada ad part for the als411 series. It can be downloaded from www.als411.ca, or ordered through your Provincial ALS Society.

Grandpa, what is ALS? To order this book, contact the ALS Society of Alberta, (403) 228-7752, www.alsab.ca.

In My Dreams…I Do! Inspired by the authors mother who continued to nurture an intimate bond with her grandchildren, despite her battle with ALS. The narrative gives testimony to the magical power of the imagination—a secret that most children instinctively possess. It has universal appeal to navigating the road of life together. It can be ordered through the Les Turner ALS Foundation at www.lesturnerals.org.

Additional resources for young people covering psychosocial issues of coping and grief and loss are listed in the Resources section of *A Manual for People Living with ALS.* This can be downloaded at no charge to healthcare professionals at www.als.ca.

RESOURCES FOR MORE INFORMATION ABOUT ALS: ON-LINE RESOURCES:

www.als.ca (ALS Society of Canada)
www.alsa.org (The ALS Association, United States)
www.als-mda.org (Muscular Dystrophy ALS Division—United States)
www.mndaust.asn.au (Motor Neurone Disease Association of Australia)
www.mnda.org (Motor Neuron Disease Association, United Kingdom)

MEDICAL REFERENCES:

A Guide to ALS Patient Care for Primary Care Physicians A CD-ROM formatted publication produced by the ALS Society of Canada.

Also available for download at www.als.ca.

Amyotrophic Lateral Sclerosis
By Hiroshi Mitsumoto, M.D., et al
Oxford University Press
2001 Evans Road
Gary, NC 27513
(800) 451-7556
ISBN: 0803602693

Amyotrophic Lateral Sclerosis: Diagnosis and Management for the Clinician
Edited by: Jerry M. Belsh, MD and Philip L. Schiffman, MD
Futura Publishing Company, Inc.
135 Bedford Road
P.O. Box 418
Armonk, NY 10504-0418
(914) 273-1014
ISBN: 0879936282

Motor Neuron Disorders
Edited by:
Pamela J. Shaw, MD
Michael J. Strong, MD
Butterworth-Heineman/Elsevier, Inc.
Independence Square West
Philadelphia, PA 19106
(215) 238-2239
ISBN: 0750674423

Palliative Care in Amyotrophic Lateral Sclerosis: From Diagnosis to Bereavement
By David Oliver, Gian Domenico Borasio and Declan Walsh
Oxford University Press
ISBN 0192637667

Provincial ALS Societies

ALS Society of Alberta (and NWT)
1-888-309-1111
www.alsab.ca

ALS Society of British Columbia (and Yukon)
1-800-708-3228
www.alsbc.ca

ALS Society of Manitoba
1-866-718-1642
www.alsmb.ca

ALS Society of New Brunswick
1-866-722-7700
www.alsnb.ca

ALS Society of Newfoundland and Labrador
1-888-364-9499
www.envision.ca/webs/alsnl

ALS Society of Nova Scotia
1-866-625-7257
www.alsns.ca

ALS Society of Ontario (and Nunavut)
1-866-611-8545
www.alsont.ca

ALS Society of Prince Edward Island
1-866-625-7257
als_society_pei@hotmail.com

ALS Society of Quebec
1-877-725-7725
www.sla-quebec.ca

ALS Society of Saskatchewan
1-306-949-4100
alssocietyofsask@sasktel.net

ALS

"I need constant exposure to other ideas, other ways of working, so that I can provide the person and family members with appropriate assistance in a sensitive and respectful way." (Social worker – Palliative care)

Communication

Effective communication within the family can help to minimize the profound impact that living with ALS can have on the children's lives. Health professionals can play an important role in supporting good communication between family members. Health teams need to know as much as possible about the disease and the family, to communicate effectively with them. The family needs to feel confident that help is being given by professionals who have a sound working knowledge of ALS and its longer term impacts. Most families living with ALS will at some time feel overwhelmed and fearful. They will know that they need answers but may not know what questions to ask.

"Families need assurance that they will not have to struggle along this path alone." (Counsellor)

Interdisciplinary team approach

The large range of professionals in a health care team can be confusing and at times overwhelming for the person with ALS and their family. It can be helpful to create a list of the professionals involved, with contact details and a simple explanation of what they do. This can help children in the family to have a clearer picture of who is involved and why. It can also help the family if they can identify a team coordinator as the

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in the decision-making itself – to be a real part of the ALS "journey."

"Dad's attitude helped me and sharing my feelings with friends/family, writing it down, sharing a project that we both felt strongly about - writing a book about his life and illness - feeling like I was part of the journey."

The health team can also support young people when making home visits by giving them the opportunity to ask questions about Mom's or Dad's care. They may not want a lot of information - you can check their comfort levels by asking what information feels like "too much" at this time. It is important their questions are answered honestly and openly. Always check if there is anything else they would like to know.

Team members might also suggest how the children could help out and spend "special time" with their parent with ALS.

This can help build their sense of belonging and self esteem. Special times spent with parents and regular routines for "chatting" helps strengthen family relationships.

Maintaining open and honest communication within the family is critical to the well-being of the person with ALS, their caregivers, and their children.

A family member who is reluctant to communicate may be reassured by a discussion of the range of feelings and reactions experienced by other families striving to manage in similar circumstances.

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The Canadian young people who contributed to *When Your Parent Has ALS —A Booklet for Teens*, for quotes that were also used in this publication.

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if they are "to blame" - they need to be reassured that ALS is not their fault. Children of this age can also believe in "miracles." Very young children do not think abstractly and may only need to know what having ALS means right now, that is, what are the current manifestations of ALS and how does it affect their parent and them. Concepts about the distant future are not well understood.

Parents can sometimes be upset and hurt if they do not understand the transience of young children's reactions. Children may ask serious questions and seem sad one minute and a moment later they will be playing happily. This is normal developmental behavior at this stage. Younger children can be obsessed with germs. They may need reassurance that Mom's or Dad's ALS is not "germy" or contagious. They also need to know that they will continue to be loved and cared for. Wherever possible, parents should maintain the children's regular routines such as meal and bed-times, and be consistent about good behaviour and discipline. School aged children should be given age appropriate options regarding how they can help at home to make them feel involved.

Example phrasing to consider:

- Your mommy/daddy came to the doctor to find out why he/she is having trouble walking lately and we found out he/she has something called ALS. We're going to help him/her stay as strong as possible and learn how to get around safely using a wheelchair.