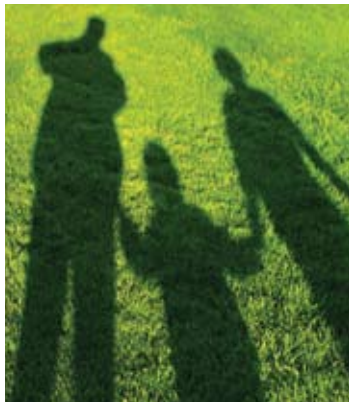
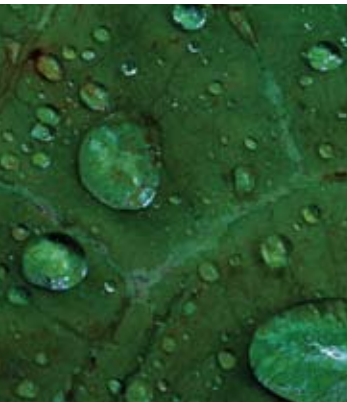




Helping Children Cope With

# ALS

A Parental  
Information Guide



# ALS

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When a family member has been diagnosed with Amyotrophic Lateral Sclerosis (ALS) children have many questions and concerns about the person they know and love. We offer these guidelines as a tool to assist your family when talking or sharing information and personal feelings about ALS. You may also want to share this information with other important adults involved in your children's lives such as teachers and coaches.

An illness such as ALS brings about many changes within a family. Every member is affected in some way. Each person will have his or her own worries and secret fears. Sometimes not talking about what is happening may seem like the easiest way of dealing with such a serious situation. However, many children who have had a parent or family member with ALS later express the wish that they had been included in more discussions, and were able to talk and ask questions.

Talking and sharing when faced with an ALS diagnosis may bring family members closer together. However, families vary greatly in the extent to which they share information and emotions. As you read this information, remember that every person's situation is different, and you must do what seems right for you and your family.

# Why children need to know the facts

Many people hope they can protect children from difficult situations by not explaining the severity of an illness. Children, on the other hand, can easily feel isolated, forgotten and misunderstood if they are excluded. Such feelings can be more damaging than sharing in the family's experience. Like adults, children need information and explanations to make sense of what is happening. If uninformed, children usually imagine something far worse and reach their own inaccurate conclusions.

**TIP:** Visit [www.als.ca/als411](http://www.als.ca/als411) for list of child-friendly resources. Keeping your child informed is important, but ensuring that they are not overwhelmed with complicated details is also vital.

Many children, especially younger children, often believe that their own thoughts, wishes, and actions can influence events. Some may be afraid they have “caused” ALS, or it is their fault that the person is getting worse. Children need to be frequently reassured that the illness and the events surrounding the illness are not their fault in any way.

Children usually know when something is wrong – they see that adults are upset or behaving differently, are preoccupied, irritable, or tearful. Children also overhear conversations, as well as noting the physical changes of the person with ALS.



## How to tell children about a serious illness

Education should be a continuous but gradual process, not overwhelming the children with information all at one time. The rate at which information is given, the amount and type will depend largely on the age of the child, as well as the illness progression rate.

Choice of words you use is extremely important – clear, correct and precise words are best so that misunderstandings are prevented whenever possible. Trying to explain a serious illness, such as ALS, to children when you yourself may not understand the disease is one of the reasons explanation is delayed or difficult. Seek assistance if necessary from a health care professional to help you find the right words to use with your children.

Initiate the conversation by referring to things the child already knows. For example, if ALS is affecting their father's legs you could say, “You know your dad has been having difficulty walking lately. He has seen the doctor who has told him he has an illness called ALS that is going to make it more and more difficult for him to walk.” You may wish to explain further or decide this is enough information for your child, but a conversation like this is a good starting point. Bringing the subject of ALS out into the open shows your child the subject is safe to discuss.





Gradually give more information about the illness and the illness progression. It helps a child to feel an adult is in control. However, it is equally important to stress how variable ALS progression can be. Talking about how you plan to manage day-to-day family affairs helps children feel more at ease.

Children are acutely aware of “differences” and may be embarrassed by the changes caused by the illness. They need help in understanding that although Mommy’s voice sounds strange or Daddy is in a wheelchair, it is still Mommy or Daddy. Close family should be kept informed and encouraged to visit as much as possible.

Explaining to a child that someone they love is ill and will not live much longer is difficult. Just thinking about illness and death is disturbing. Wanting to protect your children from these feelings or protect yourself from your child’s possible grief is normal.

What you tell your child about death should depend on the age of the child and the stage of the illness. A child’s perception of time is usually very different from an adult’s. Therefore, if it appears that death is not expected in the very near future, children should be told that death will not happen for some time. Understanding death, for children, depends not only on their age and experience but also on a family’s religious beliefs.

Parents may have had an opportunity to discuss mourning or death through previous family loss or the loss of a pet. Explaining natural feelings of sadness when losing a loved one and showing that happy memories can live on after the sadness lessens is helpful for children.

**TIP:** Consider buying a young child a pet fish. With their short lives, your child will have the opportunity to experience the transition from life to death to grief.

Children can be extremely frightened by the changes in a person with ALS. Seeing the adult who cared for them become increasingly dependent, unable to function and, at times, emotionally distressed is disturbing for children. Angry outbursts and irritability caused by intense frustration may worry children, especially if they do not understand the cause. Time spent giving simple explanations helps children cope.

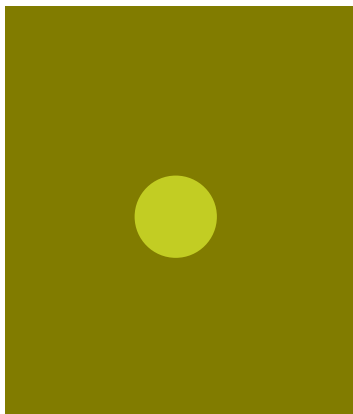
For some children, the only experience of human death is the violence reported on television news or in films. They may believe that all deaths are violent. Children need reassurance that death from disease is different from what they see in the media.

**TIP:** Remove yourself from your child’s environment at times when you feel as though you are not in control of your emotions. It is important for your child to see you grieve, but exposure to controlled grief is much less frightening.

## Answering questions

Many children dictate the pace information is given. However, you should not assume that a lack of questions is the same as a lack of interest. Children may need to be prompted to ask questions. Remember that some children feel too afraid of what they will hear to ask questions.

When answering children’s questions, be honest and truthful. Don’t be afraid to say, “I don’t know” or “the doctor doesn’t know.” It is important to remember that children will know when you are not being truthful and wonder if additional facts are being hidden. Even if you don’t know the answer, your children’s questions will give you some idea of their concerns.



Don't overwhelm children with information. An answer to a specific question may be all that is required and can present an opportunity for further discussion.

**TIP:** Consider putting out some age-appropriate information on ALS in an accessible place at home. This way, your child can choose whether or not they are ready to learn more about the disease.

Some children find it easier to talk to an adult other than a parent. They might be afraid of upsetting a loved one by talking to them about their illness or that of their partner. Another adult can reassure children that their parent is “emotionally strong” and encourage them to share more of their fears and worries with the parent.

Children want answers to many practical questions, such as “Who will take me to school if Mom can't?” or “Will we have enough money if Dad is not able to work?” or whether they will go ahead with vacation plans. Encouraging discussion and questions may reveal worries you had never thought of. Young children particularly need to be reassured that they will always be cared for.

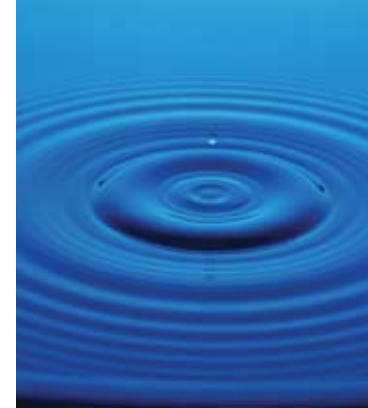
## Contact with the school

A child's teacher should be informed of a parent's ALS diagnosis. They need educational information regarding ALS and should stay informed of any effects it is having on the family. A teacher can help with many practical and emotional difficulties children may have. You may want to share a copy of this booklet and other information provided by the ALS Society of Canada to educate teachers.

**TIP:** Children often do not want their classmates to know of their parent's ALS diagnosis. Talk with your child about their thoughts on this issue and ensure their teacher is aware that discretion should be used.



[www.als.ca/als411](http://www.als.ca/als411)



## Feelings and reactions

Talk with children about feelings as well as facts. Sharing your emotions will help them understand their own emotions. Show them that openness and sharing are important behaviors that help when coping with pain and sadness.

Don't be afraid to cry in front of children, it is a natural reaction when sad or upset. If this makes you uncomfortable or frightens the children, tell him or her that you do cry in private.

Even when talking is encouraged, children express themselves in other ways – in play, drawings, or actions. Watching or participating in some of these activities helps you understand their emotions.

Denial is another common reaction many people use when faced with something painful and unpleasant. Children may hope that by not talking about ALS and pretending nothing is happening, things will either get better or go away. Older children are often particularly good at this.

Aggressive behavior is also very normal. Children can be angry or resent the changes that illness has brought into their life, including the amount of attention taken away from them. Children may express anger directly at the parent with ALS or display other attention-seeking behaviour.

**TIP:** Understand that your child's anger is a natural reaction. It does not mean that they do not love you, but is simply their way of coping. Try not to let such behaviours upset you.

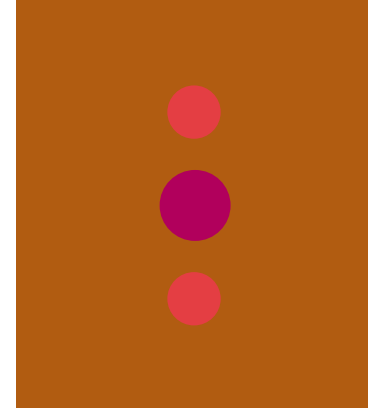
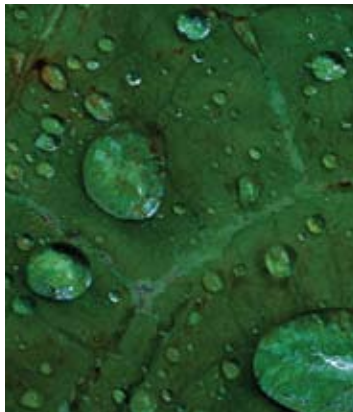
Children are often confused about changes resulting from an illness. For example, if a parent stops playing with them they might think they are no longer loved or have done something wrong. Children need help understanding that no matter what happens they are still loved. Seek different ways for the parent and child to have time together. Finding “special tasks” children can do to help allows them to remain involved and feel important.

**TIP:** When choosing activities for the child and parent to share in, find things that will not be limited by ALS. For example, a movie night allows the child to spend quality time with their parent without being reminded of the disease’s limitations.

It is easy to let ALS take over your daily life. Maintaining normal daily family routines is important for children to feel secure and safe in times of stress. Find time to give your children love and undivided attention, show them that life goes on. Accepting help with household chores allows you time for the children.

## Things to do as the illness progresses

As the illness progresses, many families find comfort making a special remembrance book or filming videos. Photographs and other mementos will be a reminder of the happy family times, as well as a reminder to the child of how much they were loved. Older children may find that discussing their future plans for college, employment, or marriage with the person with ALS can help them later during their bereavement.



**TIP:** Consider introducing a feeling box where the child can deposit things they have written down throughout the day. Arrange a time to sit down with your child on a regular basis to discuss what they have written.

## Sources of help and information

There are many sources of help. Contact the ALS Society of Canada to discuss what is available in your community or visit [www.als.ca/als411](http://www.als.ca/als411) for a list of child friendly resources.

## Acknowledgements

The ALS Society of Canada is indebted to the Motor Neurone Disease Association (UK) for their permission to adapt their original booklet for our Canadian audience.

## Provincial ALS Societies

ALS Society of Alberta (and NWT)  
1-888-309-1111  
[www.alsab.ca](http://www.alsab.ca)

ALS Society of British Columbia  
(and Yukon)  
1-800-708-3228  
[www.alsbc.ca](http://www.alsbc.ca)

ALS Society of Manitoba  
1-866-718-1642  
[www.alsmb.ca](http://www.alsmb.ca)

ALS Society of New Brunswick  
1-866-722-7700  
[www.alsnb.ca](http://www.alsnb.ca)

ALS Society of Newfoundland  
and Labrador  
1-888-364-9499  
[www.envision.ca/webs/alsnl](http://www.envision.ca/webs/alsnl)

ALS Society of Nova Scotia  
1-866-625-7257  
[info@alsns.ca](mailto:info@alsns.ca)

ALS Society of Ontario  
(and Nunavut)  
1-866-611-8545  
[www.alsont.ca](http://www.alsont.ca)

ALS Society of Prince  
Edward Island  
1-866-625-7257  
[als\\_society\\_pei@hotmail.com](mailto:als_society_pei@hotmail.com)

ALS Society of Quebec  
1-877-725-7725  
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