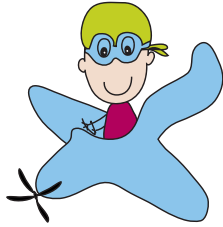


When Someone Special Has

ALS

A Booklet For Children





ALS

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You are probably reading this booklet because your Mom or Dad or someone else special in your family has Amyotrophic Lateral Sclerosis. It is a long name and for short it is often called ALS.

Not many people get this illness and some adults you talk to may never have heard of it or know very little about it.

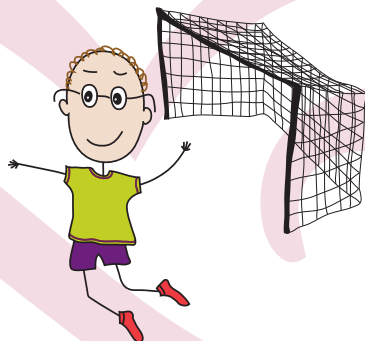
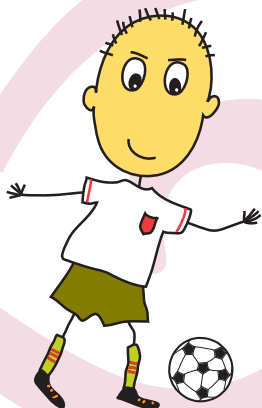
This booklet tries to answer some of the questions you may have about ALS, including: What is ALS? What parts of the body are affected? What causes it? Will I get it? Do people with ALS get better? It also talks about the feelings that you may have about ALS and what is happening.



First of all... what is ALS?

In the human body there are lots of muscles, and we use many of these muscles to move. But before muscles can move they have to receive instructions or messages from the brain. The messages are sent to the muscles by nerves. These nerves are like the telephone wires which carry messages to operate the telephone in your house.

If you want to kick a ball, a message is carried from your brain, along nerves to the muscles in your leg to tell them to kick. This happens very quickly, and you can't feel the messages going through from your brain to your leg.





When someone has ALS, something goes wrong with these nerves, which are called motor neurons. Gradually fewer and fewer messages get through, so the muscles will not move properly. If none of the messages get through, then the muscles are no longer able to move at all however hard the person tries.

What parts of the body are affected by ALS?

The main effects are on the muscles in the legs, arms, mouth and throat, but not everyone has all these problems.

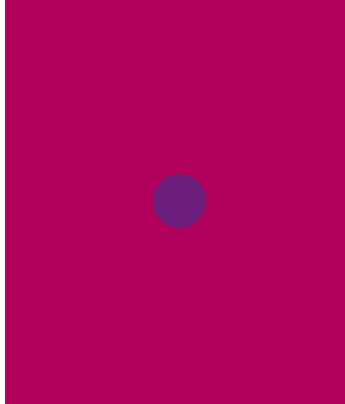
The people who have problems moving their legs, may have difficulty walking, standing or climbing stairs. They may also find it hard to keep their balance and may fall. To help them get around they may need a cane, walker, or wheelchair.

Those who have problems in their arms and hands may find it difficult to hold and carry things. They may not be able to cook, use tools or take their clothes on and off without the help of special gadgets or other people. Some people cannot move their arms at all.

When we eat and talk we use a lot of muscles in the mouth and throat. For some people with ALS it is these muscles that are affected. It may be difficult for them to talk clearly. Their voices sound strange and it may be hard to understand what they are saying. They may need equipment, such as a computer to help them communicate.

Others may find it difficult to eat and drink. Because of this they may have specially prepared food and need to eat very slowly. They are often worried that food will go down “the wrong way” and make them cough.





Other ways in which ALS may affect people

ALS affects people's bodies in different ways so nobody can say exactly what will happen next. But whatever happens, the person is still the same “underneath” as they were before the illness started.

Most people with ALS get tired quickly and need to rest a lot. Some find the illness makes them cry easily. Others find it makes their laugh sound strange or they laugh really hard for a long time at things that may not even be funny.

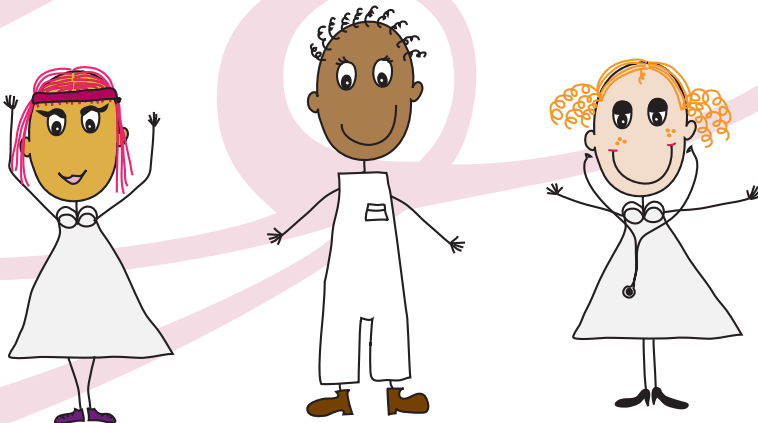


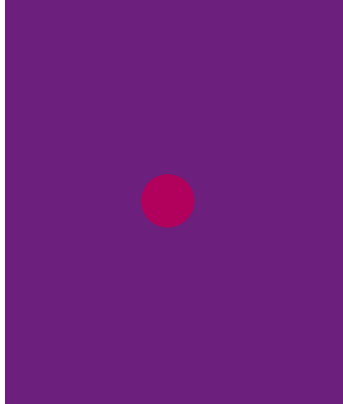
People sometimes get angry when they cannot do simple things for themselves, like getting dressed, going to the toilet, or scratching an itch. They may become irritable and mad because they have to ask for help.

Lots of things stay the same when people have ALS. They feel pain when they are hit or have to sit in one place for a long time. They can hear... see...and think...Even if talking is difficult for them they may find other ways of letting you know what they want to say, perhaps by a hug, a wink, a frown, or a smile.

What causes it?

We don't know, but a lot of research is taking place to try to find out. We do know that it is not contagious. That means you can't "catch" ALS like you can a cold or the flu.





Nobody can cause another person to get ALS or make them get worse. We all think hurtful thoughts or say horrible things to other people sometimes but this will not give them ALS.

Do children get it?

No. Only adults get ALS. It is most common in people between 40 and 70 years old. Some very young and very old adults can get ALS, too.

Will I get it when I am an adult?

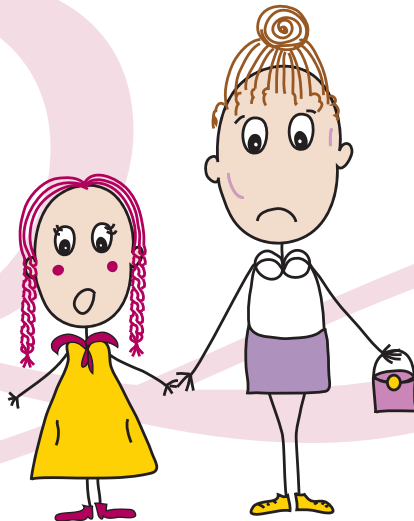
In most cases we can say that you won't. There is a rare type of ALS where more than one member of a family has it. Scientists and doctors are working very hard to try to find out what goes wrong in these cases. Hopefully, in time, we will be able to prevent people in the same family from getting ALS.

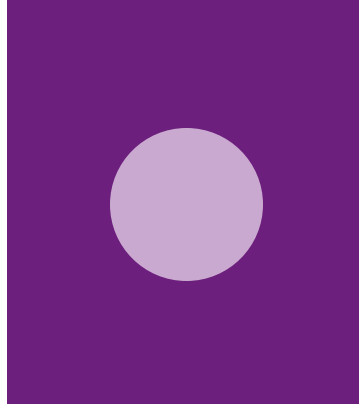
Do people die because they have ALS?

People with ALS do not get better. Sadly, it is an illness from which people die. We do not know how long a person with ALS will live because it varies a great deal from one person to another.

Your feelings

When your Mom or Dad or someone special has ALS it is natural to feel sad when you remember how they used to be. Sometimes you feel so sad that you want to cry. Don't feel ashamed or try to bottle it up. We all want to cry when we're upset. Your parents may cry too, when they are sad, even if you don't see them doing it.





You may find that grown-ups in the family often seem to be thinking of something else when you are with them. They may often seem sad or upset. They are probably worrying about what is happening. Do not think that you are the cause of their sadness or worrying. They have not stopped loving you.

You may be worried and afraid because you don't know what is going to happen. You may be frightened to ask questions. Try to talk to your Mom or Dad, or perhaps you have an uncle or aunt or another adult outside the family you could talk to. Talking often helps and it is one way of letting feelings out. It also lets the adult know how you feel...and that is important.

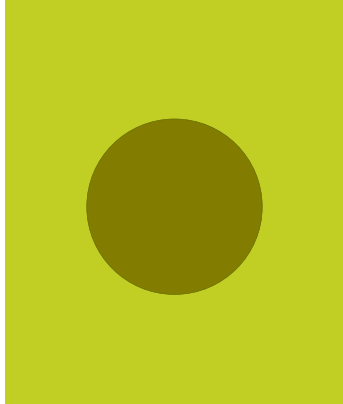
Perhaps someone has already spoken to your teacher at school and told them about your Mom or Dad's illness...try talking to your teacher if you are worried. Don't forget that the ALS Society of Canada is here for you.

You can't be sad all the time. Don't feel guilty when you are happy. Try to have fun as you used to – it's important, and it is good for the person who is ill to see you enjoying yourself.

At times you may feel angry; the person with ALS is getting all the attention and their illness seems to have changed everything. But then you may feel guilty for feeling angry. You may be mixed up inside but don't know why. We all feel angry at times when life doesn't go as we want, and we have to learn to cope with these feelings. It can be hurtful if we lash out at someone, so it is important to look at other ways to get rid of those feelings.

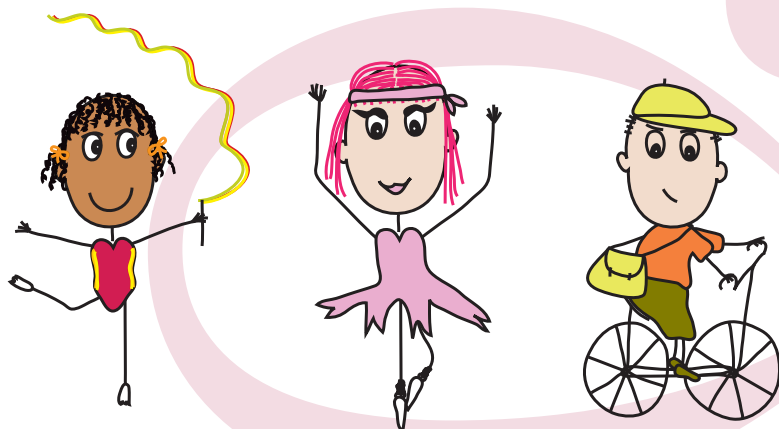
Play with your friends, play sports, listen to your favorite music, draw or write a song, story, or a poem – they are all good ways to feel better.





Your parents will not want the illness to affect your life, but of course it does in many ways.

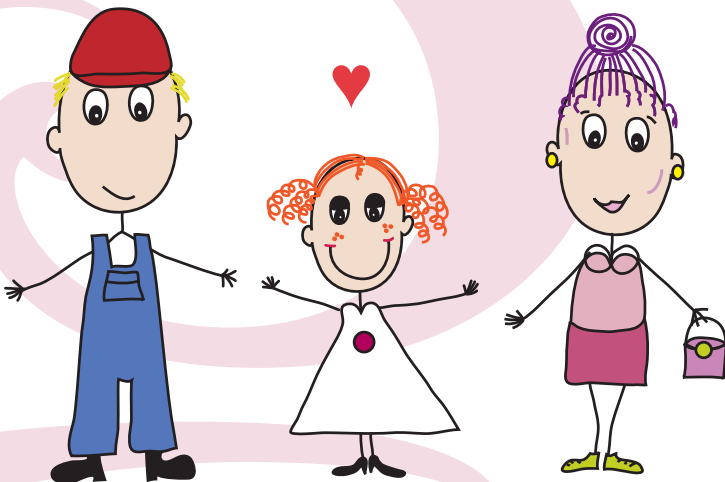
You may not want your friends to come over to your house if you feel embarrassed about the way the person has changed on the outside because of ALS. But your best friends will understand if you tell them about the illness and explain too, that underneath, the person is just the same as they used to be.



Things to do for the future

Knowing that your Mom or Dad or someone you love is not going to get better is sad, and hard for you. There may be things you can do to make your time together special. You may find small but important tasks you can do for them. Perhaps you could make a scrapbook of photographs and stories about the things you have enjoyed doing and the happy times you have had together.

You will be able to look at this book later and remember how much you loved each other. Nothing will ever be able to take away these memories from you!





Acknowledgements

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