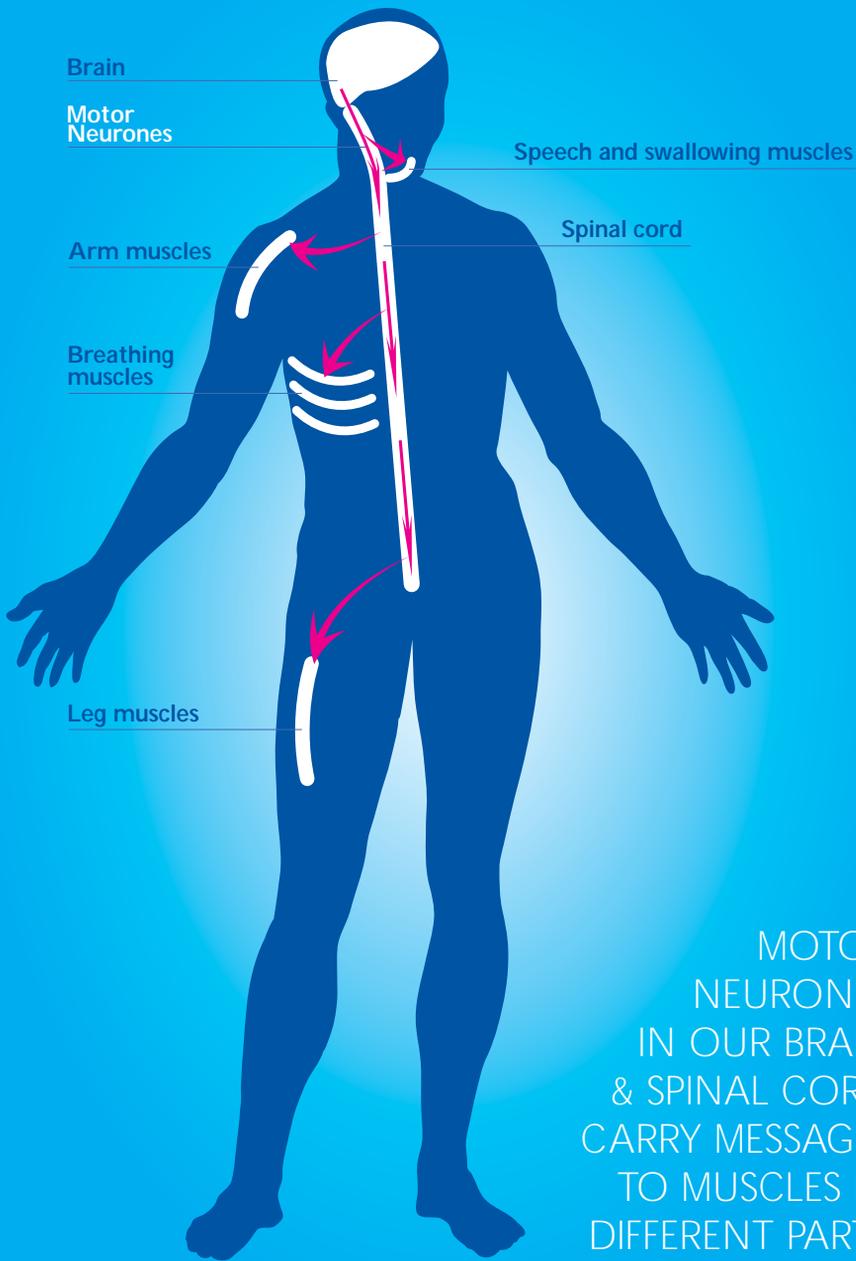




TALKING ABOUT
MOTOR NEURONE DISEASE
FOR FRIENDS



MOTOR NEURONES IN OUR BRAIN & SPINAL CORD CARRY MESSAGES TO MUSCLES IN DIFFERENT PARTS OF OUR BODY

WHEN YOUR FRIEND'S MUM OR DAD HAS MOTOR NEURONE DISEASE

There are some very useful things you can do to help a friend when their Mum or Dad has motor neurone disease (MND). The first step is to understand more about MND and how it can affect a family.

WHAT IS MND?

Our bodies are amazing - they can do so many things! That's because we have MUSCLES all over us. Muscles help us to move around. The muscles in our legs work so that we can walk. The ones in our arms let us pick up things, clean our teeth and comb our hair. Our mouth and throat muscles let us talk, chew and swallow our food and drinks.

Before a muscle can move it needs a message from the brain telling it what to do. The brain sends its messages through special nerve cells called motor neurones. Motor neurone disease (MND) is the name for what happens when a person's motor neurones stop working properly. In some countries MND is called 'ALS'.

When motor neurones break down, fewer and fewer messages from the brain get through to some muscles.

These muscles grow weaker and start to waste away. Eventually, no messages from the brain get through - the muscles won't move even when the person tries very hard to use them.

Some people with MND won't be able to walk, some can't move their arms. Others might sound 'funny' because they can't talk clearly or swallow properly any more.

MND can also start for someone as difficulty speaking clearly, or finding it harder to swallow food and liquids.

It is a serious illness - it gets worse as it spreads to different muscles in the body. Some people live longer but most have MND from one to five years. There is no cure.





WHAT CAUSES IT?

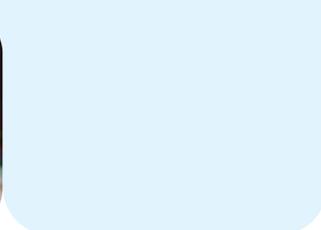
Nobody knows why people get MND but scientists around the world are working to find the causes and how to cure it. We do know that it isn't passed from one person to another by 'germs'. You can be physically close to someone with MND but you won't 'catch' it.

WHAT EFFECT DOES MND HAVE?

As the person with MND becomes weaker they may need more and more help to do things. This means that things the family can do together will change. Getting 'out and about' might be more difficult. Changes can happen very quickly and this can be very sad and difficult for the parent with MND and for everyone in the family.

Your friend's Mum or Dad might look different as they get weaker. It could become harder to understand what they say.

But their mind, the way they think, usually stays the same. They will be the same person 'underneath'. They'll remember the times you've called in and will still be interested to hear what you are doing.



HOW TO HELP YOUR FRIEND:

- Let your friend know that you are there for them if they want to talk about things.
- If they don't want to talk, don't take it personally. Just knowing that you care can be helpful for them.
- If they do want to talk, just be a good listener. Try to understand how things are for them. Don't interrupt or give lots of advice.
- Your friend probably doesn't want to be 'singled out' for special attention - they will want their time with their friends and at school to be as 'normal' as possible.
- Be a 'buddy' as far as school goes. Help them keep up-to-date with school work if they have to take time off.
- There will be 'bad' days for your friend. Changes in what their Mum or Dad can do may happen quickly. Just let them know that you're there for them.
- Keep up your contact with your friend even if they don't return your messages. Try not to delay contacting them for too long - they may feel rejected and disappointed.
- Sometimes your friend may be very sad, withdrawn or irritable because of the differences MND is making to their life.

Don't think this is because of something you've said or done. They may be having to get used to medical equipment and many health care people coming into their home. They may need to spend more time helping out at home.

HOW TO HELP YOUR FRIEND:

- Their parents may not be able to drive them around as much as they used to. A lift to sport or a party can really help your friend keep up their activities & social contacts. Don't offer more help than you can really manage, so your friend won't feel let down when you can't help them.
- Take an interest in what is happening with their Mum or Dad. If you're invited to visit, ask what changes you need to know about, so you're prepared. You may feel uncomfortable with some of the changes you notice, but this usually passes.
- Be honest if helping out and visiting become difficult for you. You could say something like:

“What’s happening to your Mum or Dad is making me really sad and I’m finding it hard not to show my feelings”.

- Don't feel guilty about having fun in your own life because your friend is having a tough time in theirs. You might want to say something like:

“I wish I could make things better for you. I don't feel comfortable talking about good times I'm having, when things are tough for you. I want to share what I'm doing, like we always have”.

- Sometimes you may feel that you need some help yourself to keep on going. Talking with someone about the effect MND is having on YOU can help you to stay available for your friend.

By being thoughtful and keeping your friendship strong, you will be a great help to your friend.



The 'TALKING WITH YOUNG PEOPLE ABOUT MOTOR NEURONE DISEASE' information pack was developed and produced as a joint project of Motor Neurone Disease Victoria and Motor Neurone Disease New South Wales, Australia.

The project was funded by the Australian Government Department of Health and Ageing under the Local Palliative Care Grants Program.

We would like to acknowledge:

- The parents, young people, schools, health professionals and counsellors who contributed to the 'TALKING WITH YOUNG PEOPLE ABOUT MOTOR NEURONE DISEASE' Project
- Consultants Dianne McKissock, OAM, author of *'The Grief of Our Children'*; Dr Elizabeth Bruce, PhD, MAPS, Developmental Psychologist, co-author of *'Through Loss'*
- Kajetan Design Group Pty Ltd, Melbourne Victoria

This booklet may be copied for personal or educational purposes only, unless authorised by the authors at info@mnd.asn.au

June 2008

