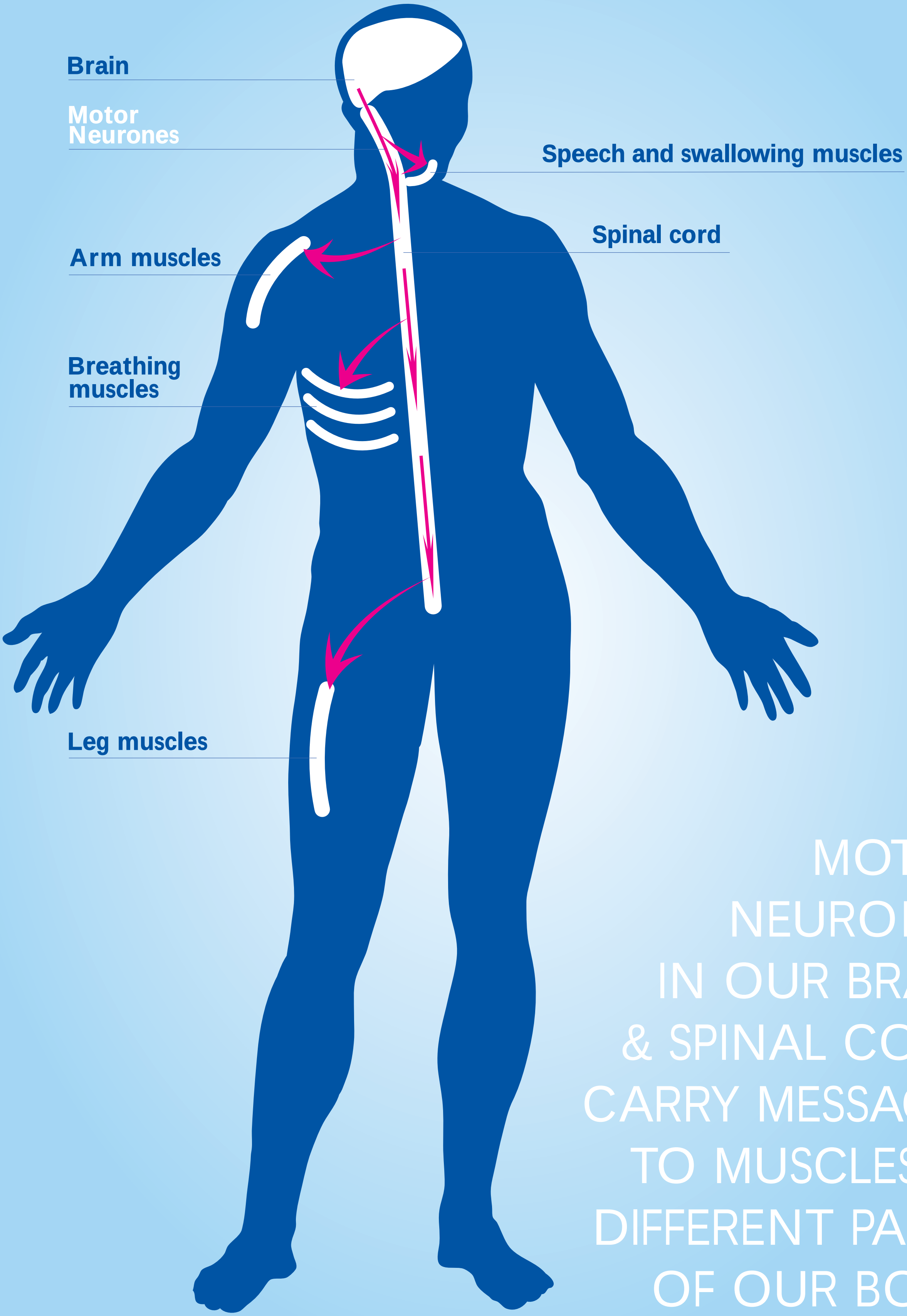
TALKING ABOUT
MOTOR NEURONE DISEASE
FOR 8 TO 12 YEAR OLDS

mnd Australia



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

Have you been feeling that your Mum or Dad has been moving more slowly and getting tired really fast? You might be worrying about what this means.

This little book is to help you understand what is happening, and some ways you might be able to help.

WHAT'S THE PROBLEM?

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.

If your Mum or Dad has MND they may not be able to do all the things with you that they did before. They may not be able to play with you or put their arms around you to give you a cuddle. But they will be happy to spend time with you.

When you feel like it, you can give them a big hug. It won't hurt them. Or you could cheer them up with a bright balloon or one of your special drawings.

Your parents will love and care for you just the same as before. Even when Mum or Dad's body begins to change, they will still be your own Mum or Dad 'underneath'.

SOME IMPORTANT THINGS TO KNOW ABOUT MND

☞ No-one knows what causes MND - it just happens.

☞ No-one is to blame. There is nothing you have said or done that has caused Mum or Dad's MND.

☞ There is no cure for MND right now, but scientists all over the world are working very hard to find one.

☞ You CAN'T catch MND. It's not 'germy'. You can always give Mum and Dad a hug and a kiss.

FEELINGS

MND affects everybody's feelings in a family as well as Mum or Dad's body. One person may feel sad, another might get angry. Another person may act as if nothing is happening.
You may have different feelings from other people in your family.

That's OK - your feelings are YOURS, and they're right for you.

Sad Feelings...

Sometimes you might feel very sad if you can't do the things you used to like doing.
Mum and Dad will be feeling sad about this too.
MND can make Mum or Dad very tired. It might make them cry more easily, which may upset you.
Sometimes you will cry too.

It's OK to cry when you feel sad. Crying helps to get rid of tight feelings that build up inside us. It helps us to feel better.

!!!Angry Feelings!!!

Sad or scared feelings can make you feel all 'mixed up', angry and HORRIBLE!

Mums or Dads with MND can also get cross because they need help now to do things they used to do themselves - like getting dressed or scratching an itchy spot. They won't like having to ask for help all the time.

MND might make YOU very angry because it can bring so many changes. It may take up so much of your parent's time and attention - time you used to have together.

And there could be a lot of strange people in the house helping Mum and Dad in the morning or when you get home from school. They are the health care team. They bring information and equipment to help make Mum or Dad more comfortable as their body changes.

Anger's OK. It can help to clear the air, so you can be honest about how you really feel.

!!!Happy Feelings!!

You are going to have happy days as well as some sad times. Remember that Mum and Dad want you to be happy. It's good for you to go on playing with your friends, having fun, and being the person YOU are.

You can 'grow' good feelings by doing things that make you feel happy about yourself.

Friends R 4ever

- It's really important that you keep in touch with your friends.
- Invite your friends to come over. Young people can help to cheer Mum or Dad up.
- Good friends will begin to understand and get used to your Mum or Dad's illness.
- Your parents have a little leaflet called 'For Friends' to give to your friends to read if you want to and if they're interested.

HOW YOU CAN HELP?

Try to make every day with Mum or Dad special.
Find out things that you can do to stay close together.

There may be new, special games you can play,
or maybe cuddle up and read, or watch a movie together.

Try to find one thing that will help Mum or Dad.
It can be your special thing to do and it can help
you to feel closer to them.
You'll be surprised how much help
you can be!

MND is a hard thing for your family to live with.
But it does give you the chance to:

- **LEARN MORE about each other**
- **Learn more about YOURSELF**
- **BE KIND & HELPFUL to each other**
- **UNDERSTAND & LOVE EACH OTHER BETTER.**

If you would like to know more about other families who are living with MND, ask Mum or Dad to show you these websites.

About MND - For Kids from Motor Neurone Disease Victoria
www.mnd.asn.au

Kids Help Line - Answers questions from young people aged 5 to 18
www.kidshelp.com.au

“What is ALS?” for KIDS - ALS is the American name for MND. A fun-style website.
www.march-of-faces.org/KIDS/moe1.html

“All for Kids” - Information on MND from the Canadian ALS Association
www.als.ca/allforkids

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

June 2008

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Victoria

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New South Wales