

Has your

Mum or Dad

got

MS?



**A BOOKLET FOR
YOUNG PEOPLE
ON FACTS & FEELINGS
ABOUT MULTIPLE SCLEROSIS**



AUSTRALIA

*Seeking the Cure.
Providing the Care.*

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Contents

About this

booklet

Someone you know has multiple sclerosis (MS) – it might be your Mum or Dad, an uncle or aunt or a friend.

This booklet will help you learn a bit more about MS. There are things to read and activities along the way – here is the first one:

Fill in the name of the person you know who has MS

.....

.....

You might want to read this book with Mum or Dad or ask someone else to read it with you. You could learn about MS together.



“ *I was fed up at first when Dad couldn't play football like he used to but now he reads to me more and I like that. Sometimes if his eyes are tired, I read to him.* **”**

Things you might ask about MS.

What a mouthful – no wonder everyone calls it MS.

MS = multiple sclerosis.

You are allowed to ask questions about MS. That's how you will learn more about it and understand it better. When you have a concern, you need to talk to someone so that they know you are worried.

This could be a close relative or friend or you could choose to contact one of the people suggested on page 14 of this booklet.

“ I didn't say anything because I thought Mum would get upset. She'd kept quiet because she thought I'd be upset. Now we talk about it and it's much nicer. ”

You might want to know:

What is MS anyway?

Why do people get MS?

What does MS do?

Will I get MS?

How do people get MS?

Is MS catching?

Do people die from MS?

Some of these questions are pretty frightening, adults ask these questions too. Most people, young or old, feel upset and mixed up about MS at times, but it's good to talk about it.

What is MS

anyway?

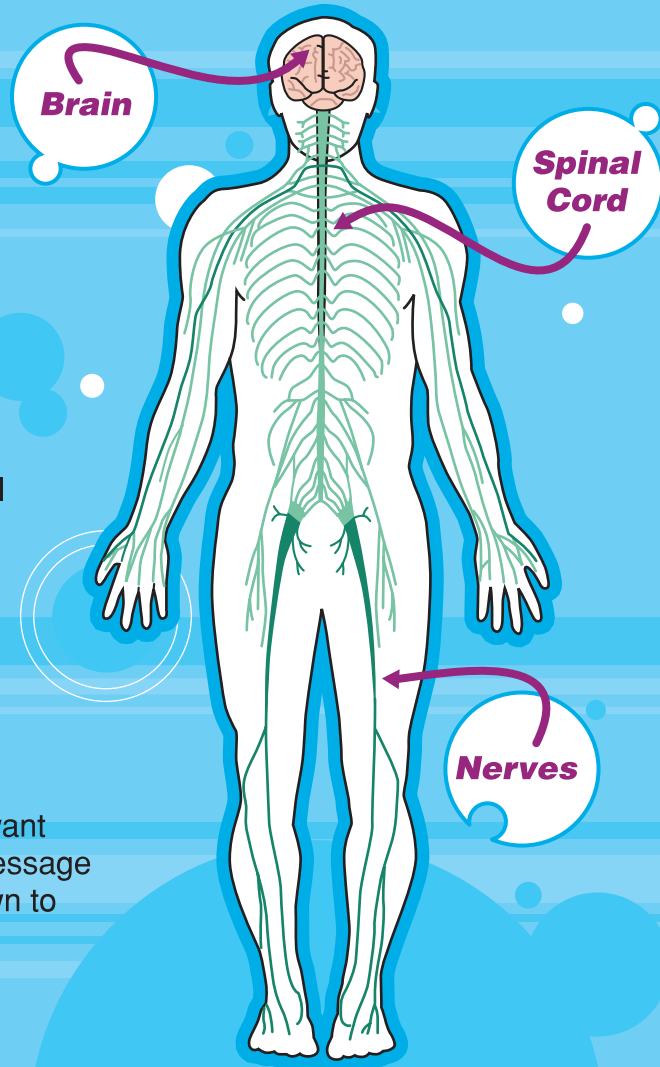


Maybe you have taken part in the **MS Readathon** and already know a bit about MS; but if not . . .

Multiple sclerosis affects the brain and spinal cord. The brain is like a computer that sends messages to the body telling it what to do.

The spinal cord is like a thick cable of wires attached to the computer. Messages travel from the brain, along the spinal cord, to the muscles and other parts of the body and back again.

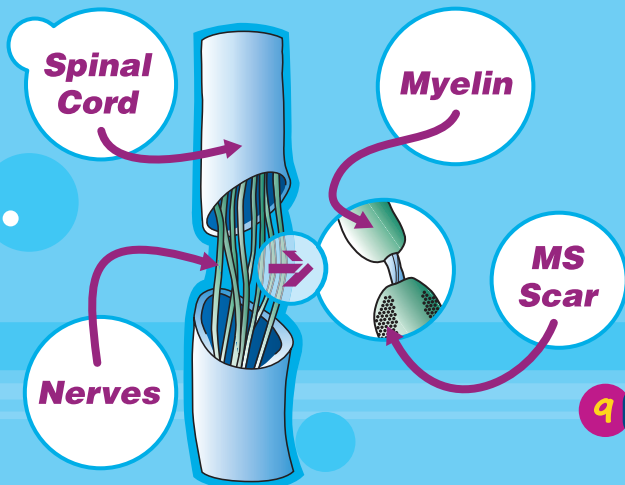
The messages go in both directions. If you want to wiggle your fingers, your brain sends a message along the spinal cord out to the arm and down to the fingers – and . . . they wiggle! In MS the messages are slowed down.



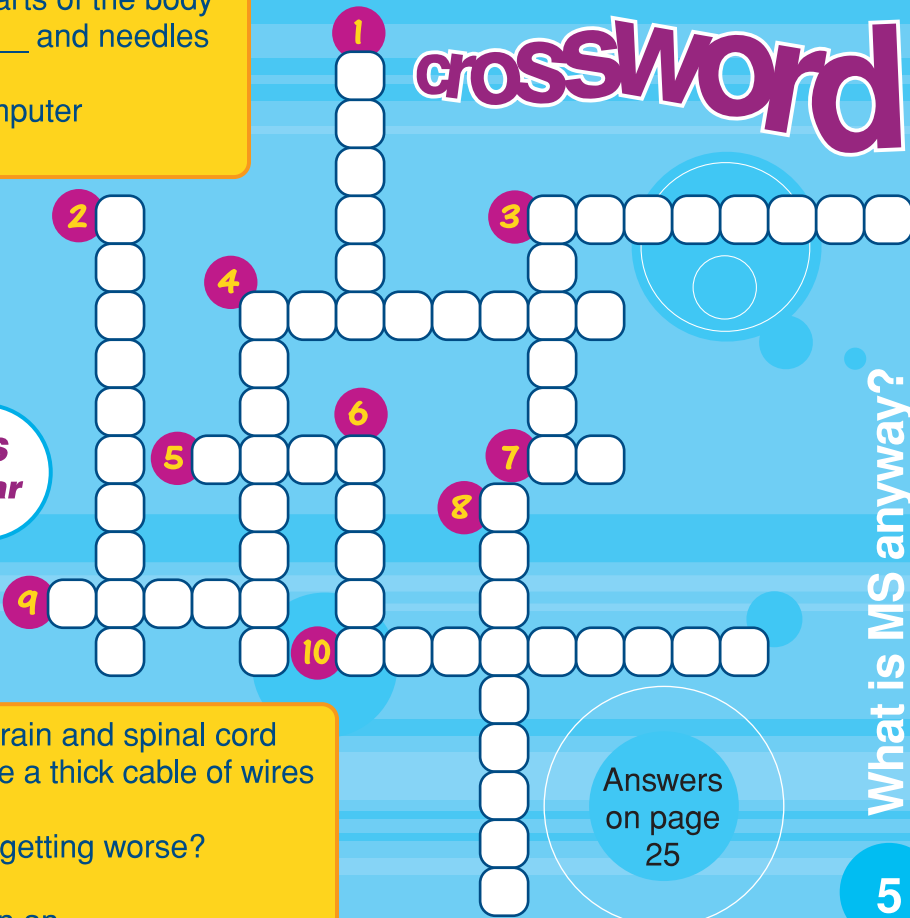
What is MS anyway?

ACROSS

3. this word means 'many'
4. the brain sends these to other parts of the body
5. one of the symptoms of MS is ____ and needles
7. is MS 'catching'?
9. this part of the body is like a computer
10. this word means scar



crossword



DOWN

1. myelin protects ____ in the brain and spinal cord
2. the part of the body that is like a thick cable of wires
3. the covering of the nerve
4. what might prevent MS from getting worse?
6. sclerosis means ____
8. some MS medicine is given in an ____

Answers
on page
25

What does

MS do?



People with MS may notice that they are having trouble doing everyday things . . . putting on their socks, making a sandwich or walking the dog.

Their bodies may feel “funny” or different. These troubles and discomforts are called symptoms. MS symptoms can be very mild, very serious or somewhere in-between. They can come and go. Sometimes the symptoms disappear for a few days, weeks or months and then come back again.

“ *Sometimes Mum can't remember something we told her. She tells us that her MS is making her thinking and memory slower and then we know it is not that she wasn't listening to us when we told her something.* ”

Feeling very tired

Have you ever stayed up very late? Remember how tired you were? Many people with MS feel tired like that all the time, even if they get enough rest.



Having weak arms and legs

Some people with MS find that their arms and legs feel very tired, as if there were weights tied to them. It makes it hard to move.



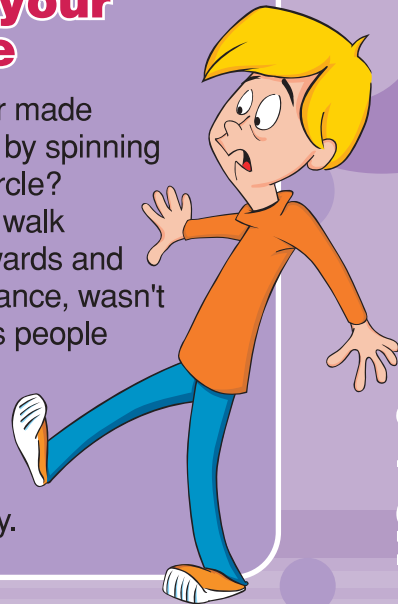
Feeling pins and needles

Remember the last time you sat on your leg the wrong way and your foot fell asleep and felt tingly and funny? Sometimes MS gives people that pins and needles feeling in their arms, legs or other parts of their body.



Losing your balance

Have you ever made yourself dizzy by spinning around in a circle? It was hard to walk straight afterwards and keep your balance, wasn't it? Sometimes people with MS lose their balance like that, even though they don't feel dizzy.



Having trouble seeing

Did you ever try to look through someone else's glasses? Some people with MS have blurry vision or see two of everything (double vision).



There are many different MS symptoms. Ask your Mum or Dad about the kinds of symptoms he or she is having. Not everyone with MS has the same ones. Learning about MS symptoms and talking to your parents about them can make you feel better.



Why do

people get MS?

Why does one person get MS and not another? Why does anyone get it?

If only we knew! We don't know why people get MS and we don't know how they get it either. There are some ideas, but scientists are still looking for more answers. MS isn't anyone's fault. It just happens.

How do people get MS?

We do not know how people get MS – it is still a mystery. It is thought that the body's defence system (called the immune system) does not work properly. BUT a great deal of research is being done by scientists and doctors investigating the cause and treatments and also trying to find a cure for MS.

Will I get MS?

MS is not hereditary, though genes do play a part in having MS. We know this because more women than men get MS.



“ *When I went to get out of bed my foot felt numb. I felt scared 'cause I thought I had MS like Dad. My brother said, 'No, it's only pins & needles you get from sleeping funny on your leg.' I felt relieved.* ”

Is MS catching?

NO – it certainly is not! You cannot catch MS from somebody else. It is not like flu or measles. Even if you are with them all day and every day, you cannot catch it. It is not that sort of illness.



“ When Dad went into hospital I was scared, but then Mum said, ‘People go to hospital to get help when they are sick.’ Dad came home after just a few days and he’s not too bad. **”**



“ My friend worried when she saw my Mum’s hand shaking. She thought she might catch MS from Mum and went home feeling scared. But her Dad explained about not being able to catch MS and my friend then felt OK. We stayed good friends after that. **”**

Do people die from MS?

People almost never die from MS. Once in a very great while, MS causes other problems that can make a person very sick or even die. But this does not happen very often.

wordfinder



E V E R Y P E R S O N W I T G
H M S I S D I F F E R E N W N
P I N S A N D N E E D L E S I
M T M X O N D G C G I A V N L
C O Q E K B N Y N Q K V U G B
L V O A M I U I K N G M L N M
U J M D K O K S E F B J J I E
M N D N I L R S J N C Q M K R
S P I T A N S Y E P D N E L T
Y H Z T I V E S E C N A L A B
T O Z C G R S S L E C F P W W
R Q Y Y B S E W S L I T I L F
N Y F Q P Z N D P H O Y C V E
W K R K E O E F Y S E E I N G
X O D K X U J Q S X O Q K G N

BALANCE
CLUMSY
DIZZY
MEMORY
MOODINESS
NUMBNESS
PINSANDNEEDLES
SEEING
TALKING
THINKING
TIRED
TREMBLING
WALKING
WEAKNESS



MS is different for each person

One of the hardest things about MS is that it is unpredictable – you don't know what it will do next!

MS symptoms can come and go. There can be days when you think MS has gone. Then there can be bad times when everything gets worse and the person with MS has to stay in bed for a few days or even go to hospital. This is when people talk about having an MS flare-up. After a flare-up, sometimes the MS gets a bit worse or sometimes it stays the same.

People with MS may have to make adjustments to how they do some things. Families may have to get used to planning things differently. This can be a drag at first, but the person with MS is still the same person.



“ Mum’s in a wheelchair now. The first time she came to school we realised there wasn’t a ramp. I felt terrible. Then my friend’s Dad and the teachers just picked up the chair and carried in my Mum! They were all laughing so it was OK then. Later the school put in a ramp. ”

Is there any

treatment for MS?

There is nothing as yet that can cure MS. BUT there are treatments which can reduce the number of flare-ups.

This means that your Mum or Dad may not have flare-ups so often. These treatments are given by an injection which is usually done at home before bedtime.

Other treatments could be pills which help with the symptoms of MS. Others could be special exercises to help improve walking.

It is important to remember that not all people with MS are able to make use of these treatments.



How do you feel *about* MS?

When someone is told they have MS they may have lots of different feelings. When you know someone with MS you may have lots of different feelings too. If things change, that can be hard to get used to.

Everyone has feelings about MS. Which ones are yours? Unjumble the words to fit the puzzle. Remember that no two people are the same!

| | | | | | |
|--|--|--|----------|---|----------|
| | | | D | ← | ODOG |
| | | | I | ← | LYISL |
| | | | F | ← | RIAFDA |
| | | | F | ← | NLFHTUAK |
| | | | E | ← | TEQUI |
| | | | R | ← | DUPOR |
| | | | E | ← | DCEARS |
| | | | N | ← | GYNRA |
| | | | T | ← | TRHU |

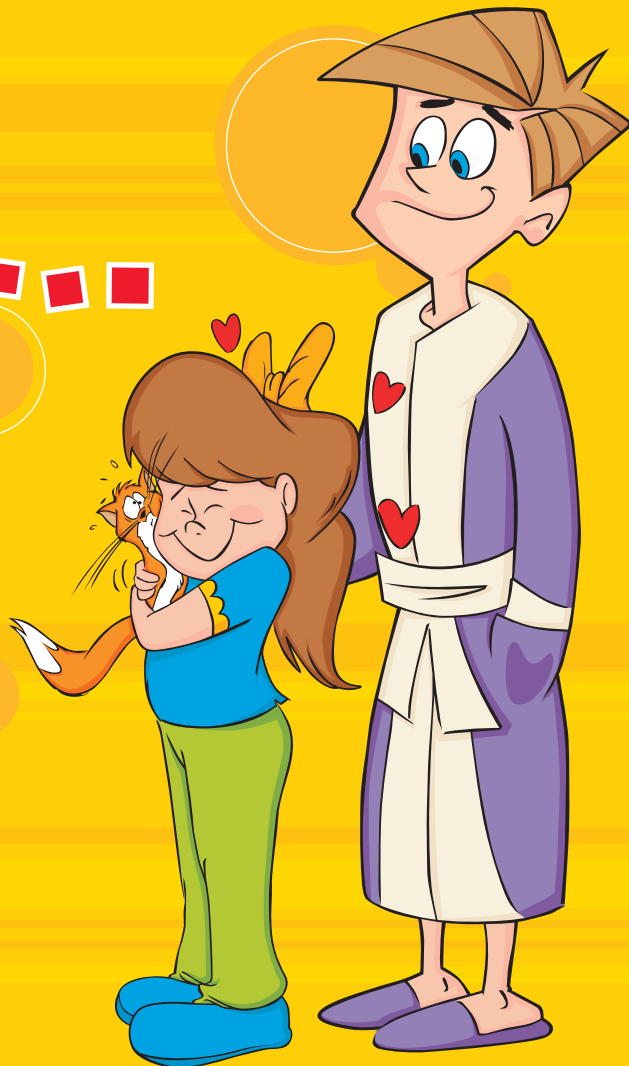
Find someone

- Who is easy to talk to
- Whom you like and trust
- Who listens to your feelings

Tick the people you could talk to

- | | |
|--------------------------------------|---|
| <input type="checkbox"/> Mum | <input type="checkbox"/> Teacher |
| <input type="checkbox"/> Dad | <input type="checkbox"/> An adult at school |
| <input type="checkbox"/> Brother | <input type="checkbox"/> Someone at church |
| <input type="checkbox"/> Sister | <input type="checkbox"/> Grown up friend |
| <input type="checkbox"/> Grandparent | <input type="checkbox"/> MS Society |
| <input type="checkbox"/> Aunt | <input type="checkbox"/> Doctor |
| <input type="checkbox"/> Uncle | |

“ *When I first found out that Mum had MS, I couldn't stop crying. I was just too sad and so was everyone. I still cry sometimes.* **”**



Coping with feelings & emotions

Express your feelings, but remember to think before you act:

- There is no need to go to extremes or hurt yourself
- There is no need to throw a wobbly or hurt others or their belongings
- There is no need to damage things around you

There are other ways to express emotions which allow you to feel OK.



Scared, afraid or anxious?

- talk to Mum or Dad or someone else you trust
- do something relaxing
- draw a picture
- write a story, a poem or keep a diary



“ When Dad got sick with MS, I began to play up at school. I didn't finish my homework and I was rude to the teacher. I couldn't somehow stop myself. ”

Sad

- talking about what is making you feel sad, is a good start to changing how you feel
- it is ok to cry sometimes



“ Sometimes I’m trying to do something good for Mum but she doesn’t realise it and she gets angry. ”

Angry, grumpy

Never getting angry is impossible. Instead, remember that how you act when you're angry can make the situation better or worse. Don't let anger control you. Take charge of it!

Anger Busters

- talk to a friend you can trust
- count to 10
- get or give a hug
- stamp your feet
- beat up a pillow because the pillow can't get hurt
- draw a picture of your anger
- play a video game
- run around the outside of the house five times as fast as you can
- sing along with the stereo
- pull weeds in the garden
- think good thoughts (maybe about a fun vacation or your favourite sport)
- take a bike ride or go in-line skating

Shy

- it is OK to be shy sometimes
- write down things you want to talk about in case you feel too shy to ask
- talk to someone



“ We always made our own beds anyway, even before Mum got MS. Some kids don't do anything! I hate emptying the smelly rubbish bin but we take turns. ”

“ I always get into a temper at home and my sister is all goody-goody. But she gets into trouble at school. Dad says it's because the anger has got to come out somewhere. ”

Happy, glad, proud

- this is also important to talk about
- or you might like to write a story, a poem or write it down in a diary

Mixed Up

- write down how you are feeling
- speak with someone who can help sort things out

Embarrassed

- talk to someone who can explain things
- work out a way to avoid embarrassment

“ *The only times Dad wouldn't talk about MS was after he'd been to the doctor. Then I got frightened he'd had some bad news. When I got the courage to ask Mum she got Dad to explain more and it turned out he'd just been tired and fed up.* ”

“ *Sometimes Mum says, 'Enough shopping! My legs don't want to work.' We used to think she was making excuses, but now we know it's because the messages get stuck on their way to her legs.* ”



Fill in the

blanks

I feel scared or afraid when

It would help me feel less afraid if I

I feel sad when

It would help me feel happier if I

I feel angry when

It would help me feel less angry if I

I feel shy when

I would feel less shy if I

I feel happy when

When I feel happy I want to

I feel proud when

When I feel proud I want to

Everyone's

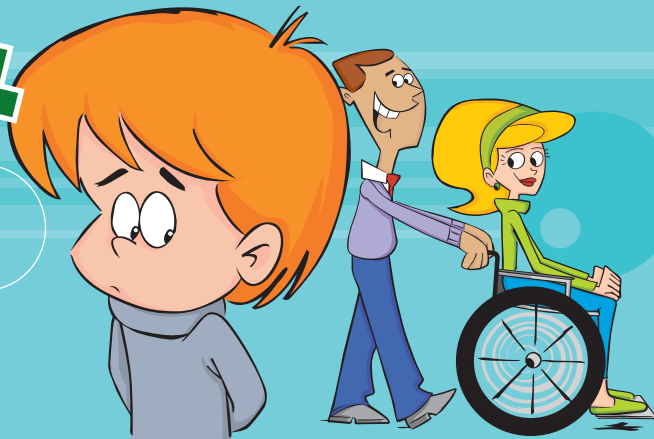
different

**Each person with MS is different.
Each person in the family is different.**

Some people cope with problems calmly, others need extra help. It's when everyone tries to help everyone else that people get to know each other better.

Nobody likes MS. But it isn't all doom and gloom either. Sometimes a big and serious thing like MS in a family can have its good side – it can bring people closer together.

You might get to know your Mum or Dad better just because MS makes you think about and talk about things more. You spend more time together. You will probably learn more about people because you learn so much more about yourself and your feelings and the way all the family feels about MS.



“ Mum’s been in a wheelchair for ages, so we don’t think about it much. But my friend’s Mum was walking OK until a few weeks ago and now she’s in a chair too. My friend wouldn’t go out with her at first. ”

There will be good days and bad days. On bad days try to bring the feelings out - they hurt more when they're stuck on the inside.

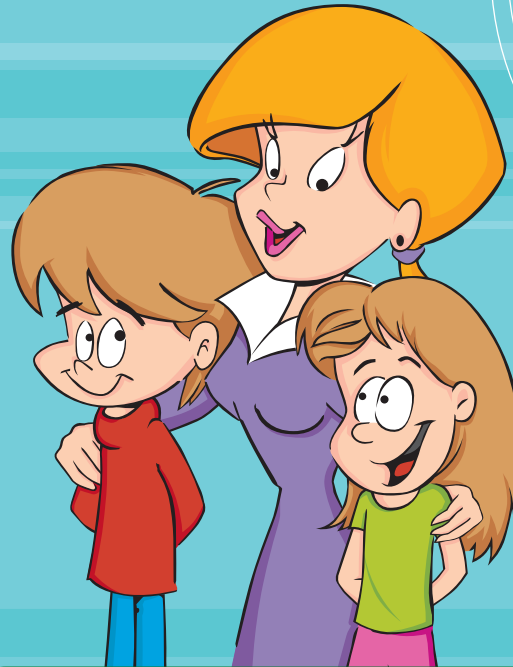
On good days, just enjoy them! Lots of people with MS and their families do live happy lives.

wordfinder

Can you find these feeling words?

H S R M B C F E S
A M M U O E R R I
P I N G L A D O L
P L U L D H I U L
Y E P R O U D O Y
O S P T L R E H C
L H R I E T N A A
F Y O P S E T P L
S C A R E D T S D

HAPPY PROUD SILLY HURT
BOLD SCARED GLAD SHY



“ I know I shout at the kids sometimes when I shouldn't. It's because I get angry with myself when I can't do something. When I saw how I upset the children I thought about it. We all sat down and had a talk and now they understand better. We still yell at each other sometimes, but it's not as bad. ”

Anything else you'd like to

know?

Anything else you'd like to know?

We may not have answered all your questions in this booklet and maybe you don't know anyone with the answers. You may have problems you can't talk about to anyone. Just about all families have problems and not all parents are as understanding as you'd like them to be. Besides, sometimes it's easiest talking to a stranger.

SO...

If you want to ask any question about MS and/or talk to someone about anything that is bothering you, because your Mum or Dad, uncle or aunt or friend has MS, then please call this number 1800 287 367 or email your local MS Society. Contact numbers are inside the back cover of this booklet.

Remember that anything you tell us in writing or when talking to us is kept **STRICTLY PRIVATE**. That means that only you and the

person you contact know what you asked and said.

You can also ring the **KIDS HELPLINE** on **1800 551 800** – open 24 hours everyday OR **Young Carers** at **1800 242 636**
www.youngcarers.net.au



“ Look, it gets you down having a Mum with a disease for which there is no cure. But I feel proud of her too, the way she manages. I know lots of Mums who don't seem to do much with their kids. My Mum does much more than some of them. ”

Where to find

out more



MS Australia:

Aussie Kids Talk MS
www.msozkids.com

The USA National MS Society website:

Someone you know has MS

www.nationalmssociety.org/Brochures-SomeoneYouKnow.asp

Keep S'Myelin

www.nationalmssociety.org/Keep%20S'myelin.asp

Teen's pages

www.nationalmssociety.org/Teen%20InsideMS.asp

The International Federation of MS Societies' website:

www.msif.org/en/people_with_ms/ms_and_children.html

The Canadian MS Society:

www.mssociety.ca/en/help/publications.htm#teens

Growing up Strong project

www.mssociety.ca/en/help/GrowingUpStrong_ProjectImplementation.htm#7

How to

find us

MS Australia & the Resource Centre (MS ARC)

www.msaustralia.org.au

Multiple Sclerosis Society of NSW

ABN 49 000 320 632

Joseph Street, Lidcombe

New South Wales 2141

Telephone: (02) 9646 0600

Fax: (02) 9643 1486

Email: msconnect@msnsw.org.au

MS Connect: 1800 042 138

Multiple Sclerosis Society of Victoria

ABN 66 004 942 287

The Nerve Centre

54 Railway Road, Blackburn

Victoria 3130

Telephone: (03) 9845 2700

Fax: (03) 9845 2777

Email: infoline@mssociety.com.au

MS Information Line: 1800 287 367

Multiple Sclerosis Society of Tasmania

ABN 95 009 484 093

15 Princes Street, Sandy Bay

Tasmania 7005

Telephone: (03) 6224 4111

Fax: (03) 6224 4222

Email: aboutus@mstas.org.au

MS Information Line: 1800 676 721

Multiple Sclerosis Society of Queensland

ABN 56 731 473 412

286 Gladstone Road, Dutton Park

Queensland 4102

Telephone: (07) 3840 0888

Fax: (07) 3840 0813

Email: info@msqld.org.au

MS Information Line: 1800 177 591

Crossword answers page 5:

Across: 3. multiple, 4. messages, 5. pins, 7. no, 9. brain, 10. sclerosis

Down: 1. nerves, 2. spinalcord, 3. myelin, 4. medicine, 6. scars, 8. injection

Multiple Sclerosis Society of SA & NT

ABN 85 662 359 859

274 North East Road, Klemzig

South Australia 5087

Telephone: (08) 8360 0800

Fax: (08) 8360 0899

Email: ms@ms.asn.au

Toll Free: 1800 812 311

Multiple Sclerosis Society of WA

ABN 75 638 080 972

29 Parkhill Way, Wilson

Western Australia 6107

Telephone: (08) 9365 4888

Fax: (08) 9451 4453

Email: multiple@multiple-wa.asn.au

MS Information Line: 1800 287 367

Multiple Sclerosis Society of ACT

ABN 64 967 612 796

Gloria McKerrow House

117 Denison Street, Deakin

Australian Capital Territory 2600

Telephone: (02) 6285 2999

Fax: (02) 6281 0817

Email: info@ms.org.au

MS Information Line: 1800 356 354

Multiple Sclerosis Research Australia (MSRA)

ABN 34 008 581 431

293 Mowbray Rd, Chatswood

New South Wales 2067

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Fax: (02) 9411 7456

Email: info@msra.org.au

Web: www.msra.org.au



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