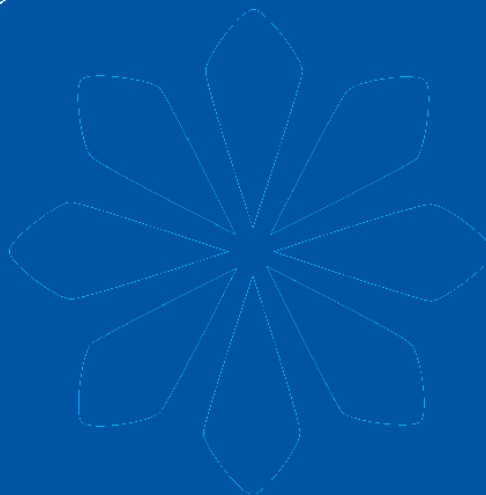
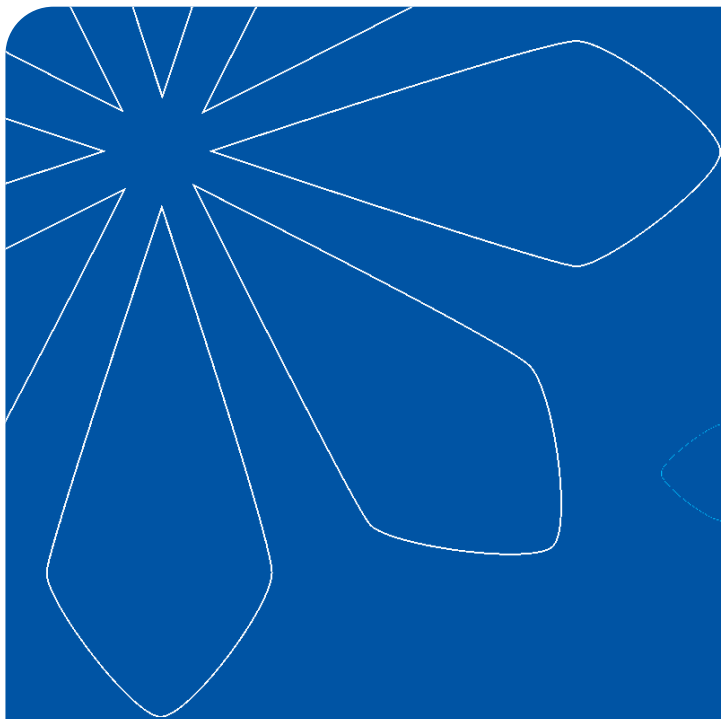




TALKING WITH YOUNG PEOPLE ABOUT
MOTOR NEURONE DISEASE
FOR PARENTS



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TALKING WITH YOUNG PEOPLE ABOUT MND

This booklet has been written for parents making the difficult journey with Motor Neurone Disease (MND). It is part of the Information Pack, 'Talking with Young People about MND'. The pack includes information that you may find helpful for your children, their friends, the children's schools and the health professionals you may be in contact with. Please feel free to copy any part of the pack or request additional copies.

The suggestions in this booklet are from parents and children who want to share their experience of living with MND with other families.

Some of Australia's leading counsellors and health specialists with experience in supporting people with a life-threatening disease have also provided their advice.

There are suggestions for ways of talking with your children following a diagnosis of MND, and ideas about how to keep communication strong as time goes by.

“It's important to constantly keep open lines of communication. The children need to know how they can help and what they need to do but also be given enough freedom to get away and have some fun.”

How you talk about MND will be different depending upon your own style and your children's ages, so there are different ideas for talking with different age groups.



TELLING CHILDREN ABOUT MND

WHEN MND IS DIAGNOSED

A person diagnosed with MND is suddenly faced with unwelcome and frightening changes that will affect them and the whole family. Their confidence and sense of self esteem can seem undermined. Many parents remember how shocked and sad they felt at the time that MND was confirmed. They describe their reactions as so 'mind-numbing' or 'devastating' that they didn't feel strong enough or informed enough about MND to tell their children until later - sometimes weeks later.

WHEN IS THE 'RIGHT' TIME TO TELL?

One of the hardest things to face is how and when to tell the children. Family counsellors recommend telling children about serious news as soon as you can. They have found that even very young children can

detect their parents' unhappiness and anxiety. Fear develops quickly if children are left to 'guess' about what is going on. They are likely to start worrying that it must be their fault, something naughty they've done.

WHO IS THE BEST PERSON TO TELL THEM?

It can take a lot of pressure off if you can arrange for your doctor or another health professional to tell the children with you there. This lets you be comforters for your children, rather than the bearers of upsetting news.

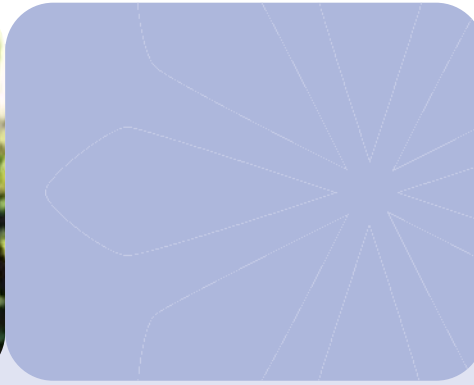
If you can't organise a meeting or want to tell the children yourselves, it can help to rehearse what you want to say with someone who understands the situation. Talk to your local Motor Neurone Disease Association about getting in touch with another parent who understands the MND experience. Someone who really knows

what you are going through can be very helpful. If you think you might get very upset and may not be able to tell the children well, ask a favourite aunt or uncle, or someone you know that they like and trust, to tell them for you, or with you.

It helps if the children can see that even if you are upset and sad you can still talk about having MND. When you feel able to talk things over with them, choose a quiet, comfortable place where you won't be disturbed. Being in a place where the children feel at ease - in the park, or walking along the beach - can reduce a sense of being 'confronted' by bad news.

Don't worry if you feel you don't get it quite right the first time. Your children will understand that they are loved and included, even if your message is unclear. You may have to repeat some information later. Younger children can forget things quickly and may not be able to take in all





the information when they are first told.

WHAT MIGHT BE HELPFUL TO SAY?

Find out first what they already know - they may have overheard whispers which have given them a false picture. You could ask them something like:

“What do you know about Mum being so tired”?

or

”What would you like to know about Daddy’s legs?”

Then fill in any essential information they don't already know.

For older children, you could give them the booklet for their age group from this pack and use it as a basis for discussion. Books to read with young children are recommended on the back pages.

Help them put their feelings into words. You might say something like:

“It felt scary when the doctor said I have MND. Sometimes it still does - but I'm having my good days ... I'll get my head around it ...”.
How are you feeling”?

Give them a hug for sharing their feelings. Reassure them that you'll get through this time together.

KEEPING COMMUNICATION STRONG

Keep encouraging your children to ask questions as Mum or Dad's MND progresses, so they can understand what's happening – in their own way.

Continue to reassure them that it's not their fault, that no-one is to blame for it.

Praise and encourage your children as often as you can. If you have difficulty talking, you can still hold up a 'flash card' that says: "You did really well"; "I'm proud of you"; "I love you". Body language like the 'thumbs up' sign or blowing a kiss can be as reassuring for a child as actual words. Think up a few signs of your own to let your kids know how you feel about them.

Have bright things around the house - photos of happy times, cartoons and paintings, colour & lightness.

Keep life as 'ordinary' as you can but also try to make your children, together or on their own, feel special sometimes. One dad with MND takes his children out of school one day

a month to do something special together.

Involve the kids in making decisions about the future, such as planning a holiday, deciding on weekend activities, organising a birthday party.

Encourage them to keep up their normal interests, sports and friendships. Your family and friends may be able to help with rides to school and social activities if you are pressed time.

Show your sense of fun so that the children know it's OK to be happy too, and that you love them even when you're all being silly.

"Keep trying to have fun. We had friends with young kids about 6 and 7 - they were great and really lifted dad's spirits. He used to take them for rides on the back of his motorized wheel chair at the park."

Prepare children for change. Involve them in decisions about planning ahead, new equipment, modifications to the house and so on.



Invite your older children to sit in on meetings with the health care team. Before the meeting, talk with them about any questions they would like to ask the team. Ideas for the health team are included in the 'For Health Professionals' booklet in this information pack.

Encourage the kids to concentrate on what they can do rather than what they can't - for their family and friends - their parents - and for themselves.

Keep things as 'normal' as you can - don't change any agreements you have already established about behaviour, bed times, coming home from school or social events.

**“Some families find it helpful to make a series of signs for their bedroom doors that make it clear what is happening. Signs might say things like ...
I NEED TIME
ALONE or I NEED**

**SOMEONE TO
TALK TO ... or
ASK ME WHAT'S
WRONG or I'M
ANGRY/SCARED/
WORRIED ...
or DON'T ASK ME
HOW I FEEL ...
whatever fits.“**

Like every family, there will be times when family unity breaks down for a while, as feelings get too much or somebody's frustration turns into misery or anger.

Children may feel an increase in anxiety about other changes at home. It's important that they don't feel 'forgotten' or unimportant. Tell them regularly that you love them and want them to be happy and enjoying themselves.



FOR CAREERS

If you're providing most of the primary care at home, you need to look after your own health and energy. Other carers have found these strategies helpful.

- Don't try to 'go it alone'. Look for help from the community services organisations in your area. They can make a big difference to how you, your partner and the children manage living with MND. Ask them to provide you with some respite, 'time out,' when you need a break.
- Keep your stress levels down by regular debriefing. Talk things over with a counsellor or someone who will listen to you properly. Choose someone who encourages and energises you to keep your strength up as a primary carer.
- A 'How I'm feeling today' chart on a door or the fridge can be useful. It's just a sheet of paper with statements on it like: "I need a hug please", "A bit of space needed today", "Great day – let's do something nice!" A fridge magnet can be used to point to the 'Feelings of the Day'.
- Family and friends may be able to give you a hand on a regular basis. Negotiate with them about what they're comfortable doing - maybe taking the kids to after-school events; keeping your partner company while you get out for a breather; weeding the front garden; or taking the dog for a walk.
- A counsellor who works with families living with MND suggests that two hours a week from another person is a reasonable time to ask for.
- Support programs can also be very helpful. Ask about the ones run by your local Motor Neurone Disease Association.
- A psychologist has suggested watching TV shows like 'Australian Story' together as a way of keeping positive and optimistic. These shows are about the lives of people who have come through very difficult situations, and are stronger as a result.





- Keep pressure off the kids. Parents can sometimes expect their children to help out too much, when they are trying to cope with their own complicated young lives.
- Encourage your older children to make contact with other young people who know about MND and can reflect on what worked to help them.
- Reassure the children that you'll get through this difficult time together. A parent who has been there herself suggests:

“It helps if you and the children take each day as it comes, and to do your best for just that day.”

- Keep a balance between sad things and hopeful ones.

“After any serious discussion, always distract when ‘enough is enough’ for that child, that parent, by doing something enjoyable. This teaches children life skills - how to limit focus on distressing things, how to live with pain and happiness side by side.”

HOW SCHOOLS CAN HELP

Children's schools become a very important part of their lives when a parent is ill. Your 'Talking with Young People' pack contains a booklet 'For Schools'. It suggests to teachers and other school staff how they can contribute to supporting the children's studies and their sense of well-being. You may want to copy it to give to the Principal or a number of different teachers.

Make sure the school understands that your children probably don't want to receive obvious extra attention. Most children want life at school to remain as 'ordinary' as possible.

It would be very helpful to the school staff if you could let them know of any changes at home that might affect your children's emotions and performance.

LIVING WITH MND

MND progresses more quickly for some people than for others. If it progresses slowly there is more opportunity to adjust to each change and to maintain regular family activities and routines and roles. Changes and their impact on family life will be more difficult to manage if MND progresses quickly.

“Do everything together you possibly can. Don't put anything off, that special trip, extra time together. Deal with today. Plan for tomorrow”.

It's a strange thing to say, but there are positives as well as negatives when a family has to share a serious illness.

It is a sad experience, because no-one ever chooses to have MND. But living with it can help your family to support and love each other in a deeper way than you might have expected. You have the opportunity and time to focus on just how important relationships are, and to put quality time into them. Other parents recall how they grew to realise that all communications were precious and how valuable it was just talking and doing things together.

“MND doesn't stop bad things happening - but it doesn't stop us doing good things!”

TALKING ABOUT MND

UNDER 4 YEAR OLDS

Children under 4 are usually too young to discuss things in depth, but they can become frightened very quickly if they have to guess why their parents are sad. Keep your explanation simple:

”Poor Mummy’s feeling sick, or tired. It’s not your fault. Mummy and Daddy love you very much, and we’ll look after you”.

Family counsellors recommend the ideas below as the best ways to communicate with young children.

- Keep them happy, secure and worry free
- Encourage them to do positive things with their parent with MND, such as having regular times for a cuddle and chat
- Reassure them every day that you love them very much.



4 TO 8 YEAR OLDS

This age group focuses on the ‘now’. They don’t think very far ahead, or question the cause and effect of things. One minute they might ask you quite searching questions about mummy or daddy’s illness and seem really upset. The next, they’re outside playing happily.

They won’t want a lot of information about MND, but they may feel anxious that the problem may be their fault, a punishment for something ‘naughty’ they’ve done.

Reassure them that they haven’t caused mummy or daddy’s illness - that no-one is to blame.

Children in this age group tend to be obsessed with bugs and germs. They are likely to think that MND is ‘germy’ and dangerous. Make sure that they know that they can still kiss and hug you and sit on your lap and they won’t ‘catch’ anything. If you can, give your partner a hug and a kiss to show your child that it’s safe for them to do it too.

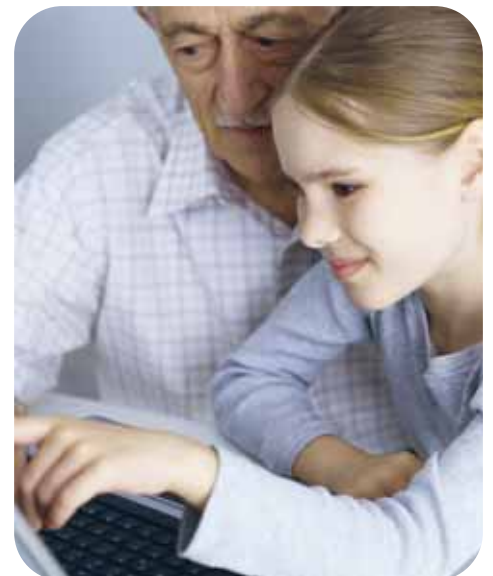
However, it’s better not to force a child to get physically closer to mummy or daddy if they show any reluctance or fear. Some children have a natural resistance that will only be overcome if it’s not made into a big deal.

8 TO 12 YEAR OLDS

It’s not so difficult talking about MND with pre-teens. They’re beginning to want to be included, respected and listened to within the family.

They usually won’t want to know much about mum or dad’s condition early on, but will probably ask more questions as it changes. When they do, ask them: “What exactly would you like to know?” Answer honestly and ask if they would like some more information. Let them decide what and how much they want.

Your Talking with Young People pack contains a booklet about MND specially written for this age group. You might like to give it to them, and then set a time to talk about things when they’ve had a chance to read it.



TEENAGERS

When you talk with your teenagers about the diagnosis of MND they may act 'cool' rather than show their real feelings. Older teens may adopt a very adult air, and try to reassure you that they're OK, they're under control, not to worry about them.

Underneath they may be busy juggling their fears and emotions with their own worries about their 'identity', their acceptance by their peer group, how to be taken seriously by adults, and getting their homework done. By 15 or so they are also beginning to move away from family-centred activities and issues towards being a young adult in their own circle.

As you know, teenagers change rapidly as their puberty hormones 'kick in'. They are at that age when their own appearance, wearing the 'right' labels and so on tend to be serious concerns. They will worry that it's going to be hard to keep on doing the things they like with their mates.

Young people may not talk about how much they are hurting, as they don't want to add to mum and dad's worries and stress. Emotionally though, they can be on a roller coaster ride with great ups and downs - flattened by grief one day, behaving like a little kid the next, then suddenly sullen or hostile.

They may feel guilty about having mixed feelings about a parent's illness. They may feel very sad about it most of the time, but also resentful that it's made them 'different' from their friends. They may resent the 'invasion' of their home by an army of health care workers, and the fact that the disease now takes up so much of their parents' time and energy.

Teenagers can feel upset if their mum or dad with MND develops 'emotional lability' - laughing and crying unexpectedly or inappropriately - or has symptoms such as trouble sitting up straight, dribbling or unclear speech. They might stop bringing their friends home, or start staying away from the house a lot.

“I used to worry about what other people would think when they saw or met Dad in the later stages. He'd wear a headband to stop his head from falling forward, and although it was functional, it wasn't stylish! I remember feeling embarrassed about him being in the wheelchair and having drink-stands/talking computers etc, even though everyone told me not to be.”

Sometimes parents fear they are losing control of the situation. It's natural then to want to protect teenagers from too much reality. But this age group can talk about the future and loss with a lot of young adult intelligence. One-to-one discussion is more effective for young people.



If you can, take your teenager to a 'cool' place like a popular coffee shop at a quiet time, or a walk in the local park. It shows them that you regard them as more of an adult than a kid.

As MND progresses, it's important for teenagers to spend quality time with their parents. They need the chance to build and strengthen their bond of love. It will also help them look at themselves later as a good person, someone who behaved decently. This is critical for helping them develop a sense of self-respect.

- It can be important for a teenager's self esteem to contribute something to their parent's care, but not to be overwhelmed by it. Try to help them get a good balance between sharing some of the caring, going out with their friends and continuing their other normal activities.
- Some parents enjoy competing with their teenagers through an ongoing computer game, or a popular board game. Or they might spend time together on the computer doing research or writing memoirs.

- If communication or movement becomes too difficult, watching videos or listening to music together can be a bonding experience - if you can bear each other's taste!
- Suggest something practical they could do on a regular basis, such as reading out loud the highlights of the news or the sports page each day.

“Don't think that because your parent has MND that they are not interested in your life anymore. I used to sit with dad every day and tell him what I had learnt at school.”

- Keeping a diary can be helpful for teenagers to record things that happen, their feelings, poems, drawings etc. It can also be used to write down things they want to discuss with their mum or dad.

“I found it really helpful to keep a diary and write down all the things I wanted to tell dad the next day. I did this at night when I went to bed as this is when I used to get really upset . . . So I wrote down what I wanted to say so I could process it and relay it when I wasn't so emotional.”



TALKING ABOUT LOSS

MND is a disease that causes a series of losses. It involves increasing levels of disability and changes in what a person is able to do.

You know that at the moment no cure has been found. Most parents find it hard to tell their children that at some time their mum or dad with MND will die, because that can sound as if there's no hope. But there will come a time when you need to prepare the children for the idea of loss and death. How soon to tell them, and how to do it, usually depends on how resilient each child is - how quickly they bounce back from a hard knock.

When you do feel ready, these suggestions from other parents and counsellors could help.

UNDER 4 YEAR OLDS

Change is almost unnoticeable for a small child. Their sense of time is not very strong. As the months go by, they will be aware that it may be harder for mum or dad with MND to physically show them love and affection.

You could compensate for this by letting them play around and sit on your knee if you're in a wheelchair.

Being snuggled up on your lap can be just as reassuring for a little kid as playing a game with you outside.

There are some excellent picture books you can read to 3 and 4 year olds that can help them understand that everything has a special 'life time' - some longer than others. The books other parents recommend are at the back of this booklet.

4 TO 8 YEAR OLDS

Children in this age bracket will usually ask for any information they want. For example, they might ask: "Why won't Daddy play with me any more?" To explain, you could refer to something your child is familiar with, like a toy that isn't working properly. If you're asked: "Is Mummy going to die?" you might say something like: "Well, some time. Some people have a long time to live and some a shorter one. So we're all going to make Mum (or Dad)'s time as good as we can, together. What nice things can we do?"

Encourage your children to do little things to help with caring for mum or dad, such as helping to prepare special meals, or holding their drink bottle for them.

This age group loves stories. Read with them whenever you can. Later on, you may find the books at the back helpful when you need to talk with them about the idea of loss.

8 TO 12 YEAR OLDS

Older children are likely to start asking more penetrating questions as MND progresses. Honest replies to their questions are better than trying to simply make them feel good.

You can prepare your pre-teens to be ready for loss in practical ways.

- Give them a beautiful notebook or diary, or start a Memory Box. You can add to it by writing stories from your childhood; funny memories; biggest adventures; favourite pets; best movies, songs and poems. Memory boxes work well when they are filled with drawings, letters, old tickets to shows, photos, small bits of fabric from favourite clothes - a picture of your lives together.

- Look for projects to share, like researching your family's history on the Web, playing computer games together, or working on a school project.
- Try to balance bad news with good news. For example, if a new piece of equipment is needed, show the children how it improves mum or dad's comfort.
- Without putting too much responsibility on them, let them participate as a carer. They could help prepare meals, read aloud and run errands.
- Encourage the kids to bring their friends home.

“My dad loved it when me and my brother's friends would come over and sit and talk to him about general stuff going on.”



TEENAGERS

Grief affects young people in different ways. They may show their feelings of helplessness, hopelessness and fear of the unknown in the form of moodiness, childish behaviour, missing school or not wanting to come home after school.

Counsellors describe other reactions as “anger; shutting off; isolation, sadness; bleakness”.

They may be embarrassed and resentful about a parent's physical changes. It helps if mum or dad admits they also find it hard to get used to the changes and sometimes feel embarrassed when people are looking at them.

Sometimes anger can be misdirected at others, especially siblings and friends. These reactions can be very painful for parents as well as the young person.

Encourage your young people to be angry about the disease, but not with mum or dad. Remind them that MND is rotten, but it's no-one's fault.

Keep an eye on your children's more negative moods. If they continue and grow darker, think about getting professional help, such as a counsellor who has worked with other families living with a life-threatening illness.

Your local Motor Neurone Disease Association may be able to suggest a counsellor who has worked with families living with an illness like MND.



STAYING POSITIVE

It may be difficult sometimes, but young people say it helps if their parents can be realistic and positive. If you can show your children how to manage a really challenging situation like MND, you set them a good example of how to manage tough times in their future.

There may be days when you feel hopeless, overwhelmed, generally fed up and resentful. EVERYONE feels that way sometimes, even when they don't have to cope with a life threatening illness like MND as well.

Try to keep talking to your children during or after a bad patch, as well as during good times. They will learn that it's OK for them to have 'down' days too. You are helping them to learn how to manage life's ups and downs.

It helps to keep yourself as healthy, positive and rested as possible, to focus on what you can do now, and to make the most of each day.

Wherever possible try to see the funny side of things. A sense of humour can often help to relieve stress.

Find new things that you can all do together.

“Dad’s attitude helped me and sharing my feelings with friends/family, writing it down, sharing a project that we both felt strongly about - writing a book about his life & illness - feeling like I was part of the journey.”

Hope and courage are very important to a family living with MND. One Dad with MND builds his children's sense of optimism by reminding them:

“There may be some wonderful outcomes in the future with research such as stem cell research”.

MND is a very hard thing for a family to have to live with. Yet it can also be a chance for every member of the family to grow as an individual and become closer to each other.

Time you spend together can be very precious, a positive focus in life forever.

“It would be an incredible journey ... we'd grow close, become friends, get to know each other in a way other parents/children wouldn't.”



INFORMATION

FOR PARENTS AND CHILDREN

These books & websites are recommended by parents and counsellors. If your local library or bookshop don't have them, ask them to order them for you.

FOR 2 TO 7 YEAR OLDS

- *Beginnings and Endings with LIFETIMES in Between – A Beautiful Way to Explain Life and Death to Children* by Bryan Melville & Robert Ingpen. A beautifully illustrated book about the natural lifetimes of all things and how sometimes a life can be cut short.
Recommended ages: 2 to 6
- *The Fall of Freddie the Leaf* by Leo Buscaglia. A charming picture book about how the seasons change and affect living things.
Recommended ages: All



FOR 8 TO 12 YEAR OLDS

- *When Someone Special has MND* from your local Motor Neurone Disease Association
- *Nicki's Mum* by Dot Meharry & Dale Tutill. An intelligent and attractively illustrated story about how a young girl manages when her mother has cancer.
- *Sad Isn't Bad: A Good-Grief Guidebook for Kids Dealing With Loss* by Michaelene Mundy. A sensible and easy to read book.
- *When Dinosaurs Die: A Guide to Understanding Death* by Laurie Krasny Brown & Marc Brown. A picture book where friendly dinosaurs explore their problems - the same sort that human beings have.
- *With You and Without You* by A.M. Martin. Mum, Dad and their four children react differently when Dad's told he will die within the year because of his heart condition.
- *You, Me and the Rainbow* by Petrea King. A book to help parents express their love and connect-edness with their children.

FOR TEENAGERS

- *The Grieving Teen - a Guide for Teenagers and their Friends* by Helen Fitzgerald. This is an e-book, downloadable for a small fee to your home computer from: www.diesel-ebooks.com
- *Something I've never felt before: how teenagers cope with grief* by Doris Zagdanski - an intelligent book for young people.



INFORMATION ON THE WEB

- **'When Someone Special has Motor Neurone Disease'**
from the MND Association of Victoria, (About MND, Information for Kids)
www.mnd.asn.au
- **'All for Kids'**
Information about MND for young children, adolescents and parents - Canadian ALS Association
www.als.ca/allforkids
- **"What is ALS?"**
for KIDS - a funny American website for younger children
www.march-of-faces.org/KIDS/moe1.html
- **Lou Gehrig's Disease (ALS) Nemours Foundation** - from America
www.kidshealth.org/kid/grownup/conditions/als.html
- **Real life stories about people living with MND** - from Great Britain
www.mndassociation.org/life_with_mnd/experiences_of_mnd
- **MND Research**
www.mndresearch.asn.au



SUPPORT SERVICES FOR CHILDREN AND TEENAGERS

Kids Help Line: 1800 55 1800

- 24 hour free call service for young people from 5 to 18. From anywhere in Australia (except from mobile/cell phones)
- Questions can be answered on the web site www.kidshelp.com.au
- Online counselling for young people www.kidshelp.com.au
Web Counselling

National Centre for Childhood Grief

info@childhoodgrief.org.au

E-mail support & counselling for teenagers

Reach Out

www.reachout.asn.au

Web-based service for young people to help themselves through tough times. The web site has a lot of useful fact sheets, including one on coping with grief

Carers Australia: 1800 242 636

- **Who Cares? We Do! Support for Young Carers**
Information, referral, support and activities for young people under 26 caring for a relative with a long-term illness or other problems. Free call anywhere in Australia except from mobile/cell phones
- **Young Carer Website www.youngcarers.net.au**
Helpful information and contacts for local Carers Associations when a child is the only carer at home, or helps out whenever they can

Carers New South Wales

- **Young Carer Project www.youngcarersnsw.asn.au**
Discussion Board, stories, poems, information and more

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