



TALKING ABOUT
MOTOR NEURONE DISEASE
FOR TEENS



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WHEN YOUR MUM OR DAD HAS MOTOR NEURONE DISEASE

Finding out that your parent has a life-threatening disease can feel as if your whole world has changed. This booklet is based on the experience and thoughts of several young people with a parent with MND. It can help you understand what is likely to happen to you and your family and it suggests practical ways for looking after yourself.

On the last pages there are web sites, an e-mail help-line and other places for information for young people about living with MND. At the beginning, it can be hard to make sense of what's happening. The first thing that can help is to understand a bit more about MND and its effects.

WHAT IS MND?

Motor neurone disease is the name used to describe the breakdown of a body's motor nerve cells, or 'motor neurones'. Motor neurones in our brain and spinal cord carry messages to muscles in different parts of our body.

Before a muscle can move, it has to be activated by a message from the brain. When a person has MND, fewer and fewer messages from the brain get through to some muscles, which grow weak and start to waste away. Eventually, no messages get through - the muscles don't respond even when the person tries very hard to use them.

There are different forms of MND. The most common is called amyotrophic lateral sclerosis, or 'ALS'. Amyotrophic comes from the Greek language: 'a' means no, 'myo' refers to muscle, and 'trophic' means nourishment, so amyotrophic means 'no nourishment to the muscles'.

In the United States, the term 'ALS' is used, or sometimes 'Lou Gehrig's Disease' after a famous American baseball player, while Australia and Great Britain prefer the term 'MND'.

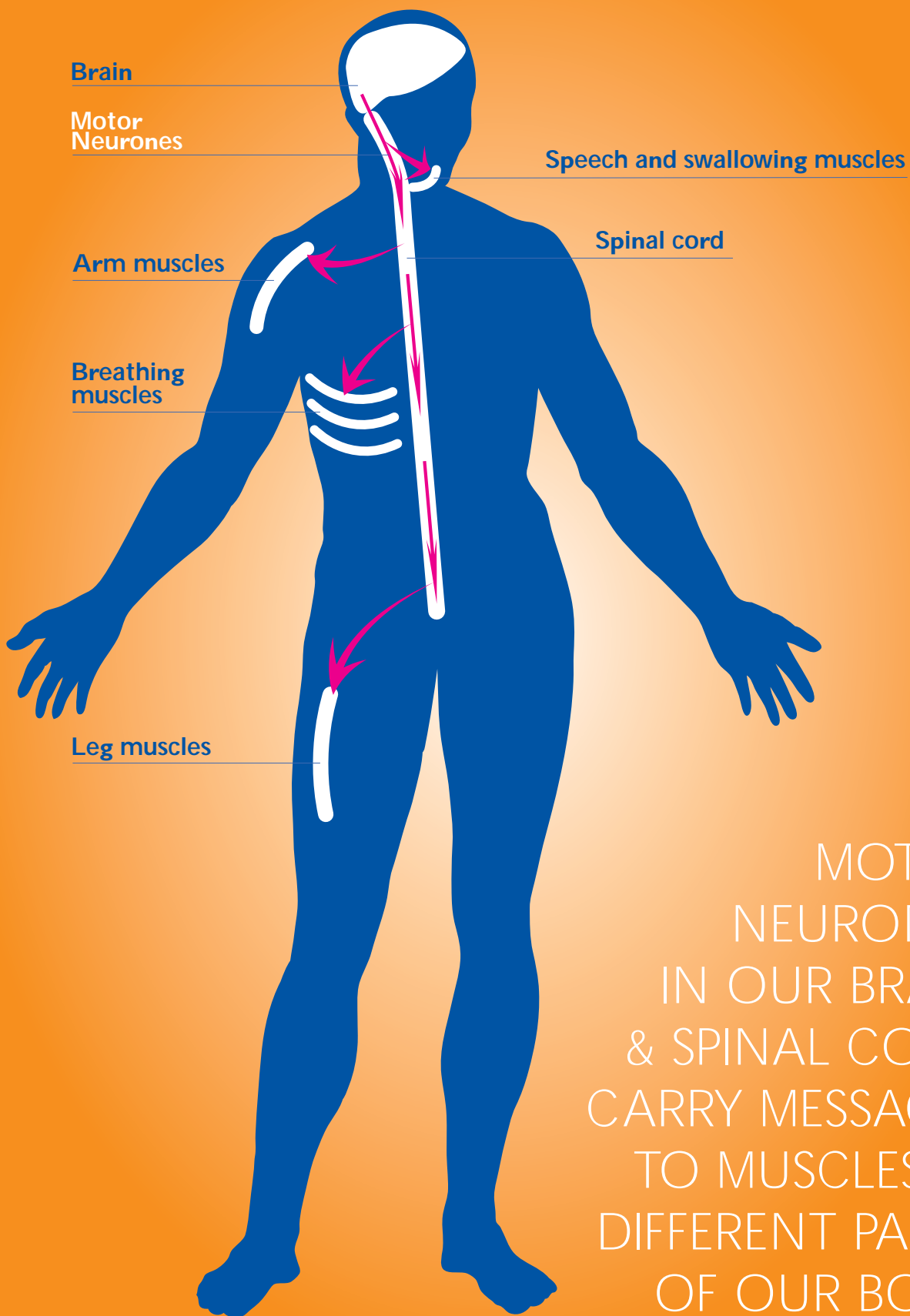
Every person who has MND is different, so no two people will have exactly the same symptoms.

- Weakness may start in the legs or feet - the person may trip easily, have difficulty walking and climbing stairs. Later, they may need a walking aid or a wheelchair to get around.
- Arms and hands may be the first to be affected in someone else. They will have trouble lifting their arms, picking things up, doing up buttons, and writing.
- For other people the speech and swallowing muscles will be the first to become weak. They will have difficulty speaking clearly and swallowing food and drinks.

Sometimes people with MND may also experience:

- Tiredness and shortness of breath after the smallest activity.
- Laughing or crying suddenly at unexpected moments.
- Not so much pain but very sore joints. They may also experience cramps and spasms in the muscles.
- Feeling very uncomfortable if they can't move their arms and legs to change position when sitting or lying down.





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

WHO GETS MND?

Most people are around fifty to sixty years old but it can appear in adults of any age. Ironically, they have often lived very healthy and active lives.

WHY DOES SOMEONE GET IT?

No one knows yet, it's still a mystery. Scientists in many countries are working towards a cure or treatment, but so far these haven't been found. Only one medicine, Rilutek, has been shown to slow MND down a bit.

CAN YOU CATCH IT?

No, you definitely can't. It's not a virus or carried by germs. Even if you spend a lot of time with someone with MND you won't catch it. You can stay close to your parent with MND and share food and drinks with them.

CAN YOU INHERIT IT?

For most families MND just happens 'out of the blue'. There is no chance of it being passed on to anyone else. A very small number of families can inherit a kind called Familial MND.

It is very rare and a family will usually know if other relatives have had it.

WILL THE SYMPTOMS GET WORSE?

Unfortunately they will, because MND weakens other parts of the body. This happens faster for some people than others.

“It was hard to understand why dad couldn't hold a plate of sausages one day, when he seemed to be able to do it OK the day before.”

Some people live longer, but most have MND from one to 5 years.

WHAT IS NOT AFFECTED BY MND?

MND doesn't usually affect the bladder and bowel.

There is no change in the way a person understands, sees, hears or feels things. Although they may have difficulty moving and sometimes speaking, they generally stay the same person they've always been.

Some people slow down mentally, but most don't.

They can keep their sense of curiosity and interest in what's going on in the family and the world outside.

Even when their arms, legs or speech don't work as well as they used to, people with MND will still like a hug or a kiss, listening to you talking about your day, or sharing family stories and time with you.



MND AND FEELINGS

Your parents would have felt shocked and anxious when they found out about MND. They would have been worried about the effect it might have on the whole family. They probably have had to rethink their plans and expectations for you and each other.

Some parents find it very difficult to talk to their children about MND because they need a lot of time to think through the situation themselves. Others try to protect their family from something that is going to be so difficult and sad to live with.

Families experience a whole new set of feelings when MND comes into their lives. Your parent may get depressed or frustrated sometimes, which is understandable. They can experience a range of feelings throughout the day. It can be a challenge to try to help keep your Mum or Dad's spirits high, even when you may be feeling sad yourself. Try not to think of them as always feeling depressed. Remember, it's not your responsibility - it's all part of managing in a difficult situation.

HOW ARE YOU FEELING?

When a family is told that one member has a serious disease, it can take a while for everyone before the truth 'sinks in'. Then it might feel that everything has suddenly become meaningless - all the things you've taken for granted about your life and your family are changed.

“I felt as though the rug had been pulled out from under me when mum told me that dad had MND.”

There is no right or wrong way to feel. When there's a serious change or loss in our lives everyone reacts in their own individual way. Some young

people feel terribly sad, others feel numb, or get angry and want to blame someone.

“I wanted to be with dad as much as possible, to get to know him better and I thought that my brother would miss out on this by going out so much. This caused tension between us but now I understand that everyone has their own way of coping. For him it was very

important to have support from his friends.”

These feelings are a normal part of grieving and they can come and go at different times and in different strengths.

ANGER

“For a while I was so angry at the world for my Dad having MND.”

It's natural to ask: *“Why has this happened to ME - to US?”*

You might feel angry with MND itself, or because the doctors can't make Mum or Dad better. You could resent friends and relatives who don't seem to understand, or whose lives seem so carefree.

Sometimes you may even feel angry with your Mum or dad for taking up so much attention and energy from the rest of the family, and from you.

You may feel like hitting out at the world.



GUILT

Young people can feel guilty about having angry or resentful feelings. They may even worry that they might have done something to contribute to Mum or Dad getting MND.

“I would sometimes feel guilty, especially if something bad happened while I was out, or if I was away from dad for too long, I would feel like I had neglected him.”

Don't feel guilty about having your own life. It is really important to go out and have fun with your friends. You need to do *‘ordinary’* things to keep strong and positive. Your parents can find happiness in these things continuing for you.

“One thing that was very important was that dad emphasized there is no one to blame.”



BEING ANXIOUS OR SCARED

It's natural to feel worried about the effect MND will have on the future. It's sensible to ask questions like: *“What about me?”*, *“Will I get MND?”* and *“How will this affect my life?”*

You may feel anxious about whether the rest of the family will stay healthy and be able to cope. You might also worry about how your family is going to manage financially. These are perfectly reasonable things to think about.

FEELING SAD, LONELY & HELPLESS

It is hard feeling that you have suddenly become 'different' from your friends because Mum or Dad has MND. You may feel quite isolated at times, really sad and alone.

“I often felt that everyone was talking about me in whispers & stuff, who knows though, I know it was mostly in my head. However this did make school hard.”

There will probably be times when you feel almost overwhelmed, helpless and confused. These are genuine feelings, but they are likely to pass if you can share them with your friends.

WHEN OTHERS DON'T UNDERSTAND

Many young people worry about how people outside the family will react to an illness like MND. It is a complicated disease to explain.

“Some people didn’t know how to talk to me and treated me differently when they knew my dad was sick. This can be very hurtful as I found that some of my friends didn’t know what to say to me so they ignored me.”

People are often unsure or embarrassed about what to say - it's not a personal thing. It can be difficult for them to understand what your family is going through.

“I didn’t tell many people because most people don’t know what it is. You say “my parent (mum or dad) has MND and they say “oh, that’s not very good” like you just told them you have a cold.

And I don’t like explaining it because it makes me sad. So they can’t understand why it is such a big deal.”

When a friend expresses interest, offer them the leaflet Talking about MND - for Friends in the pack your parents have. It will help them understand the situation better. Friends can also look up other information on the MND Australia website.

TRY TO EXPRESS UNHAPPY FEELINGS

“Quite often I felt helpless as there was nothing I could do. I couldn’t fix anything but just accept what was happening.”

It's difficult to 'turn off' sad and angry feelings. Negative thoughts can make it hard to concentrate on school work, to sleep and to have enough energy to go to school or work, or spend time with friends.

One of the best ways of handling unhappy feelings is to get them off your chest. Find someone you like who is also a good listener. It could be Mum or Dad if that seems OK,

or a close friend, a teacher or your school counsellor.

“Sometimes I didn’t want to talk to my parents for fear of upsetting them, but it made me feel better to discuss my feelings & thoughts.”

There's no need to put a 'positive' face on when you talk. Share what you really think and feel. By talking through your worries or sadness you can start to feel more positive and able to cope better.

“It’s important to be honest with everyone. If it’s a bad day, it’s a bad day and friends will understand.”

The more you talk with each other, the closer you will grow to your family and friends. If you can't talk with them, think about seeing an experienced counsellor.

“If I had been organized to talk to someone like a counsellor I would have gone.

But I wasn't so I pretended everything was alright and I was coping. When I look back, I don't think I was."

WHEN IT'S HARD TO TALK

"Quite often I felt helpless as there was nothing I could do. I couldn't fix anything but just accept what was happening."

If you don't feel like talking, try something else. Other young people say these things helped them.

"I used to write and draw pictures, write poems, and song lyrics, anything really inspirational. I felt that writing helped me a lot."

- **HAVE A GOOD CRY.** Crying is not a sign of weakness, it's a sign of caring. It can really help to relieve tension and strain.

- **LET ANGER OUT.** Hit a tennis ball hard, kick a football or punch a pillow. Go for a long walk to clear your head.

- **WRITE YOUR FEELINGS DOWN**

"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."

- **VISIT A PLACE OF PRAYER; LIGHT A CANDLE.**

- **LOOK AFTER YOURSELF.** Eat well and get enough sleep. Exercise regularly – keep playing your favourite sport, jog with the dog, take a hike on a bike, dance or listen to music. These will all help to get rid of anxiety and tension.

Don't try to block out feelings with drugs or alcohol.

Unhappy feelings will just keep coming back – and you'll feel awful and out of control.

- **HAVE SOMETHING TO LOOK FORWARD TO.** Don't be too ambitious – try to make your targets ones you can achieve successfully. Help to plan a family outing, arrange to go camping with your friends, learn a new computer application, organise a party.
- **AND DON'T FORGET TO HAVE FUN WITH YOUR FRIENDS.** They can help to keep you positive and strong.

Remember to be patient with yourself – there's no perfect way to handle situations like this. Expect some disappointments. There will be mistakes along the way and times when things could have been handled better.

Accept yourself and your own reactions. How you feel is 100% right for YOU!



CHANGES AT HOME

MND involves many changes. Mum or Dad may not be able to go on doing things that they've always done around the house, or socially. The bathroom, kitchen and their bedroom may have to be altered to make them easier and safer to use.

You may feel uncomfortable when the health team starts arriving in the mornings or is there when you get home from school. The house could feel as if it's been invaded. You may run into people from the local Motor Neurone Disease Association, an occupational therapist, a physiotherapist, a speech pathologist, nursing care people and maybe a home care worker.

If you're interested and your parents agree, sit in on their meetings with the health team. The meetings review the support your family needs and the equipment available to help. A walking frame or a wheelchair could be needed if Mum or Dad's legs are weak. If they are having difficulty talking clearly they may be able to use a speech synthesizer or 'LiteWriter', a small computer that speaks the message typed onto its keyboard.

If swallowing is difficult, a 'PEG' may be recommended. This is a small tube painlessly inserted into the stomach for special food and liquids. Some young people like helping with their parent's meals and drinks; some don't.

You may find that the health care team is so busy thinking about your parent's needs that they forget to include you in their discussions. If this happens, talk it over with your parents and the health team.



RELATIONSHIPS AT HOME

You may experience changes in what everyone does in the family and the way you relate to each other. Your parents might feel that they are losing control of many aspects of their lives. They might try to protect you from the realities of MND and their worries, disappointments and sadness. This might clash with your wanting to be more independent and adult.

You may feel that you're expected to behave more like the 'head of the family' or 'mother of the house', but don't feel ready for so much responsibility. You may wish that you could go back to being a little kid again. Sometimes you may behave like one, which is a completely normal reaction as you work out how to communicate in new ways.

KEEPING THE LINES OF COMMUNICATION OPEN

The best way to keep communication strong is to make sure that you do keep communicating, it is very easy to let everything apart from MND pale into insignificance, but all the little things are still important and still need to be talked about. You can communicate more effectively if you are aware of how everyone in the family is feeling as the situation changes. There will be frustrations, upsets, and disappointments along the way, but it helps if everyone tries to work as a team. Some families have found it useful to put 'Emotions Thermometers' on their bedroom doors to show what's happening for them. A thermometer might say things like:

I Need Time Alone
I Need A Hug
Ask Me What's Wrong
I Feel Great Today
I'm Angry/Scared/Worried
Let's Do Something Fun!

Don't Ask Me How I Feel I Need Someone To Talk To

A pointer can show today's 'emotional weather'. Mum or Dad might want to make one too for the fridge, where everyone can see it.

FRUSTRATIONS & DISAPPOINTMENTS

“I know dad was stubborn and determined to live life as normal, but sometimes that caused tension and frustration. I think we all needed to be better prepared and more tolerant of the changes that were happening, it's just that there were so many things changing, preparation for every change was impossible.”

People and families are all different and manage in different ways. It can be very hard for a person with MND to let go of their normal roles in the family and at work, and start relying more on the rest of the family. They may not want to use the equipment recommended by the health team. They may try to fight the disease by doing the things they always have. Everyone else may feel irritated by this, which can make the person with MND even less co-operative.

It really helps if your parent with MND has a positive attitude but some people can become very angry. They may be upset and frustrated about the difficulties and changes they're experiencing. They may have strong mood swings and focus only on their own needs. This can put a lot of pressure on the rest of the family. Try not to take it personally - MND affects people in different ways and no-one is to blame.

AS MUM OR DAD'S MND PROGRESSES

One of the really tough parts of MND is that that some people find it difficult to speak, which will probably make them feel sad and frustrated. This can be a real challenge for all the family but try to be patient. "You have to try very hard to understand what they want to tell you ... it is as hard for them to say it as it is hard for you to understand, but they know exactly what they want to say."

THINGS THAT HELP

Although MND is a rotten thing for a person to have, it gives their family and friends the opportunity to get to know them so much better. You could:

- Find out more about Mum or Dad's life and your own background.
- Help them write letters or record their life story. Make a memory book or a scrapbook.
- Take photos with them and make audiotapes, DVDs or videos.
- Develop a communication system to help them signal their ideas and feelings.
- Help them achieve the goals they have for themselves and the family.

"One of the best things I ever did for my Dad was to make up a board that sat on the arms of his wheelchair to rest his arms on."

Think creatively about little things that can help a lot. Working on the computer together can be

fun looking up the internet, playing computer games or helping with a special communication program.

"We would joke together and sit and watch car-racing or other shows on TV. I could always poke fun at him and he would take it in the way I intended."

Sometimes it's good just spending time quietly together watching a DVD, looking through photo albums, playing cards or a favourite game.

Everyone is different, so don't worry if you can't think of something that you would like to do together right away. Ideas may spring to mind as time passes.

"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."

The things that your parent can do will change and your relationship with them may alter. But some things don't change. No matter what happens, your Mum or Dad still cares about and loves you in the same way as always.

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

They may not be able to put their arms around you but they'll want to. And there will be ways for you to show them your love.

FOR CARERS

WHEN SOMEONE IS THE CARER

A 'carer' parent is likely to have to do more and more at home. They may also be trying to hold down a job as well as helping you with your life. They may have worries about the future, family finances and doing the best thing for you. They may feel tired and stressed a lot of the time.

Just listen. Encourage your parent with MND to think of their partner, what might please them, for example ... buy flowers on their behalf, write notes of thanks, etc.

It is important that they get extra help. You and the family can help to some degree, but support from outside services is usually essential to keep everyone going. If your carer parent hasn't already found someone outside the family to talk to, suggest they do. The MND Association or the health team can help find them someone who understands.

“The best advice I can give is to give your other parent a break. Quite often, I would sit with dad and watch a movie with him just so mum could have some time to herself.”

Encourage your carer parent to take time out to do their own thing. They need regular breaks to get the strength to go on for all of you. Be there for them too.

Make sure that both parents know that you are there to help them when things get hard. Tell your parents that you love them every day.

IF YOU ARE THE MAIN CARER

There are many young people caring for a single parent. If there's just you and Mum or Dad living together you may find that you become the main carer. This means you could become responsible for things like cleaning, cooking and personal care for the both of you. It may be hard to keep up at school and you might feel very tired and stressed, so it will be very important for you to get support. There may be organisations and services in your area which provide support for young carers. Some contacts are on the back page.

If you are looking after your Mum or Dad, remind the health team when YOU need a break. Caring can be hard work, but you will grow up quickly and learn things that will be helpful in later life, including how people 'tick', practical things like budgeting, managing a home and balancing time in a meaningful way.

GETTING A GOOD BALANCE

It's important to get the balance right between staying at home to help and continuing your own interests, activities and friendships.

“Being a teenager is hard enough and you often think the world revolves around you. You really have to put all that teenager self-centered crap behind you and think about what your parents are dealing with”.

Time spent helping your parents means you can build memories of your lives together.

“When it comes to doing your own thing ... not only does your parent with MND not want to have to go through what is happening to them, but they do not want to put you through it either. Dad wanted me to go out and have fun and he wanted to see me enjoy myself - he didn't want him being sick to affect my life.”

It's really important to have this outside focus and not to let MND dominate your life.

You don't have to let MND define who you are. You have your own goals, needs and desires.

FAMILY & FRIENDS

People outside your immediate family are often happy to help in very practical ways. If your parents aren't able to take you to places you want to go, then relatives, family friends or your friend's parents might give you a lift. Ask them, don't be a victim. They may want to help but don't know how.

Support from your close friends is so important at this time but it can be hard for them to understand how things are for you. Talking to them about how MND is affecting your Mum or Dad and the family can bring back all your sad and difficult feelings. Remember though, the less you talk, the harder it can get.

“I was dealing with so much and to not have your friends understand or know how to react when you tell them can be very hard. Also I found that I had to summon so much strength and courage to tell people only to feel almost rejected when I did. Also a lot of friends didn't know how to talk about it with me.”

Some of your friends will be there for you and will be supportive and helpful. Others may not want to know about painful things, or don't understand how serious your parent's condition is. Offer them the 'For Friends' leaflet from your parents' Information Pack.

It's important to be honest with everyone. If it's a bad day, it's a bad day and friends will understand.

BRINGING FRIENDS HOME

When someone is stuck at home a lot, having bright young people coming to visit is like a breath of fresh air.

“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.”

However, not everyone wants to bring their friends home. Some young people prefer to keep their friendships in a different world from their life at home.



“I think I developed two different lives - one with school /university friends where I would joke around and try to be the funny guy of the group, and the other my less-exciting normal home life. I tried hard to keep the two separate as I felt I needed to be free to go out and have a good time like all young blokes.”

As with everything about MND, there is no right or wrong way to react.

If your friends want to visit, it's a good idea to help them feel comfortable about it.

Your friends need to understand that things have probably changed since last month when they came over, things may be a bit more confronting.

You need to explain very clearly to your friends especially those who already know your parent that there is absolutely nothing wrong with their brain ... they are still the same person, they still know who you are, what you're interested in and the time you wet the bed when you first stayed the night.

MND can quickly change Mum or Dad's appearance and what they are able to do.

“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.”

It's OK to feel embarrassed, but keep asking your friends over. Your friends will get used to the changes. They will understand you better, and they can help Mum or Dad to remain part of your world.



WHAT ABOUT SCHOOL?

You spend so much time at school it can be really helpful to get support from the staff and students you feel comfortable around. However, you may not want to be singled out for special attention just because you have a parent with MND.

“... generally it was more important to me that school was exactly the same as it was for everybody else.”

An information booklet for schools is included in the pack which your parents can give to the school principal or your home group teacher. Talk to Mum and Dad about what you want to happen, who you want to know about MND - and who you don't.

Make sure that other people are clear about how YOU want to handle living with MND.

“I guess it is important for teachers and staff to be aware that there is a situation at home for the child and that sometimes some support might be required. I think it is important to let the child know of the support options and pick whatever he or she feels most comfortable with.”

When you are helping to care for a parent with MND you may have trouble concentrating on lessons or finishing homework and assignments on time. Teachers need to know that you can have bad days and might need special consideration from time to time.

Some teachers are naturally more understanding than others. It helps to have someone at school you can talk to and who can keep an eye on what you need. This could be a friend, a favourite teacher, the school counsellor or the Principal.

“My closest friends were great, they kept the teachers up to date with what was happening and kept my recesses and lunchtimes light and fun but were there if I needed to collapse in a heap.”



CONTEMPLATING LOSS

As you know, MND can last from about one to about five years. It is very hard to face the possibility of a parent dying - not being around to share life's highs and lows with you. Even when someone is very ill and will not get better, their death can still be a terrible shock. It can seem as though your whole world has fallen apart and it can take a long time to adjust to the changes.

Once again you may feel all those strong emotions like grief, anger, resentment. Some feelings will last much longer than others, some will last forever.

But there can also be a great sense of relief. Mum or Dad no longer has to face all those difficulties and discomforts. The journey with MND is over.

COMING THROUGH

Coping with the inevitable changes and adaptations life asks of us can be a real achievement.

“Our whole family summoned an inner strength to pull us all through. I don't think I really knew who I was until I found that strength.”

We all have untouched strength and creativity. Yours will help you through this hard time. You can look more deeply into your values, hopes and friendships.

People who live through a very painful time say they came out of it 'older but wiser'. You will learn what's really important and how to cope with the setbacks that life may bring.

“Experience life as much as you can. Don't take your family for granted. Get to know your parents on all levels. Don't give up hope”.

You can also discover how precious it is to give and receive love and share the lives of the people you care about.

“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.”

USEFUL INFORMATION

About MND “Just For Kids”, from MND Victoria

www.mnd.asn.au

‘All for Kids’ - information for young children, teenagers and parents,
from the Canadian ALS Association

www.als.ca/allforkids

Lou Gehrig’s Disease (ALS) Nemours Foundation - from America

www.kidshealth.org/kid

Real stories from people living with MND

www.mndassociation.org/life_with_mnd/experiences_of_MND

Research on MND

www.mndresearch.asn.au



SUPPORT FOR YOUNG PEOPLE

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

Carers Australia: 1800 242 636

Who Cares? We Do! Support for Young Carers.
Information, referral, support and activities for young people under 26.
Free call anywhere in Australia except from mobile/cell phones

Young Carer: www.youngcarers.net.au

Helpful information about where to find your local Carers Association.

Carers New South Wales: www.youngcarersnsw.asn.au

Young Carer Project - Discussion Board, stories, poems, information and more.

National Centre for Childhood Grief: info@childhoodgrief.org.au

Support & counselling for teenagers by email.

Reach Out: www.reachout.asn.au

A site to help you through tough times. It has a lot of useful fact sheets including one about coping with grief.

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