Talking With Young People About MND

"Although we were a close family, we didn't talk much about what was happening or what might happen in the future. I wish we had talked more because a lot of my worries would have been dealt with. I remember worrying that dad would become ill looking after mum and that she would have to go into a hospital. Only after she died did I find out that dad was as determined as I was to keep that from happening. I would encourage people to communicate; it can save so much worrying".

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 the IMNDA 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, 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. 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.

Keep 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 lifts to school and social activities if you are pressed for 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 motorised 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.

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.

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.

How schools can help

Teachers at your child's school should be told if someone in the family has MND. If they have the information and know how the disease is affecting the family, they can be a real source of support for the child.

Children's schools become a very important part of their lives when a parent is ill.
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!"

Sharing your own feelings with your child will help them to understand their own:

- Don't be afraid to cry in front of the child - to them it is a natural thing to do. If you are worried about distressing the child, it can help simply to let them know that you do cry in private
- Children use a range of ways to let out their feelings, including play and drawing. Watching what they do may well be the best way to gauge their feelings
- Children, particularly older children, use denial as protection. They may withdraw or refuse to talk about it, hoping that by doing so it will go away. Remember that this is a normal reaction
- Children might use anger to express their fears, anxiety or even jealousy at the amount of attention their loved one is getting

- Children need to be shown that they are loved. If a parent suddenly can't play with them or take them to school, they may interpret this to mean that they no longer love them. However disabling the disease, there should still be 'special' times to be alone together
- Finding 'special tasks' for children to do to help their parent is a great way to make them feel involved and important
- Maintaining as normal a routine as possible for the child goes a long way to keeping their sense of security. Show them that life must go on and, if necessary, get outside help with routine things so that you have more time to spend with your child
- Many children - and parents - find comfort in putting together a special book filled with photographs and momentos of happy times. This will be a wonderful source of good memories for the child in years to come
- Older children often find that simply talking to their parent about their plans for the future helps. Again, in later years, they will be glad to have had the chance

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 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.

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 and 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 face issues towards being a young adult in their own circle.

As they get older, children have more mature perceptions and a different level of understanding. They may shoulder a heavy responsibility as a carer, or they may be at college and feel torn between home and student life. Encouraging young people to maintain their links with the outside world is vital. Reassure them that their friends and activities are essential in maintaining a balanced life.

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 professionals 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 cafe 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 child.

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.

What you do say will be determined by the child's age and the stage of the disease. However, it's worth remembering that children have a very different sense of time - anything described as 'in the future' could mean tomorrow, so try not to worry them unnecessarily.

What your child knows about death and dying will depend on their experiences, age and quite possibly their religion. Whatever they understand, it's important that they realise that even though someone they love will die, the happy memories will be with them forever.

Equally important is to dispel any fears your child might have about the actual process of dying. Their only experience may be violent death in films or on the news and they should be reassured that this is not what usually happens.

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.

➜ See 'Living With MND' section

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.

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."

Reading for parents, children and teenagers

There are a number of publications available that help parents talk to their children about death and dying. These can be found in your local library, bookshop, hospice, online at sites such as www.amazon.com or enquire at the IMNDA.

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 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

Older children

- *When someone special has motor neurone disease* - aimed at 6-12 year-olds, this is an illustrated booklet about the disease and its impact on the family. It is written for children to read on their own or with an adult
- *Grief in Children – A Handbook for Adults* by Atle Dyregrov. How to respond appropriately to a grieving child's needs
- *Someone to Talk to – A Handbook on Childhood Bereavement* by Pat Donnelly (produced by Barnardos)
- *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 Anne.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 connectedness with their children

Teenagers

- *Something I've never felt before: how teenagers cope with grief* by Doris Zagdanski - an intelligent book for young people
- *Helping Teens Work through Grief* by Mary Kelly Perschy - this book helps adults connect with grieving teens
- *When your parent has motor neurone disease - aimed at teenagers and young people, this is written by young people themselves*. It describes their feelings and experiences when a parent has MND

Support Services for children and teenagers in Ireland

- Barnardos Bereavement Counselling for Children & Young People.
  Hyde Square, 654 South Circular Road, Dublin 8
  Helpline: 01 473 2110
  Email: bereavement@barnardos.ie
  www.bereavement.ie

- Childline Online
  Freefone: 1800 666666
  www.childline.ie

- Rainbows Ireland Ltd - a peer-support programme to assist children, youth and adults who are grieving a death, separation or other painful transition in their family.
  Loreto Centre, Crumlin Road, Dublin 12
  Phone: 01 473 4175
  Email: ask@rainbowsireland.com
  www.rainbowsireland.com

➜ See 'How To Get More Information From The IMNDA & Other Organisations' section for further information.

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