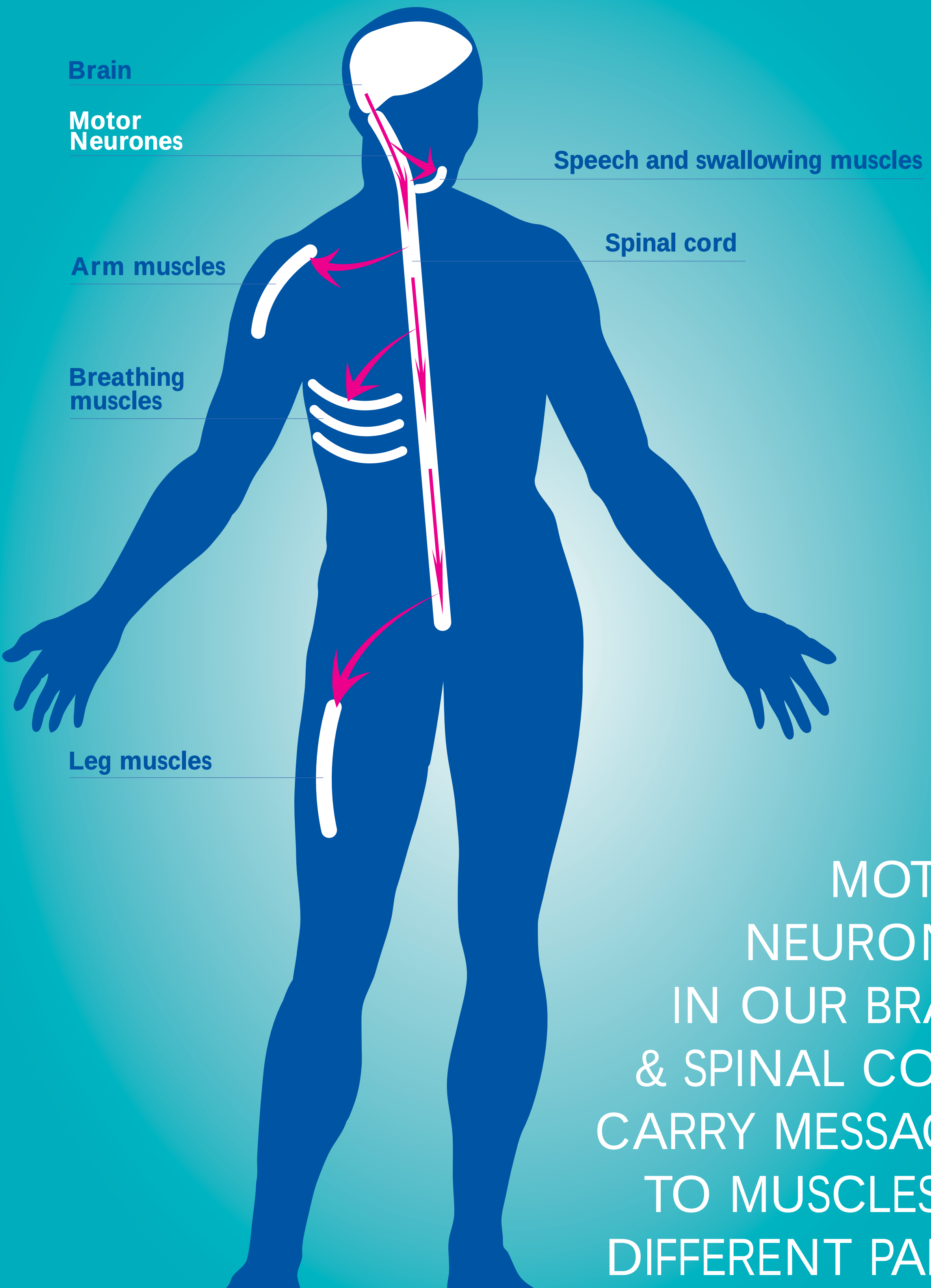
TALKING WITH YOUNG PEOPLE ABOUT MOTOR NEURONE DISEASE

FOR HEALTH PROFESSIONALS

mnd Australia



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

ABOUT MOTOR NEURONE DISEASE (MND)

Motor neurone disease (known as amyotrophic lateral sclerosis or ALS in North America) is the name of a group of diseases in which the nerve cells (neurones) controlling the motor muscles deteriorate and die.

As the motor neurones degenerate, the muscles they activate gradually weaken and waste, causing the person with MND to become increasingly disabled.

The patterns of weakness and rate of progression vary from person to person. However, people with MND are likely to face rapidly increasing levels of disability.

- Intellectual function and sensation are rarely affected.

- There is limited treatment and no known cause or cure. Life expectancy is usually around 1 to 5 years following diagnosis, although some people may live longer depending on the type of MND they have.

- Familial MND is a hereditary condition affecting approximately 5 to 10% of people diagnosed with MND.

- The worldwide incidence of MND is 2:100,000. At any given time there are about 400,000 people with MND. Approximately 1300 Australians are living with the disease.

- MND usually occurs randomly throughout the population. It is not contagious.

Other sources of information are listed at the back of this booklet.

MND AND THE FAMILY

DIAGNOSIS

Receiving a diagnosis of any life threatening disease is traumatic for a family. Plans and expectations are suddenly turned upside down. Family members generally experience waves of strong emotions - shock, bewilderment, anger, denial, sadness, guilt, fear and withdrawal. The emotional experience will be different for each person in the family. It is likely that they will only absorb information about MND and how to manage it gradually, and will need to revisit early decisions about the management and care of the parent with MND.

CLIENT CENTRED DECISION MAKING

A parent with MND experiences a spiralling process of loss, but their ability to reason is not usually affected by the disease. It is vital for their emotional well-being and sense of self that they remain central in the decision-making about their care. Care needs should be negotiated and prioritised with them and the rest of the family.

MANAGEMENT

Health professionals can help a family talk through their feelings and the issues the disease raises. Sometimes additional counselling may be needed and may range over a wide area including emotional, psychological, social and financial concerns.

There is no 'formula' for managing the physical aspects of MND. Each family's way of coping emotionally will be different. Health professionals need to recognise and work within these unique dynamics and support requirements. It is important to avoid making judgments about the way a family copes; it can undermine trust and block communication. Health professionals may find it useful to talk with other teams about their experiences of working with MND to compare approaches and strategies.

> "I feel I need constant exposure to other ideas, other ways of working, so that I can provide the person and family members with appropriate assistance in a sensitive and respectful way."
>
> (SOCIAL WORKER – PALLIATIVE CARE)

COMMUNICATION

Effective communication within the family can help to minimise the profound impact that living with MND can have on the children's lives. Health professionals can play an important role in supporting good communication between family members. Health teams need to know as much as possible about the disease and the family, to communicate effectively with them. The family needs to feel confident that help is being given by professionals

who have a sound working knowledge of MND and its longer term impacts.

Most families living with MND will at some time feel overwhelmed and fearful. They will know that they need answers but may not know what questions to ask.

> “Families need assurance that they will not have to struggle along this path alone.”
> (COUNSELLOR)

MULTIDISCIPLINARY TEAM APPROACH

The large range of professionals in a health care team can be confusing and at times overwhelming for the person with MND and their family. It can be helpful to create a list of the professionals involved, with contact details and a simple explanation of what they do. This can help children in the family to have a clearer picture of who is involved and why. It can also help the family if they can identify a ’key worker’ or team coordinator as the central person for liaison between the family and the team.

MANAGING CHANGES

Over time, changes of roles within the family may intensify existing family dynamics. There will be many layers of change and loss as the parent with MND becomes less able to do things with his or her children and requires more help, forcing the carer parent or a child to take on more roles. Families are likely to confront the loss of normality and privacy and may need to manage the reactions of close relatives and friends. These changes can bring people closer together as they discover previously untapped personal strengths and begin to work as a team. They can also put pressure on relationships.

FAMILIAL MND

The inherited form of MND known as Familial MND brings parents the added concern of knowing the impact living with MND has had on relatives. They are likely to be concerned that it will be passed on to the children. Information about genetic counselling is available through MND Associations.

SUPPORTING A ‘CARER’ PARENT

A parent providing primary care is likely to have less time to spend with the children and may be feeling exhausted, anxious, stressed, depressed, helpless, hopeless and fearful. Accurate information about MND and its progression at the right time is important in helping them be prepared and able to plan ahead.

> “The important thing is to make sure families know they can have access to whatever information is required, when it is needed. They simply need to know that it is OK to ask, and that someone will help them find what they need.” (COUNSELLOR)

Many carer parents experience emotional and physical ‘burnout’ and become resentful and ambivalent about the caring role. They may describe this process as feeling ‘numb’. Carer parents need to be aware of respite care available to give them some time to recharge their energy. Stress caused by the potential loss of one or both incomes may require professional assistance. It can be helpful to explore financial issues as early as possible.

Some parents rely heavily on their children for emotional and practical support and this can be hard on the children. In single parent households a child may have to become the primary carer. They will need special support and encouragement from health professionals.

TALKING WITH CHILDREN ABOUT MND

'Opening up' a conversation with the children about a parent's diagnosis can be one of the hardest things parents have to face. They may ask the health team's advice about when and what they should tell the children. Counsellors suggest it is better to tell children as soon as possible. Even very young children can detect when parents are unhappy and anxious. They may start worrying that what is troubling their parents might be their fault, something bad that they have thought, said or done.

Parents need some time to understand MND and come to terms with their own reactions and grief before preparing to talk to the children.

"The parent needs to have a certain level of psychological comfort in talking about MND. Poor communication is often about 'where the parent is at' in coming to terms with the disease as well as established family patterns of communication and emotional expression".

(PSYCHOLOGIST)

Their desire to protect the children - and even themselves - from the distress of facing the full implications of MND is understandable.

"MND is often rapid and involves losses at every level. Explanations to children can be even more complex and challenging."

(SOCIAL WORKER – PALLIATIVE CARE)

However, the rapid progression of MND can mean that there is limited time to prepare the children. Parents need to know that it is alright if they don't get it quite right the first time they talk with the children. Children understand when they feel loved and included, even if a message is unclear. Being 'included' can also help to develop their sense of trust and self esteem. Parents don't need to know all the answers – they simply need to convey to children that all questions are acceptable and they will help the children to find information.

Information should be given gradually and clearly at a level and pace appropriate to the child's intellectual and emotional maturity. The health professional team may be able to support the parents in talking through the issues, and even rehearsing how to tell the children.

"Parents should always be the decision maker in terms of timing of information, amount of information and who provides this information. Our experience has been that parents are happy to accept

> guidance but want to be the ones involved in telling their children the ‘hard’ news.”

(SOCIAL WORKER - PALLIATIVE CARE)

Parents can become the ‘comforters’ rather than the bearers of bad news if health professionals, such as the family doctor, explain the diagnosis to the children in the context of a family meeting. Discussion can begin by exploring what the children already know about their parent’s health problems. Questions from the children should be encouraged to clear up any misunderstandings.

CHILDREN’S RESPONSES TO MND

Parents may be challenged by their children’s reactions to MND. These might include ‘acting out’, withdrawal, regression, aggression, disturbed eating and sleeping patterns, difficulty with concentration and poor performance at school. Tensions within the family can also be increased when siblings react very differently. Some may want to keep close to their parents; others may want to stay away from home. Effective communication between family members can help reduce the long term impact that living with MND can have on young and adolescent children.

YOUNG CHILDREN

Children under 4 are too young to understand a parent’s serious illness. However, they have a ‘magical’ way of thinking, and can wonder if they are ‘to blame’ - they need to be reassured that MND is not their fault. Children of this age can also believe in ‘miracles’.

Parents can sometimes be upset and hurt if they do not understand the transience of young children’s reactions. Children may ask serious questions and seem sad one minute and a moment later they will be playing happily.

Younger children can be obsessed with germs. They may need reassurance that Mum or Dad’s MND is not ‘germy’ or contagious. They also need to know that they will continue to be loved and cared for. Wherever possible, parents should maintain the children’s regular routines such as meal and bed-times, and be consistent about good behaviour and discipline.

PRE-TEENS & TEENAGERS

Older children’s’ emotional and physical maturity and experience of the family’s dynamics strongly influence the way they react to living with MND. Adolescents already face many changes as they shed their identity as a child, and orientate strongly towards their peer group. Emotionally, most young people are on a roller coaster ride with dramatic ups and downs of mood. They may have mixed feelings about their parent’s condition, perhaps feeling deep sadness but also resentment about how their life has suddenly changed. Changes in what their parent with MND can do, and in family routines, can cause confusion. Teenagers are also likely to have concerns about their own health and worry about their carer parent and how the family will cope emotionally and financially.

They may feel lonely because MND has marked them as ‘different’ from their peers. Some will be reluctant to bring friends home because of embarrassment about their parent’s disability. Some teenagers may even ‘act out’ and reject the parent with MND. Subsequent feelings of guilt can complicate the situation as they struggle with their conflicting reactions, such as anger, regression, ‘shutting off’, sadness, guilt, and

isolation. At times their emotions may feel out of control. Young adults may adopt a very grown-up attitude to their parent's condition and its effect on the family, but this can hide a lot of emotional turmoil.

> "I just remember being very sad, but determined to try to be a strong person, and not be seen to let it affect me."
> (YOUNG PERSON)

Validation of the full spectrum of feelings is important. Young people need to be reassured that it is OK to react and feel the way they do.

CHILDREN AND HOME VISITS

When a parent is diagnosed with MND, the child's home may not seem like the safe and secure place it used to be. Changes such as home modifications and the introduction of medical equipment can be unsettling and confronting for children. The arrival of the health care team can add another level of uncertainty and confusion as the range and frequency of visitors can seem overwhelming.

> "As I was at school most of the time I didn't really have any contact with the people who came and talked to us at home. I was often getting home and there were people I didn't know leaving. I didn't really have any information apart from what my mum told me."

It can be helpful to reduce the mystery about what is happening and who people are by including children, especially older children, in therapy, counselling and care planning sessions. Teenagers in particular are likely to feel more in control if they understand and are prepared for the changes involved in the progression of their parent's MND. They may want to know the reasons for decisions about their parent's care and be included in the decision-making itself – to be a real part of the MND 'journey'.

> “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 and illness - feeling like I was part of the journey.”

The health team can also support young people when making home visits by giving them the opportunity to ask questions about their Mum or Dad’s care. They may not want a lot of information - you can check their comfort levels by asking what information feels like ‘too much’ at this time. It is important that their questions are answered honestly and openly. Always check if there is anything else they would like to know.

Team members might also suggest how the children could help out and spend ‘special time’ with their parent with MND. This can help build their sense of belonging and self esteem. Special times spent with parents and regular routines for ‘chatting’ helps strengthen family relationships.

Maintaining open and honest communication within the family is critical to the well-being of the person with MND, their carers, and their children.

A family member who is reluctant to communicate may be reassured by a discussion of the range of feelings and reactions experienced by other families striving to manage in similar circumstances.

PRACTICAL STRATEGIES FOR SUPPORTING YOUNG PEOPLE

Although the time health care professionals might have with the children may be limited, it is very valuable when people outside the family encourage and validate young people.

Experienced health professionals’ suggestions include:

- When arranging home visits, be sensitive to family routines such as school pick-up time. Joint home visits can help to reduce disruptions to home life.
- Make a special connection with the children by knowing their names, ages and interests.
- Provide opportunities for them to ask questions about their parent’s care and answer honestly, taking into account their language level and familiarity with medical terms.
- Invite older children, with parents’ permission, to attend therapy, care planning and counselling sessions. If they do attend, check their understanding of the situation and clarify any confusions or misunderstandings.
- Encourage open communication within the family. Suggest ways parents can keep communication strong.
- Encourage parents to help the children create a balance between helping and sharing activities with their parent with MND, and keeping up

their own interests and friendships.

- Be aware of any cultural and religious/spiritual attitudes likely to influence the way the family communicates and manages living with MND. Consider seeking the family's permission to involve interpreters, ethnic support organisations and pastoral care workers.

- Encourage parents to keep in contact with the school so they are aware of any difficulties or behavioural changes the children may be experiencing at home, in school or with their friends. Help the parents talk through their concerns if there are serious changes in a child's behaviour.

- Explain the value of personal counselling. Children may prefer to talk to a person not directly involved in supporting their parents.

MND is a distressing illness which can have a strong emotional impact on care providers, as well as on family members and friends.

Members of a health care team need ongoing support, information and feedback.

Resources about MND for health professionals

Professional Development can be provided by local Motor Neurone Disease Associations as an effective way of informing health professionals about MND, the effects it can have on young people and the resources available to inform and support them.

Motor Neurone Disease: A Problem Solving Approach, for general practitioners, health and palliative care workers and members of primary health care teams responding to the challenges created by MND. MND Australia booklet, 2nd edition, downloadable from www.mndaust.asn.au.
Other information about MND and support services can be obtained from:

- **www.mndresearch.asn.au** (Australia)
- **www.als.ca** (Canada)
- **www.mndassociation.org** (United Kingdom)
- **www.alsa.org** (United States)
- **Carers Associations**
- **Palliative care teams**
- **MND Clinics**

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