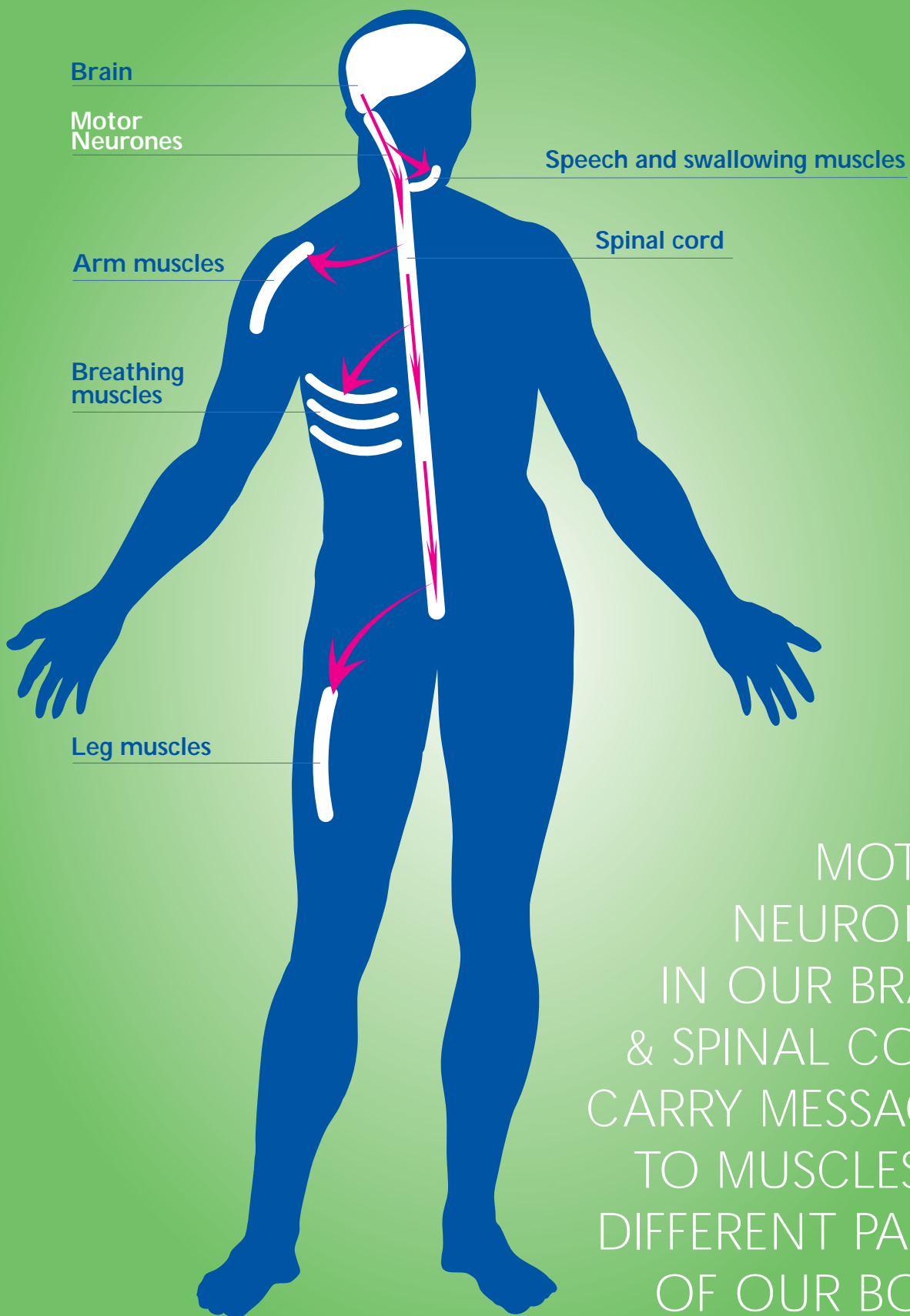




TALKING WITH YOUNG PEOPLE ABOUT
MOTOR NEURONE DISEASE
FOR SCHOOLS



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

ABOUT MOTOR NEURONE DISEASE (MND)

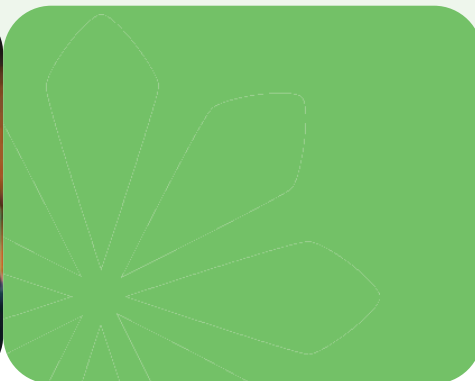
Motor neurone disease (known as amyotrophic lateral sclerosis or ALS in North America) is the name of a group of diseases in which the nerve cells (neurones) controlling the motor muscles deteriorate and die.

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.



HOW MND CAN AFFECT YOUNG PEOPLE

Schools have many years of experience providing pastoral support for students who are facing loss and grief. However, few staff are likely to have worked with a young person who has a parent with motor neurone disease (MND). MND is less common than most life-threatening illnesses but it is also one of the toughest conditions any family has to confront.

MND is different from other life-threatening diseases because of its speed of progression and change - parents and children face a rapid series of impacts with each increasing level of disability. The pressure on the parent who is the primary carer and the children to support the parent with MND emotionally and physically can be very intense and exhausting.

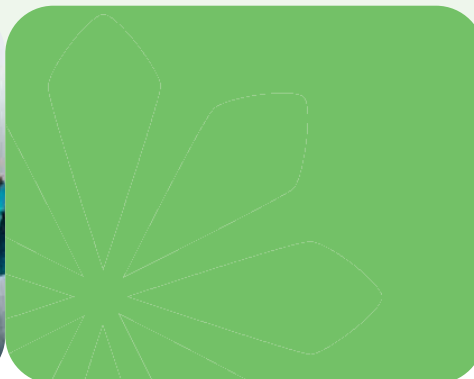
Many children and teenagers have to make the hard journey of MND with their parent, sometimes in company with another parent, sometimes on their own.

“During the MND journey students can become isolated at school, exhausted by having to manage their anxiety and growing sense of loss, as well as the demands of growing up, managing school

work and trying to meet the expectations of their teachers and friends. Many young people also take on considerable responsibilities for the care of their parent. They often display magnificent qualities

of resilience and courage as they and the rest of their family strive to live as normal a life as can be possible in such circumstances”.

(DR PAUL BROCK, DIRECTOR OF LEARNING AND DEVELOPMENT RESEARCH, NSW DEPARTMENT OF EDUCATION, 2007. DR BROCK HAS MND.)



All children living with a parent's terminal illness are living with grief. They will grieve in their individual ways, sometimes experiencing unexpected waves of sadness, anger and resentment as well as moments of normal happiness and fun. Students may be destabilised by these feelings. They may not be able to control how or when they will occur.

The world for a young person living with MND can seem out of control. Their home may no longer feel like a safe and familiar place - different health professionals will be coming and going and they may feel 'on the outer'. They may want to punish a parent with MND for 'messing up their life,' so when asked to help, they might react dismissively with a "Why should I?" They may feel guilty about their behaviour later, which can compound their feelings.

On the other hand, some young people devote all their time and energy to helping at home to the exclusion of their own friends and interests. They still need close friends and their support.

HOW THE SCHOOL CAN HELP

Parents living with MND appreciate regular information about how their children are managing at school. They also need to be alerted to any worrying changes in their young people's behaviour that may require professional

help. For example, anxious children may start being bullied in the playground or an angry child may start bullying others.

Teachers may notice negative changes in behaviour or academic performance. It is important that anti-social attitudes or activity are managed with compassion and tact, so that the young person continues to see school and its routines as a helpful and friendly balance to the many changes in life at home.

Parents in turn could be asked to inform the school of changes at home likely to affect their child's performance or behaviour.

The Principal could invite the family to discuss any particular needs that could be addressed by the school. The issue of student confidentiality should be discussed with the student and parents and an agreement reached about the boundaries of confidentiality.

It can be helpful to identify a staff member with whom the student is particularly comfortable, as a special friend or mentor. The child is more likely to turn to them when feeling distressed.

Trust in individual teachers is likely to develop through the child's own interests in sport, art, English etc. Being given a task they can complete successfully can be a terrific boost to a young person's sense of competence and confidence. Praise from teachers the student

respects can be very helpful in improving lowered self-esteem.

Some teachers have found that students like compiling a My Mum/Dad Book for their parents. The child whose parent has MND can use the exercise to strengthen the bond with their mother or father, without feeling singled out as a 'special' student.

A number of schools have found that puppet shows or plays around the theme of disability are valuable in creating a better understanding of a parent's illness.

For older students, it can be helpful if they can go home for a while, or chill out in the library, if things are getting on top of them.

"I knew that I was free to leave whenever I needed to and did not have to report to or ask anyone and that was enough. I never did leave but it was good to know that I could if I needed to."

Wherever possible, disability access should be provided so that a parent with MND can continue attending school activities as their condition changes.

WHAT SCHOOL STAFF CAN DO

“My principal knew most of the students’ names and had been my brother’s principal two years before. When I first started in year eleven she called me to her office and we had a general chat about things and about dad ... She was very laid back and let me talk and let me know that she was always there to talk. She didn’t actually do anything to help me but I always knew she was there if I needed her help, and I felt very comfortable talking to her.”

- Negotiate how much school and home work is manageable, for an agreed period. Review the targets if the student starts falling behind.
- With the young person’s agreement, the Year Teacher could arrange for a ‘buddy’ to help with school and homework, particularly when they may need to miss school.
- Encourage the young person to get involved in activities like art, sport, music, and journal or diary writing. These can help them to express their feelings in a safe and contained way.

“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.”

- Make allowances for ‘bad’ days by being flexible and relaxed if the student
 - is late with assignments
 - has outbursts of anger or misery.
- Normal school rules and boundaries should remain important. They help to provide security as the young person learns that some things in life remain constant, even if the world seems to be falling apart. They also prevent the student from being seen as ‘different’, or singled out as a ‘favourite’.
- Offer them a choice of tasks wherever possible. A grieving young person’s level of frustration and irritability can boil over if they feel they are being pushed into a corner.



STUDENTS AND MND

The following notes may be helpful for staff with less experience of working with students who are living with a parent's life-threatening illness.

“In English in year twelve I had to write a personal piece and I wrote a piece about watching my Dad die. I felt that if I didn't write it I wasn't being true to myself or my Dad and I actually really wanted my English teacher to know where I had drawn my strength from. I didn't know whether or not she had known that my Dad had died six months before.”

PRIMARY SCHOOL STUDENTS

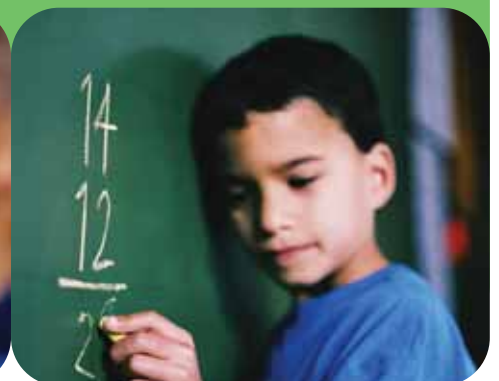
Psychologists and counsellors working with families living with MND advise that younger children tend to be very practical and concrete in the way they process their world.

- Very young students may not understand the permanence of a parent's illness or death. They may appear not to grieve at all. This can be difficult for adults to understand.
- They may not always be able to separate cause and effect, and may fear that they have

caused their parent's illness. (“If I'd been good, Daddy wouldn't have got sick.”)

- They tend to be obsessive about germs, so despite repeated reassurances, they may be afraid that they will catch MND themselves.
- They may have mixed feelings of love for their parents and resentment that their world has changed. They may believe that their parents have ‘cheated’ them - nice things that their peers at school have, and they want, may not be possible.

- A child may try to punish parents, particularly the parent with MND, by rejecting or belittling them when that parent can no longer do ‘normal’ things. Their mother or father may not be able to hug them any more, help with homework, play games or take them out.
- Primary school students may have difficulty paying attention, focusing on schoolwork, remembering things, or completing tasks.
- They may start to bully other children or ‘act out’ their unhappiness and anxiety.



YOUNGER TEENAGERS

School staff often find that young teenagers are probably the most volatile age group. A young person living with a parent with MND also has to manage their own hormone upheavals, development of self-image, peer group expectations, and measuring themselves against popular models of the 'with it' teenager.

They are just beginning to get more of their sense of self from their friends and their own achievements than from parents or teachers. They tend to be mortified if viewed as 'different', and particularly, as less 'successful' than their friends. Some students may not want anyone outside the family to know about their parent's circumstances.

Students in this age range stress that they did not want to be singled out in public at school or in front of friends. They were more comfortable when staff expressed empathy obliquely and casually - 'Wish Happy Birthday to Dad from me'; 'Say hi from me to your Mum.' One young woman recalled:

“I think the thing that was most helpful to me is that school was a normal experience ... generally it was more important to me that school was exactly the same as it was for everybody else.”

It is important for adolescents living with MND to understand that boundaries and rules also apply to them as much as to other students. Too much leniency can make them unpopular - being treated 'normally' can help the student keep their friends.

Sometimes it can be hard to distinguish between normal adolescent rebelliousness and disturbed behaviour. It is very helpful if all staff are sensitive to the young person's needs and alert to any disturbing changes in their behaviour in or outside the classroom. A useful question to ask is: "Is this new pattern of behaviour an exaggerated form of their previous behaviour resulting from grief, or is it completely out of character?"

OLDER STUDENTS

Young adults may adopt a very grown-up attitude to their parent's condition and its effect on their lives. They may seem philosophical about the situation, very 'cool', appearing not to relate what's happening at home to their own feelings or needs.

They are having to grow up more quickly than expected - they are increasingly losing the security of being able to lean on their parent with MND. They may also need to support

their carer parent emotionally and practically, while managing school assignments and getting ready for exams. They may even be the primary carer themselves.

At home they are likely to be taking on extra responsibilities and may be feeling quite stressed a lot of the time. A boy whose father has MND may think he needs to assume the 'man of the house' role. A girl whose mother has MND may feel she has to look after her father and any other children.



COUNSELLING

Students whose behaviour has changed in concerning ways may benefit from counselling, either at school or privately. However young people do not agree on the value of counselling when they are dealing with a parent's MND. One student suggested:

“I think maybe the young person could have an interview with a counsellor and agree upon some things that their teachers may need to know; the counsellor can then report this to the teachers. It is different for every young person so teachers need to understand

the complex dynamics, but only what the young person agrees upon.”

The possibility for choice in this area is very important for older students.

“I absolutely do not think that a school counsellor should be forced on the young person unless it is necessary or requested by the child. You cannot replace friends and family for counselling.”

If a student experiences a prolonged period of negativity, it would be wise for their preferred contact teacher to

talk with them before getting in touch with the family.

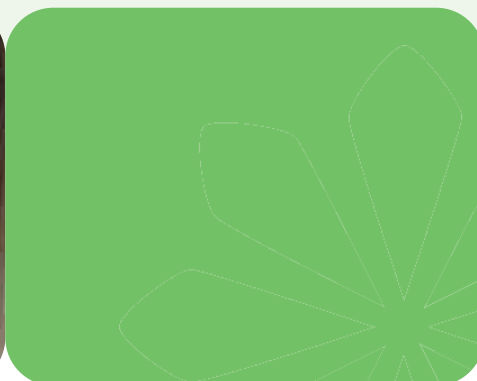
A young person's hatred of life should always be treated seriously - they may need professional help outside the school.

BEREAVED STUDENTS

When the student's mother or father dies they will grieve in a way that is unique to them. As you know, grieving takes time. The intensity and duration of their overt grief will also be completely individual.

Don't try to 'buck up' a grieving student - young people, like adults, never really 'get over' the pain of losing someone they love. It just changes shape and is stimulated, felt and expressed differently as they learn how to build life around the painful emptiness.

While the student may prefer to talk to the school counsellor





or chaplain, it can be helpful if other staff are aware of the child's loss and acknowledge it gently. "I'm sorry that you and your family are having such a tough time" may be enough support, unless the student requests more.

Many students find it easier to talk to a counsellor outside the school system. Visits to the school counsellor may be too obvious and can make the bereaved young person feel 'weak' for needing help.

It's important to respect a young person's pain even if you are not comfortable about how they express it. Compassionate support helps a child to manage grief.

Listening, without expressing an opinion, is a useful way of helping a bereaved young person.

“Teachers who allow their students time and support for healing provide a real gift to them.”

(THE DOUGY CENTER FOR GRIEVING CHILDREN AND FAMILIES, USA)

RESOURCES ON MND, LOSS & GRIEF FOR SCHOOLS

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

General information about MND is available from www.mndaust.asn.au

Useful reading includes:

- **When Someone Special has Motor Neurone Disease** - Information for Kids booklet, from your local MND Association
- **A Child's View of Grief** - A guide for parents, teachers and counsellors, Alan Wolfelt, Center for Loss and Transition - USA, revised 2004
- **Grief In School Communities** - effective support strategies, Louise Rowling, Open University Press - UK, 2003
- **Helping the Grieving Student** - A guide for teachers, The Dougy Center for Grieving Children and Families - Portland, USA, 2003
- **I thought I was the only one: Coping with grief and loss in schools** - a resource for teachers, Hazel Edwards - Collins Dove, Australia, 1992
- **Mindmatters** - A Whole School Approach to Loss and Grief, Dr Louise Rowling, Australia, 2000, www.curriculum.edu.au/mindmatters
- **Yeah Right! Adolescents in the Classroom**, Rob Long - David Fulton Publishers, UK, 2003
- **Young Carers** - At Risk Program: At risk of missing out on school, Carers Australia, 2006, www.youngcarers.net.au

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