

# The International Symposium on ALS/MND is coming to Glasgow

## 4th – 9th December 2018

Motor Neurone Disease (MND) is a rapidly progressing, muscle wasting, terminal illness. There is currently no cure or effective treatment for MND and the average life expectancy from diagnosis is just 20 months. There are over 450 people in Scotland currently living with MND, and on average almost 200 people are diagnosed each year.

MND stops signals from the brain reaching the muscles. This means the muscles start to waste and weaken, and eventually stop working. This may cause someone to lose the ability to walk, talk, eat, drink or breathe unaided.

MND can affect anyone at any time and not everyone with MND will develop all symptoms. How it affects people can vary significantly.

Please do not assume that someone with MND needs your help – offer it, but should they refuse, do not feel offended.



# MND – what you need to know



## Talking

Some people with MND may have difficulty speaking. Their speech may be slurred or they may not be able to talk at all. They might use equipment to help them communicate, such as a computer, iPad, or pen and paper. Some people with MND will use a breathing mask, which means their speech could be muffled, slow or difficult to understand. Just because someone with MND has difficulty speaking, it does not mean they cannot hear you or don't understand you.

- Try to maintain eye contact so you can hear and see articulation of words
- Allow extra time for communicating with people with MND; be patient and don't talk over them
- Don't answer for people with MND and if you don't understand them ask them to repeat themselves; don't ignore them
- Speak directly to the person with MND, not who they are travelling with, unless it is apparent that this is what the person with MND wants



## Walking

MND can affect some people's ability to walk unaided. Some may use a walking stick or similar, for extra support. This could mean they will move slower and there is a greater risk of falling. Some people with MND may use a wheelchair.

- Allow extra time for people with MND to get around
- Signpost elevators rather than stairs, and accessible toilets
- Accessible rooms, including wetrooms will enhance mobility for people with MND
- Wheelchair users will require additional space when dining
- When offering to open doors for people with MND, check if they already have their hands on the handle – pulling the door open may result in a fall if the door is the only thing keeping them propped up



## Eating and Drinking

MND can affect someone's ability to eat and drink. The muscles in someone's arms and hands may be weakened, meaning they could find it hard to physically feed themselves. Some people will have difficulty swallowing, increasing the risks of choking, and some people with MND will use a feeding tube.

- It may take people with MND longer to eat and drink than others; as food may go cold, people with MND may ask for it to be re-heated
- Food and fluids may be spilled or dribbled
- Poor dexterity may mean that people with MND have difficulty handling money

**For information about MND or to get advice please call MND Scotland on 0141 332 3903 or email [info@mndscotland.org.uk](mailto:info@mndscotland.org.uk). You can also find out more on our website at [mndscotland.org.uk](http://mndscotland.org.uk).**