

MOTOR NEURONE DISEASE



Motor Neurone Disease (MND) is a fatal, rapidly progressive disease of the brain and central nervous system. It can leave people locked into a failing body, unable to move, walk and talk. Although there is no cure for motor neurone disease, treatment can help to ease symptoms and disability.

UNDERSTANDING NERVES

Nerves (neurones) are like wires that carry tiny impulses (messages) between the brain, spinal cord and the rest of the body. Motor nerves carry messages from the brain and spinal cord to muscles and make muscles contract. Sensory nerves carry messages of touch, temperature, sound, smell and taste from various parts of the body to the brain.

THE FACTS

- Around 7 in every 100,000 have the condition in the UK
- Over 5,000 people affected in the UK today
- It usually starts in middle age
- Men are about twice as likely as women to be affected
- MND kills 3 people every day. More than the number dying of AIDS
- There is no treatment or cure
- 1,200 newly diagnosed every year.

There are various 'sub-types' of MND. In each type, symptoms tend to start in different ways. However, as the disease progresses, the symptoms of each type of MND tend to overlap. This means that symptoms in the later stages of each type of MND become similar.

There are various types of Motor Neurone Disease.

The main types Of MND are:

- Amyotrophic Lateral Sclerosis (ALS). This is the most common form and is characterised by weakness and wasting in the limbs. Someone may notice they are tripping when walking or dropping things.
- Progressive Bulbar Palsy (PBP). About 2 in 10 people with MND have this type. The muscles first affected are those used for talking, chewing and swallowing (the bulbar muscles).
- Progressive Muscular Atrophy (PMA). This is an uncommon form of MND. Early symptoms may be noticed as weakness of the arms or clumsiness of the hands. It normally affects the lower motor neurones (nerves) that control muscles in the body. The muscles become steadily weaker and smaller and this results in progressive muscle weakness, causing shrinkage in muscle bulk and weight loss.
- Primary lateral sclerosis (PLS). This is a rare type of MND. It mainly causes weakness in the lower limbs. Some people with this type may also develop clumsiness in the hands or develop speech problems.

THIS IS MIKE'S STORY

My thanks go out to Mike Findley for sending me information on MND, which assisted me in compiling this fact sheet.

Mike Findley former Divisional Representative for the North East was diagnosed at 1pm on Friday the 17th June 2005. He was 60 years of age fit & well (apart from two knee replacements – due to playing various sports). Mike's prognosis was 2 to 5 years.

In September 2004, whilst having a shave, Mike's right arm started to weaken. He had also been suffering pains in his neck for a while. Mike's doctor started to treat him for arthritis; however things didn't get any better, so he was sent to see an orthopaedic consultant who, after examination, sent Mike to see a Neurologist. After some electronic tests Mike went into St James Cook University Hospital on Friday 17th June 2005 when he was told he had Motor Neurone Disease.

MND started to affect Mike's shoulders, killing the nerves that controlled his arms hands & fingers, in 2007. After some tests his consultant told Mike that he had Progressive Muscular Atrophy (PMA). This affects only a small number of people, with a life expectancy of 5 to 10 years. In April 2010 the disease progressed to the muscles in his back, meaning he now has to rely on a wheelchair to get about.

HOW DOES IT EFFECT MIKE?

- Mike has to drink through a straw,
- Needs food cut up.
- Uses just a fork.
- Cannot clap his hands or shake hands properly.
- Needs help to put his shirt or jacket on etc
- Gets tired easily due to lack of muscle in his upper body.

Mike remains confident and positive and to date 'The Mike Findley MND Fund' launched on 15/09/05, has raised £54,035.95 for research.

“Life with MND may be short – but it's worth living”

Every year Mike helps out the Neurosciences Department at James Cook University Hospital as a 'guinea pig' for student Doctors. On Wednesday 9th June 2010 Mike attended the Palace and received an MBE a truly amazing member of our union.

FAMOUS PEOPLE WHO LOST THEIR LIVES THROUGH MOTOR NEURONE DISEASE:

- David Niven – Actor
- Willie Maddren – Boro & England Footballer
- Don Revie – Leeds & England Manager
- Willie Johnstone – Celtic & Scotland Footballer

The Exception is:

- Stephen Hawking – Developed Amyotrophic Lateral Sclerosis in 1962 – 47 years with MND

RESOURCES:

Motor Neurone Disease Association

PO Box 246, Northampton NN1 2PR

Tel: 01604 250505

Fax: 01604 624726/638289

Email: enquiries@mndassociation.org

Website: www.mndassociation.org

MND Connect 08457 626262

Advice, practical and emotional support and directing to other services and agencies, for people living with MND, carers, family members, Health and Social Care Professionals and Association staff and volunteers.

Open Monday to Friday 9.00am to 5pm.

Linda Roy

National Equality Officer

Email: lroy@cwu.org

Tel: 0208 971 7238

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