

Physical activity and motor neurone disease

What you should know

- Motor neurone disease (MND) weakens muscles across the body, affecting amongst other things mobility, movement and physical activity
- More research is required to determine whether exercise with MND is helpful or harmful. Studies suggest exercise may help with performing daily activities and quality of life in the medium to long term. However, in people carrying the C9ORF72 mutation, frequent and intense anaerobic burst activity may be detrimental.
- Physical activity with MND is best undertaken with the guidance of a health professional and tailored based on functionality, needs and preferences
- Fatigue should be closely monitored as part of physical activity with MND
- People living with MND report that personal enjoyment of physical activity is more motivating than a physiotherapist recommendation to be active

About physical activity

Physical activities include anything that involves body movement and increases breathing and heart rates [1]. Walking, gardening, bicycle riding, yoga and many other forms of physical activity may benefit health, such as helping with blood pressure, cholesterol, managing pain and reducing stress and anxiety and helping with sleep. Physical activity is also a great way to stay connected with friends and others in the community.

Research finds that there are barriers, however, to participating in physical activity. Disability, lack of time, low levels of confidence, lack of enjoyment and other barriers can all make it challenging for many people to improve their health and wellbeing with physical activities, including those with MND [2].

Physical activity and MND

Intense physical activities and MND

While physical activity generally has many benefits, researchers are still debating whether it is helpful for someone living with MND, and if it increases the risk of developing the disease [3] [4].

Some studies have raised concern about intense kinds of physical activities and MND. For example, repetitive head injuries from contact sports (e.g. professional soccer or football) may increase the risk of developing neurodegenerative issues, including dementia, Alzheimer's disease and MND [5]. Another recent study, identified that in people carrying the C9ORF72 mutation, frequent and intense anaerobic burst activity may be detrimental. Much remains unclear though about the risk. More research is needed.

While it helps to be mindful of risks to health and safety during physical activity, it's important to keep enjoying their many physical, emotional and social benefits.

Therapeutic physical activities and MND

Other research finds that for some people living with MND there are a number of benefits from participating in therapeutic physical activity [4]. Benefits include positive changes to physical and mental health.

Therapeutic physical activity generally refers to activities involving a health professional that are used to help treat the symptoms of disease. For people living with MND, therapeutic physical activity has involved working with clinicians on aerobic, strength and endurance exercises, and functional training or stretching. Activities are normally tailored based on a person's level of function and needs, including setting limits for their intensity and duration. Activities can be performed at clinics, in the home, in pools as part of hydrotherapy and other settings that patients feel comfortable and can access [7].

A recent systematic review found that therapeutic physical activity could contribute to slowing down the deterioration of muscles in the body of people with MND [4]. Physical activity helps to counteract the muscle weakness caused by the degeneration of nerves from MND by strengthening healthy nerves and muscles. Daily activities can become easier and quality of life may improve, particularly in the medium to long term. Research also suggests that physical activity may:

- help maintain joint range of movement
- prevent contractures
- reduce stiffness and pain
- support overall wellbeing and enjoyment of daily life [8].

For some, physical activity with MND might be able to help with distraction from worry, build confidence and a sense of control and encourage social interaction and feelings of being supported by others [9] [10].

It's important to note, however, that physical activity becomes harder over time with MND. The degeneration of upper and lower motor neurons leads to progressive weakness of bulbar, limb, thoracic and abdominal muscles causing stiffness and immobility. The disease affects a person's ability to walk, speak, swallow and breathe, all of which are important for participating in physical activities.

Recent research has also found that personal enjoyment of physical activity, as opposed to a physiotherapist recommendation to be active, is more motivating for some people living with MND [11]. It can help for people living with MND to consider activities they enjoy doing, and for healthcare professionals to find ways of supporting those activities.

Fatigue is a considerable barrier to physical activity and part of daily life for people living with MND and needs to be carefully managed as the disease progresses [11].

How to manage physical activity and MND

Speaking with a healthcare team can help people living with MND manage movement and mobility for remaining physically active for as long as possible, and to address fatigue and other barriers to physical activity. A physiotherapist and occupational therapist are able to perform an assessment and continuing review for:

- managing aerobic, strength and endurance exercises (e.g. range of motion exercises, limbs relaxation, trunk balance, gait training and hydrotherapy)
- managing functional training or stretching (e.g. upper and lower limb exercises)
- positioning and pain management
- prescription of appropriate assistive technology to assist independence, mobility and comfort.

A health care team can also advise on a program of tailored physical activity with MND. A tailored program is able to address:

- fatigue and finding ways to get an appropriate amount of rest
- posture
- the value of a resistance program, an active-assisted program or a passive program
- whether family members and/or carers (as appropriate) are willing and able to help with exercise programs
- advice on safe manual handling.

A person may need a brace, splint or similar device to help with muscle problems. If so, the person should be referred to an orthotics service as soon as possible.

More information

Your state MND Association or an MND clinic or service

Your General Practitioner or Neurologist

Physical Activity and MND (Plain language)

To find out about motor neurone disease and other fact sheets in this series contact the MND Association in your state or territory ph. 1800 777 175 or visit www.mndaustralia.org.au

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