

Introduction

In Motor Neurone Disease (MND), the body's muscles become weaker and waste away. As a result, someone with MND will become less mobile in terms of moving their head and limbs. Often, the associated joints then become stiff and painful. Involvement of a Physiotherapist following a diagnosis of MND can be beneficial as an early assessment and planned exercise programme can assist people with MND to maintain mobility and independence for as long as possible.

It is important to realise that exercise will not strengthen muscles that have been weakened by MND. Once the motor neurones which control a particular muscle have degenerated, the muscle cannot be regenerated by exercise. Despite this physiotherapy can be of great benefit.

The physiotherapists tasks may include the following:

- Making a home assessment.
- Providing a detailed analysis of abnormal movement (eg, analysis of how you walk,)
- Optimising your strength, function, and provide guidance on positioning for comfort
- Designing and monitoring an appropriate therapeutic exercise programme;
- Assisting with respiratory care.
- Providing training in energy conservation.
- Assisting in providing useful specialist equipment;
- Advising on how to manage falls

MND Scotland is the only charity funding research and providing care and information for those affected by MND in Scotland.

Forward Planning

People with MND need to understand their own limitations and the importance of not over-exercising. Exercise programmes should be tailored to the individual, depending on their specific abilities, fatigue levels and stage of the disease.

Physical Problems

MND can give rise to altered muscle tone and loss of voluntary movement. Weakness may begin in any group of muscles, and progress differently in each individual person. This may result in:

- Prolonged contraction (contractures) of affected muscle groups – particularly the joint muscles,
- Pain in affected muscle groups – and also in joints which have become stiff,
- Loss of head control due to weakened neck muscles,
- Altered trunk control
- Problems associated with weakened shoulder
- Impaired arm and leg function,
- Peripheral oedema may occur. (e.g. swelling of ankles, hands and fingers.)

Going from a sitting position to standing, even if assisted, often achieves a number of aims – including stretching joint muscles, weight bearing, maintaining bladder and bowel function and provision of pressure relief.

Range of Movement Exercises

A person with MND may benefit by moving each affected joint through a series of range-of-motion (ROM) exercises. This can help to prevent joint stiffening, and to keep the body as flexible as possible and the joints mobile. The objective of ROM exercises is to move each affected joint through its full range of motion. However, it is important to understand that not every person with MND can do a full set of active exercises.

Active Exercises

An active exercise is one the person does themselves without any assistance, when their muscles can perform the full movement. When someone cannot move through a ROM exercise on their own, they can still complete the movement as an active-assisted exercise. A helper may assist the muscle through the movement, or there may be a way to do a self-assisted range of motion exercise.

Passive Exercises

Passive exercises are done completely by a helper when muscles can no longer perform any of the movement. The helper moves the joints through their ROM by manipulating the limb. Passive exercises work the joints but not the muscles. Physiotherapists can train carers to do these exercises properly where it is appropriate.

The transition from active to passive exercise is seldom abrupt. Some people may find that they can do some exercises actively, some with assistance and still others only passively.

Each person with MND needs an exercise programme tailored to their own individual needs and abilities. GPs and physiotherapists can prescribe the exercises that are right for someone at any given time. The physiotherapist can

demonstrate the exercises to ensure that they will be performed correctly. Diagrams of the exercises can help patients and caregivers remember the techniques.

Moderation in Exercise

It is important that all exercise be performed in moderation. Fatigue will only increase weakness and rob the person of energy they need for their daily routines and the activities they enjoy. If you find that the prescribed set of exercises tires you, you should talk to your physiotherapist in order that changes can be made to eliminate the risk of fatigue.

Similarly, no exercises should cause pain. If someone does experience pain when exercising, they should stop that exercise and talk to their physiotherapist. It may be that they are not doing the exercise correctly, or perhaps some modification to their exercise program is required. Maintaining mobility and flexibility can help relieve pain and make daily tasks such as dressing and washing easier.

Regular changes in position may help prevent limb stiffness and ease pain. However, this depends on the wishes, abilities, and handling tolerance of the person with MND.

Deep massage can help loosen tight muscle groups. While this is not offered on the NHS, MND Scotland offers massage as part of its Complementary Therapy Service.

Referral Process. There are different referral methods depending on the region in which you live. It is best to contact your MND Clinical Specialist for advice about how to request Physiotherapy services. MND Scotland also offers a Physiotherapy service.

The information in this leaflet is believed to be accurate at the time of production, MND Scotland cannot give detailed medical advice, this leaflet should be regarded only as general background information.

MND Factsheet 5C Getting the Best From Physiotherapy

Useful Resources

If you have difficulty obtaining aids or equipment check with your MND Clinical Specialist as some items are available on loan through MND Scotland.

Chartered Society of Physiotherapists
www.csp.org.uk

Patient leaflets

MND Association

MNDA have a leaflet on Physiotherapy
<https://www.mndassociation.org/wp-content/uploads/2015/06/06a-physiotherapy.pdf>

ALS Society of Canada

Mobility and Independence -Adapting to changes in mobility and maintaining independence from “ALS Manual – manual for people living with ALS” Available to download online from
www.als.ca/als_manuals.aspx

Books

Muscular Dystrophy Association (USA) has a whole section on ALS. Their patient guide, Everyday Living with ALS :A Practical Guide has a chapter on how to get the best out of physiotherapy in **Chapter 8**

<http://www.mda.org/sites/default/files/publications/Everyday Life with ALS P-532.pdf>

Multidisciplinary care: physiotherapy by Ulrike Hammerbeck and Emily Jay from “Palliative Care in Amyotrophic Lateral Sclerosis - From Diagnosis to Bereavement”, Chapter 12, edited by David Oliver, Gian Domenico Borasio and Wendy Johnston, 2014

Further Reading

Factsheet 5A	Assistive Equipment
Factsheet 5B	Maintaining Mobility
Factsheet 5D	Aids to Maintain Mobility

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