

LIVING WITH NMO

Staying Active With NMO

Activity should be based on individual function and capabilities.

Exercise comes in many different forms depending on the individual!

It enables you to do the things you want to do and helps to prevent complications that can result from inactivity.

Recent studies have shown that people can have significantly reduced balance even when they have no problems with walking.

You may have limited access to participation in exercise or physical activity. Don't let it stop you!

It is hoped the booklet will provide you with explanations, reassurance, ideas to maximise your energy levels and tips to use your energy levels effectively.

Why should we be active daily?

- Improves posture/balance (decreased falls risk)
- Helps to maintain ability to perform everyday tasks with ease
- Improves muscle strength and fitness
- Prevents joint stiffness and discomfort
- Maintains strong bones and healthy circulation
- Helps maintain a healthy weight
- Increases energy

- Improves self-esteem and happy feelings (chemicals released in the brain)!
- Improves relaxation
- Reduces stress
- Great way to meet people and make new friends

How much should we do?

- Adults Age 19+ should aim to be active daily.
- 2.5 hours per week of moderate intensity activity in bouts of 10 minutes or more.
- Regular exercise improves muscle strength.
- Minimise the amount of time being sedentary (sitting) for extended periods.

Activities come in many forms!

- Look at your daily activities/lifestyle when deciding on exercises everyone is different
- Little and often! Intersperse short bursts of exercise with periods of rest
- Sight problems should not be a barrier to keeping fit
- It doesn't always mean a trip to the gym

Types of activity

Moderate Intensity

- Causes you to get warmer, breath harder and your heart to beat faster
- You should be able to carry on a conversation
- Brisk walking, dancing, cycling or swimming

- Housework or Gardening-weeding / working at a table
- If you are wheelchair based get self-propelling!
- Complete an exercise DVD or a game on the Wii
- Park the car a little further away from the shops
- Regular walks around the garden or up and down your street

Vigorous Intensity

- As above but the heart beats more rapidly
- It is more difficult to carry on a conversation
- Housework, climbing stairs
- Brisk walking, wheelchair based sports

Strengthening activities

- Involves using muscles to lift/resist things
- Disabled Exercise sessions/classes at your local leisure centre
- Carry heavy loads such as groceries, washing basket
- Physiotherapy Exercise Programme: Core stability/Pilates exercises

Balance activities

- Tai chi, yoga ,Wii, Pilates

Reducing sedentary (not moving) behaviour

- Reduce time spent watching TV, using the computer gaming.
- Take regular breaks at work
- Breaking up sedentary time such as swapping a long car/bus journey for walking part of the way or self-propelling further.

What are your daily activities?

- Identify those which you have no difficulty doing
- Those affected by fatigue, pain or weakness due to living with NMO
- Identify your most important roles and activities
- Find new ways of performing an activity
- When exercising work towards small goals that suit you
- Change the time of the activity
- It is normal when becoming more active that you may have days when you can do more or you might do less. This is normal
- Keep an activity diary over 24hrs, record activities that require help

Start setting goals and build them into your daily life.

Once you have the motivation to start you can set some individual goals depending on your ability

Please note that every person with NMO is individual as to their symptoms:

If there are specific neurological/balance issues then you may require specialist Physiotherapy.

Frequent NMO Physical Symptoms:

- Pain often like a pressure feeling band like around part of your body
- Altered muscle strength in the control of arms or legs

- Altered balance in standing and when mobilising.
- Difficulty tightening your abdominal muscles and back muscles to hold your body still and balance prior to walking (see later section on core stability)
- Joint pain or discomfort
- Nerve associated pain (neuralgia)
- Altered coordination
- Altered sensation in arms/legs, sometimes total loss of sensation
- Increased sensitivity in arms or legs when being active (tingling/pins and needles)
- Partial sight/total loss of sight making it more difficult to be active when you can't see things around you. This can also affect your balance as you often rely on your eyes to check where you are in relation to your environment.
- Spasms in certain positions leading to sudden movements.
- Decreased bladder control affecting confidence with movement/activity

Balance and Core Stability

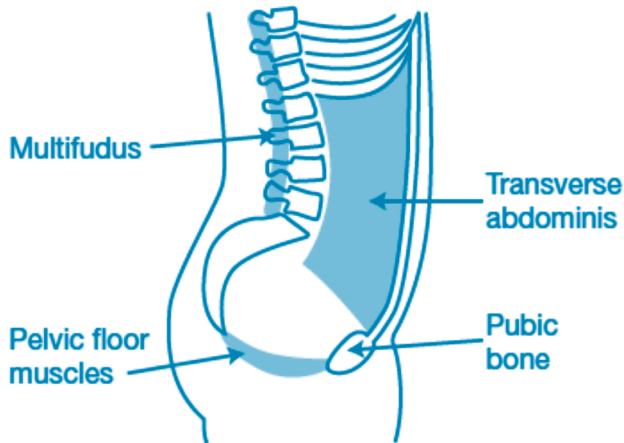
NMO can affect balance and mobility in many ways. This can cause difficulty with everyday activities such as maintaining balance whilst reaching, carrying a drink whilst walking or climbing stairs.

Recent studies have shown that people can have significantly reduced balance even when they have no problems with walking.

What is core stability?

Core stability is the stability of the human trunk

Core stability muscles



When we reach out an arm or take a step to walk:

- The nervous system switches on our muscles in a specific order
- Trunk muscles contract before our arms or legs
- FIRST the deepest muscle, transversus abdominis switches on to stiffen the trunk
- SECOND muscles that brace the trunk against the direction of a limb movement
- This stabilises the body making sure that we are not pulled off balance by the moving arm or leg

People with neurological conditions have been found to have:

- Reduced trunk stability during arm movements
- Individuals with delayed trunk muscle activation have reduced balance

- Many Physiotherapists believe that this then impacts on their balance and mobility

Who can help me make a personal exercise programme?

Fitness instructor/gym-can individually guide you in the gym and taking into account your goals to plan an exercise programme (see IFI reference)

Do I need to see a physiotherapist?

Local NHS Physiotherapists- aim to help you reach your full potential for physical independence, strength, flexibility, mobility and fitness.

Physiotherapy is both useful post relapse as symptoms are changing rapidly or to assess and achieve your best potential based on what you have to work with on a daily basis.

Your GP will have details of other NHS Physiotherapy services in your area which may be appropriate. Services and waiting times differ throughout the UK.

Specialist /NMO Physiotherapists can be accessed as part of your Clinic at one of the 2 specialised NHS NMO centres in Liverpool or Oxford, refer to contact details at front of booklet. If you require more specific exercise therapy then your GP or specialist NMO Physiotherapist can refer you for Neurophysiotherapy assessment and treatment, either as an outpatient or at home depending on your needs.

Private Practice Physiotherapy- those with a special interest in

neurological conditions. They are registered with the Chartered Society of Physiotherapy (CSP) and will guide you to therapists registered near you. They will also be able to advise on expected costs. Tel: 020 7306 6666

www.csp.org.uk/your-health/find-physio

How do you know if the Physiotherapist is fully qualified?

They are all required to register with the Health Professions Council (HPC) regulatory body and the CSP.

www.hpc-uk.org

What will happen when I see a physiotherapist?

The Physiotherapist will assess and plan treatment to maximise your movement ability by health promotion, exercise and activity advice on preventing loss of remaining function

- Advice about Physical activity
- Advice on posture and relaxation
- Specialist stretches or advice on positioning to avoid spasm
- Advice and provision of walking aids
- Specific exercise programme to maintain function.

Exercise comes in many different forms depending on the individual!

Should I gain medical advice if I am not seeing a physiotherapist before starting a new form of exercise?

It is advisable to discuss with your GP, neurologist or NMO clinic prior to the start of any new exercise. You will be able to check if there is anything special that you have to take into consideration. Your GP may be able to refer you to a local active health team, this is exercise on prescription.

Access/Transport Issues:

- It is often difficult finding a suitable exercise facility or difficulty getting to the gym due to transport issues.
- Perhaps it may be a lack of confidence in the benefits of exercise or not being confident the people in a gym/ fitness centre will know about your condition and know how you can safely exercise.

Advice on access to exercise and transport is often a major factor in accessing activities. Information is available through your GP or local council r/e car services/ dial-a-ride/council run schemes.

Useful organisations

- www.sportability.co.uk enabling sports /activity access no matter what.
- Multiple sclerosis society have exercise DVDs available suitable for NMO www.mssociety.org.uk
- www.inclusivefitness.org Inclusive fitness aiding disabled access to gym facilities www.inclusivefitness.org must have disability awareness training. 01509 227750.
- www.ableize.com facilities in your locality
- www.disabilitynow.org.uk/living/features/fitness-getting-right-to-the-core
- Yoga for All www.getfitwhereyousit.com
- www.pilatesfoundation.com
- Pilates for Life DVD Darcy Bussell-with beginner level exercises. Also available from local libraries.
- Disabled ramblers www.disabledramblers.co.uk (England and Wales) www.ftdr.com (Scotland)
- Age UK.
- www.britishblindsport.org.uk 01296 424247
- Backup- spinal group offering a buddy system for skiing and outward bounds.
- British blind Sport Tel: 01926 424247
www.britishblindsport.org.uk
- Tandem club disabilities@tandem-club.org.uk 01522 695781
- joggingbuddy.com

- Actionnaires club children and young people sports activity club (8-16 yrs.) organised by action for the blind
www.rnib.org.uk
- Disability Rights UK- Doing sport Differently Information pack with contact details for national sports organisations.
- A programme that supports the fitness industry to become more inclusive, catering for the needs of disabled and non disabled people alike.

You can find out more and search for your nearest IFI accredited centre at

www.efds.co.uk/facilities.asp

Tel: 01509 227750

Email: ifi@efds.co.uk

**For Further Advice on activities contact your NMO
Physiotherapist.**

