



Living with NMO

Movement, mobility and travel



LIVING WITH NMO

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This booklet is part of a series of “Living with NMO” booklets bringing together practical information, ideas and contacts for people with NMO, family and friends.

Here you will find information on topics including keeping fit, sport, fatigue, driving, transport, travel and holidays.

A wide range of services exist for the millions of people with a neurological condition in the UK to help maintain and improve quality of life.

A small minority of these people have NMO however you are part of a much wider community of people with the ability to access all of the help and information available.

Always remember help is often just a telephone call away, with the right information life with NMO can be easier.

Foreword

Kay Day

Kay qualified as an Occupational Therapist in 1991 and has since worked extensively for the National Health Service and charitable organisations.

She developed a specialist interest in information provision whilst working at the Oxford Independent Living Centre.

Kay now specialises in working with people with neurological conditions at the Oxford NMO Clinic and the Neurosciences Occupational Therapy Department at the John Radcliffe Hospital, Oxford.

Thank you

Thank you to:

- The people living with NMO who teach us all what it really means to live with such a rare condition.
- Jon Revis NMO Clinical Nurse Specialist, Oxford for his support and encouragement.
- Kate Browne, NMO Physiotherapist, Oxford.

Contents

Keeping fit, Sport and Physiotherapy

4

Managing Fatigue

15

Wheelchairs and Scooters

22

Driving Transport and Travel

32

Holidays and Tourism

39

NMO Publications and Information

43



Keeping Fit, Sport and Physiotherapy

• Why is exercise important?

Regular exercise from gardening to sport is important for everyone and especially for people with NMO for the following reasons:

- **Joint stiffness** is a discomfort after a period of inactivity (such as after waking up in the morning or after sitting down for a long time)

Exercises and stretching are often useful.

- **Muscle weakness** is a reduction in the strength in one or more muscles affecting mobility or activity

There are no medications to improve weakness.

Exercise and stretching can be beneficial.

- **Loss of vision** can lead to a reduction in activity and exercise for a variety of reasons including loss of confidence and increased difficulty in getting around.

Sight problems should not be a barrier to keeping fit, and it may feel daunting to get involved in some activities. Many sports and forms of exercise are accessible to people who are blind or partially sighted.

The loss of sight does not mean loss of action or loss of motivation and determination

- **Psychological impact of NMO** – exercise is well documented in helping to lift mood and increase confidence, it helps to reduce stress and is also a great way to meet people, make new friends and have fun.

This section of the booklet hopes to provide ideas and advice to get you going, there is **much you can do yourself** to get started and always remember keeping fit and active is not about being a top athlete but in finding activities that suit you at your pace and your interests.

• How Activity Can Help You

- More energy
- Weight loss if you are over weight
- Build muscle strength
- Improved balance and mobility
- Increased confidence and self esteem
- Above all, **exercise can be fun**. Whether it's walking the dog or salsa dancing enjoyment is the best motivation and will help you stick to your routine when tempted to give up.

• Should I Gain Advice From A Physiotherapist?

Physiotherapists are the “movement experts” whose main aim is to help you achieve your full potential for physical independence, flexibility, strength and fitness levels.

They can be a useful source of advice and practical tips on any new movement problems that arise. Physiotherapy is especially useful if physical

symptoms are changing or during the recovery phase after a relapse.

- **Do Any Physiotherapists Specialise in NMO?**
- Specialist **NMO Physiotherapists** can be accessed as part of your clinic appointment at one of the two specialised NHS NMO centres in Liverpool and Oxford, refer to contact details at front of booklet.
- **Local NHS Neurological Physiotherapists** are based at your nearest NHS Neurology Unit.

It may be that due to the rarity of NMO the therapist may not have treated an NMO patient before. However they will have neurology expertise and will know who to contact for further help including the NHS NMO Centres. Request a referral via your local GP or hospital Neurology team.

- Your GP will have details of all **other NHS**

physiotherapy services in your area which may be appropriate. Services and waiting times differ throughout the UK.

- **Private practice Physiotherapists** with a special interest in neurological conditions. The Chartered Society of Physiotherapy (CSP) is the professional body for Physiotherapist and can guide you to registered therapists near to you. They will also be able to advise on expected costs.

Tel: 020 7306 6666

www.csp.org.uk

- **How do I know if a Physiotherapist is fully qualified?**

All Physiotherapists are required to register with the Health Professions Council (HPC) regulatory body. The HPC is responsible for conduct, and ethical behaviour of its registrants.

Check by contacting HPC.

Tel: 0845 300 4472

www.hpc-uk.org

- **What will happen when I see a Physiotherapist?**

The specific treatment will depend on which symptom you are experiencing at the time.

Treatment could include:

- Advice about a range of exercises or physical activity
- Advice on posture and relaxation
- Specialised stretches to relieve stiffness
- Advice on walking aids

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

It is advisable to discuss your plans with your GP, neurologist or NMO clinic prior to the start of any new exercise. You are sure to receive a positive response and will be able to check if there is anything

of importance to take into consideration.

Your GP may be able to refer you to a **local Active Health Team**, it is exercise on prescription. The team will work out a programme of exercise that is safe and manageable for you.

- **Exercise at home – Exercise DVDs, books and Wii fit**

Your home can be a great way to start getting more active and you can do it on your own or with family.

Fitness DVDs are easy and inexpensive ways to start.

- Both **Parkinson's UK** - Tel: 0808 800 0303 www.parkinsons.org.uk and **The Multiple Sclerosis Society** - Tel: 0808 800 8000 www.mssociety.org.uk have exercise DVD's available suitable for NMO.
- **Age UK** produce a range of materials designed to help strengthen muscles and bones.

- Free download “**Staying Steady Guide**” guide is for everyone, whether you are fit and active, have difficulty getting around and walking or are worried about falling
- DVDs “**Be Strong, Be Steady**” designed to help strengthen muscles, increase flexibility and improve balance.

Includes chair based and standing exercises. Clear instructions.

- “**Step to the Future**” Progresses through two levels, focus on improving endurance as well as strength and balance. Programme includes chair based, standing and floor exercises.
- Exercise book – “**Strength and balance exercises for healthy ageing**”

An A4 work book with step by step chair based and standing exercises

Tel: 0800 169 6565

www.ageuk.org.uk/health-wellbeing/keeping-fit/exercise-materials

- **The Wii Fit** can also be a good way to get active. It has games that can help all areas of fitness in standing and sitting, including stability and balance.
- **Build Physical Activity Into Daily Life**

Very small changes to your lifestyle can help you become fitter and more active. Refer back to the “Living with NMO” – Independence in daily life - Doing Things Differently section. Here you will find advice to help you restart activities.

These changes all add up to a positive change.

- Do the housework! Hoovering and cleaning will all help to get your heart working a bit harder
- Get out in the garden, weeding and digging , fresh air and nature will all help you to feel good

- Park the car a little further away from the shop than you would usually
- Get off the bus one stop early and walk the rest of the way
- If you are mobile enough, walk up the stairs instead of using a lift

• What is Stopping You?

People with NMO can sometimes find there are barriers stopping them from being more active. These can include fatigue, anxiety, embarrassment and feelings of inadequacy, comparing their abilities prior to a diagnosis of NMO and the sense of loss this can create.

• Tips to help

- Remind yourself of the information in the “Managing Fatigue” section for advice and tips
- Light exercise can help build strength and endurance in your muscles meaning that you can move around with less effort
- Gentle walking is a good way to start, some trial and error might be necessary in order to know how much you can cope with.
- Do the best you can for yourself by eating well, drinking plenty of water and getting enough sleep
- Give yourself rest days and never exercise if you feel unwell.
- Make sure that you have found ways of managing any continence problems so that you can exercise freely and without worry.
- Find sessions arranged for people with disabilities at your local leisure centre or via your local council if you feel this would help you.
- Start small and build up slowly, sometimes trying a new activity can release you from memories associated with previous activities that may not now be possible.

• Setting Goals

Setting goals can help you to stick with your plans.

Goals are individual to each person depending of level of ability and health, they could include:

- Completing an exercise DVD four times per week.
- Hoovering daily
- Taking responsibility to walk the dog every other day
- Gardening once a week
- Walk for 10 minutes each day

Keep a diary to record your achievements, it will boost your motivation. After a few months you will be able to look back and be proud of you achievements.

Don't make your goals too difficult but having something to work on will help keep you focused.

• Accessible and Inclusive Facilities

The Inclusive Fitness Initiative is a scheme in England,

Scotland and Northern Ireland helping more people to exercise regularly. It caters for the needs of disabled and non disabled people with a directory of accessible facilities.

Gyms accredited must have fitness equipment that can be used for a full body workout by a wide range of users with different conditions and all staff must have disability awareness training

To learn more about the scheme, find a facility in your area or read about users feeling the benefit of physical activity contact Inclusive Fitness at **Tel: 01509 227750**
www.inclusivefitness.org

• Further Sources of Support

• Sportability

A registered charity with an aim to provide sport and leisure opportunities for disabled people of all ages to take part in activities.

Sportability groups run throughout Britain and many are linked with local councils

and colleges. Scuba diving, sailing, skiing, angling, abseiling, quad biking and clay pigeon shooting are all available to try and enjoy.

Members have disabilities ranging from spinal cord injury to MS and strokes.

www.sportability.org.uk

- **The Multiple Sclerosis Trust**

The trust has several resources to help maintain fitness of interest to a person with NMO. Their “StayingActive” webpages contain a host of ideas from sports to gardening. There is something to suit all tastes and ages. Also produce a helpful booklet on managing falls.

Tel: 0808 800 8000

www.mssociety.org.uk

- **Yoga For All**

Lakshmi Voelker Chair Yoga DVD – an accessible path to fitness. Chair yoga can relax the body and mind, improve musculoskeletal fitness and flexibility and enhance overall health and sense of well being.

Traditional Yoga has been adapted by founder Lakshmi Voelker into a chair sitting exercise program.

Go to website to learn more about chair yoga

Order online at www.getfitwherewaysit.com

- **Pilates For all**

Pilates is an exercise method designed to elongate, strengthen and restore the body to balance. Pilates can be beneficial for many regardless of age or fitness level.

Further details of the potential benefits of pilates and local contacts are available from

The Pilates Foundation

www.pilatesfoundation.com

Ableize – the www virtual library of UK Disability Resources features listings for Pilates services for disabled people.

www.ableize.com

- **Disabled Ramblers**

A group of like minded disabled people who enjoy being in the countryside and who get about using paths and trails of all kinds.

The group are true ramblers although most members can walk less than a few yards. Membership consists mainly of mobility disabled people who use a variety of mobility aids, ranging from electrically powered pavement buggies, scooters, powerchairs and manually propelled wheelchairs.

Rambles are organised of varying difficulty all over England and Wales and along with spouses, volunteers and friends each event provides recreation and challenge to suit every taste.

The group has covered over 1000 miles off road trail so far. Regular rambles across England and Wales from the New Forest to the Thames Path, North Yorkshire Moors to the Gower peninsula. Distance covered is usually 8 miles.

www.disabledramblers.co.uk
(England and Wales)

www.ftdr.com (Scotland)

- **Keeping Fit and Sport for Sight Loss**

Sight problems should not be a barrier to keeping fit although it may feel daunting to get involved in some activities. Many sports and forms of exercise are accessible to people who are blind or partially sighted.

The loss of sight does not mean loss of action or loss of motivation.

Sports and leisure activities include bowls, cricket, water skiing, jogging, rambling, swimming, weight lifting, archery and tandem cycling. The list can be endless.

Some of these activities may require modest adaptations of rules and equipment to make them accessible, for example playing cricket with a size 4 audible ball or using a sighted or audio guide to help you to the tee in golf. There are also sports such as “goalball”

which are played by blind and partially sighted people only

- **British Blind Sport** governs most competition from local to international level. Blind and partially sighted people can gain the same enjoyments and benefits as everyone else, feeling good in mind and body and above all fun and enjoyment.

Tel: 01926 424247

www.britishblindsport.org.uk

- **Joggingbuddy.com** a web based buddying site for joggers has teamed up with British Blind Sport to seek guide runners from its own sporting community to support blind and partially sighted athletes. The joggingbuddy site was launched in 2008 and now has members in 71 countries.

Contact Joggingbuddy or British Blind Sport for details

- **The Tandem Club**

A national cycling organisation with many affiliated groups.

The Disability Liason officer can offer advice on how to get started and enjoy cycling.

Tel: 01522 695 781

www.tandem-club.org.uk/disabilities

- **Ramblers Association**

Encourages and supports walkers of all abilities, including those with sight loss throughout the UK. Lots of regional groups.

Tel: 020 7339 8500

www.ramblers.org.uk

- **Actionnaires Club**

Actionnaires clubs for **children and young people** (Sports and Activity Clubs for 8 to 16 year olds)

The clubs are organised by Action for Blind People (part of the RNIB) throughout Britain. 16 years plus are encouraged to attend as leaders and younger children are welcome to attend with siblings, parents or carers.

The clubs have a strong element of sport such as swimming, athletics, basketball,

goalball, judo and also include activities such as music, drumming, ten pin bowling, art and dance.

All activities are organised to ensure children can take part regardless of their vision. Clubs have adapted sports equipment and cater for all abilities.

Tel: 0303 123 9999

www.actionforblindpeople.org.uk/actionnaires

- **How The RNIB National Leisure Service Can Help You**

Contact for information on any **sport and activity** including spectator sports.

Tel: 0303123 9999

www.rnib.org.uk

RNIB website features stories of two blind and partially sighted students who cannot imagine student life without dancing, yoga or playing cricket and goalball.

Accessing your local gym - contact RNIB for details of their “Activate” programme.

The programme helps gyms and leisure centres become more accessible to people with sight loss. This includes raising awareness of with instructors and offering guidance on how they can make their equipment more accessible.

“Leisure Link” is an RNIB buddy system which puts people with sight problems in touch with sighted people to take part in activities outdoors. Activities include rock climbing, sailing, and tandem cycling.





Fatigue and NMO

Many people with a neurological condition experience feelings of fatigue including people with NMO. Patients report varying degrees of fatigue at different times from all consuming fatigue to it not featuring as a symptom.

- **What is Fatigue?**

Fatigue is an overwhelming tiredness that features in every person's life and fluctuates greatly at different stages of a person's life. We can all relate to fatigue from perhaps studying as a student,

a late night out with friends, "burning the candle" at both ends, the exhaustion of a demanding job or the effects of caring for a young child and the accumulating lack of sleep.

- **Fatigue In NMO**

However few of us are able to identify with the overwhelming exhaustion experienced by some people with NMO by simply taking a bath, attempting to visit a local shop or ironing a few clothes, such previously simple everyday activities can suddenly feel like huge challenges.

This level of tiredness can be difficult to understand for the person themselves, for family and friends and for employers and can lead to understandable frustration and possibly feeling of guilt or inadequacy.

• **What Causes Fatigue?**

Fatigue is very common in people with many neurological conditions. There is no one reason and sometimes the specific reason may be unclear, here are some possible causes:

- Fatigue when your body is recovering from an initial event or a relapse in NMO is to be expected. Your body will be working hard to compensate for the changes that have occurred and will be using extra energy in the healing process. With time your fatigue may improve or go completely.
- Living with NMO is not easy, you may be getting used to doing things differently. Getting used to a

new way of life is physically and psychologically tiring, especially at first.

- You may experience sleep disturbance perhaps due to pain or due to continence issues, this can have a cumulative effect leading to sleep deprivation and tiredness.
- Low mood, depression, frustration and anger can all be understandable feelings associated with changes to your life. All can lead to fatigue.
- Some medications can lead to feelings of tiredness and lethargy

• **What Causes Your Fatigue?**

Many people with NMO are able to work out what causes fatigue for them and which activities or events are likely to increase or decrease the chances of it.

For some it will be physical activity, whilst others find they benefit from being active and find other activities and roles increase fatigue.

Sometimes fatigue be caused by trying to do too much, too soon. You might be trying to pack too much into your life, you may feel pressurised by others to be “your old self”, even though it may be unrealistic.

- **What Is It Like To Live With Fatigue?**

Fatigue is very subjective, hard to explain and hard to quantify. It is invisible.

Often people look fine and it can be difficult for others to appreciate and understand how debilitated a person may feel. Employers, friends and loved ones may all struggle to understand and empathise with fatigue, in turn creating more anxiety and stress for the person with NMO.

- **The Spoon Theory**

One aspect of fatigue that others often don't understand is the way that it can limit what a person can do.

In a blog called “The Spoon Theory” Christine Miserandino, a speaker,

journalist, blogger and patient advocate from New York describes her experience of living with fatigue. The theory is available to read in full on her blog www.butyoudontlooksick.com where you can even buy posters of it for comfort and inspiration!

It is hoped your friends, loved ones and employers may be able to understand a little of what you are experiencing, here goes:

Christine and her friend were in a restaurant when her friend asked Christine what it was really like to live with a long term health condition.

Christine grabbed a handful of spoons and handed them to her friend. The spoons each represent one task or one thing that uses up energy. The point is that for people with a disability, there is only a limited number of spoons available to use in one day and in some days you will have more spoons than on other days, for example after a bad night's sleep.

With just one spoon left at the end of the day, Christine explained to her friend that if she cooked, she wouldn't have enough energy to wash up. If she went out for dinner she may be too tired to drive home safely. She has learnt to plan her day and always keep a spoon in reserve incase it is needed.

Many people identify with this story does it sound familiar?

• **Ideas To Manage Your Fatigue**

Fatigue management is a way of organising your life around fatigue.

Try the following ideas to minimise its effect on your life

- **Planning** is the key.
- **Rest** is not failure – resting is an important coping strategy
- **Sleep** - Make sure you get a good night's sleep, if pain or continence issues result in disturbed sleep try to seek support to resolve some of these issues, try to reduce caffeine intake from drinks several hours prior to bed

and receive support from your partner if your sleep is disturbed by caring for children in the night. Try not to get upset if you can't sleep, have a warm milky drink and listen to some relaxing music

- **Daily Activities** - Refer to your activity list of all the activities you are involved in however small, so that you can identify the ones most important to you and save the necessary energy. See "Living with NMO – Independence in daily life"
- **Cleaning** - It can be difficult to break lifetime habits such as daily vacuuming or bathroom cleaning however by altering the frequency, doing "a quick wipe" or accepting help from others energy will be saved. Take note of how heavy your vacuum cleaner is, lighter models help to save energy, if you normally need to carry your Hoover upstairs think about having a light small cleaner just for upstairs.

- Carefully time any larger cleaning you wish to do allocating a specific amount of your energy or look into the possibility of employing a private cleaner to help.
- **Ironing** - a little at a time is best, only iron what needs ironing, try to hang clothes carefully after washing and drying to reduce creases, consider using a tumble dryer which takes away the two stages of hanging out and often ironing. When purchasing new clothes look at easy to care for fabrics, many exist to make life easier. Take care of not adding too much water to your steam section in the iron as this makes the iron heavier.
- **Food Shopping** - Consider using home delivery services, shop online or accept offers of help from family or neighbours. Try to make weekly lists to reduce the frequency of having to shop for forgotten items.
- **Meal Preparation** - a good meal is a source of energy and its preparation can be an important part of your life and your role in the family, this does not have to change:
 - **Plan meals** – a weekly meal plan will help you to feel more organised and in control. Choose simple meals with few stages. Consider using a slow cooker which will enable you to have a hot meal ready at the end of the day perhaps when you are feeling most tired.
 - **Batch cook** – by making more than you need you will have meals left to freeze to use on other days
 - **Pre made meals** – readily available chilled or frozen from stores, specialised home delivery services available nationwide **www.wiltshirefarmfoods.com**
Tel: 0800 773 773 and **www.oakhousefoods.co.uk**
Tel: 0845 643 2009

- **Electric appliances** – these can save energy but not if they are complicated to dismantle and clean.
- **Pace yourself** – Divide food preparation throughout the day, you may have previously thought nothing of preparing, cooking and serving a meal as one process, it is O.K to split this down.
- **Wire mesh pan baskets** – To help reduce effort required to serve out a meal consider placing wire mesh baskets in your pans which can easily and lightly lifted out to serve out food removing need for heavy draining of pans full of hot water, available from hardware stores or equipment suppliers.
- **Cupboard essentials** – Consider making some changes to your cupboard store , precut, washed vegetables and fruit and frozen or tinned foods can all save steps. Make sure

you have a good stock of “basics” such as pasta, rice, eggs, cheese, tinned fish, ham etc which can be turned into simple and nutritious meals from omelettes to jacket potatoes.

- **Work** – A similar exercise of closely considering all of your roles, responsibilities and activities related to work may need to be carried out in order to identify ways of managing your energy reserves or adapting aspects of your job. Frequency of breaks and also a relook at working hours may need to be reviewed, your Occupational Health Department should be able to support and help you in this.

Utilise NMO booklets and resources as an employers’ knowledge and understanding of NMO is likely to be very limited if

they have any knowledge at all. Take into account the effect of your travel time to and from work. If you do not feel supported at work see “Living with NMO – Work and money – who can advise” booklet.

- **Mobility** – Each person's ability to walk and level of mobility is very different, some people with NMO will have none or very small restrictions whilst others will use walking aids or a wheelchair. It is important to remain as active and mobile as possible however do not forget the effects on depleting energy levels. A combination of utilising all forms of transport along with walking or using your wheelchair will help to reserve energy.
- **Leisure Activities** – It is widely recognised that a person's interests, hobbies and leisure pursuits provide an important meaning, balance and purpose in life.

Sadly many find that there is not enough energy left, especially at the end of the day to pursue interests previously enjoyed or to try new activities. Timing, saving energy and even considering new activities will help you regain your leisure interests.

- **Further sources of information on fatigue**
- The Multiple Sclerosis Society book “Living With Fatigue” features comments and thoughts from people living with fatigue, packed with anecdotes and advice.

Tel: 0808 800 8000

www.mstrust.org.uk



Wheelchairs and Scooters

People with NMO can experience a decrease in their mobility due to Transverse Myelitis (inflammation of the spinal cord). Many people experience a small reduction in their strength perhaps requiring the use of a walking aid such as a stick or crutches whilst others can experience a greater loss resulting in an inability or difficulty in standing and walking.

For many this situation improves with treatment and rehabilitation to such a degree that use of a wheelchair is no longer needed, a smaller number of people require the permanent use of a wheelchair.

For many the use of a wheelchair does not have to be all or nothing, sometimes it can be helpful to view a wheelchair as an option amongst other solutions at particular times or to get around more easily in certain places.

A wheelchair may be the preferred option because of symptoms like weakness, fatigue or to conserve energy for other activities. People often find wheelchairs give them more freedom rather than less.

Some people use a wheelchair for outdoor use only and others also use a wheelchair indoors for example at times of increased fatigue or to create greater independence around their home. People who rely on their wheelchair for all mobility may choose to describe themselves as a permanent wheelchair user.

If you are finding it hard to get around this section of the booklet will guide you through learning a little about wheelchairs, NHS and private purchase options and sources of specialised advice and information.

- **Types of Wheelchairs**

There are hundreds of styles of wheelchairs for differing

needs and abilities, they fall into three main categories:

- **Self propelled wheelchair** – enables the wheelchair user to propel the wheelchair themselves by using the large side wheels. When required most wheelchairs can also be pushed by an attendant (someone who helps push a wheelchair on someone else's behalf)
- **Attendant Propelled** – the wheelchair does not have large wheels to self propel instead the wheelchair is always pushed by an attendant
- **Powered Wheelchairs/ Scooters** – powered by a battery enabling the user to move easily and quickly without any physical effort. Designs vary for indoor and outdoor use. Batteries are charged overnight or when not in use.
- **Important** – All wheelchairs should be used in conjunction with an appropriate wheelchair

pressure cushion for greater comfort, support and pressure relief (to help prevent skin damage/pressure sores due to prolonged sitting)

- Wheelchairs are available in many different sizes and dimensions in order to provide correct levels of comfort and support. Some are able to tilt to create differing seating angles and others increase in height to enable a user to reach something high up or communicate with others more easily at eye level.

- **Options of how to get a wheelchair**

- **NHS Wheelchair Service**

NHS Wheelchair services are run by local health authorities. It is important to note that the way services are organised and provided varies between locations. This includes “eligibility criteria” used to decide what type of wheelchair to provide.

The basic process is as follows:

- You are referred to a local NHS Wheelchair Service. An assessment of your needs takes place
- Timescales and funding options are discussed
- The wheelchair and training in its use are provided
- A maintenance and repair plan is arranged

- **Referrals and Assessments**

- **Referrals** – you can be referred by a clinic, doctor, consultant, occupational therapist, physiotherapist or the service may operate a self-referral service.

Each service has its own eligibility criteria. Your referral should be acknowledged within a week or so. The time between referral and assessment can be several weeks, ask your referrer to enquire about approximate waiting times at the time of referral so that you know what to expect.

Always feel free to contact the service yourself in order to check on the progress of your referral.

- **Assessments** are normally carried out at the NHS Wheelchair centre or clinic however home visits are sometimes arranged if needed.

The person carrying out the assessment will be a healthcare professional qualified in wheelchair assessments, often an Occupational Therapist. Some wheelchair services allow an outside healthcare professional to prescribe a wheelchair without an assessment by the wheelchair service.

The process may involve a rehabilitation engineer responsible for how the wheelchair works and any adjustments or fixtures it needs.

All the situations in which the wheelchair will be used like

home, education, work, leisure, using transport and social activities will be part of the assessment.

The assessment will include an assessment for a wheelchair cushion to help prevent pressure damage to your skin. The cushion will be chosen carefully to meet your pressure, comfort, continence and method of transfer (the way you will move in and out of your wheelchair) needs.

The assessment may include other professionals across health, education and social services. This is especially important for a child with NMO who has development needs. Parents and carers should be part of the assessment and their views considered.

- **Re-assessment of your needs** If a person's needs change perhaps due to a relapse, change of environment at home, work or leisure where the

wheelchair is used or the changing needs of a carer e.g a requirement for a lighter wheelchair for ease of pushing or lifting into a car, you can request a review.

This may include a change of pressure relief, cushion or changing from a manual to a powered wheelchair.

- **Getting your wheelchair, maintenance and repair**

When your wheelchair will be delivered will vary depending on financial resources, or if it is from standard stock or bespoke. Your wheelchair service should be able to provide you with an approximate time.

When ready there is a formal handover which could be at the wheelchair clinic or at your home. You will be shown:

1. How to use the wheelchair, including safety issues
2. Relevant documents and a point of contact for future enquiries

3. Insurance information and how to arrange repairs and maintenance.

- **If you move house**

If you move to a different area, the wheelchair should go with you. Depending on what type of wheelchair you have the new Wheelchair Service may take over the future maintenance of the equipment.

- **Types of powered wheelchair**

Indoor and outdoor powered wheelchairs and scooters are used by people who cannot self propel a manual wheelchair, this could be due to such symptoms as weakness, pain issues or fatigue. Equally a person may have additional medical conditions which create a need for a powered wheelchair including a heart condition or arthritis.

There are criteria for using some types of powered wheelchair. For example

meeting DVLA eye test requirements for road use.

There are 4 types of powered wheelchairs:

1. Electric Indoor Chair – user controlled
2. Electric Outdoor Chair – attendant controlled
3. Electrically Powered Indoor/Outdoor Chair – user controlled
4. Dual Purpose Chair – user controlled indoors, attendant controlled outdoors

Outdoor powered wheelchairs are grouped into two categories:

1. Class 2 wheelchairs and scooters must have a maximum speed of four miles per hour (6.4 kilometers per hour) and are for pavement use only.
2. Class 3 wheelchairs and scooters must have a maximum speed of eight miles per hour (12.8 kilometers per hour) and can be used on roads.

Class 3 vehicle must have certain construction features including: an efficient braking system, a rear view mirror, direction indicators and rear and front light reflectors. If all of the conditions are not met you may be prosecuted by the police.

- **Legal Requirements**

Class 3 vehicles need to be registered with the DVLA for road use, be licensed in the “disabled” taxation class and display a nil duty tax disc.

To register and license you need to complete form V55/5 for used vehicles and form V55/4 for new vehicles.

Send the form to your nearest DVLA office with the required documentation stated on the form, this includes documentation confirming your name and address.

You cannot license a Class 3 vehicle at a Post Office branch or by using the Electronic Vehicle Licensing Service.

Class 3 vehicles are not legally defined as a motor vehicle. For this reason the user does not have to have a driving license or take a test. You have to be at least 14 years old to drive this class.

- **Insurance**

It is strongly advised, although not legally required, that you take out an insurance policy. Suitable schemes are available to cover your personal safety, other people's safety and the value of the vehicle.

- **NHS Wheelchair Voucher Schemes**

Voucher schemes are designed to increase the choice of wheelchairs available to you. Services decide locally whether to have a scheme and how it is applied.

If your wheelchair service operates the scheme there will be three options available to you:

- 1. Standard Option**

You will be provided with a wheelchair that will be

supplied, repaired and maintained free of charge.

- 2. Partnership Option**

You choose an alternative to the type of wheelchair you are assessed as needing. This lets you buy a wheelchair of a higher standard than that which the NHS supplies. The voucher reflects the value of the wheelchair originally recommended and you then pay the difference in cost.

The wheelchair will be repaired and maintained free of charge.

You have to choose a wheelchair from an "approved supplier" who has to meet certain standards including quality of service.

- 3. Independent Option**

This is similar to the partnership option but you own the wheelchair and are responsible for its repair and maintenance. However the voucher you receive will include an amount towards the likely costs of repair and maintenance.

Further voucher information:

The voucher period is usually for five years and you will not normally be eligible for a new voucher within that time however if your needs change, making the wheelchair you bought unsuitable you will be eligible for a re assessment of your needs.

You cannot exchange the voucher for cash. If you buy a wheelchair privately from a commercial company or individual you cannot "claim back" the money from the NHS Wheelchair Service.

The voucher is non taxable so it does not affect any disability benefits you are receiving.

- **Buying or Hiring A Wheelchair**
- **Other Ways To Get a Wheelchair**
- The Motability Scheme is run by an independent, not-for-profit organisation Motability. It gives disabled people the opportunity

to own or hire powered wheelchairs and scooters at an affordable price.

Contact for in depth leaflets or to view their website.

Tel: 0845 456 4566

Textphone: 0845 67 009

www.motability.co.uk

- **Charities and Other Organisations**

If you are not eligible for an NHS wheelchair or you choose to hire or buy one yourself you may be referred to a voluntary organisation or charity such as the British Red Cross and Shopmobility who locally loan out wheelchairs, especially for short term needs.

Some charities like Whizz-Kidz and the Association of Wheelchair Children, provide wheelchair skills training.

Contact your nearest DIAL UK (local disability information and advice service run by and for disabled people) or Assist UK (represent Disabled Living Centres) for local wheelchair hire and details of

local suppliers and free and impartial demonstration and advice of equipment.

- **DIAL UK**

Tel: 01302 310 123

Textphone: 01302 310 123

Fax: 01302 310 404

www.dialuk.org.uk

- **Assist UK**

Tel: 0161 832 9757

www.assist-uk.org

- **Mobility Centres**

Mobility Centres are networks of independent organisations in the UK who offer professional, high quality information, advice and assessment to people who have a medical condition or are recovering from an accident or injury that may affect their driving.

Some centres can assess your ability to control a powered wheelchair or scooter and can provide information and advice about choosing one. To find your nearest centre contact:

The Forum of Mobility Centres

Tel: 0800 559 3636

www.mobility-centres.org.uk

- **RADAR**

A national network of disability organisations, run and staffed by disabled people.

Produce a free, independent guide to help you purchase a powered wheelchair or scooter, will help you assess your own needs, be aware of risks and help you decide what is right for you, also takes you through other considerations such as operating costs.

Tel: 020 7250 3222

Fax: 020 7250 0212

Textphone:

020 7250 4119

www.radar.org.uk

Yourable.com

A website for disabled people. It has information on a wide range of subjects with a lot of practically useful detail.

Includes information to help you choose a wheelchair or scooter. On line shop sells a variety of products including wheelchairs, scooters and accessories.

Tel: 01384 473728

Fax: 01384 480260

www.yourable.com

- **Ricability**

Produce a range of reports and guides related to wheelchairs and have a product review site **www.product-reviews.org.uk**

Tel: 020 7427 2460

www.ricability.org.uk

- **Spinal Injuries Association**

National advice and support for people affected by any spinal cord injury. Lots of relevant information for people with NMO.

Produce a series of 18 books on living with a spinal cord injury including “Wheelchairs and Equipment For Daily Living”

Tel: 0800 980 0501

www.spinal.co.uk

- **The Multiple Sclerosis Society**

Produce a large series of guides on living with MS including Wheelchair information and “Are You Sitting Comfortably?” Self help guide to good posture in sitting. Printed and audio copies available.

Tel: 0808 800 8000

www.mssociety.org.uk

- **Direct gov**

UK government website, detailed information related to all aspects of Wheelchairs and Scooters.

www.direct.gov.uk



Driving, Transport and Travel

Transport and travel is essential to everyone . This section of the booklet hopes to provide you with information to get where you need to go with the greatest of ease.

- **Driving and NMO**
- **DVLA**

Having NMO does not necessarily mean you cannot or will not be allowed to

drive however you have a responsibility to inform the Driver and Vehicle Licensing Agency (DVLA) in accordance with instructions on your driving licence.

Find out how to tell the DVLA about NMO, how to surrender a driving licence due to a medical condition and how to renew after surrender by going to **www.direct.gov.uk/driverhealth**.

The information is extensive with clear instructions of what to do.

Leaflet INF 94 Customer Service Guide for Drivers With Medical Conditions is available to request in leaflet form or as a PDF download, the leaflet clearly explains the three stages that result in a decision regarding your driving licence, Stage 1 requires you to fill in medical questionnaire B1.

Tel: 0300 790 6806

Fax: 0845 850 0095

- **Forum of Mobility Centres**

A network of 17 independent organisations across the UK that offer professional information, advice and assessments to people who have a disability or medical condition which may affect their ability to use a motor vehicle.

Choose the centre nearest to you. People attend who wish to return to driving or begin driving with a medical condition or disability, advice on getting in and out of a vehicle, advice on loading

and transporting wheelchairs, advice related to adapting vehicles.

Tel: 0800 559 3636

www.mobility-centres.org.uk

- **Disabled Motorists Federation (DMF)**

A registered charity providing advice to disabled people and their carers on motoring and transport matters

Tel: 0191 416 3172

www.dmfed.org.uk

- **National Association for Bikers with a Disability (NABD)**

Provides help in the form of learner grants, learner machines and obtaining discounted insurance.

Tel: 0844 415 4849

www.nabd.org.uk

- **Public Transport and NMO**

Most public transport is now accessible however the amount, type and frequency differs greatly depending where you live, the following organisations may be of help.

- **National Rail Enquiries**

Contact for booklet “**Rail Travel Made easy**” which includes details of train operating companies and accessibility features of stations.

Tel: 08457 484950

Textphone: 0845 6050600

www.nationalrail.co.uk

- **Ricability**

Contact for report “Wheels Within Wheels” giving information on using a wheelchair on buses, trains, taxis and coaches. Contains information on travel concessions.

Tel: 020 7427 2460

Textphone: 020 7427 2469

www.ricability.org.uk

- **Website “Door To Door”**

Comprehensive travel information for disabled and less mobile people. Information on all forms of transport including travel by road, air, sea and in and

around London. Going shopping, to work school and college, hospital and going on holiday.

www.dptac.gov.uk/door-to-door

- **Bus Stations**

Contact your local bus station for details of accessible facilities, for example the station may have designated “drop off” areas for elderly and disabled users.

- **Bus Users UK**

An independent group which gives bus users a voice. They talk to major and smaller bus companies, bus trade organisations, government and local authorities.

Tel: 01932 232574

www.bususers.org

- **Special Transport**

- **Dial –a- -Ride Schemes**

Door To Door bus services exist in many areas in the UK. The schemes have different local names and are for

people who are unable to use or have difficulty using public transport. Journeys can be to anywhere in the the specified areas with the exception of hospital or social service centres.

Contact your local authority or Independent Living Centre for details.

- **Community Transport**

Local councils and some local voluntary groups arrange transport services. For information of what is available near you contact your local council, Independent Living Centre, www.a2binfo.net or Community Transport Association

Tel: 0845 130 6195

www.ctauk.org

- **Coach Travel - Concessions**

- **National Express Limited**

National Express offer **half price tickets** to disabled people and those age over

60 years. 30% discount if you travel at peak times.

Disabled Persons Travel

Helpline – **Tel:** 08717 818179

www.nationalexpress.com

- **Rail Travel - Concessions**

If you are over 60 years old or have a **disability** you can apply for a Senior Persons or **Disabled Persons railcard**.

If **another person** is travelling with you they can also travel at the same discounted rate.

Special arrangements can be made for disabled or mobility impaired passengers. For example staff can meet you at your departure station and accompany you to the train and similar arrangements can be made at your destination.

- **Disabled Persons Railcard**

Tel: 0845 605 0525

www.disabledpersons-railcard.co.uk

• Bus Travel – Concessions

You can apply for a concessionary bus pass if you are over 60 years old or have a disability.

Contact your local authority for details of their scheme.

• Motability

The Motability Scheme

enables disabled people to exchange their Higher Rate mobility component of Disability Living Allowance or their War Pensioner's Mobility Supplement to obtain a new car, powered wheelchair or scooter. Currently 580,000 people use the scheme. The mobility packages available can include the following:

- Car, powered wheelchair or scooter
- Insurance
- Servicing
- Tyres
- Breakdown cover
- Adaptations and wheelchair accessible vehicles

To learn more about Motability, request an information pack or one of the Motability guides available contact:

Tel: 0845 456 4566

Textphone: 0845 675 0009

www.motability.co.uk

• Blue Badge Scheme

The Blue Badge Scheme provides a national arrangement of parking concessions for people with severe walking difficulties who travel either as drivers or passengers. The scheme also applies to registered blind people and people with severe upper limb disabilities. It allows badge holders to park close to their destination.

You can get a badge if:

- You receive the higher rate of the motability component of the Disability Living Allowance
- You receive War Pensioners' Mobility Supplement

- You use a motor Vehicle Supplied for disabled people by a Government Health Department
- You are registered blind
- You have a severe disability in both upper limbs, regularly drive a motor vehicle but cannot turn the steering wheel of a motor vehicle by hand even with a turning knob

You have a permanent and substantial disability which means you are unable to walk or have considerable difficulty walking. In this case you may be asked to answer a series of questions to help the local authority determine your eligibility. (Note children under two years of age do not qualify for a badge as they would not normally be expected to be able to walk independently)

Where To Apply:

In England and Wales

- To the Social Service Department of your County,

Unitary, Metropolitan District or London Borough Council.

In Scotland

- To the Chief Executive or Social Work department of your local Council

For more information of the scheme including a number of fact sheets and leaflets contact the Department for Transport at:

Tel: 020 7944 2914

www.mobility-unit.dft.gov.uk

• **Road Tax Exemption**

You may be entitled to a free road tax disc for your car if your disability means you receive the higher rate of the Disability Living Allowance or a War Pensioner's Mobility Supplement.

• **How to apply**

For DLA applicants contact Disability Living Allowance Unit,

Tel: 08457 123456

Textphone: 08457 224433

For War Pensioner's Mobility Supplement applicants

contact Service Personnel and
Veterans Agency

Tel: 0800 1692277

Textphone: 0800 163458

- **Ricability**

Produces a range of reports
on choosing and using a car
if you are older or have a
disability.

Tel: 020 7427 2460

www.ricability.org.uk



HOLIDAYS AND TOURISM

For many of us holidays, travel, day trips and outings are the highlights of our year, the memories that we hold close and the treats that we look forward to.

A diagnosis of NMO does not have to change this, you can continue to enjoy this important part of your life perhaps with a few more considerations or in doing something differently. Read on to learn how and **Bon Voyage**.

- **Tourism for All UK**

The UK's leading charity working to make tourism accessible. Their guide **“Easy Access Britain”** describes over 800 accessible places to stay. Tourism for All's information services includes a searchable directory you can use to find hotels, B&B's, self catering accommodation, camping facilities, and hostels that have been inspected and rated for the National Accessibility Scheme.

You can search for facilities that are wheelchair accessible, suitable for people with other mobility impairments or for hearing or visually impaired people. It also has lists of accessible attractions and services, escorted holidays, equipment and travel products and information on travelling and accommodation abroad.

Tel: 0303 303 0146

www.tourismforall.org.uk

- **Motability Scheme “The Rough Guide To Accessible Britain”**

Revised guide includes great information on days out, visitor reviews and useful contacts. Guide is FREE if you hold a Blue Badge, a Disabled Person’s Railcard or are a Motability Customer.

Tel: 0800 953 7070 or visit

www.accessibleguide.co.uk

- **Ricability**

Produce a helpful and detailed report “Holidays and Tourism”.

Includes everything from specialist companies and charities to accessible caravans and boats.

Tel: 020 7427 2460

www.ricability.org.uk

- **Back – Up Trust**

Runs activity holidays for people with a spinal cord injury including skiing, drama, sailing and wheelchair skills.

Tel: 020 8875 1805

www.backuptrust.org.uk

- **Disabled Holiday Directory**

Details of accessible accommodation and specialist holiday services

Tel: 0800 993 0796

[www.](http://www.disabledholidaydirectory.co.uk)

[disabledholidaydirectory.co.uk](http://www.disabledholidaydirectory.co.uk)

- **Disabled Holiday Information**

Has information on sites and facilities in England, Wales and Scotland and useful links to other resources including accommodation,

activity holidays and helpful organisations.

www.disabledholidayinfo.org.uk

- **Owners Direct Holiday Rentals**

Have searchable world wide database of wheelchair accessible self catering accommodation.

Tel: 01372 229330

www.ownersdirect.co.uk

- **Holiday Care**

A long established organisation providing information about transport, accommodation, visitor attractions, activity holidays and respite care establishments, here and abroad.

They have nearly 120 information packs on holidays and accommodation, a database of respite care facility and information on specialised services such as advise on travelling with oxygen

supplies, escort services and equipment hire.

Contact them through Holidays For All – see below

- **Holidays For All**

A group of disability charities and tour companies that work to improve facilities for disabled people and provides information on specialist and mainstream holiday services.

Tel: 08451 249973

www.holidaysforall.org

- **Directgov**

UK Government website
Links to organisations that provide specialist holidays, services and self catering holidays and more.

www.directgov.uk

- **Travel Insurance**

There are many different types of travel insurance available. You will need to decide what type of cover you require and check thoroughly that the policy you choose suits all of your needs.

Pay special attention to cover for a relapse in your condition whilst on holiday.

Consider cover for any medical costs that may be needed as many policies do not cover claims arising from “pre – existing medical conditions”.

- **Directgov**

Includes “Travel Insurance For Disabled People” section, lots of helpful advice.

www.directgov.uk

- **MS Society**

The MS Society is able to provide details of holiday insurance cover to meet the needs of people with M.S and other neurological conditions.

Travel insurance designed specifically with disabled people in mind, includes cover for medical expenses, mobility aids and replacement medicines.

Tel: 0808 800 8000

www.mssociety.org.uk

- **Motability Travel Insurance**

Travel insurance designed with disabled people in mind.

Tel: 0800 519957

www.aceonlineinsurance.co.uk

- **Neurosupport**

Advice for people with a neurological condition. Travel insurance advice available.

Tel: 0151 298 2999

www.neurosupport.org.uk

NMO Publications and Information

Neuromyelitis Optica – A guide to the condition

Living with NMO – Independence in daily life

Living with NMO – Work and money - who can advise?

This booklet, and the ones listed above, can be provided in other formats including large print or as an audio file. Please contact either specialist centre for details, or go to www.nmouk.nhs.uk

NMO Service

John Radcliffe Hospital
West Wing
Headley Way
Oxford OX3 9DU

nmo.advice@orh.nhs.uk

Tel: 01865 231905

NMO Service

Walton Centre Foundation Trust
Lower Lane
Fazakerley
Liverpool L9 7LJ

nmo.advice@thewaltoncentre.nhs.uk

Tel: 0151 529 8357

Notes

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