



# Living with NMO

Independence in daily life



# LIVING WITH NMO

## **Independence in daily life**

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 carers.

Here you will find information on maintaining your independence in daily life and sources of practical help and advice. Having the support you need to live the life you choose.

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

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### **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

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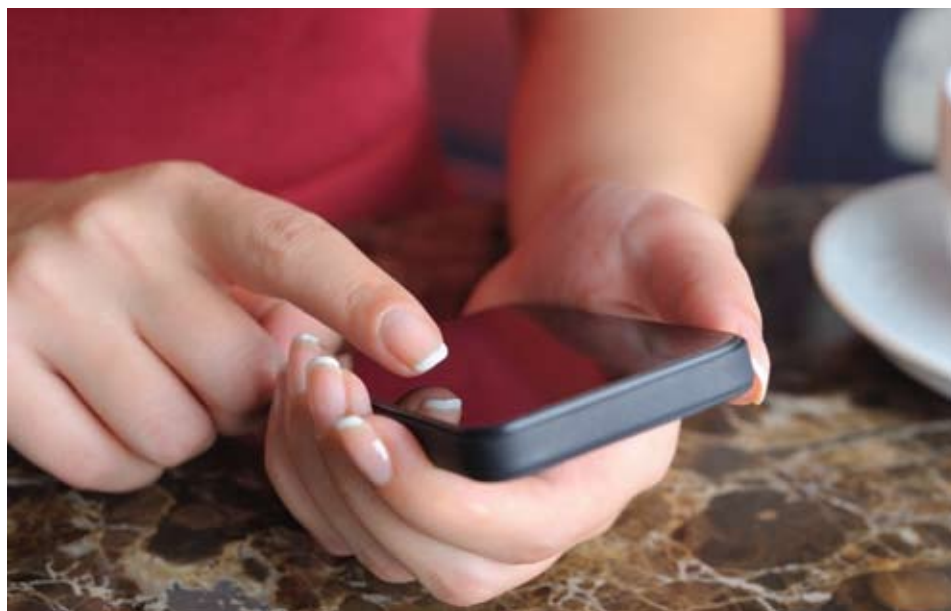
### **Thank you to:**

- 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.

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## **An Introduction To Key Services**

Here you will find an introduction to key services and support of special interest to people with NMO.

The “Living with NMO” series of booklets contain a vast array of contacts however the ones listed here are likely to be of particular importance for a person with NMO.

National Health Services, Social Services and specialised charitable organisations all exist to provide you with the

support and information you may be looking for.

- **National Health Services**
- NHS services exist at a local level from your General Practitioner (GP) at your GP Practice or Health Centre. From here you are able to access a range of healthcare professionals from Community Nurses to community rehabilitation services using Physiotherapists and Occupational Therapists.

- A person with NMO is likely to have been referred by their GP for specialist neurological assessment by a Neurologist (a doctor specialising in working with people who have a neurological condition).
- The Neurology team can be based in a local hospital, neurology centre, neurorehabilitation unit or neurosurgery centre depending on your location.
- Two NMO specialist centres in Liverpool and Oxford provide a UK diagnostic and advisory service. Full details of these centres can be found at the beginning of this booklet.

All NHS services are **free of charge**.

- **NHS Choices** [www.nhs.uk](http://www.nhs.uk)

Information from the National Health Service on conditions, treatments, local services and health conditions.

- **NHS Direct**  
[www.nhsdirect.nhs.uk](http://www.nhsdirect.nhs.uk)

**Tel:** 0845 4647

Medical information, guidance and reassurance 24 hours.

- **Social Services**

Local Councils are required by law to provide community care services to residents in their area, usually through social services departments. Services available include:

- Help with personal care
- Home care help with things like cleaning and shopping
- Specialised equipment to use in your home to increase independence
- Day care for your child if either you or they are disabled
- Free or subsidised travel on public transport

You may have to meet certain criteria to be eligible for services and you may have to pay for some of them. You have a right to services

if you have a substantial and permanent disability, are blind or partially sighted, deaf or hard of hearing, mentally ill or have a mental illness.

You do not need to be registered as disabled to get them but the council does have to accept that you really need them.

A **health and social care assessment** is often the first step towards getting the help and support you need.

To learn about these assessments go to “ Help with Daily Life – Council Community Care Services” section of booklet.

- **Services for Children with NMO**
- **The Children’s National Service Framework** published in 2004 sets standards for children’s health and social services, and how those services interact with education.

Your child has the same rights to appropriate health, social and educational services as everyone else.

The medical professionals treating your child are most likely to specialise in treating children. This is known as paediatric care.

The possible effects of NMO may mean that your child will be covered by the legal definition of disability entitling them to be considered for additional services.

- **Social Services Assessment of Need**

Your child is entitled to be assessed by **social services** at any age in order to establish what services can be provided for you and your child, for example practical assistance at home or home adaptations. You know your child best and your views as well as those of your child should be listened to and taken into account.

- **Extra Educational Help**

If you think your child has special educational needs (SEN) you should talk to their early years education setting/school about your concerns. You can ask your local education authority to carry out an SEN assessment which could lead to your child having a Statement of their SEN and the extra help needed to meet their needs.

- **Transition Plan**

At age 14 the local education authority will produce a Transition Plan for your child. This plan will review your child's needs as they reach adulthood. It will include education and training needs, employment opportunities, accommodation requirements and leisure activities. Parents and the young person will be invited to the Transitional Plan review meeting.

- **Neurosupport - Charitable Organisations**

- **Neurosupport**

A neurological charity based in Liverpool offering nationwide, non medical advice to people with neurological conditions and the families, friends and carers who support them.

Neurosupport is an active member of the campaigning organisation National Neurological Alliance

They are experienced in dealing with a wide range of enquiries, from people who are newly diagnosed, those with specific questions and those needing information about any aspects of living with a condition.

Neurosupport can signpost to local and national sources of support using their database and stock a huge selection of leaflets, booklets, reports and newsletters.

The majority of the information is written for



patients and carers. Check out their online catalogue or contact with an enquiry.

- **The Neurosupport Working Life Service** exists to help and advise people affected by a neurological condition with any issue regarding employment or in finding meaningful alternatives to work.

**Tel:** 0151 298 2999

**Textphone:** 0151 298 3289

**Working Life Service:**  
0151 298 3282

[www.neurosupport.org.uk](http://www.neurosupport.org.uk)

- **Disability Alliance**  
A national charity which works to relieve poverty and improve living standards.

Provides information on social security benefits, tax credits and social care to disabled people, families, carers and professional advisers.  
Authors of:

**“The Disability Rights Handbook”**, DLA/AA - A guide to claiming Disability

Allowance or Attendance Allowance for people age 16 or over.

**“ESA – Employment and Support Allowance”**, includes medical test rules.

Disability Alliance information and advice to individuals is only available via their website, however their online guide **“Finding A Local Advice Centre”** can point you in the right direction for telephone or face to face support.

[www.disabilityalliance.org.uk](http://www.disabilityalliance.org.uk)

- **DIAL UK**  
A national organisation for a network of 140 local disability information and advice services run by and for disabled people.

Contact to find your nearest centre to be able to receive information, advice and support from people who are informed and have personal experience of living with a medical condition.

**Tel:** 01302 310123

[www.dialuk.info](http://www.dialuk.info)

- **RADAR** – the disability rights people, opening doors to independent living.

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

Produce a range of free information guides and sell a number of services and products in their online shop. Including:

- **Radar National Key Scheme (NKS)** Guide and key – Your guide and key to almost 9,000 locked public toilets around the UK.
- Radar Publications including **“If Only I’d Known That a Year Ago”** – an information packed guide to services, welfare rights and facilities for disabled people, their families and friends. **“Children First”** – guides parents, carers and professionals through key areas of interest for children with lived experience of disability or health conditions.

- **“The Doing Things Differently”** guides are straight talking, informative and written as if they were your friend, someone who cares. The ever growing guides are written by and for people with lived experience of disability or health conditions. The series includes the topics: Work, Information Technology, Money and Transport
- Holiday and Leisure Guides **“Open Britain”** and **“Get Caravanning”**. Powered wheelchair and Scooter Guide.
- Radar members receive New Bulletin Magazine, e.newsletter and opportunities to keep up to date with the latest developments around disability.

**Tel:** 020 7250 3222

**Fax:** 020 7250 0212

**Textphone:** 020 7250 4119

**www.radar.org.uk**

- **RNIB – Royal National Institute of Blind People**

RNIB offers support and advice to blind and partially sighted people in the UK, helping people who have lost their sight to find their lives again.

Services are extensive covering all aspects of the practical and emotional aspects of living with sight loss including sources of local support:

- Telephone helpline
- Publications and factsheets
- Talking Books Service
- RNIB Insight radio
- RNIB job opportunities
- Leisure and Sport Advisers

**Tel:** Helpline – 0303 123 9999

**[www.rnib.org.uk](http://www.rnib.org.uk)**

- **Action For Blind People**  
Part of the RNIB group, an expert national organisation ensuring blind and partially sighted people receive practical support an all aspects of their lives. This includes:

- Action for Blind People job opportunities
- Local action teams in 17 different UK locations
- Working Life Resources
- Information about sight loss and practical support
- Emotional support

**Tel:** Helpline – 0303 123 9999.

Helpline is joint with RNIB in order to provide a wider source of knowledge and expertise from a single number.

**[www.actionforblindpeople.org.uk](http://www.actionforblindpeople.org.uk)**

- **Brain and Spine Foundation**  
A non profit organisation for people affected by brain and spine conditions in the UK.
- Helpline is run by neuroscience nurses offering information and support
- Factsheets and online discussion boards

**Tel:** Helpline – 0808 808 1000

**[www.brainandspine.org.uk](http://www.brainandspine.org.uk)**



# Expert

An expert is someone with some experience through extensive knowledge called in for advice

## SELF HELP- SELF MANAGEMENT FOR NMO

Self management means different things to different people. For most it means developing an understanding of how their condition affects their lives and how to cope with symptoms, taking control by building confidence and getting more out of life.

People report it helps them live better lives and puts them more in control of their condition.

Picking up this booklet and reading about sources of support and information is part of self management and will hopefully help you to feel more in control of your NMO.

There is no single approach to self management. People are individuals with different reactions to receiving a diagnosis and different ways of coping.

- **The Expert Patient Programme** is a training course run by the NHS in England that helps people manage their long term

condition and covers the following topics:

- Dealing with pain and extreme tiredness
- Coping with feelings of depression
- Relaxation techniques and exercise
- Healthy eating
- Communicating with family, friends and healthcare professionals
- Planning for the future

The courses are free and consist of six consecutive weekly sessions. Sessions are mostly run by tutors with personal experience of living with a long term condition.

- **Courses for children and parents**

There are also several courses for parents or guardians of **children** with a long term condition and workshops especially for children 12-18 years of age run by tutors who are 14-25 years of age who also live with a chronic condition.

- **Online self management**

courses are also available if you would prefer to take part from home with the benefit of online tutors.

- **The benefits** – according to research the benefits of self management include:

- A decrease in pain
- A feeling of being more in charge of the condition
- An improvement in life satisfaction
- Feeling more able to cope day to day

To learn more about the courses contact The Expert Patients Programme at **[www.expertpatients.co.uk](http://www.expertpatients.co.uk)** or telephone **0800 988 5550**

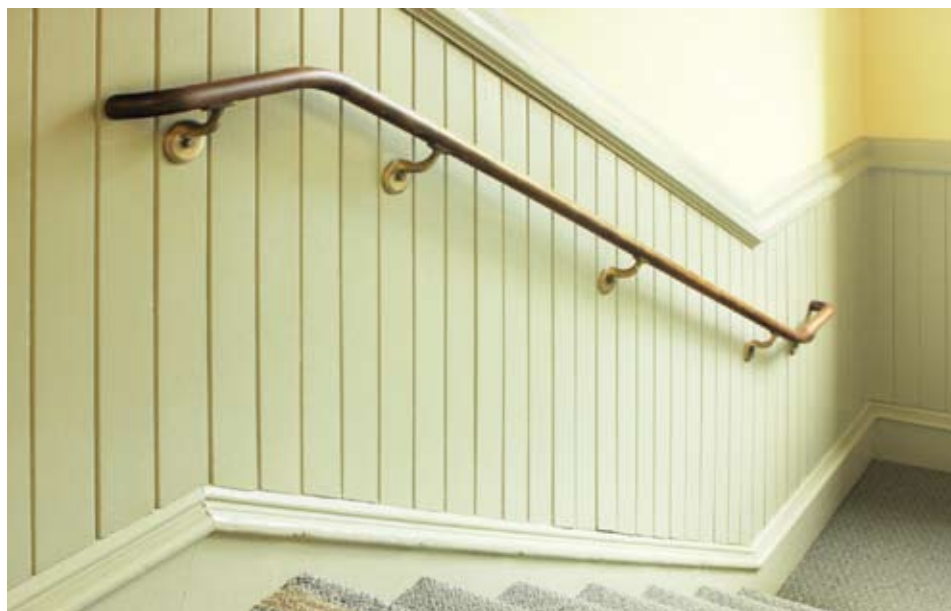
- The **NHS Choices** website [www.nhschoices](http://www.nhschoices) has further information on self management including a series of “video walls” featuring members of the public sharing their experiences of living with a long term condition.

To view the videos go to [www.nhschoices](http://www.nhschoices) videowall long term conditions. There is also a useful video wall on ideas to lift your mood, living with pain and being a carer.

- **The Multiple Sclerosis Society** produces a self management guide “MS and Me – A self management guide to living with MS” Some of the content will be of interest to a person with NMO.

**Tel:** 01462 476 700

**[www.mstrust.org.uk](http://www.mstrust.org.uk)**



## HOW EQUIPMENT CAN HELP

The effects of NMO can sometimes make previously simple, everyday tasks more difficult. Equipment is available that can help to lessen these effects and help you to regain greater independence.

This equipment is called Daily Living equipment. It may be a small gadget such as an electric tin opener which could help a person with reduced grip. A stairlift is an example of a larger

product, this may be chosen to overcome difficulties in climbing stairs due to weakness or pain.

Some products can be found in general stores and are used by non disabled people simply for their ease of use. Other products have been specifically designed to meet the needs of a particular disability and need.

Equipment can help with routine activities such as washing, dressing, cooking, getting out of bed, moving around and travelling.

Equipment can help to assist people with NMO to retain more of their independence at home, work and during leisure time.

- **Where can I learn more about equipment?**

The following organisations have supportive, knowledgeable and understanding staff and can be great starting points.

- **Disabled Living Foundation**

DLF is one of the UK's leading health charities providing expert and impartial advice to people of all ages, helping them to find equipment to assist in the everyday tasks essential to independent living.

DLF can provide tailored advice on independent living via their helpline, fact sheets, Independent Living Centre in London or website.

Their website **[www.livingmadeeasy.org.uk](http://www.livingmadeeasy.org.uk)** contains comprehensive, independent information on all items of daily living equipment. It features product

information, details of where you can buy, video clips and plenty of helpful advice from DLF's team of Occupational Therapists.

Visitors to the site can ask DLF Occupational Therapists questions about equipment on the websites discussion forum and post product reviews. Information on thousands of products is available

DLF can also provide **support for parents:** help and advice for parents of disabled children and disabled parents.

**Tel:** 0845 130 9177

**Textphone:** 020 7432 8009

**[www.dlf.org.uk](http://www.dlf.org.uk)**

- **Assist UK**

Assist UK leads a UK wide network of local Disabled Living\ Independent Living Centres. Each centre includes a permanent exhibition of products and equipment that provide people with opportunities to see and try equipment and request information and advice.



Assist UK can let you know your most local centre, there are over 325 advisors throughout the network who respond to an average ¼ million enquiries made each year.

Their services are free and all information is impartial and designed to meet your individual needs. They are independent of any commercial or other interests so you can rely on the information they give.

Many advisors have personal experience of disability and living with a health condition.

If you decide to visit a centre you will be able to try out equipment to help you with everyday tasks including:

- Eating and drinking
- Cooking, cleaning and other household tasks
- Bathing, showering, using the toilet and personal care
- Chairs and beds
- Mobility, getting around , walking aids, wheelchairs

- Hobbies and interests
- Emergency alarms
- Environmental Controls that allow you to do simple things without getting up from your chair such as open doors, switch on lights and close curtains.

**Tel:** 0161 832 9757

**[www.assist-uk.org](http://www.assist-uk.org)**

### • **Ricability**

Ricability (RICA: Research Institute for Consumer Affairs) is a research charity dedicated to providing independent information about disability equipment and other related topics to disabled and older customers.

Ricability produce a wide range of reports under the headings below, as booklets or to view on their website.

- Mobility
- Cars and Driving
- Holidays
- At Home
- Personal Care
- Parenting

- Money and Benefits

Ricability also provide product review information via the website [www.product-reviews.org.uk](http://www.product-reviews.org.uk).

You can search for reviews or post a review under the following headings:

- Around the home
- Bathing and personal care
- Cars and motoring
- Household appliances
- Leisure and travel
- Phones and alarms
- Transport
- TV, radios and computers
- Wheelchairs and scooters

**Tel:** 020 7427 2460

**Textphone:** 020 7427 2469

**[www.ricability.org.uk](http://www.ricability.org.uk)**

- **Who Supplies Equipment?**

**Local Authorities and the NHS** may supply equipment free of charge if you are eligible for their help. Contact your local social service department for details of their services and eligibility. You will find their details via your GP,

telephone book or online at [www.direct.gov.uk](http://www.direct.gov.uk) by typing in your postcode.

If you are in hospital and an assessment of your needs shows you need equipment for your discharge home the NHS should loan you this free. It will usually be an Occupational Therapist who carries out this assessment. Occupational Therapists in hospitals provide equipment essential for daily living in order to ensure a safe discharge from hospital. This could be installing a second bannister on your stairs or raising the height of a chair to make it easier to stand up from. Equipment is usually loaned and is only provided with your consent.

If you require a range of larger pieces of equipment and are likely to have ongoing equipment needs Health and Social Service Occupational Therapists often work together so that there is no gap between what the hospital provides and what can be provided by Social

Services. The Social Service Occupational Therapist will be your point of contact for any equipment or home adaptation needs once out of hospital.

**Other local authority and health service staff** who advise and provide specialised health equipment include:

- **Tissue Viability Nurses** advise on and provide pressure relief mattress and cushions to help prevent pressure sores to your skin. This equipment can also be arranged via your District Nurse or Occupational Therapist.
- **Continence Advisors** advise on continence issues and can provide a range of aids to assist.
- **District Nurses** at your local GP practice advise and provide equipment needed to nurse a person at home. These can include electric beds, commodes and continence pads.
- **Physiotherapists** advise and provide mobility equipment such as walking sticks and frames.
- **Trusted assessors** are employed by some local authorities' social services. They may assess for and fit basic daily living equipment such as chair and bed accessories, household equipment and bathing equipment.
- **Occupational Therapists and Physiotherapists** work in specialised NHS Wheelchair Services to assess and provide a range of wheelchairs including powered wheelchairs.
- **Buying Equipment**  
Equipment is available to buy, hire or borrow from suppliers and organisations including charities such as your local Red Cross, retailers, mail order catalogues and web based providers.

## • Useful Tips On Buying

There are thousands of products and suppliers to choose from, you may simply wish to privately purchase in order to avoid waiting lists from your local social service, may not be eligible for a product or you may prefer a different design or style of product. You may also simply want to “go it alone” without input from health or social service staff.

- Make sure that you have done your research, are clear of the product to meet your need and beware of retailers who have little knowledge of disability.
- There are many reputable retailers and equipment providers who have good customer service and your best interests in mind. However there are also companies who have little knowledge of disability and who are willing to charge inflated prices for poor products.

- Contact Disabled Living Foundation or Assist UK for details of providers of the product you wish to purchase. You will be able to compare prices on the product and receive information of the type of retailer that suits you best e.g. a local shop, mail order or home demonstration. Contact details above.
- If you are keen to receive a demonstration of a product but feel wary about receiving the demonstration at home your local Independent Living Centre( contact Assist UK contact details) may be able to arrange for the demonstration to take place at their centre.
- If the product demonstration does need to take place at your home do not feel under any pressure to agree to a purchase at the time of demonstration and have a family member or friend present to support you.

- **The British Healthcare Trade Association (BHTA)**

The trade association for the healthcare industry. It has a national membership and register of manufacturers and suppliers of healthcare equipment. Their Code of Practice requires members to trade professionally and ethically. It is only possible to receive information of their members online.

**[www.bhta.net](http://www.bhta.net)**

- **Accredited retailers**

Some local authorities give prescriptions for equipment rather than provide it directly. You can exchange the prescription at a locally accredited shop. If you wish to buy privately an accredited shop could provide you with peace of mind as they are required to provide a certain standard of service including up to date staff training, impartial advice, an installation and delivery service.

Your local social services will be able to provide you with a list of accredited shops if they operate such a scheme.

- **VAT**

You do not pay VAT on a product designed specifically for disabled people. Full details are available from HM Revenue and Customs National Advice Service.

**Tel:** 0845 010 9000

**[www.hmrc.gov.uk](http://www.hmrc.gov.uk)**

Ask for details of VAT Notice 701/7 VAT relief for people with disabilities.

- **Legal Rights**

You have the same legal rights when you buy disability equipment as you do when you buy any other product.

- **On line shops and mail order catalogues**

Hundreds of on line shops are at your fingertips, **Youreable.com** is a large website which includes an online shop and information about equipment  
**[www.youreable.com](http://www.youreable.com)**

Many companies produce free catalogues which are well illustrated and can provide you with ideas of possible solutions. If you are unsure if a product is right for you contact your local Independent Living Centre, DLF or your Occupational Therapist. DLF will be able to provide you with sample brochures and contact details, below are a selection of what is available:

- **Nottingham Rehab Supplies, Ways and Means Catalogue.**

**Tel:** 0845 121 81111

**Fax:** 0845 121 8112,

**www.nrs-uk.co.uk**

- **Keep Able**

**Tel:** 0844 888 1338

**www.keepable.co.uk**

- **Homecraft Rolyan**

**Tel:** 08444 124 330

**www.homecraft-rolyan.com**

- **Go Independent**

**Tel:** 0151 922 4455

**www.goin.co.uk**

- **British Red Cross Shop**

**Tel:** 020 7427 2460

**www.redcross.org.uk/shop**

- **Promedics**

**Tel:** 01254 619000

**www.promedics.co.uk**

- **RNIB (Royal National Institute of Blind People)**

**Tel:** 0303 123 9999

**Text:** 18001 0845 766 9999

**Fax:** 020 7388 2034

**www.rnib.org.uk**

- **RNID (Royal National Institute for Deaf People) Solutions Catalogue**

**Tel:** 01733 361199

**Text:** 01733 238020

**Fax:** 01733 361161

**www.rnid.org.uk**

- **Second Hand / Reconditioned Equipment**

Can provide an affordable route to equipment, care should be taken when considering buying electrical items to ensure that they are safe and working correctly.

Some retailers sell second hand products as part of their service, these will be referred to as reconditioned products for example stair lifts and electric wheelchairs.

Such products should be sold with a guarantee or warranty and sometimes service backup.

Make sure that you know the current new retail price of the product you are interested in before considering second hand. It may be that you can find good deals on a new product by carrying out a good search.

The following links will help you find second hand equipment:

- **The Disabled Living Foundation** can provide you with a list of where to find second hand equipment (contact details above)

- **Disability Equipment Register (DER)** is an internet-only based service of specialist equipment for sale or wanted. Products are on line with contact numbers for direct one to one buying and selling.

**Tel:** 01454 318818

**[www.disabilityequipment.org.uk](http://www.disabilityequipment.org.uk)**

- **Gumtree** is a large on line free ads. There are gumtree sites for many towns and cities where you can type in the product you are looking for. Gumtree also has a freebie and an items wanted section.

**[www.gumtree](http://www.gumtree)**

- **Ebay** online bidding marketplace with thousands of products for sale.

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

- **Local newspaper** free ads and disability magazines often have many products for sale. [www.disabilitynow.co.uk](http://www.disabilitynow.co.uk) is an example.
- **DisabledGear.com** is a website with free adverts for second hand equipment.

[www.disabledgear.com](http://www.disabledgear.com)

### • Hiring and Borrowing equipment

You may wish to hire a piece of equipment following a stay in hospital or to take with you for use on a holiday. Some people hire equipment prior to purchasing to ensure it meets their needs fully, check if the supplier offers a “try before you buy” scheme first.

Before hiring check with your local social services if you are able to be loaned equipment free of charge or if you are due to leave hospital check with the hospital

Occupational Therapist incase the equipment is “essential for a safe discharge” as it should be loaned to you free of charge from the hospital.

There are local and national companies who hire equipment for short and long term loans. Local Independent Living Centres produce local hire fact sheets. Disabled Living Foundation can help information.

- **The British Red Cross** have a volunteer led equipment service. The main types of equipment they loan are wheelchairs, walking aids, bathing equipment, toileting equipment, bed handles and perching stools. Contact for details of your local centre.

If you are going on holiday you can hire from Red Cross near to your holiday destination or you can contact your holiday Tourist Information Board who often keep details of where to hire locally.

**Tel:** 0844 871 1111

[www.redcross.org.uk](http://www.redcross.org.uk)



For further details of wheelchair or scooter hire please refer to NMO booklet “**Living with NMO**” – **Movement, mobility and travel**

- **Prior to hiring it may be helpful to consider the following:**
- Does the company provide a deliver/collection service?
- Does the company require a deposit?
- Will the equipment need to be serviced during the hire period?
- Ensure that the equipment is the correct size and has the correct weight capacity for your weight. All equipment has a different capacity. Equipment for larger and heavier people is called Bariatric Equipment.
- Ensure that you know how to use the equipment safely
- If the equipment has any moving parts check who is responsible for any repairs.

- Check if the company has an emergency repair / replacement service if the equipment should stop working – essential to check if you are hiring electrical equipment such as a stairlift, hoist or riser recliner chair.
- Consider how long you plan to hire for as costs can build up and it is sometimes cheaper to purchase reconditioned such as in the case of a stairlift.

### • **Feelings Around Using Equipment**

The impact of a diagnosis of NMO on people varies. Some people experience shock and disbelief whilst other people feel a sense of relief to know the reason for their difficulties. It is important to recognise that such responses are completely understandable, normal and may include a fear of being seen as “disabled” by your loved ones, friends, employers and your wider community.

This fear can sometimes result in an unwillingness to want to use any daily living equipment especially a product outside of the home. Some people feel this way initially whilst others feel like this for much longer. It is ok, it is normal and most importantly it is completely up to you if you choose to use a piece of equipment, how many and where.

You are likely to find your own solutions and ways around many difficulties in your own time and you will become the person who is most knowledgeable of your own needs.

However, if you feel able to consider some items of equipment it could open a door to greater independence, less reliance on others and possibly enable you to do something previously not possible.

An example of this can be seen in the use of mobility equipment which for some can have differing uses and benefits at different times.

A person without any mobility needs will sometimes walk, cycle, use a car, access public transport or even fly depending on their journey, all are useful at different times. The same scenario can be used for a person who uses a range of mobility equipment, there may be times when no equipment is needed, times when the use of a stick can help or others when using a wheelchair enables the person to achieve what they are wanting to.





## Occupational Therapy – Helping You To Live Life Your Way

Occupational Therapists are health professionals who work with people who have a medical condition, a physical disability, a mental health difficulty or a learning disability.

They help people who have difficulties with everyday tasks such as preparing a meal, taking a bath or lifting their legs into bed.

The aim of Occupational Therapy is to enable you to live as **independently** as possible at home, in employment, in education and during leisure time.

An Occupational Therapist can help you to adapt to changes in your life and to overcome practical problems by:

- Looking at ways an everyday task can be done differently to maintain your independence or reduce the effects of pain and fatigue.

- Provide advice on daily living equipment that may help you to maintain your independence with a specific task or activity.
- Recommend alterations or changes to your home to make it more accessible or safer for you.
- Help to address education or work issues.

- **How To Find An Occupational Therapist**

- NMO Occupational Therapists can be seen as part of your clinic appointment if you are attending one of the two specialist UK NMO centres in Oxford and Liverpool , go to front of booklet for contact details.
- Ask your GP, district nurse or social care professional for a local referral, they will know of the Occupational Therapy services in your area.
- Contact your local social services department or health service provider via the phone book or the internet.

- See an independent Occupational Therapist privately. For details and fees contact their enquiry.

**Tel:** 0800 389 4873

**www.cot.co.uk**

- **Are Occupational Therapists Registered?**

- All Occupational Therapists are required to register with the Health Professions Council (HPC) regulatory body. The HPC is responsible for conduct, performance and ethical behaviour of its registrants. Contact the HPC to check if an Occupational Therapist is registered.

**Tel:** 020 7582 0866

**www.hpc-uk.org**

- **The British Association of Occupational Therapists**

The professional body for Occupational Therapy, oversees all training.

**Tel:** 020 7357 6480



## DAILY ACTIVITIES - DOING THINGS DIFFERENTLY

You may be experiencing no difficulty in carrying out your daily activities, just a slight change in coping or your NMO may have had a bigger impact. Difficulties can be experienced for a variety of reasons including fatigue, pain and weakness and due to the psychological impact of living with NMO.

Sometimes **solutions** are within your grasp by asking yourself is there a way of doing this differently?

- **Identify Your Most Important Roles And Activities**

It may be helpful for you to write a list of all the activities you carry out throughout a 24 hour period. Start with the moment you wake up in the morning through to going to sleep last thing at night and during the night if you wake. Next to each activity record if it is O.K or if you need help,

perhaps with a comment at the side.

You will be astounded at just how complex our daily lives are in meeting our basic of needs such as washing and dressing through to household chores, shopping, cooking plus employment, leisure activities and socialising.

Such a list will provide you with detailed information of activities that are causing you and maybe your partner or family difficulties and others in which you are independent.

- **Why Are Roles Important?**

The roles that we all have make us who we are and define us, you may never have thought about these roles before as they make up our lives without us often giving them a second thought.

Examples of roles are many and varied including employee, student, care giver, homemaker, cook, shopper, cleaner, mother, father,

daughter, son, volunteer, friend, lover, DIY expert and animal carer..... to name but a few!

When a person is ill they may be supported in their roles by family and friends or may have stopped being involved in the role at all.

When you feel able, try to resume the roles that make you the person you are and which have important meaning in your life. Find ways around the difficulties so that you can continue to play an important part in the role.

- **What Next?**

From the list you could next identify which activities are essential, which are desirable and which ones do not need to be part of your daily routines. This can help you focus your energies on what is most important to you.

Each person's day, roles and routines will be very different.

Some people may live alone whilst others will have dependent children or care for an elderly relative. Each person's situation is unique and brings with it its own difficulties and also sources of support and solutions.

The lists you create will provide you with a clear picture of which activities and roles are essential and desirable in your life and which you would like to find solutions to if they are difficult.

### • Solutions

Solutions may be in the form of equipment or they may be in changing the timing of an activity or in receiving support from a family member, colleague or carer.

There are lots of ideas in the “**Help With Daily Life**” section of the booklet.

Contact RADAR to learn about their range of “**Doing Things Differently**”

guides. Contact details in “Introduction To Key Services” section of booklet.

A solution may require you to use your left hand for activities rather than your usual right hand if your NMO has affected your hands or arms. If this is the case contact the “Anything Left Handed Store”. You will be amazed at the range of 250 products designed for left handed people from golf clubs to pens.

**Tel:** 0845 872 3272

**[www.anythingleft-handed.co.uk](http://www.anythingleft-handed.co.uk)**

A computer solution may be needed, **Ability Net** can advise on adapting and adjusting computers and the internet to make them easier to use.

**Tel** 0800 269454

**[www.abilitynet.org.uk](http://www.abilitynet.org.uk)**

It is easy to fall into routines and habits without realising and good to **talk about changes** which might now be possible.



## Help With Daily Life

### Council Community Care Services

A health and social care assessment is often the first step towards getting the help and support you need.

Assessments are with the social service department of your local council. The assessment is also known as an “assessment of need”.

If you have internet access your local council is likely to have full and clear information detailing what is involved and the process of applying for an assessment in your area. Often you are able to apply on line yourself.

If you do not have internet access look in your phone book under county council or via your GP or local library. The social service team involved is often called an Access Team (providing access to services).



Your GP will have full details of your local team and can help to refer.

### • **Can I have a needs assessment?**

You have a right to an assessment no matter what your ability to pay for the care you need. You may have:

- Sight difficulties
- Hearing difficulties
- Mental health problems
- Frailty because of old age
- Learning disabilities
- A short term illness or injury
- Permanent or substantial physical disabilities
- Problems related to the misuse of drugs or alcohol

### • **What Happens In The Assessment?**

The assessment will involve talking to you, your partner, relatives or friends to find out exactly what care you need.

The discussion may be over the phone or face to face. You may want to ask for the help of an advocate (a member of your family, a friend or someone independent). This is someone who is independent from the council who you wish to speak on your behalf.

### • **What Does The Process Involve?**

Your needs will be assessed. This will involve talking with you, your carer and other people who know you well about different aspects of your life, which may include your physical health, your emotional health, how you manage to look after yourself and your current family and support networks.

The assessment should take into account your personal wishes in deciding what sort of care, advice or information would be of help.

- **How will the council decide what care I receive?**

Your care assessment will show what level of care would be of greatest help. The council decides this by using a scale of:

- Low
- Moderate
- Substantial
- Critical

This is in line with the Government's "Fair Access To Care Services" which you can view online or ask for details from your council.

- **Do I have a say in the services planned for me?**

Social services will discuss with you:

- The type of help needed
- When it is needed
- Who will be providing the assistance
- How long they will be with you each day

- Your religious and cultural needs
- When the service will be reviewed (remember – if you have a change in your needs due to your NMO do not wait for the planned review date, contact social services immediately)

- **What will my package of support look like?**

The assessment should show which needs are most important and the risks to you if you were not given any help.

If needed social services will put together a package of support for you. They will discuss with you and write a care plan. This may include services from both private and voluntary organisations.

If you need other services such as housing or equipment advice you will be put in touch with the relevant local service.

- **Services and support you may be entitled to**

- Personal care help for tasks including washing, dressing and meal preparation.
- Help with cleaning and shopping
- Day care for your child if either you or they are disabled
- Care homes
- Disability equipment and adaptations to your home

- **Care Charges**

Depending on your financial circumstances you may be expected to pay for or contribute towards the cost of your care. Following a financial assessment you will be given a clear idea of what you can be expected to pay and how the charges are calculated.

Charges are **not** made for:

- Assessments
- Services provided for young people and children under 18

- Services provided for carers – although charges may be made to the person being cared for depending on their financial circumstances.

If you have savings and capital assets of more than £23,250, you will be expected to pay the full cost of care services.

If you have less than £23,250 you will be financially assessed to find out how much you can contribute towards the cost of care. (Figures correct 2012)

Clients are financially assessed taking into account all income, savings and investments, but usually excluding the cost of your home.

Offset against this are standard living costs and expenses that arise from disabilities such as extra heating, clothing, gardening and domestic work.

Each client will also be offered an independent benefits check to see if you are receiving all benefits and allowances to which you are entitled.

- **What is self directed support?**

If you were assessed as needing help you can receive the services directly from your council however more recently some councils have offered clients more choice over the support needed. This has enabled people to take control over their own care and support.

Key factors are:

- Everyone who is eligible for care can be allocated a personal budget
- A range of options are available to help plan and arrange suitable care for each individual
- The council retains its duty of care.
- People who contact social services for support are offered a personal budget and self directed support if they meet eligibility criteria.
- Self directed support offers several ways of managing

the personal budget and **direct payments** are one of these.

- **What are direct payments?**

Direct payments are cash payments given instead of a care service. It is a different way of getting the support you need, with you in the driving seat.

You spend the money on getting the support you want that has been agreed as part of your assessment. Giving you more choice and control in how you are supported.

For example instead of the council simply allocating you a care worker at an allocated time you can choose your care provider, even a friend or neighbour and decide how and when you will receive the care.

Direct payments can be made to:

- People aged 16 or over who are in need of community care services

- Carers aged 16 or over in respect of carer services
- People with parental responsibility for disabled children

You can use the money to employ a personal assistant or you can use an agency to provide staff for you. Or you can “mix” and “match” and have some support provided by your council and some as a direct payment.

You must use the money to meet your assessed needs. You are not usually able to employ a close relative or a person living in your home.

Your council will have full details of how the scheme operates in your area including what to do if your circumstances change.



## Buying Your Own Care Services

You may have discovered that you are not financially eligible to receive council care support or you may wish to arrange your own support for other reasons.

Care agencies and providers operate throughout the UK however it is sometimes difficult to know where to start and what to look out for to ensure you receive the right care for you.

- **Guidance from your local social service**

Often social services can help you find the personal services that suit you regardless of your financial circumstances.

They can provide you with contact numbers of contracted agencies who can provide personal and domestic help. They have lists of approved personal assistants who are checked, trained and sign a code of conduct.

Councils are also able to give helpful guidance in searching for **care** or **residential homes** in your area. Councils often produce booklet guides of care options for your local area.

- **Who else can guide me?**

Local disability organisations, carers organisations and support groups have a wealth of local knowledge and first hand accounts of accessing such services near to you. They will be very happy to share their experiences and provide helpful information.

Such groups could include: local disability organisations, local associations for people

with vision loss and Age UK for older people.

National organisations such as Neurosupport and RNIB can also be of great help.

- **Directory of reports on care services**

- **Care Quality Commission**

The Care Quality Commission is responsible for ensuring hospitals, care homes, dentists and home care providers meet government standards.

Find independent reports and quality ratings on all your local care homes, home care and other registered services, plus address and contact details to help you make the right choice.

The CQC website enables you to search for the reports and ratings or you can telephone for details and how to complain about a service.

**Tel:** 0300 616161

**Fax:** 03000 616171

**[www.cqc.org.uk](http://www.cqc.org.uk)**

## • Care Choices

A web site that details thousands of care providers, enables you to carry out a search for your local area of care homes, services and care products.

**Tel:** 01223 207770

**Fax:** 01223 207108

**www.carechoices.uk**



## Assistance Dogs

Guide dogs for people with vision loss **Tel:** 0870 600 2323 **www.guidedogs.org.uk** are familiar to many people and full details can be found in the Living With Sight Loss section of the booklet however it is less well known that assistance dogs support adults and children with a wide variety of disabilities every day.

There are several assistance dog charities that train and provide dogs in different locations around the UK.

## • What does an assistance dog do?

For adults with physical disabilities a dog can offer practical support with tasks many people take for granted, for example opening and closing doors, helping people undress and emptying the washing machine.

For children with physical disabilities dogs provide many of the tasks they do for adults plus support with physiotherapy.

Pet owners are often reported as saying that their dog brings far more than just an excuse for a walk in the park. Many people find their dog brings huge emotional and physical benefits, improving their fitness, relieving stress and helping as a social icebreaker.

Through practical tasks assistance dogs can offer freedom and independence, in addition they become a reason to go out, giving new found confidence that opens doors to fresh opportunities including friendships, hobbies, education and careers.

- **Assistance dog charities and how to contact**

- **Canine Partners**

Location – Midhurst, West Sussex, England

Services - Assistance dogs for adults with physical disabilities

**Tel:** 08456 580 480

**[www.caninepartners.org.uk](http://www.caninepartners.org.uk)**

- **Support Dogs**

Location – Sheffield, South Yorkshire, England

Services – Assistance dogs for adults with physical disabilities, seizure alert assistance dogs, assistance dogs for children with autism.

**Tel:** 0114 261 7800

**[www.support-dogs.org.uk](http://www.support-dogs.org.uk)**

- **Dogs for the Disabled**

Location – Banbury, Oxfordshire, England

Services – Assistance dogs for children with physical disabilities (age 7-16), assistance dogs for adults with physical disabilities (age 17+) and assistance dogs and other services for families with children with autism.

**Tel:** 01295 252600

**[www.dogsforthedisabled.org.uk](http://www.dogsforthedisabled.org.uk)**



## **The Red Cross Social and Health Care**

**The Red Cross** can provide free short term practical support following a recent admission to hospital.



Support is offered by volunteers who can smooth the process of getting back to a normal routine and enable people to regain their confidence and independence.

Services include:

- Assistance with shopping
- Collecting prescriptions
- Offering companionship
- Rebuilding confidence

Referrals are accepted from GP's, hospitals, health and social care professionals and individuals.

Therapeutic care is also available in the form of hand, neck and shoulder massage, given through clothing from the Red Cross Therapeutic care Service . Available for anyone recovering from an illness or a carer. The service:

- Assists relaxation
- Reduces Stress and Pain
- Promotes a sense of wellbeing

- Offers the chance to talk to someone trained in listening skills

Contact below for details of your local Red Cross Branch Office.

**Tel:** 0844 871 1111

**[www.redcross.org.uk](http://www.redcross.org.uk)**



## Making Your Home Easier To Live In

Some of the effects of NMO such as reduced mobility, pain or vision loss can result in difficulty getting around your home.

The **layout of your home** may provide you with full independence and ease of access however many people who are newly effected by NMO can find that their home prevents them from moving freely around and

gaining access to all areas especially upstairs and into garden areas.

**Solutions** are many and varied, they may come in the form of a simple grab rail fit to the wall in your shower to help you feel safer, a second bannister on the stairs in order for you to be able to hold on either side, carefully positioned lighting to enhance eye sight or more complex additions such as a stair lift or permanent ramp to your front door.

A well designed and accessible home can make the world of difference to your independence and ease of living, there are hundreds of ideas and solutions available it is just a question of receiving the correct information and support for you.

You may come across the term “accessible home or “accessible environment” which are terms used to describe a home which enables you to do what you need and want to do.

Each person’s home has a differing ability to make changes in. Some houses cannot accommodate the necessary changes. A house move can be a positive move to greater independence however time is often needed to come to terms with the changes needed. Our homes hold many memories which can be painful to leave.

Housing associations and local councils are able to help you look at possible re housing options if your disability has resulted in difficulty getting around your home.

Private home owners could refer to information held at **The Centre For Accessible Environments** as guidance on the type of home environment that will provide maximum ease of use and independence.

- **Centre For Accessible Environments (CAE)**
- Provides specialist information to the general public, designers, builders, architects and therapists on good design and accessibility.
- Is a registered charity and has been the leading authority on inclusive design for over thirty years.
- You can request free information by telephone, fax, letter, e.mail or face to face.

- C.A.E can put you in touch with the House Adaptations Advisory Service ( H.A.A.S) a national database of architects, surveyors and others who have experience of house adaptations.

The following are examples of guides produced by C.A.E that may be of help:

**“Planning Your Home For Safety And Convenience”** – practical advice for disabled and older people. ISBN number 0 903976 34

**“Good Loo Design”** – ISBN number 1 85946143 3

**“Wheelchair Housing Design Guide”** – aims to offer the latest information on designing a home that is fully manageable by wheelchair users and maximises independence. – ISBN number 1 86081 8978

**“Designing For Accessibility”** – the acknowledged benchmark reference and used as an access standard

for grant providers. Includes extensive plans and dimensional data. – ISBN number 1 85946 143 3

**Tel:** 020 7840 5811

**www.cae.org.uk**

### • Disabled Facilities Grants

A Disabled Facilities Grant (DFG) is a **local council grant**. It helps towards the cost of adapting your home to enable you to continue to live there. A grant is paid when the council considers that changes are necessary to meet your needs and that the work is reasonable and practical.

Full details and explanations of who is eligible for a grant, what you can use it for and how much money you can receive are available on the government website **www.directgov**, by contacting your local council or viewing the Citizens Advice Bureau Advice guide “Help With Home Improvements”

**Tel:** 08444 111 444

**www.adviceguide.org.uk**

To apply contact the housing or environmental health department at your local council and ask them to send you an application form. You must apply before you start any work. You won't normally get any grant if you start work before the council approves the application.



### • Home Improvement Agencies

Not-for-profit organisations run by housing associations, local authorities and charities. They can help people who own their homes or who live in privately rented

accommodation and who are elderly, disabled or on a low income to repair, maintain or adapt their home.

For example:

- Arrange for repairs to be carried out
- Help you to get funding for repairs
- Give advice about a range of issues which affect your living conditions
- Organise the fitting of small aids and adaptations to increase your independence such as grab rails
- Install security measures such as door locks and viewers

### • Foundations

Tel: 08458 645210

[www-foundations.uk.com](http://www-foundations.uk.com)  
(England) and

**Care and Repair Cymru**  
(Wales)

Tel: 029 2057 6286

[www-careandrepair.org.uk](http://www-careandrepair.org.uk)  
can put you in touch with local organisations.

- **Moving House**

Your home may be a council or housing association property which has been assessed as not being suitable to adapt. Alternative housing options can be explored with you.

Your local housing association or council will be able to provide information and guidance regarding the application process in your area.

If you feel you need further impartial advice and support regarding any issue around rehousing contact:

- **EAC FirstStop Advice**

An independent, free service providing advice and information for older people, families and carers about care and housing options in later life.

**Tel:** 0800 377 7070

**[www.firststopcareadvice.org.uk](http://www.firststopcareadvice.org.uk)**



## Living With Sight Loss

**Visual problems** are common in people with NMO who have experienced inflammation of the optic nerve. The optic nerve is the cable transmitting electrical signals from the light sensitive inner layer at the back of the eye (called the retina) towards the vision area of the brain.

**Sight loss** takes many forms. Visual impairment is a deeply personal experience and no two cases are the same. Some

people don't see in the dark, others are affected by bright sunlight. Some have restricted field of vision and many a loss of contrast. Sight varies, some days we see better than others.

- **How is visual impairment measured?**

Partial sight can be hard to judge, there being so many variables. However put simply, if you cannot read normal newsprint whilst wearing glasses or contact lenses then you could be considered partially sighted. Blindness

and partial sight are formally defined terms which relate to the quality of vision but blindness does not necessarily mean the absence of light.

- **Sources of Support and Services**

Coming to terms with having a sight problem can be tough. Dealing with the emotional and practical impact of changes to your sight can be overwhelming especially if there has been a sudden and unexpected deterioration as can be the case in NMO.

It is important to remember that **you are not alone** and the support, services and information to help you live your life independently is available.

- **RNIB – Royal National Institute for the blind**

UK wide charity who work to enable people with sight problems to live independently. Contact for details of their extensive services and how they can help.

RNIB guide “**Coping With Sight Loss**” contains information and links to sources of help.

Aswell as selling a wide variety of products to increase independence and safety through their RNIB catalogue and online shop, RNIB produces a number of magazines including “Vision”

RNIB can provide information and advice on every aspect of living with sight loss including the emotional impact, the financial impact, banking and handling cash and bank cards, employment, benefit advice, local sources of support, technology to increase safety and independence, talking books, help with telephones and radios and NHS and social service support.

**Tel:** 0303 123 9999

**[www.rnib.org.uk](http://www.rnib.org.uk)**

- **Local Associations for the Blind**

The RNIB will be able to direct you to your local



association, often an independent charity providing information, advice and practical support, including assistance in form filling.

You will be able to meet and talk to people who have been through a similar experience to yourself

Local associations are often able to visit you at home and many have supportive and informative website.

- **Telephones for the Blind**

This fund can help pay for the cost of providing and renting a telephone for people who are registered blind and could not afford a telephone themselves.

**Telephone/Fax:** 01737 248032

**[www.tftb.org.uk](http://www.tftb.org.uk)**

- **Help from your local council and NHS**

Aids and equipment are often provided through the social service department of your local council. The National Health Service (NHS )

Hospital Eye Service can also prescribe a range of aids for people with partial sight. NHS Low Vision Clinic Services aim to maximise the use of remaining vision through the use of optical low vision aids including magnifiers, closed circuit television, especially enlarged print, talking watches, calculators and screen readers. Request a referral from your local doctor (GP) to a low vision clinic at your local eye hospital.

All blind and partially sighted people are entitled to a **health and social care assessment** from their local council. This means someone from social services will assess your needs to help you receive the equipment and services that are right for you. For details go to “Help At Home” section of booklet.

Your local social service department may put you in touch with a rehabilitation worker usually based in a **Visual Impairment Team.**

The worker can visit you at home and help you learn new ways to manage everyday tasks.

Rehabilitation workers can also teach you how to get around safely indoors and out and about and how to communicate more easily, for example by teaching you to type or use writing aids and communication software.

- **Everyday equipment to make life easier**

A wide range of tools and gadgets are available to manage household tasks.

A few examples are:

- Devices that alert you when a pot of liquid begins to boil
- Gadgets that make a sound when a cup you are pouring water into is nearly full
- Knives with an adjustable guide to help you cut even slices
- Tactile watches and alarm clocks

## **Accessible technology and telephones**

Computer products and telephone systems that can be very useful include:

- Mobile phones with tactile, well spaced buttons and a function that reads text messages aloud
- Telephones with a large colour contrasting keypad
- Computer screen reader
- Magnification software

Further information and advice on all products available from **The Disabled Living Foundation**, go to “How Equipment Can Help” section of booklet for contact details.

- **Registering as sight impaired**

For details please go to “Disability Registration” section at the end of booklet for contact details.

- **Dogs for blind or visually impaired people**

**Guide Dogs** (formally The guide Dogs for the Blind Association) is a registered

charity providing training and support for people with serious sight loss who would like to have a guide dog.

To become a guide dog owner, you must be resident in the UK and have a significant visual loss. This may be combined with other disabilities. You must be able to use and care for the dog.

There is a wealth of information on Guide Dogs website and you can find contact details for your local Guide Dogs Teams in their local to you section.

**Tel:** 0118 983 5555

**Fax:** 0118 983 5433

**[www.guidedogs.org.uk](http://www.guidedogs.org.uk)**



## Managing Bladder and Bowel Problems

Incontinence can have a huge impact on a person's life resulting in feelings of embarrassment and low mood. Incontinence often greatly restricts social activities and impacts on relationships and work opportunities.

It **does not have to be this way**, solutions and products exist to make a huge difference and to help regain your freedom. There are many experts waiting to help you.

Detailed explanations of the causes of continence problems in NMO are available in the NMO booklet "Neuromyelitis Optica – A guide to the condition"

Here it is hoped to provide further sources of support and reassurance and enable you to make informed choices to help you feel more in control.

- **NHS Continence Services**

Your GP can refer you to a team of NHS specialists in your area who are able to assess your particular needs

and identify solutions for you. They have expert knowledge of all forms of treatment and management available.

- **NHS NMO Clinic**

Specialist advice is available from the Clinical Nurse Specialist at the Liverpool and Oxford NMO clinics who you can speak to as part of your clinic appointment or by telephone.

See front of booklet for contact details.

- **Promocon – Promoting Continence and Product Awareness**

Promocon provides a national service, working as part of Disabled Living, Manchester.

It aims to improve life for all people with bladder and bowel problems by offering product information, advice and support to both the general public and healthcare professionals.

- Advice for adults
- Advice for children
- Products – expert

knowledge on continence products

- Extensive lists of product suppliers, catalogues and online sales
- Publications and resources for general public and healthcare professionals, includes guide to working with continence problems.
- Telephone helpline for confidential, impartial advice
- Buy products from online store
- Visit Promocon in Manchester, explore the Promocon interactive house and find products to help you.

- **Promocon Publications**

Promocon produces a range of booklets and leaflets covering bladder and bowel problems in adults and children. They are freely available on the website to view and download. A number may also be available in hard copy.

The “**Talk About...**” range are aimed at children to help them understand what is happening and what needs to be done to get better.

The “**Understanding.....**” range is aimed at carers and professional to help them understand and support a person experiencing problems.

**Helpline:** 0161 607 8219

**[www.disabledliving.co.uk/](http://www.disabledliving.co.uk/)**

**Promocon**

- **Bladder and Bowel Foundation**

The foundation is a registered charity providing information, advice and support.

- Helpline – a free service, speak in confidence to a healthcare professional for medical advice and support
- Resources – all information is available to both patients and professionals. Patient information, including a range of easy to read booklets looks at bladder and bowel problems in

more detail. More specific information such as medication, products, diet and exercise and emotional wellbeing is available in a factsheet range.

- Bi Annual magazine where you can read articles on the latest research, patient stories, treatment updates and latest news
- “Just Can’t Wait” toilet card – one of the biggest problems can be in finding a toilet to use when out and about. Help is at hand in the form of a small credit card sized. The toilet card states clearly that the card holder has a medical condition which requires urgent use of a toilet. Although the card does not guarantee you a toilet, most places will be willing to help you. Donation of £5.00 is requested to be sent a card.
- If you become a registered supporter you receive toilet card and magazine free.

**Helpline**, call free on 0800  
011 4623

**www.  
bladderandbowelfoundation.  
org**

- **RADAR**

Contact for details of Radar National Key Scheme and to purchase key and guide to thousands of locked public toilets in UK.

**Tel:** 0207 250 3222

**www.radar.org.uk**

- **ERIC – Education and Resources for Improving Childhood Continence**
- ERIC is the UK's only childhood continence charity who work to reduce the distress to children and families caused by bed wetting, soiling and associated conditions.
- ERIC receives up to 8,000 viewing on it's website per month from young people, families and health professionals.
- On line shop sells wide range of continence

products including chair and bed protectors. Over 33 books available to order including "Bowel and Bladder Management in Children With Special Needs" A Guide for parents.

- Online message boards for children, young people and parents.

**Helpline** 0845 370 8008

**Sales/Customer Service**

0117 301 2100

**www.eric.org.uk**

- **The Multiple Sclerosis Society**

Contact for MS factsheets on bladder and bowel problems.

**Tel:** 0808 800 8000

**www.mssociety.org.uk**



## Support for Carers and Parents

Caring for a relative, loved one or child with NMO can be a rewarding and fulfilling experience but without the right support it may also be difficult at times. Some carers live with the person they are supporting whilst others do not. Carers are people of all ages, including children who provide care support for a parent.

Carers often have a need for information, financial and

other support, opportunities to take time off and contact people in a similar situation to themselves.

We all need regular breaks from our daily responsibilities to keep us in good health and carers are no different. Your local social services department can advise on respite care and how to access it.

Sometimes short breaks will involve someone else caring for your relative or friend for a few hours a week, leaving you free to do your shopping



or visit friends. At other times it could mean care is provided for a week or longer. Respite services are also available for independent organisations below.

There is no need to feel guilty about wanting a break or to think you need time off because your caring role is not a conventional job. In the long term, you will cope better with the demands of caring if you also take time off yourself.

- **Information and Support organisations**

- **Carers Direct**

Carers Direct is a information, advice and support service for carers operated by the NHS. It's website has practical guides on assessments, getting practical support, young carers, work and education.

It has links to local services that you can search by putting in a place name or postcode.

Telephone helpline is open 7 days a week and can give information about local care support, assessments, benefits, direct payments, individual budgets, young carers, time off, work and education.

**Freephone:** 0808 802 0202  
(calls from mobiles may be charged)

lines open 8am-9pm Monday to Friday and 11am-4pm weekends and bank holidays.

[www.nhs.uk/carersdirect](http://www.nhs.uk/carersdirect)

- **The Princes Royal Trust for Carers**

The trust provides support for carers through over 140 local centres. These provide information and advice, emotional support for carers and local representation. Some provide practical support such as time off, respite breaks or help with shopping.

**Tel:** 0844 800 4361

[www.carers.org](http://www.carers.org)

- **Youngcarers.net**

The Princes Royal Trust also has a website for young carers. Online discussions, information and lots of practical and helpful advice for young people.

If you register for YCCet Interactive you can chat to other young carers and find a buddy. There are experts and youth workers online to help you. Sign up for a free monthly email newsletter.

**[www.youngcarers.net](http://www.youngcarers.net)**

- **Contact a Family**

Provides information, advice and support for families with disabled children

- Helpline
- Medical Information
- Local contacts, events and news
- Publications
- Parent Stories
- [makingcontact.org](http://makingcontact.org) – links families with disabled children for support

**Tel:** 0808 808 3555

**[www.cafamily.org.uk](http://www.cafamily.org.uk)**

- **Crossroads**

Caring for carers. Crossroads provide respite care, they take over from the carer to give them a break. There are over 120 local schemes in England and Wales. Some schemes have additional services such as carer projects.

**Tel:** 0845 450 0350

**[www.crossroads.org.uk](http://www.crossroads.org.uk)**

- **Vitalise**

UK charity providing short breaks, respite care and holidays for people with physical disabilities, visual impairment and carers.

“V-Zone” on website allows you to see images and find out about people who have accessed Vitalise.

**Tel:** 0303 303 0145

**[www.vitalise.org.uk](http://www.vitalise.org.uk)**

- **Carers Assessments**

Whoever you care for their entitlement to support is arranged from social services through a community care assessment. You can ask for your own needs to be

included in this assessment and you are entitled to a carer's assessment under the Carers and Disabled Childrens Act 2000.

A carers assessment provides an opportunity to discuss your caring role and the support you need. It is not an assessment of how well you care for your relative but an evaluation of the support you are entitled to. You will get a chance to discuss issues such as:

- Do you get enough sleep?
- Are you worried you may have to give up work?
- Do you get enough time to yourself?
- Is your caring role affecting your health?

### • **Finances and Employment**

You may incur costs because of your caring role and your income may be reduced because you are unable to work.

Check out your entitlement to welfare benefits by contacting

the above organisations or refer to **“Living with NMO - Work and money – who can advise?”**

More than three million people juggle their caring responsibilities with employment. The Carers (Equal Opportunities ) Act 2004 and the Work and Families Act 2006 have given carers greater rights in relation to employment, education and leisure opportunities.

Since April 2007 carers have had the right to request flexible working from their employer, who must consider the request seriously.

### • **How You Feel**

It is perfectly normal to have complex feeling about your caring role. You may also find it hard to cope with the life changes you experience when you start caring.

Carers of people with NMO can feel isolated to the rare nature of NMO, do not forget that NMO is a neurological condition of which there are

millions of carers involved and who will access the organisations in this section.

Looking after your health is crucial. Eat well, exercise regularly and seek help from your GP if you feel stressed or depressed.

- **Find Out More**

England - visit the NHS Choices website at [www.nhs.uk/carersdirect](http://www.nhs.uk/carersdirect) or the “caring for someone” section on the UK government website at [www.direct.gov.uk/caringforsomeone](http://www.direct.gov.uk/caringforsomeone).

Northern Ireland - visit the “caring for someone” section on the [www.indirect.gov.uk](http://www.indirect.gov.uk)

Wales – visit [www.wales.nhs.uk/carers](http://www.wales.nhs.uk/carers)

Scotland – [www.careinfoscotland.co.uk](http://www.careinfoscotland.co.uk) is a telephone and website service.

- **Courses to help you**

Learn more about what being a carer involves.

Courses can often be accessed at your local carer’s centre and through the NHS Expert Patients Programme [www.expertpatients.co.uk](http://www.expertpatients.co.uk)  
**Tel:** 0800 988 5550.

The Expert Patients Programme only operates in England.



## Disability Registration – Is It For Me?

### • What Is A Register of People With Disabilities?

Every local authority is required by law to maintain a “Register of People with Disabilities” to help them plan their services for the needs of local people.

If you have a substantial or permanent disability, are over 18 and are a permanent resident in your local county you can apply to be registered

with your council under the Chronically Sick and Disabled Persons Act 1970.

### • How Could It Help You?

Registering with your local council can make it easier to get practical support from your social service department. However you do not have to register. It can also be a “passport” to getting concessions, such as travel, parking and TV licence concessions, free NHS sight test, help with telephone installation charges and line rental and cinema and theatre concessions.

- **Is The Register Compulsory?**

You do not have to register, you are free to choose if you wish to register. You will be eligible for all council services if you choose not to.

You do not have to be registered to be exempt from paying VAT on some goods directly related to your disability. (See HM Revenue and Customs-VAT relief for Disabled people). Your retailer can give you a claim form or you can print your own from the HM Customs and Excise web site. Although you do not need to be registered you will need to sign a declaration that you have a disability.

- **How To Apply**

Contact your local council social service department for details.

- **Sight Loss and Registration**

If you are have impaired vision that cannot be improved with spectacles or contact lenses

you will be advised by your consultant Ophthalmologist (eye doctor) if you are eligible to be registered with your local council as either Sight Impaired (Partially Sighted) or Severely Sight Impaired (Blind).

Classifying your sight in this way does not affect the provision of any medical care and it is not an indication that your vision will get worse.

If you agree to be registered your consultant will record this by signing a Certificate of Visual Impairment (CVI).



If you agree with the completion of the form CVI the following will happen:

- A copy will be sent to your own doctor (GP)
- A copy will be sent to the Sensory Impairment Team at your local social service department who are responsible for local social care to sight impaired people.
- Your local social service department will contact you to ask if you wish your name to be added to the relevant register. You are not registered until this happens.

# NMO Publications and Information

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Neuromyelitis Optica – A guide to the condition

Living with NMO – Movement, mobility and travel

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](http://www.nmouk.nhs.uk)

## **NMO Service**

John Radcliffe Hospital  
West Wing  
Headley Way  
Oxford OX3 9DU

[nmo.advice@orh.nhs.uk](mailto: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](mailto:nmo.advice@thewaltoncentre.nhs.uk)

**Tel:** 0151 529 8357



# Notes

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