



Living with NMO

Work and money – who can advise?



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.

Employment and finances can often be a source of worry and concern for people with NMO however knowledgeable and experienced support services can guide you carefully to the best solutions for you.

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 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.

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Employment and Volunteering

Work is central to many people's life providing not only financial independence but also social interaction, confidence and self esteem, exercise and opportunities for travel and continued learning. This section aims to provide you with details of the help available to decide on the best way forward for you and your family including both employment and volunteering information.

Worries about work can be very common for a person with a neurological condition, organisations are waiting to help.

Employment

- **Neurosupport – Working Life Service**

Help and advice for people affected by a neurological condition with any issue regarding employment or in finding a meaningful alternative to work.

Trained advice and guidance workers are experienced

in helping people to retain their existing jobs wherever possible. You can telephone or email at any time.

Advisers can liaise with employers, talk to managers, offer advice and adaptations to your workplace or working day which may enable you to continue with your work.

Many people with newly diagnosed or long term neurological conditions find it difficult to break into the job market for the first time, support and help can be provided with all aspects of securing a job.

Tel: 0151 298 2999

www.neurosupport.org.uk

- **RNIB – Supporting Blind and Partially Sighted People**

Specialist information from RNIB and Action for Blind People to help you get a new job, retain your current one and know your rights in the workplace:

- Access to work
- Looking for work
- Staying in work

- Self Employment
- Your rights in employment
- Success stories
- Factsheets
- Employment research

RNIB produce a series of detailed factsheets covering all aspects of employment. All factsheets are available in braille, large print and audio.

Tel: 0303 123 9999

www.actionforblindpeople.org.uk

- **Jobcentres**

Jobcentres Plus is responsible for the national network of Jobcentres. These give skilled advice and ensure you know which benefits or allowances you are entitled to claim.

They can also support you if you are concerned about the impact of your disability on your existing job.

- **Disability Employment Advisers**

You and your Jobcentre Plus adviser may decide that getting further specialist

advice would be helpful from their Disability Employment Adviser (DEA). Services provided include:

- An employment assessment to help you identify what type of work or training suits you best
- A job matching and referral service
- Information on employers who have adopted the “two ticks” disability symbol

- **Remploy**

Remploy's mission is to transform the lives of disabled people and those with complex barriers to work by providing sustainable employment opportunities.

Remploy provides a comprehensive range of employment services to support disabled people.

Remploy remain one of the largest employers of disabled people in 54 factories throughout the UK.

In 2010/2011 Remploy found more than 20,000 jobs in mainstream employment

Tel: 0845 155 2700

www.remplo.co.uk

- **Occupational Health Input – Health for Work Adviceline for small business**

Following a diagnosis of NMO many employees of larger organisations choose to discuss their health needs at work with their Occupational Health Department.

A plan of action is usually formed to advise managers of adjustments to working environments or hours of work in order to accommodate individual needs. Reviews are arranged to provide an opportunity to discuss the impact of NMO at work and if support plans in place are working for both the employee and employer.

- The Health for Work Adviceline is coordinated by NHS Plus and offers tailored occupational health (OH) advice to support managers of small to medium sized businesses.

It is recognised that many smaller to medium sized businesses do not have their own Occupational Health Department. They may not provide help and support to staff who suffer from ill health because they are so focused on delivering business improvement and growth.

The Health for Work Adviceline recognises this and provides free, quick and easy access to effective professional advice to help managers:

- Find the advice and support they need to help an employee experiencing ill health
- Develop a plan to effectively and sympathetically deal with employee sickness absence.
- Establish how to deal with similar problems in the future should they occur

Advice can be sought in three ways:

- Telephone advice on **freephone** 0800 077 8844

- Self – service information through access to on line knowledge base **www.health4work.nhs.uk**
- On-line communication with a contact centre by submitting a question to the support team, instant messaging

If you find yourself with no Occupational Health Support at work and are experiencing difficulty in communicating your particular needs and required adjustments it may be helpful to **inform your employer of this free service.**

The service could help both you and your employer to establish a positive way forward.

- **The Multiple Sclerosis Society**

Produce booklet “At Work with MS – Managing life and work” which includes many relevant sections of interest to a person with NMO including employment rights, who needs to be told, who is on your side and balancing work and life.

“Sometimes I feel my life is like a room where, from time to time, the walls move in a few inches. Work is one way of pushing them back.”

Tel: 0808 800 8000

www.mstrust.org.uk/information/publications/at-work-with-ms

- **Spinal Injuries Association**

Produce booklet “Returning to employment, volunteering and retraining” – Moving Forward series book 10.

Tel: 0845 678 6633

www.spinal.co.uk

- **Directgov**

UK government website. Comprehensive and clear advice and information on work issues.

www.direct.gov.uk/disabled

- **Jobs for Disabled People Cooperative**

Website for charitable cooperative, job vacancies targeted at disabled people. Positive about the skills and experience disabled people can bring to the workplace

www.disabledworkers.org.uk



Volunteering

Volunteering can be provide a meaningful alternative to work either as a short term or long term option.

Volunteering can bring with it all of the additional benefits gained from employment such as maintaining self esteem and confidence without the restrictions that paid employment can sometimes place on an individual.

For those people viewing volunteering as a route into the job market volunteering can help you:

- Develop new skills
- Gain experience
- Get training in new areas of work
- Explore career interest
- Build your confidence
- Enhance your CV

Support and guidance

regarding getting started is available both locally and nationally with opportunities from inside your own home to your local community and overseas.

What are you waiting for?!

Community Service Volunteers (CSV)

The UK's leading volunteering and training charity

CSV runs a number of supported volunteering projects for people with disabilities and employment training.

Tel: 020 7278 6601

www.csv.org.uk

- **Search online**, there are around 914,000 volunteering opportunities in the UK.
- **www.do-it.org.uk** enables you to quickly find opportunities in your area by typing in your postcode
- **www.voluntaryworker.co.uk** is a reference source to volunteering in the UK and abroad

- **Jobcentres**

Offer “Work Together” scheme, local help with volunteering and guidance regarding any restrictions in relation to benefits.

- **Local Volunteer Bureaux**

Operate in most communities, contact via your library, on line or telephone book.

Opportunities range from short term opportunities to long term projects in your local area.



MONEY AND FINANCES

A diagnosis of NMO can inevitably lead people to worry about money especially if your NMO has had an effect on your ability to work or resulted in your partner reducing their work hours to provide care and support.

Many people are unfamiliar with sources of financial advice and support and may have no experience of the benefit system.

Money can be a complicated subject and receiving up to

date, independent and clear information is vital to ensure you do not miss out on help that you are entitled to for both yourself and your family.

This section will provide you with specialised contacts who can help you through the maze of money and benefits.

- **Benefits**

The government benefits system is there to help you. It is not a charity but a service you have a right to call on. The services below can all guide you.

- **Neurosupport**

Tel: 0151 298 2999

Textphone:

0151 298 3289

www.neurosupport.org.uk

- **Benefit Enquiry Line**

Freephone: 0800 882 200

Textphone: 0800 243 355

Email: BEL-Customer-Services@dwp.gsi.gov.uk

- **Directgov**

UK government website covering all government services, pages are clear and easy to navigate. Information on all benefits, pensions and managing debt.

www.direct.gov.uk/disability

- **Citizens Advice**

CAB is a long established UK wide advice charity. Get advice:

- **Online** via Citizens Advice self-help website adviceguide.org.uk.
- **Online** for under 25's advice4me.org.uk
- **By phone** is available from

your local Citizens Advice Bureaux . Details in your phone book, library, GP.

CAB is currently in the process of developing a national phone service. You will hear options for recorded information on the following numbers:

Tel: 08444 111 444

Textrelay: 08444 111 445

- **From a Citizen Advice Bureau**

Free, impartial and independent advice from over 3,500 locations. These include high streets, community centres,, doctor's surgeries, courts and prisons.

- **Advice** may be given face to face or by phone. Most bureaux can arrange home visits and some offer e.mail advice, text, online chat and webcams.
- **CAB website** explains what to expect from a CAB visit, you can watch and listen to an introduction to the



Citizens Advice Service and access advice sheets.

www.citizensadvice.org.uk

- **Help With Health Costs**
- **The Help With Health Costs Advice Line**

Provides NHS patients with information about entitlements to prescription charge exemptions and information on the requirements to qualify for charge exemption at dispensing chemists.

Tel: 0845 850 1166

www.nhsbsa.nhs.uk

- **Department of Health Publications Orderline**

Contact to request NHS leaflets and publications such as the ones below:

HC11 Help With Health Costs

HC12 A Quick Guide To Health Cost – includes optical vouchers

Tel: 0300 123 1002

www.orderline.dh.gov.uk

- **Directgov**

UK government website has full details of all financial assistance available including application forms to download.

www.direct.gov.uk

- **Disability Alliance**

- Provides information on benefits and tax credits to disabled people. They publish the Disability Rights Handbook which provides comprehensive details of the benefit and welfare system. Also publish other factsheets including Claiming Disability Living Allowance.

- Factsheets explaining key benefits available to download including guidance and advice on the medical assessments involved in certain benefits.

Tel: (voice and Text) 020 7247 8776

www.disabilityalliance.org

- **Help With Fuel Bills**

- **Winter Fuel Payment**

If you are aged 60 or over you should automatically get a Winter Fuel Payment towards the cost of keeping warm, the amount ranges from £250 to £400 dependent on age.

It is usually paid automatically, if you have not been paid, check with the pension service that you qualify. You can telephone or download an application form.

Tel: 08459 151515

Textphone: 0845 601 5613

www.thepensionservice.gov.uk/winterfuel/how-do-i-get-it.asp

- **The Home Heat Helpline**

- Free and practical advice for people who are worried about paying their fuel bills.

Tel: 0800 336699

Textphone: 0800 027 2122

www.homeheathelpline.org

- **Debt**

- **Citizens Advice**

Debt advice available, see previous entry for how to contact.

- **The National Debtline**

Gives free, confidential and independent advice by phone or e.mail. You can download self help materials and factsheets from their website and they will help you with a debt management plan. They have sample letters on a variety of situations which you can adapt to suit your own circumstances.

- In England and Wales contact:

Tel: 0808 808 4000

www.nationaldebtline.co.uk/englandwales

- In Scotland contact:

Tel: 0121 410 6230

www.nationaldebtline.co.uk/scotland

- **Consumer Credit Counselling Service**

CCCS is a charity that gives confidential advice and

support to anyone worried about debt. You don't have to give your name and their service is free. You can telephone or email.

Helpline: 0800 138 1111

Email: contactus@cccs.co.uk

www.cccs.co.uk

- **Tax**

- **Taxaid** gives free tax advice to people who cannot afford a professional advisor. If your income is £300 a week or less they should be able to help you.

All advice is given by qualified staff. Their website has basic information on the tax system.

Tel: 0845 120 3779 (10-12am Monday to Thursday)

www.taxaid.org.uk

- **Financial Help – Charities, Trusts and Funds**

Many local and national funds can offer help in the form of money or services such as equipment, counselling, help at home, furniture, training, utility bills and holidays.

There are often little known local funds that you can apply to.

To find out who you could apply to :

- **Association of Charity Officers (ACO)**

Helpline: 01707 651777

www.aco.uk.net

Other sources of help include:

- **Local Independent Living Centre**

- Can carry out a search for you, contact DIAL UK for your nearest centre

Tel: 01302 310123

www.dialuk.info

- **RNIB**

Provide information about grants available to blind and partially sighted people from other organisations.

Tel: 0303 123 999

www.rnib.org.uk

- **Age UK**

Has a useful benefits factsheet for older people.

Tel: 0800 169 6565

www.ageuk.org.uk

- **Charity Search**

Can assist older people in finding a charity and provide advice and support in making an application, provide encouragement and support until the problem is solved.

Tel: 0117 982 4060

www.charitysearch.org.uk

NMO Publications and Information

Neuromyelitis Optica – A guide to the condition

Living with NMO – Independence in daily life

Living with NMO – Movement, mobility and travel

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

nhs.uk

Tel: 0151 529 8357