



One Voice

NMC Physio Client Newsletter
Summer 2005 - Edition 01

Welcome!

A big welcome to you all on the first edition of One Voice

The purpose of this newsletter is to share our knowledge and experiences. It is for existing, new and potential physio clients alike. It is a new venture and one that I hope will be of benefit to us all. We aim to produce the newsletter twice per year.

We are all at different stages of one type of muscular dystrophy or associated neuromuscular condition or another. Some of us have had a diagnosis since birth whilst others have been only recently diagnosed. Some may not yet have a diagnosis. We represent a wide age group and have different family circumstances. You may be a mother, father, partner, young child or teenager. You may be in employment, education or you may have retired. A carer might help you with daily living.

Whatever your personal circumstances, we all have one thing in common: that we have to live day-to-day with the frustrations that such conditions bring. And the frustrations are endless. I guess we have all acquired an "expert knowledge" about our "own" condition and organisations that can help us with daily living. You may have knowledge of mobility aids, ventilation or of hotel and leisure outlets that offer good accessibility for those of us who are less mobile.

We all know, that for most of us, there is no miracle cure and unfortunately that is outside our control. However, with the right support, we as individuals can enjoy a full and active life. Getting out and about may require greater planning but there are opportunities for us all. Like you, I get moments of frustration with my body's inability to do the things I want it to do and as a result face constant hurdles on a day-to-day basis. Some days it is hard to remain positive. However, knowing that there others out there who are probably feeling just the same can be a source of comfort. If we can make small positive changes to our daily living then this can have a positive effect on our well-being.

So let's share our knowledge and try and make a difference to all our daily lives.

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HOLIDAYS & DAYS OUT

Yes it is that time of year when we start thinking about days out, a weekend away or booking our summer holiday. For some of us that is an exciting prospect but for others it can fill us with fear and dread. Whilst we have as much entitlement to travel as our non-disabled peers, greater attention to detail is required. We need to ensure that the facilities are accessible and any additional equipment can be provided at our chosen holiday destination. Thankfully there are lots of organisations that can help take the strain out of booking a trip. Here are a few;

- ¥ Accessible Travel and Leisure Tel: 01452 729739
www.accessibletravel.co.uk
- ¥ Can Be Done Tel: 0208 907 2400 www.canbedone.co.uk
- ¥ Ability 2 Travel Tel: 01536 501928
- ¥ If travelling by air do ensure airlines are aware of your specific access needs. For travel to and from British airports, contact Access and Mobility, Transport for London Tel 020 7941 4600

Holiday Insurance

Many companies offer insurance packages for disabled people. Prices vary widely so it's worth checking out all the options. Please remember to check any policy (normally just a standard package) that you take out at the time of booking a holiday. Rarely will they cover a pre-existing medical condition. Additional insurance will normally be required. Try;

- ¥ En Route, that specialises in specific pre-existing conditions
Tel 0800 783 7245
- ¥ J&M Insurance have re-launched Travelbility, a specialist insurance cover for disabled people and those with pre-existing medical conditions Tel: 01902 566919
- ¥ Post Office Travel Insurance. Worth considering. Reasonably priced. For pre-existing medical conditions you will need to go through a medical screening process. This can take place by telephone and does not take long. For further details call into any main post office.

Tried & Tested! - Gaer Cottages

Cribbyn, Near Lampeter, Cardiganshire

Five star self-catering cottages for all the family with a particular emphasis on facilities for disabled visitors. Six out of the nine are single storey Welsh stone cottages easily accessible from the car park. Indoor heated pool with hoist. Games room. Picnic area. Short breaks available in low season. Contact Richard and Linda Burgess Tel: 01570 470275 or visit www.selfcateringinfo.wales.co.uk

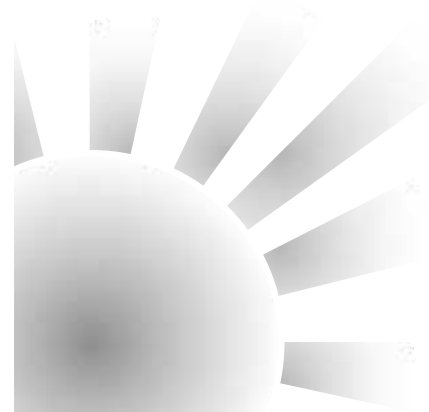
Client visitor comment; Accessible. A real retreat. Complete relaxation. Friendly owners, nothing was too much trouble. Super pool. Nearest town -Lampeter, nearest beaches Aberaeron and New Quay.

Do you live in Cheshire?

For information on accessible venues for days out please look at the www.cheshireforall.com website. Designed by the county's tourism team, it provides independently verified information on access facilities at the county's attractions as well as approved hotels.

Tried & Tested!

- ¥ Stapeley Water Gardens, Nantwich, Cheshire. A special sensory garden for smell and touch with a huge array of colours. A haven for peace and quiet.
- ¥ Bridgemere Garden World. Wide and level paths. Excellent parking close to main entrance. Wheelchairs are available without charge.



Thinking of buying a caravan?

Bromley Motor Caravans sell a range of caravans specifically adapted for use by disabled people. Items include ramps, lifts, altered seating and interior layout. Interested? Please contact 020 8311 3500.

Caravan Sites with accessible facilities

Visit www.caravanable.co.uk
This website was set up to provide information about UK caravan sites with accessible facilities. The database has brief details of more than 500 sites across England, Wales, Scotland and Northern Ireland that have a minimum of an accessible shower, basin and toilet with ramped access.

For further details and brochures of disabled friendly venues for days out and holidays (UK and Overseas) please refer to our in-house display (in the yellow box files near the reception desk) at the NMC. Please feel free to add to our collection.
Thank you.

PHYSIO TEAM UPDATE

As some of you already know Ruth Lambert, one of the physiotherapists will be retiring from The NeuroMuscular Centre in late June. Ruth has worked at the Centre for seven and a half years. Many of you see Ruth on a regular basis and I know you would all want to wish her a long and happy retirement. She will be missed by colleagues and clients alike.

The physiotherapy department have recently purchased a new tilt table and a pair of "sequential wellies". The wellies have proved popular with users.

TRIAL UPDATES

There have recently been trial developments for people with SMA and Duchenne For further details please visit the following websites;

www.jtsma.org.uk www.muscular-dystrophy.org

Updating your Driving Licence

Apparently there has been an increase in the number of customers who experience delays when collecting their new car, as a result of failing to update their driving licence.

It is legal a requirement to inform the Driver and Vehicle Licensing Agency (DVLA) when you change your name and/or address. Failure to do so could result in fines of up to £1000. For more information please call 0870 850 0007 or visit the DVLA website www.dvla.gov.uk

Boost for disabled

Diving for disabled people has now become a possibility at the Blue Planet Aquarium in Ellesmere Port. The Aquarium prides itself in having divers qualified in assisted dives. For further details please call 0151 357 8800.

Are you over 55?

Odeon Cinemas (check your local branch) offer Senior Screen films for the over 55's. Admission is £2.50 including refreshments. They also offer Wheelchair Access Screen Days on the ground floor.

Some cinemas will allow under 55's with a disability to participate in this offer. Again just ask at your local branch. Seats can be pre-booked.

Disabled Persons Railcard

The Disabled Persons Railcard allows you to buy discounted rail tickets. If another adult is travelling with you, they can also travel at the same discounted fare.

The Railcard currently costs £14 and is valid for 12 months. To qualify, you must meet at least one of their set criteria which include receiving Disability Living Allowance (in the higher rate for help with getting around, or in the higher or middle rate for help with personal care).

For further information please visit www.disabledpersons-railcard.co.uk or telephone the Disabled Persons Railcard application helpline on 0191 218 8103.



NMC — 15th BIRTHDAY NEWS

This year the NeuroMuscular Centre (NMC) celebrates its fifteenth birthday. Yes, it is fifteen years since The NMC first opened its doors.

The Centre remains the only such facility in Europe for those affected by muscular dystrophy and other neuromuscular conditions.

By way of celebration, and to raise money and awareness the NMC team are asking clients if they would like to host a tea party, dinner party, organise a cake sale or donate at your coffee break at work.

Whilst the NMC's actual birthday was the 1st of April 2005 you can hold an event however and whenever you want. You could join forces with a few friends.

The aim is to have fun. If you are interested in holding an event please call Sharon on 01606 861733.

DO YOU HAVE A CARER?

Does a relative or friend help with your care needs? This may include physical help, emotional support, personal care or practical help such as shopping, washing or cleaning. If the answer is yes then do consider contacting one or all of the following organisations who can offer help, support and advice.

Princes Royal Trust	020 7480 7788	www.carers.org
For Carers (PRTC)		
Carers UK	0808 808 7777	www.carersuk.org
Contact a Family	0808 808 3555	www.cafamily.org.uk
Crossroads	01788 573653	www.crossroads.org.uk

If you live in the Cheshire area, Cheshire Carers Centre can also offer help. Set up by The Princes Trust to offer advice, support and information to carers in Cheshire. They have offices in Northwich, Crewe, Macclesfield and Ellesmere Port.

Cheshire Carers Centre Contact Details

Helpline	0800 085 0307 (Tues -Fri 1.00 - 4.00)
Website	www.carers.org/cheshire
e.mail	advice@cheshirecarerscentre.org.uk
Main office address	8 Albion Walk, Northwich, Cheshire, CW9 5XU

How to get help in looking after someone

If you look after a relative, disabled child or friend and caring has a major impact on your life then a carer's assessment could help you. A carer's assessment is your opportunity to tell social services about the things that could make caring easier for you. Social services can provide services for the person you care for as well as services for you the carer. This may include benefits advice, help with household tasks, with caring tasks during the day/night or activities for the person you care for.

To arrange an assessment contact either your own GP or your local council social services department. It is important to remember that the carer needs to remain fit, well and healthy to fully support the disabled person.

New Rights for Carers from 1st April 2005

The Carers (Equal Opportunities) Act 2004 places a legal duty on Local Authorities to inform Carers of their right to an assessment of their needs. They should consider any work, study and leisure interests that a carer might have.

DID YOU KNOW?

Help For Cinema Goers
The Cinema Exhibitor's Association card is a national concessionary card available from 1st October 2004. The card will entitle the holder to one free ticket for a person accompanying them to the cinema. To apply, a person will need to meet one of the following criteria -

- be in receipt of disability living allowance
- be a registered blind person
- be a holder of a disabled persons railcard.

Cards are valid for three years from when they are issued and a £5 processing fee applies. Application forms can be collected from cinemas, or printed from the website www.ceacard.co.uk which also lists the national and independent cinemas supporting the scheme.

PERSONAL DETAILS

We hope all your details are correct but if they are not please let us know. How would you like to receive this newsletter? By hardcopy or by e.mail? Please fill in the attached slip and return it to me at the centre. Thank you.

ROTARY DISTRICT 1180 DISABLED GAMES

18 September, 2005

Do you have a disability? Do you fancy a fun day out? Do you want to try something different? Then you cannot afford to miss this event. Entry is free and there are medals and t-shirts for all competitors. The date is Sunday 18th September, 2005 and the venue MBNA Europe Bank, Field of Dreams, Chester Business Park, Chester.

The inaugural District Disabled Games took place in 2001 at The Kings School, Chester. Since then, the Games have been held annually with the financial support of MBNA Europe Bank at their Field of Dreams leisure facilities in Chester. The games came about to give the general disabled community the opportunity to try sports that they perhaps would not realise they could participate in. The event is organised through a committee of Rotarians and others with specialist knowledge, headed by David Towers from the Rotary Club of Oswestry.

There are eight sports: archery, boccia, carpet bowls, cricket, darts, new age curling, table tennis and tennis. Competitors enter the games as individuals and are asked to choose their first choice of three disciplines in order of preference. Registration is mainly in advance but entries are accepted on the day. As the games are for participation and not competition there are no age or handicap limits applied.

The day concludes with a medal presentation ceremony when every single participant has a medal individually given to him or her. Everyone is a winner.

For further details please contact:

David Towers

Rotary Club of Oswestry

Tyn-y-pistyll

Quinta

Weston Rhyn

Oswestry

SY10 7LU.

Telephone 01691 772230

E.mail david.towers@lineone.net

DATES FOR YOUR DIARY

Mobility Roadshow

Thursday 7th, Friday 8th and Saturday 9th July 2005,
at Donnington Park near Derby. 10am - 5.00pm
Thursday and Friday, 10am - 4pm Saturday.

See and test drive the latest adapted vehicles, plus walking aids, wheelchairs, scooters, hoists, ramps, stair lifts and other mobility products and services from a range of exhibitors. Pre-bookable wheelchair and scooter loans are available to help you get around. For further details call, 0870 770 3222

or visit www.mobilityroadshow.co.uk

Disability Awareness Day 2005

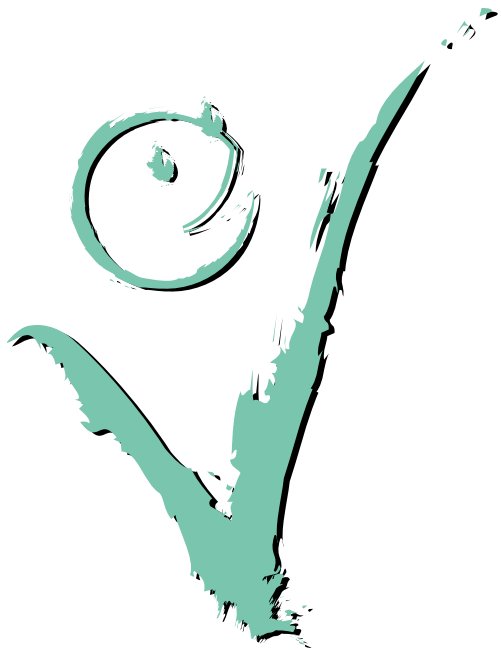
Sunday 10th July, Walton Hall Gardens, Warrington
(off A56).

Over 300 exhibitors. Information about support groups and services, equipment, transport, holidays, employment and more. All facilities are accessible. Wheelchair loans, free park and ride schemes. For further information call The Disability helpline on 01925 240064 or visit www.disabilityawarenessday.co.uk.

Fourth Rotary Disabled Games

Sunday 18th September, 2005

Held at MBNA Europe Bank, Field of Dreams, Chester
Business Park, Chester, Cheshire.



FROM THE EDITOR

For those of you who do not know me, I am Andrea Duckworth, 37 years old and the mother of two young children, the eldest of which has special needs.

I have a type of muscular dystrophy and was diagnosed in February 2002 following a muscle biopsy.

I have been receiving weekly physiotherapy and hydrotherapy at The NeuroMuscular Centre for just over two years.

For me personally the Centre has been my lifeline, supporting me both physically and emotionally, giving me the drive to fight this condition. I have met some wonderful people, both employees and users of the centre. One thing the Centre has in abundance is laughter - I think that is the magical ingredient that gets you through!

FINALLY . . .

Please remember that this is your newsletter - please let me have your ideas and suggestions. What would you like to see in the next edition? Do you have particular subjects that you require further information on or websites that may be of interest? Can you recommend a disabled-friendly holiday destination either in the UK or overseas? Have you a delicious recipe that you wish to share? Could you think up a little rhyme that might brighten our day?

Please drop me a line

by post to the NMC

or e.mail andrea@nmcentre.com

or telephone 01606 861733.

FORTHCOMING EDITION

Next issue due November 2005 to include nutritional advice, alternative therapies and Christmas ideas.

UNTIL NEXT TIME .

Try and remember what you can do and enjoy the present. The past has gone, the future, who knows what that will bring but let us enjoy the here and now.

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e.mail andrea@nmcentre.com