



Winter 2007

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## NMC STAFF NEWS



### A fond farewell to Katia

*In September we said a fond farewell to Katia who had worked for the NMC for just over 20 months. She took up a new role in fundraising to develop community fundraising and in particular work with clubs, schools and other groups to support them in raising awareness and money for the Centre. I'm sure you would join me in thanking Katia for all her hard work and wish her well as she heads back to France.*

### A Warm Welcome to Karen Lamb

*We extend a warm welcome to Karen Lamb, our new Development Officer in the Fundraising Team. Karen will work closely with local schools and firms to encourage them to support the NMC. Karen's most recent role was working for North West Foods as a project manager organising local food producer events. She brings a wealth of experience to this role.*

## FROM THE EDITOR

Welcome to the Winter edition of One Voice. The days are shorter, the weather is colder but let's wrap up warm and make the most of this festive season. With Christmas almost upon us there are lots of people to see, places to visit and things to do, not least of all finish off that Christmas shopping! If you are shopping on-line, which really is hassle-free, do remember to use the NMC link as every time you buy it raises funds for the NMC.

The past few months have been filled with activity. The children have settled back into school life and at weekends we have enjoyed trips to Chester Zoo and the Anderton Boat lift. Both venues are very disabled friendly.

In October I attended the annual conference for glycogen storage diseases in Reading. As ever, it is always good to talk to others in a similar situation and share experiences. We had the opportunity to ask questions to a panel of medical experts from hospitals around Europe which was invaluable. As is often the case with a rare medical condition, patients become very knowledgeable about their condition and are a key driving force in managing their condition. This is true in so many cases, so what ever your condition, do subscribe to your representative group because together you do have a very strong voice.

I have enjoyed putting together the NMC Christmas Raffle and hope the lucky winners enjoy their prizes. Along with NMC colleagues, we are busy organising the second NMC Complementary Therapy Day which will be held on Tuesday 11th March 2008.

I am thrilled that so many of you want to share your experiences in One Voice and hope that you will continue to do so during 2008.

I hope this newsletter finds you all well. May I wish you all a happy and peaceful Christmas and every good wish for the coming year.

**Andrea**

## PHYSIO TEAM NEWS

- \* **NMC EQUIPMENT ON LOAN** - Please could all clients who have borrowed equipment, let Gordon know, as he is carrying out a stock control check of all physio equipment. Please ring Gordon T 01606 861799 if you have anything belonging to physio.
- \* **STUDENT.** In November, Charlotte Draper, a student from Manchester Metropolitan University joined the team for a five week placement.
- \* **SOCIAL ACCOUNTING QUESTIONNAIRE.** A big "Thank You" to all those who completed the Physio Questionnaire. Without your help we would not have been able to review our service and look for areas where we can improve. The findings were generally positive, with 90% of you saying that you had achieved your main goal or reason for coming to physio. Almost everybody likes the relaxed atmosphere, and values the professionalism and specialist knowledge/experience of the physio team. Rosie will be sharing the results with the Physio Users Group, who represent our clients, to discuss any improvements that we might consider for the future.
- \* **HYDROTHERAPY.** Just to remind clients that we are lucky enough to have the use of the Hydrotherapy facility at Hebden Green School which is accessible to all clients. We have both lunchtime and evening sessions. Hydrotherapy helps manage the symptoms of a neuromuscular condition. If you are not currently having hydrotherapy and would like to try it please speak to a member of the physio team.
- \* **PARKING.** As you may have noticed the car-park has been re-marked and re-surfaced. We hope this has made it more accessible to all clients.
- \* **Christmas Holiday Dates.** Please be aware that there will be no physiotherapy from Monday 24th December 2007. Treatments will recommence on Thursday 3rd January 2008.

## WINTER WARMERS! Thermals.

The weather is getting colder so do remember those thermals. For most of us with muscle disorders circulation can be a real problem and there's nothing worse than having a cold back or cold hands and feet. There are lots of items on the market ...thermal gloves, hats, underwear, insulated shoes etc. Some products are available on the high street. You could try Marks and Spencer, BHS, Debenhams, Boots, Ethel Austin.

### Heated Gloves.

Not just thermal gloves but heated gloves! Gloves that use a battery operated heating system which circulates warmth around the hands and fingers. Priced at around £25. From Leisure Direct. Just type Leisure Direct into google and do a search for "heated gloves".

## BIG CONGRATULATIONS TO KAREN AND ALAN.

In July, Karen Pritchard (a physio client and designer) gave birth to a son, Evan. We send our congratulations and best wishes to Karen, Alan and baby Evan.



Karen & Evan

# OUR PERSONAL EXPERIENCES

## Personal Experiences

**Neil Thompson** has found the elevating closomat toilet a real breakthrough and he says it is far superior to using a frame over the toilet.

**Mike Jackson** has a hoist in the bedroom with tracking and has found this meets his particular needs. He also uses a sling when transferring from one position to another which makes him feel safe and secure. His electric bed enables him to be elevated at night which helps with his ventilation.

**Heather Murrant** uses both a slide sheet and a slide board to help transfer from one position to another. She finds the slide sheet very comfortable and says it also makes it easier for her carers. Heather uses these products both at home and on aeroplanes. Also, she has an attachment on her bed, a u-shaped lever, that fits under the mattress, provided for by social services, which helps her when pushing up to standing. Whilst Heather uses a track hoist at home, she says she would in fact prefer a portable hoist. At the moment she sometimes feels trapped and limited in what she can do around the home. For example if she had a portable hoist she would have more opportunity to get about her home and go and sit in the garden. Furthermore, she would be able to take the portable hoist on holiday with her. Heather's hoist was completely funded by Wirral Borough Council and it is serviced every 6 months.

**Simon Birchall** has both a track hoist and a mobile hoist. He had had the track hoist since he had an extension, almost twelve years ago. This was funded by the council. He bought his mobile hoist four years ago on e.bay and takes it with him when he stays at hotels.

**Matt Cundall** has had a track hoist for many years. He has one in the bedroom and one in the bathroom. Supplied by social services it is serviced every two years. He finds it suits his needs when moving from the chair to bed and the chair to the bath.

### **Further information:**

Disabled Living Centres Council - T 0870 770 2866 [www.dlcc.org.uk](http://www.dlcc.org.uk)

Disabled Living Foundation - T 0845 130 9177 [www.dlf.org.uk](http://www.dlf.org.uk)

Chester Mobility - 18 Knutsford Way, Sealand Road, Chester T 01244 377363

Ableworld - [www.ableworld.co.uk](http://www.ableworld.co.uk) - Visit this website to find your local store.

# CARERS NEWS

\* **New Funding For Services in East and West Cheshire.** Thanks to a successful funding bid by Cheshire Carers Centre to Big Lottery's Advice Plus Programme, a new grant was made available for East and West Cheshire. The project started in October and funding has been secured for three years. Members of staff will be based at Macclesfield and Chester, providing advice and guidance on benefits, access to services and carers rights.

\* **Carers Rights Day - Friday 7th December, 2007**

Do you know your rights? Are you aware of the benefits you may be entitled to as a carer? For up to date information on events happening in your area T 0800 085 0307.

\* **Carers UK Equal Partners offers Free Carers Training**

Carers UK Equal Partners helps carers to make their voice heard and improve local services. Carers can access briefings, training and information and join their network of carer campaigning across the UK for free. There are still opportunities to take part in FREE carers' training to help build your confidence for local campaigning. For more information e.mail [equalpartners@carersuk.org](mailto:equalpartners@carersuk.org)

\* **Carers Handbook**

A revised edition of the Carer's handbook has just been published. The book aims to be a one-stop shop for all those in a caring role and it also looks at how carers can care for themselves. Priced at £10.99, published by How To Books, ISBN 978-1-84528-194-6

## LEIGH LAWSON SAILS ON THE TALL SHIPS

Leigh Lawson had an unforgettable experience sailing on the Tall Ships from Cherbourg to Swanage. Leigh joined members from Bramhall Rotary Club on the three masted tall ship TNS Tenacious in the Fastnet race.

He flew from Manchester to Southampton, was driven to the ship Tenacious, which sailed to the Isle of Wight then across the English Channel.

Taking a slight detour due to strong winds and rain, they finally arrived in Cherbourg.

On the return journey they had good sailing weather, stopping at Swanage and the Isle of Wight before arriving back at Southampton.



Leigh said it was a wonderful experience and he was thrilled he had been given this opportunity. He said the ship was rough at times, but it was great fun, a real team effort and he had learned a lot. The ship was so accessible, crew members very helpful and it had boosted his confidence. Leigh would recommend this to others and explained that you do not need to have had any previous sailing experience.



The Jubilee Sailing Trust offers the experience and thrill of a lifetime regardless of physical ability. Established in 1978, their aim is to promote the integration of people of all physical abilities through the challenge and adventure of sailing on board the purposely built tall ships. STS LORD NELSON and SV TENACIOUS.

To find out more:  
The Jubilee Sailing Trust,  
T 0870 443 5781  
or visit [www.jst.org.uk](http://www.jst.org.uk)

## CHRISTMAS SHOPPING

Stuck for an idea for Christmas?  
The NMC can help.

\* Something different? Do you want to wake up to birds singing in your garden? Why not brighten someones day with a bird table or nesting box? In return for a donation to The NMC, Ken Hester, a regular Thursday morning client will make one for you. To place an order please ring Ken on T 0151 632 1029. This makes a special and long lasting Christmas gift.

\* Go Green this Christmas with the NMC Eco Friendly bag. Priced at £3.50, they can be purchased from Dee in Training.

\*Gowrings Mobility Atlas.. for just £5.. now that's a bargain!  
To ensure trouble-free motoring then this is a must! Previously featured in One Voice we have a limited supply of these for sale at just £5! (rrp £12.99) Makes an ideal present, with all sale proceeds going to the NMC.

\*Buying Gifts on-line. Shop and raise money for the NMC this Christmas by shopping at [www.buy.at/nmc](http://www.buy.at/nmc). With over 100 high street retailers including HMV, Marks and Spencer, John Lewis Amazon, and more being added all the time, each retailer will make a donation to The NeuroMuscular Centre when you buy through this website. So whether you are looking for the perfect CD, stocking up on your wine cupboard or picking up the latest electronic gadgets please remember our website and help raise funds for the charity whilst you do your Christmas shopping. It's so easy, takes the hassle out of Christmas shopping and the NMC benefits at the same time. We are all winners! Do tell your family and friends. Happy shopping and Thank You for your support.

\*Out with the old and in with the new!  
Will you be having a good sort out over the Christmas holidays? Are you having a new gadget or piece of equipment for Christmas? Before you decide to part with the "old" please remember that someone else might be looking for that very thing. Do put up an advert (preferably with a photo) on the SALES and WANTS board at the NMC. You never know your luck!





# BE FASHIONABLE

- You don't have to live in jogging bottoms!

Sadly today, many disabled shoppers find it hard to buy suitable clothes and just seem to "make do" with what they can find on the high street or in supermarkets.

To start with, the actual shopping experience can be a nightmare. Some shops are not that accessible, stands of clothes are often too close together and added to that, shops tend to be so crowded and there are always queues at the tills. It can be difficult to shop no matter what your level of mobility.

It's not always easy to find clothes that fit properly. For example if you are in a wheelchair you need trousers and skirts that are shorter cut at the front and longer at the back. The problem is that ill-fitting clothes can cause so much discomfort.

There appears to be only one clothing company in the UK that produces garments especially for disabled people of all ages. Their clothing range was designed after much discussion with wheelchair users, carers and professionals to ensure that they got it right. They now produce high quality clothes such as tailored trousers, jackets, skirts, underwear and waterproofs in addition to a range of clothes for disabled children. They also offer wheelchair and scooter accessories, bath time and nightwear products. Their website is well worth a look. For more information visit [www.able2wear.com](http://www.able2wear.com) or T 0141 774 8000. No need to trawl around the high street just look online!

Thankfully, things are slowly changing. Young designers are keen to fill what they perceive as a gap in the market and universities and colleges are teaching students about accessible design. In September, New York Fashion Week looked at fashionable clothes for those of us with a disability, with particular focus on being glamorous whilst in a wheelchair.

Everybody should be given the same opportunity to look smart. With the appropriate fastenings, zips and poppers and an array of colour, those of us with a disability can look as fashionable and glamorous as the next person! So bring on the Christmas parties!

### **Further information:**

\*The Disabled Living Foundation - publishes fact sheets including lists of people who rip/remove clothes etc.  
visit <http://factsheets.disabledliving.org.uk>

\* [www.able2wear.com](http://www.able2wear.com) T 0141 774 8000

\* [www.wearableclothing.com](http://www.wearableclothing.com)  
T 0141 774 9000

\* If you are looking for specially-designed clothing for a disabled child (up to the age of 14 years) visit Rackety's - [www.racketys.com](http://www.racketys.com) or T 01538 381 430

\* Tanni and Annie's teenage Fashion range. Adaptive clothing that is colourful, vibrant and edgy. Offers several choices as to how you put on the garment. For information just type Tanni and Annie into google.

\* Wheelie-chix. Launched in September in London at a charity fashion show, the fashion collection for stylish women in wheelchairs. To view the collection visit [www.wheeliechix-chic.com](http://www.wheeliechix-chic.com)

## **SUPPORT SERVICE - Imminent changes to Direct Payments for Cheshire**

Cheshire County Council is moving from direct payments towards "Self Directed Support" in 2008. For newly assessed clients the model will be up and working from September 2008. As you are re-assessed for direct payments you will move into the scheme.

The idea behind the new scheme is that it will lead to a more customer focused system, give more choices, involve the client in the decision-making process and thus increase individual independence.

As this is such a very important change, and it will affect you now, or at some point in the future, our next Information Meeting at the NMC will be devoted to "Self Directed Support". There will be a speaker from social services, Wynn Spencer, who will explain the new model and how it will work for you.

The meeting will be held on Thursday 7th February 2008 at the NMC, from 1.30pm until 4.00pm. Please join us and bring your thoughts and questions. Thankyou.

**Sue Walker - Support Worker**

### **HIGHLIGHTS FROM THE CONSULTATIVE AND ADVISORY GROUP MEETING**

\* With fundraising costs for the NMC at 14%, this is well below the charity sector average.

\* As part of Muscle Week, six local primary schools took part in The Big Push.

\* Proposed Research Project. Funding has been received for research at The NMC with Manchester Metropolitan University. Sandra Hartley is hoping to visit in December to conduct face to face interviews. The research will look at the benefits of The NMC including physiotherapy.

\* It was agreed that two new members would be added to the group.

# MOVING AND HANDLING EQUIPMENT FOR THE HOME AND Y



Mobile Hoist

Everyday tasks that most people take for granted such as getting in and out of bed, having a bath or shower, getting on and off the toilet can be difficult for those of us with impaired mobility. Maintaining independent living and a good quality of life is dependent on having the right lifting, moving and handling equipment that is safe and easy to use. This can effect not just the person with a disability but also their carer(s) and/or assistants.

There is a great deal of equipment on the market which generally speaking falls into three categories; hoisting equipment, standing and short transfer aids and finally, small manual moving and handling aids.

## 1) Hoisting equipment.

Track hoists, permanently fixed to the ceiling are particularly useful for transferring someone over a relatively long distance. They can be used by the user or the carer. Most are powered by either mains electricity or rechargeable batteries. Prices for fixed ceiling hoists start around £1300.

**Mobile Hoists:** These are not permanently fixed and can be detached from one track and moved to another elsewhere.

Although mobile hoists can be a bit bulky when erected, most can be folded down, put into the boot of the car and packed away when not in use. Starting at £800 and not requiring any track installation, mobile hoists are a more flexible alternative for moving people short distances. However, you do need to make sure that there is enough room to manoeuvre the hoist into the right position and

## Thinking of buying a

### wheelchair or scooter?

Contact Phoenix Group for a free comprehensive assessment of your needs by an experienced therapist. Your assessment will cover, postural needs, pressure care needs, physical needs, and medical history. They are able to supply equipment from all the leading manufacturers at low prices.

**Ableize.** Disability, disabled and health related sites offering health goods, services, social are and mobility aids. Visit <http://www.ableize.com/>

**Disability Rights Handbook** - A guide to benefits and services for all disabled people, their families and carers. For further information visit <http://www.disabilityalliance.org/drh32.pdf>

**Council Tax Banding.** If you have made adaptations to your home, you may be entitled to having your council tax reduced by one band. The idea behind the scheme is to ensure that disabled people do not pay more council tax because they need to live in a larger property. In order to qualify for the reduction, the property needs to be the main residence for at least one disabled person and it must have at least ONE of the following:-

- \* an additional bathroom or kitchen
- \* any other room (not a toilet) that is mainly used by the disabled person
- \* enough space for the use of a wheelchair.

For more information visit [www.direct.gov.uk](http://www.direct.gov.uk)

that the floor surface is suitable to allow the hoist to move easily.

## 2) Standing and short transfer aids.

These are ideal for those people who are able to bear their own weight for a short time. They are particularly helpful for transferring from a seating to a standing position. Swivelling standing aids enable you to transfer yourself more easily or encourage you to be more involved in the actual transfer with the help of your carer. These aids start at around £100. It is important to remember that the base of any standing and short transfer aid needs to be placed close to the wheelchair to minimise injury to either party whilst transferring.

## 3) Small moving and handling equipment.

Hoists, standing aids and short transfer aids can take up a lot of space and cost quite a bit of money. In certain situations there are many small moving and handling aids on the market that could make a big difference to your daily life.

For those with sufficient upper body strength, **transfer boards** are ideal, for example when moving from your wheelchair to a chair. They are available in a range of designs - curved, straight and with or without handholes.

Another useful transfer aid is a **handling belt**, a fabric belt with grab handles. These can be used by your carer to get into a standing position and are a safe, secure and comfortable way of lifting yourself out of a chair for example. They cost from £30 upwards.

**Leg lifters** are a good option for people with weakened legs and need help in and out of bed. They consist of a strong rope with a foot hole at the bottom and a loop for the hand to grip at the top. They cost around £15.

**Slide Sheets** enable carers to move people who are less mobile without having to lift them. Starting at around £20, they enable the carer to roll the sheet, and hence move the person without having to lift them. This clearly minimises pain on transfer.

Smaller aids/devices are not very costly but they can make a real difference to your daily life.

## Referral and Funding

Choosing the right aids is really vital and best done by getting an assessment of your needs by an Occupational Therapist (OT) from either your local social services department or Disabled Living Centre.

Your OT will source most products and they are offered on a loan basis. Unfortunately waiting times for equipment vary considerably, and if items have to be specifically ordered directly from the manufacturer then this can often take much longer.

Depending on the type of equipment you might need and any additional work that may be required in your home, you could be entitled to a Disabled Facilities Grant.

It is also worth remembering that over time your condition may change so as a result your moving and handling equipment needs will change.



Mobile Hoist

# A New Year A New You!

A Second NMC

Complementary

Therapy Day –

Tuesday 11th

March

2008.

Relax and Re-

charge. Following

the success of

Complementary  
Therapy Day

this year's event, the NMC will

once again offer a day of

pampering and relaxation for

physiotherapy clients, their carers

and NMC staff. In partnership with

South Cheshire College, Crewe,

there will be various treatments to

choose from including; massage,

reflexology, manicures, pedicures, facials,

makeovers and hairdressing. Advance

booking is essential and places will be

allocated on a first come first served basis.

Tickets will be £10.00 and this will entitle you to

three treatments. Please keep an eye on the notice

boards for further information. If you haven't been to

this event before do come along and try some of these

treatments. If you have then the date will already be in your

diary!



## MOTORING

### **Motability - Mileage Allowance Increased**

From 31st October, the mileage allowance increased for all Contract

Hire customers, from 45,000 to 60,000 miles. For clients with

wheelchair accessible vehicles the allowance has increased to a total of 100,000 miles over their five year agreement.

This mileage increase applies to all customers - old and

new and also applies to both existing and new agreements.

You do not need to do anything.

### **Motability Car Insurance - Are all your drivers covered?**

It is important to remember the following to ensure that both you and your drivers are fully insured on your motability vehicle:

- \* They should be named as permitted drivers on The Certificate of Motor Insurance for your Motability car.
- \* The Certificate of Motor Insurance only covers named drivers for the motability car. It cannot be used for another vehicle.

It is vital that you do not assume that family members can drive the car. If for instance a wife lets her husband (and he is not a permitted driver) drive the motability car and it is caught speeding on a mobile camera, the picture clearly shows a male driver but no male drivers are permitted on the policy. As a result, the driver could be prosecuted and the motability car taken away from the client.

To add a driver to your policy or for any other information call, Royal & Sun

Alliance Motability on 0500 37 37 37.

# VOLUNTEER PROFILE

This edition we have the pleasure in sharing in the life of Bob Blaney, an NMC volunteer who helps the NMC Physio team on Mondays and Thursdays.

I was born in Withington hospital in May 1939. In September of that year, the Second World War started, it wasn't my fault - honestly! Late in 1941, my parents and I moved to the Isle of Islay, where my father was in command of the High Frequency radio station. From my earliest memories, I was made aware that respect, responsibility and duty to others was to be my only justification for being alive at all! This sounds rather grim in the light of today's promotion of self interest and the celebration of "celebrity status". From every responsible adult I came in contact with, came a sense of wonder at the diversity of life, plant and animal; literature, engineering achievements, exploration, science, and philosophy. Later at school, I was fortunate enough to have teachers who taught me to never accept anything on "faith" alone, seek knowledge for its own sake, never be subservient nor denigrate others. All this has given me a joy of just being "alive".

During my life I have known people with disabilities, some of whom faced discrimination because of their disability or were denied the right to work because of lack of suitable access. I found this totally unforgivable in a country that supposedly supplied care "from the cradle to the grave".

My life, forever changing through circumstance, changed dramatically after attending the NMC as a PA / carer, employed by Frank Carter in November 2000. Things were not that bad after all!

After this, I became actively involved with groups engaged in rights and access issues for the disabled. In May 2004, after retiring at 65, I began voluntary work at the NMC. I wish to continue this for as long as I can.



My main interests are; visiting as many of these wonderful islands as possible, reading, wildlife, history, current affairs, anything mechanical, watching films, gardening and enjoying good food.

Talking to the many interesting people who visit or work at The NMC is a particular pleasure. Add to this, lager, Murphy's, Boddingtons and my life is complete!

All this has been interrupted occasionally by service in the Royal Navy and British Army (being shot at brings a whole new appreciation to life), marriage (twice), moving home seven times, being employed by 14 different companies, being sacked twice and being made redundant 5 times .... who said life was boring!

Only one ambition remains....more of the same for as long as possible. Caring and trying to make a difference through helping others is the only option, leading to a better quality of life for us all.

**Bob Blaney**

## SNIPPETS...

### ...Athletes Foot Remedy...

Pour two litres of hot/warm water (as hot as you can bear) into a bowl and add half a capful of dettol. Place feet inside and soak until water has gone cold. Let feet dry naturally. Do this once a day for a week and it should clear up your athletes foot!

### Make Light of washing your hair...

A new product that revolutionises hair care particularly for those who find it difficult to shampoo and condition their own hair. Called the "Rinse Free Shampoo Cap" it is impregnated with gentle conditioning shampoo. The cap takes just 20 seconds to warm up in the microwave and is then placed over the head and the head then massaged. After one to three minutes, hair is left clean, "towel dry" and ready to style. For further information T 08000 960 901.

### Do you suffer from the pain of trapped wind?

A tried and tested remedy of "Indian Brandee" will ease the pain. Available from pharmacists and herbalists.

### Flu jab.

It's that time of year again. If you have a long term medical condition then you are entitled to a free flu jab. It really is important for you to get your your jab as soon as possible in the Autumn before the flu starts to circulate. To arrange an appointment just give your GP a call.



**Merry Christmas  
from all at  
The NMC**