

# One Voice

Winter 2006 - Edition 5

## NMC STAFF NEWS

In September, we said farewell to Sue McClure our Business Care Assistant. She had worked at the NMC for over three years and had been a great source of support to so many people. Sue will be greatly missed. I know you would join me in extending our warm wishes to Sue and Nigel in their new venture.

## NEW BUSINESS CARE ASSISTANT

In September, we welcomed Linda Owen as our new Business Care Assistant. Linda has been a keen supporter of the NMC for many years and has helped at various events including The Spirit Of Christmas. She has also run the London 10k twice in aid of The NMC. For sixteen years Linda has been a volunteer for the Guide Dogs for the Blind and currently supports them for 10 hours a week. Linda brings a great deal of practical experience to the role at the NMC and has found the Centre a very welcoming and friendly place to work. Linda works 3 days per week, Tuesday, Thursday and Friday.



## NEW SUPPORT WORKER

Following a three year funding grant from a Trust, the NMC will be recruiting a New Support Worker. This new position will play a vital role in expanding the NMC's support services.

## NMC DESIGN + PRINT

### WINS AWARD

NMC Design + Print received The Highly Commended in Cheshire Business Awards and WON The Cheshire Positive Awards For Business! This is a real accolade for the business and will be endorsed on NMC Literature. Please spread the word.

## CLINICIAN'S OPEN DAY

On 21st September, The NMC welcomed 25 Senior Clinicians and their teams, many for the first time. The day was a huge success and we received lots of positive feedback about the NMC and all that it has to offer.

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## MOTORING

### M6 Price Increase for Disabled Drivers

The cost of an M6 Toll Mobility Exemption Pass (MEP) has leapt from £5 to £15. The pass which allows free passage to disabled drivers receiving exemption from Vehicle Excise Duty is valid for three years and applies to the nominated vehicle only. It is not transferable to any other vehicle, even a temporary replacement. This charge applies to all new applications and renewals. SHOULD you change your vehicle, or the registration details of the vehicle change, before the expiry date of The Mobility Exemption Pass, you must return it and obtain a replacement. Unfortunately this will be classed as a NEW Application and the £15 administration charge will be applied. For further information call Midland Expressway on 0870 850 6252.

### New Power To Inspect Blue Badges

It is now the LAW that a blue badge can be inspected whenever it is displayed on a vehicle. When asked to show the blue badge, the person in the vehicle should hand the badge over to the authorised officer eg: police officer or traffic warden. The new checks are to STOP people MISUSING badges, or using stolen or counterfeit ones. They are NOT about whether you are entitled to a badge. For more information and the guidance leaflet please speak to The Department for Transport, Tel: 0870 1226 236 or e.mail [dfi@twoten.press.net](mailto:dfi@twoten.press.net)

### OUT AND ABOUT - At Alton Towers

For those who can provide proof of disability, you will be able to purchase discounted tickets for yourselves and up to two helpers. In addition, priority wristbands are issued, so that you do not have to queue. There is also an "Express Parking Zone" which is for disabled blue badge holders only. For more information visit [www.altontowers.co.uk](http://www.altontowers.co.uk)

### Accessible Loos!

These appear to be a rarity, with just 10 across the whole country open to the public. Visit [www.changing-places.org](http://www.changing-places.org) for the up to date campaign and listing of accessible toilets in towns and cities around the country. The website lists where they are - The Trafford Centre, Gateshead, Nottingham, Milton Keynes, Cardiff, Bradford and Maidenhead with a surprising number in Scotland. Please do add your voice to the campaign.

## PHYSIO TEAM UPDATE

### Staffing

The physio team have benefitted from clinical input from volunteers, both student and qualified physiotherapists. The physio staff are very grateful for this contribution to the team which will ensure that the waiting list for assessments will be cleared in the New Year.

### Record Number of Treatments

Since the beginning of April, 1500 treatments (including physiotherapy and hydrotherapy) have been given to patients. This is 20% up on last year.

### Reassessments

Recently physio clients may or may not have had a reassessment of their needs. We are keen to ensure that individual client programmes, whether they involve stretches and/or exercises remain appropriate. Reassessments are on-going and all clients will receive one in due course.

### Cough Assist Machine

Those clients most likely to benefit from using the cough assist machine have all now had a trial of the machine.

### Fundraising

The Physio team have put forward various bids for funding. They include;

- u A bid to purchase a computer software programme entitled "Physio Tools" which is widely used in the field of physiotherapy. Amongst other things, the NMC physio team will use it to produce "Exercise Reminder Leaflets" to encourage clients to carry on their NMC exercises at home in order to gain maximum benefit from them.
- u A bid for a new tilt table.
- u Nick has written up some "Standard Swiss Ball Exercises" and Rosie is producing some photos so that we can produce our own in-house leaflet.

In addition, funding has been granted for two new shower chairs for clients using the hydrotherapy pool at Hebden Green.

### A Licence for Acupuncture

Our Head of Physio, Rosie Paver is now licenced to offer Acupuncture to clients at the NMC for the relief of pain. If you are interested in having Acupuncture please chat with Rosie. The NMC are delighted that Rosie has received this accolade.

### Christmas Holiday Dates

Please be aware that the Physiotherapy Dept will be closes on Friday 22nd December 2006 and will re-open Wednesday 3rd January 2007.

## "YOU MATTER" SUGGESTION SCHEME

### - The NMC Needs You!

The NMC has recently launched the "You Matter" suggestion scheme. The idea of the scheme is that we can always improve things at The NMC to become even better... more services, better facilities, more support, better information, wider publicity..... the list is endless!

All clients should have received details of this scheme by now. If by any chance you have not received a leaflet then you can either pick one up when you are next in The NMC or give me a call and I will send you one. Please do take a moment to put your ideas on the suggestion card, your ideas really matter. Every suggestion will be given thorough consideration. If you put your name on it then we'll keep you informed about progress and you'll be entered in a prize draw every 6 months. The winner will receive Argos vouchers worth £10. So, please have a good think about the NMC and try to come up with some suggestions that would improve it for you and for other people. Thank you.

## NEW MINIBUS JOINS NMC FLEET

As those of you who use The NMC's commuter service are aware, The NMC recently took delivery of a brand new minibus, a Renault Master. It has been a very welcome addition to our fleet and replaces the rather old and tired vehicle that we previously had. The new vehicle has been allocated to Paul Drinkwater as he tends to do the longer journeys.

## HOME COMPUTER FOR SALE

Desktop PC 1,000 MHz CPU Fujitsu-Siemens  
RM Accelerator model - As used in schools  
Powerful, Reliable - ideal for home or office, EBAY etc

Fast Pentium 3 chip, 1000 MHz (1GHz)256 Mb RAM  
20 Gigabyte Hard Drive, stereo speakers, keyboard,  
15" monitor, wheel scroll mouse,  
Modem and Broadband fitted. Pay-as-u-go ISP set up.

READY FOR eBay, to SURF THE NET and SEND EMAIL  
Windows XP Professional, Office XP Professional  
(Everything except the desk !!!!)

**(0151) 200 2088      £125**

**All proceeds to The NeuroMuscular Centre.**

# LIFE WITH A VENTILATOR - NIGHT TIME VENTILATION

All the patients who have shared their experiences of night ventilation are using non-invasive ventilation (NIV). It would be useful at this point to explain what this actually means and what benefit there is to the patient.

What is Non-Invasive Ventilation (NIV)?

In non invasive ventilation, we are artificially correcting the respiratory muscles, which have often become very weak, through the use of a machine. Patients wear a mask over their nose, which may or may not include headgear. The mask is attached to a tube which runs from the ventilator. The ventilator is then plugged in to the mains.

Why the need for Non-Invasive Ventilation (NIV)?

There are several reasons why NIV might be considered. Patients often describe feeling constantly fatigued and having severe headaches particularly on waking. This is due to the build up of carbon dioxide in the bloodstream as the diaphragm muscle is not strong enough to expel all this waste gas. Other reasons include poor concentration and irritability. All these symptoms can be described as early respiratory problems where breathing may be compromised.

What does Non Invasive-Ventilation offer a patient?

The objective of using non invasive ventilation is to ultimately improve the patient's quality of life and their independence. By artificially correcting the muscles through ventilation, we can reduce the build up of carbon dioxide in the bloodstream, thus eliminating the headaches and giving patients optimum health.

## PERSONAL EXPERIENCES

As the following accounts confirm, it can be a frightening thought having to start ventilation and yes there can be teething problems. Mask reactions are not uncommon. However, no matter what your family circumstances, with the right support and equipment, ventilation can be a success and a turning point in your life. It is often the beginning of a better quality of life. In some forms of Muscular dystrophy, physicians are putting children on ventilation earlier, more as a preventative measure, and in doing so, giving them a better quality of life.

**Mike Jackson... *it's made me feel a different person.***

Mike uses a Breas 403 Peep ventilator.

Mike has been on night ventilation since 1997. He also uses the ventilator for a couple of hours in the daytime or early evening. Mike describes a feeling of being very tired and being unable to breathe deeply. For him, that is an indicator that he needs a boost to get through the day. Mike's ventilator usage is 14 hours -

12 hours at night and 2 hours in the day.

Mike uses a mask with headgear along with a humidifier. The humidifier has sensors to keep the temperature constant. However, sometimes when he forgets to top up the reservoir it beeps, waking him up. It's not all plain sailing! The humidifier helps to relieve a dry mouth which is common when using ventilation.

Prior to starting ventilation, Mike complained of feeling very very tired, almost falling asleep and of having bad headaches. He was initially given a "Nippy" ventilator and on using it he fell asleep straight away, so comfortable was he using it. Having started, he felt a completely different person. He had more energy and as a result felt more alert.

Mike went on to say that there are a few drawbacks of using ventilation namely that when you wake up in the morning your body feels full of air, but he finds that peppermint oil helps. Also, the mask does rub his nose and it can become sore but he finds that putting some melanin on the mask helps.

Two years ago, Mike changed machines. Firstly this was because his machine was getting old and secondly because his existing ventilator didn't have a battery back-up. His new machine, the Breas 403 Peep has a two hour battery back up and an external battery just in case. Generally speaking the mask rarely wakes him up.

Mike explained to me that using a ventilator has become part of his life now, to the extent that he is unable to sleep without it. However, he did have to when he had a power cut (with no battery back up at the time) but couldn't sleep because he couldn't breathe.

**Paul Cardwell.... *I feel so much brighter.***

Paul uses a Harmony ST machine.

Paul has been on night ventilation since December 2000. He had previously been suffering from headaches. A sleep study test at home together with various muscle strength and lung capacity tests at hospital revealed that Paul would benefit from using a ventilator at night. Although it was not considered an essential, it was thought to be a sensible option. He was admitted to hospital for a couple of days to try out various machines and decide which was the most appropriate.

Paul wears a nasal mask with straps over his head. Paul explained that initially, he had a reaction to the mask and as a result his nose became very sore. However, he managed to get some "Primapore" on prescription from

the doctors and this helped dramatically. He went on to say that for him, the main drawback of ventilation was the initial discomfort of having the mask. In the early days he would often wake up in the night in a panic. Eventually however, this settled down.

Paul uses a humidifier which he finds helpful in relieving a dry nose. He explained that it is always easier to breathe in damper air. Paul's machine is mains operated and he does not have a battery back up.

Once on night ventilation, Paul explained that he experienced a gradual change in the way he was feeling. He was not having the morning headaches and felt much brighter on waking.

Paul's ventilator usage is about 8 to 9 hours per night. His machine is serviced regularly to ensure it is in good working order.

**Matt Cundall..... it was pretty straightforward.**

Matt uses a Breas 403 Ventilator with battery back up. Matt explained that he has been on night ventilation for 4 years and his average usage is 8 hours per night. Occasionally he uses it in the daytime, for about an hour or so when he feels lethargic or worn out. This just gives him an extra boost to get him through the day.

Matt went on to explain that he was first admitted to outpatients at Newcastle hospital as a candidate for ventilatory support, because there was a slight build up of excess carbon dioxide in his blood stream. Therefore it was felt that Matt would benefit from night time ventilation.

Matt said he was lucky enough to find that the first mask he tried was suitable, it made him feel relaxed and not at all claustrophobic. He quickly got used to using his mask at night time and hasn't had any major problems other than waking up with a dry mouth.

Matt said that the ventilator has become part of his life. It is very portable, he takes it everywhere with him, including the office! Matt has a battery back up in case of an emergency and would recommend this to all ventilator users.

Every six months Matt attends an outpatient clinic where his blood gases are checked.

**Andrea Duckworth... how do you explain it to two young children?**

I use a ResMed VPAP111 ST machine. I started night time ventilation almost four years ago, in January 2003. I can vividly remember the day that I was told I would need to use night ventilation. We were at an outpatients appointment. My husband and I were in a complete state of shock. We knew it would happen one day, sometime in the future but not now. Like most people in this situation, I did not have a choice in the matter. I wanted to be as fit and healthy as I possibly could and to be around for my children.

I had previously been suffering from quite severe morning headaches, felt fatigued most of the time, to the point of falling asleep, and lacked energy. Test readings at the hospital confirmed that my carbon dioxide was at a very high level and my breathing was being compromised.

My biggest fear was, what was I going to tell my children who were only five and two at the time. I went to see my son's headteacher for some advice. In her usual sensitive manner, she helped turn a challenging situation into a positive experience.

I decided to introduce the ventilator to the children by way of a scrapbook entitled "gadgets", which included the hairdryer, the t.v, the new ventilator, the microwave etc. Each picture was accompanied by an age appropriate explanation of how the gadgets worked. The ventilator became a part of our household gadgets. I encouraged the children to have a go on the ventilator so that they wouldn't be frightened of it and ask any questions. They have both been very accepting of it and understand that Mummy needs it to help her breathe at night. Now, if we are away together and happen to be sleeping in the same room, they do moan that Mummy's ventilator is noisy!

It did take a while for me to get my head around night ventilation. It was claustrophobic to start with, and my nose used to get so sore. However, these problems were not insurmountable and the benefits of an improved quality of life have far outweighed the disadvantages of night ventilation.

I had a good team of nurses who spent time explaining everything to me and supported me throughout. They always gave me a number to ring if there was a problem and that gave me peace of mind. They also gave me some melanin to place on the mask to stop it rubbing my nose. My machine is mains operated, it does not have a battery back up.

Over time, there was a marked improvement in how I was feeling on a daily basis. I didn't have any more headaches, felt more awake and as a result had more energy. My carbon dioxide and oxygen levels soon returned to within normal limits.

I attend clinic every three to four months, to have my blood gases checked. Last year I was given a new machine as mine was getting old. I have had the pressure increased slightly twice but there is plenty of scope to increase the pressure as and when it should be needed.

Generally I sleep well. When I first used night ventilation I was very worried about moving slightly whilst in bed, in case I disturbed my tube. Now if I do move, the ventilator tube automatically comes too! Occasionally, the ventilator does wake me up, but I generally fall back to sleep quite quickly. It competes with my husband's snoring! Night ventilation has become part of my life. Now, I could not sleep without it.

## CHRISTMAS SHOPPING

### Buying Gifts On-Line

Shop and raise money for the NeuroMuscular Centre this Christmas! Help raise vital funds this Christmas by shopping at [www.buy.at/nmc](http://www.buy.at/nmc). Over 100 high street retailers including HMV, Marks and Spencer and Amazon, 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 your wine cupboard or picking up the latest electronic gadgets, make sure you check out [www.buy.at/nmc](http://www.buy.at/nmc) and help to raise money for the charity whilst you do your Christmas shopping. Its so easy, takes the hassle out of Christmas shopping and the NMC benefits at the same time. We are all winners! In addition, for every purchase made between 1st November and 3rd January 2007 an extra 25p will be given to the NMC. So the more you shop the more we earn! Please note that if you are buying 2 or more items from the same supplier would you be kind enough to make each one a separate transaction if you possibly can. Happy shopping! Thank you for your support.

***shop for less and support***



### NMC Christmas Cards

On sale now at The NMC priced at £3.00 for a pack of 10. You can either have a mixed pack or if you prefer a pack of just one design. Please tell your friends and family.

For all the ebay enthusiasts among you

Every time you sell something on ebay you can choose to donate between 10-100% of the profits from the item you sell to the charity. Whether you are an ebay enthusiast yourself or you know someone who is, this will give you the perfect opportunity to recycle those unwanted Christmas gifts, whilst benefitting the NeuroMuscular Centre at the same time. Visit ebay at [www.ebay.co.uk](http://www.ebay.co.uk)

## DATES FOR

## YOUR DIARY

.... there's something for everyone!

The NMC Complementary Day  
- February / March 2007.  
Please keep an eye out at The NMC for further details and booking forms for this event. Places will be limited and allocated on a first come first served basis.

Thursday 22nd February -  
Ladies Lunch at Crewe Hall

Saturday 3rd March -  
Gorgeous Grub at The Grosvenor

Friday 23rd March -  
Line Dance at Winsford Civic Hall

Sunday 25th March - Liverpool Half Marathon

April (date to be confirmed) -  
Ladies Lunch Wrexham -  
Wynnstay Arms, Speaker -  
Barbara Steele

Thursday 26th April - Wine Tasting Evening - Hunters Lodge, Crewe

Wednesday 11th July - Jazz Evening at Eaton Hall, Nr Chester, Cheshire

SOME SONGS TO GET  
YOU THROUGH PHYSIO

\* How many can you  
remember?

When you first start  
physio at The NMC

Fragile- Sting

When the going gets tough –

Billy Ocean

Everybody Hurts - REM

If you need me now –

Chicago

That's my goal –

Shayne Ward

Before I fall, please

Hold me now –

Thompson Twins

Time to stand

You raise me up -

Secret Garden

(Westlife also did a version)

Lifted -

The Lighthouse Family

After all those stretches

You make me feel like

dancing –

Leo Sayer

(The Scissor Sisters also did

a version)

Basically,

Life's a Rollercoaster –

Ronan Keating

Life's what you make it! –

Talk Talk

To the NMC Physio team

Thank you – Dido

You're simply the best! –

Tina Turner

**.. you make us feel**

Forever Young – Alphaville

**..and you bring us**

Back to Life - Soul to Soul

Thanks to Gordon and  
physio clients for their  
contributions!

## HEALTH AND WELL BEING –

### NMC COMPLEMENTARY THERAPY DAY –

**The NMC's first complementary therapy day will take place early in 2007 at the NeuroMuscular Centre. There will be various treatments on offer including acupuncture, foot massage, reiki, manicures, mini-facials and hair treatments. Places will be limited. To secure your place, you will need to fill in a booking form, enclose your £10 payment and pass to The Fundraising team at The NMC. Please keep an eye out on the noticeboards at the Centre for up to date information and booking forms for this event.**

**Flu Jab** –Have you had yours?

It's that time of year again. Do remember that people with a long term medical condition are entitled to a free annual flu jab. It is important to get your jab as soon as possible in the autumn before the flu starts to circulate. This year however it worth bearing in mind that due to production problems there is currently a delay in some GP surgeries in administering the flu jab. Because the virus is constantly changing it is necessary to protect you against the latest strains of the virus. Just give your GP a call to arrange an appointment. Don't delay, get it today!

**MEDIC ALERT** – let's you live life!

MedicAlert is a life-saving identification system for people with hidden medical conditions and allergies. As a MedicAlert member, you wear a bracelet or neckless engraved with a personal identification number, main medical condition(s) and an emergency telephone number. In an emergency, medical personnel have immediate access to vital information on the back of the MedicAlert disc. It allows international access 365 days per year. Membership to the service starts at just £19.95 plus the first year's membership at £20. As a registered charity, Medic-Alert can also provide free or subsidised membership to individuals on a limited income. Medic-Alert offers you peace of mind and protection. To view their product range and obtain further information visit [www.medicalert.org.uk](http://www.medicalert.org.uk). or telephone 0800 581 420.

### CARERS NEWS –

**Carers Relaxation Vouchers** – Time out to unwind

As a Carer it is often difficult to take some time out for yourself. However, if the Carer is not fit and well then this has implications for the person they are caring for. Taking a little bit of time out for yourself to relax and re-charge can make all the difference. The vouchers entitle you to have £25 of free treatments (hair and beauty) at any of the local colleges. So go on treat yourself! For further information please call The Cheshire Carers Centre on 0800 085 0307 Tuesday - Friday

### POSITIVE ASPECTS

Positive Aspects is a free new bi-monthly e.mail bulletin which is for anybody who has an interest in disability, mental health issue and/or illness who lives in England. (People who live outside England are welcome to receive Positive Aspects but must be aware that some of the articles regarding law, benefits etc might not apply to them). It is packed full of useful items - law, events, holidays, benefits, useful websites, putting people in touch and much more.

To subscribe, please send an e.mail to [trudy.1@ntlworld.com](mailto:trudy.1@ntlworld.com) with subscribe and the county you live in, in the message/text of the e.mail.

# FROM THE EDITOR

A warm hello to you as the festive season is upon us. I hope this newsletter finds you all well and you have enjoyed the warm and spectacular autumn colours. The past few months have been quite busy. In September, we went to a family wedding in Italy. It was wonderful to experience an Italian wedding and the sumptuous feast that followed! We also enjoyed a weeks holiday afterwards. Despite a very stressful few days prior to departure, Easyjet proved to be very disabled-friendly and we were well looked after by both crew and ground staff. However, during the holiday, there were times when I felt on the periphery of family life. For example, the swimming pool at the hotel was not really accessible so I had to watch my husband and children having fun in the pool rather than be a part of it. However, there were things I could join in with and I did enjoy the Italian food!

During the past few months I have had several falls, and this has really knocked my confidence and reinforced my fragility. However, like many of you, you just have to battle on and keep smiling!

Recently, I have been fortunate to start treatment for my condition. Whilst I know this treatment is not a cure, it will hopefully slow down the progression of this disease and give me a better quality of life. The treatment involves fortnightly infusions at a Manchester hospital. I have a very supportive team of nurses and doctors and that makes all the difference. It is a long-term commitment which I have embraced. To date I have had six infusions. It's amazing just how quickly it becomes a part of your life.

Well that's about it for now folks. So that leaves me to wish you a very happy and peaceful Christmas and all good wishes for the coming year.

Andrea

FINALLY . ...

Thank you to all of you who have contributed to this edition of One Voice. Sharing your experiences really helps others.

FORTHCOMING EDITION

..Spring 2007 - to include, adapting your home, combating the fear of falling....

...UNTIL NEXT TIME....

Enjoy the festivities. If you'd like to contribute to the Spring Edition please do get in touch.



Merry  
Christmas!  
from us all at The  
NMC

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