

# OUR VOICE

The News Briefing of  
The NeuroMuscular Centre  
July 2019

## INTRODUCTION

Summer is coming and the NMC grounds are looking bloomin' lovely thanks to the hard work of our volunteers. With plants donated by the NMC community and supported by seed donations from: • Meadowmania • Franchi Seeds • Grow Wild • Kings Seeds • Real Seeds. 'Potterers' (of the green fingered rather than the wizarding variety) are urgently required to help with planting, potting up and watering. Whether for five minutes or a couple of hours; whatever time you can spare will be greatly appreciated.

In May the Connect Up project, which aims to tackle loneliness and social isolation (supported by Brightlife) celebrated it's 1st birthday. Connect Up has been a roaring success. There were several well attended workshops on themes including accessible holidays (see Page 2), employment and keeping yourself well.



The amazing diversity of activities on offer in May alone included a theatre trip, hair cutting by the lovely Josette, a fishing day, a canal boat trip and 'muchas gracias' to Ann Duffy for delivering great conversational Spanish lessons too.

**Coming up: Not to be missed - The Big Debate on Thursday 27th June is billed as one of the most important and exciting things ever hosted at the NMC over the last 30 years.**

It will be a fantastic chance to get expert professional guidance about the legal duties of Social Services and the NHS, and how those legal duties are (or are not) met for those living with neuromuscular conditions.

The Big Debate is aimed primarily at those in our community who have a neuromuscular condition.

We're aiming to inspire and develop greater confidence and assertiveness in our community in relation to how they access support from Social Services and

from NHS Continuing Health Care. Keynote speaker Professor Luke Clements is renowned for his expert legal knowledge in these areas. The debate will include a session from Miro Griffiths about attitudes to disability in society both here in the UK and worldwide. Also attending are Directors from local councils and NHS Commissioning Groups to give a rounded appreciation of how it all works and how it all should work.

**NMC Events and Training Space**  
**Thursday 27th August**  
**From 9.30 – 4.00**  
**Lunch provided**  
**And then BBQ and drinks in the meadow.**

Places are limited. To book your place there is sign up sheet in Training or contact Denise.



**SARAH LALIEU**



NeuroMuscular  
Centre

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## ACCESSIBLE HOLIDAYS

Whether you're planning a day out or a trip away in the UK or further afield , if you have a physical disability then that old adage 'failing to plan is planning to fail,' does spring to mind. The extra organisation and research required is worth it though.

The impact on our health and wellbeing of a change of scenery or spending time with friends and family away from home shouldn't be underestimated.  
More than 60 people participated in 2 lively and informative workshops on the theme of accessible holidays at the NMC.



There were some inspiring presentations that shared experiences of accessible holidays, days out and top tips about travelling with a disability:

- Amy Gittens, our very own NMC daredevil, demonstrated that experiences such a tandem sky dive and skiing can be possible when you're a wheelchair user.
- Anne Craig shared her holiday experiences of travelling with her scooter (affectionately known as Madge) to South Africa, the USA and cruising.
- Rod Birchall shared his family's travel experiences including Europe by ferry and his attitude was, 'we try everything we can!'
- James Taubman shared handy hints for visiting Dublin and delights on offer including affordable accommodation... oh and Guinness!
- Mille Hawes shared her experiences of a business trip to New York - organised at very short notice and her girlie trip to Bratislava. Millie's top tip - always ask for photographs of the hotel room and bathroom to make sure your needs can be met.



We are in the process of collating all the information from both workshops and also continuing to collect leaflets and brochures for days out and holiday destinations both in the UK and overseas. We are creating a holiday resource at NMC which covers:



- Travel Insurance companies that cover pre-existing medical conditions.
- Accessible Holidays in the UK.
- Accessible Holidays overseas.
- Accessible days out in the UK.
- Accommodation checklist and tips when travelling.

We plan to have printed copies available and also put it on the website. Ideally it will be updated regularly.

A third holiday workshop is planned for Wednesday 3rd July with a travel counsellor.

In the meantime, if you have any examples of accessible accommodation or places you'd like to share and include in the directory please speak to Andrea Duckworth.

# ASK ME!

Splinting hands/wrists  
by Sandie Wilson

All people with a neurological condition such as muscular dystrophy are at risk of having a restriction in range of movement which can lead to changes in soft tissue structures. These may then lead to contractures/shortening/increased stiffness/pain in their hands and wrists.

Splinting will prevent or correct any abnormalities occurring and

so help to increase or maintain movement and function. The provision of a soft comfortable resting splint to wear as much as is practically appropriate is all it takes. Most people opt to wear them at night. Here at the NeuroNuscular Centre we have had splints donated and now have a stock of Neurotec splints ready for use.

Anyone who would like to be assessed for suitability please speak to Sandie Wilson or your physiotherapist to make an appointment.



## GROOVY GADGETS.

### Disposable Urinal

Continuing the holiday and days out theme..... an important consideration is the availability of appropriate toilet facilities.

Disposable urinals are useful for long journeys, camping trips or other wee-emergencies! Travel John and Travel Jane are examples of a range of similar products on the market.

They are discreet and lightweight and contain non-toxic gel crystals which turn urine solid in an instant with no smell and no leaking. Available from Amazon for about £8 for a pack of 3



Also continuing the theme..... Manchester Metropolitan University are currently undertaking a 'bathroom break survey' at NMC and would really appreciate your assistance. If you are aged over 18 and have a form of muscular dystrophy you could help with understanding an important contributor to quality of life. Simply complete an anonymous 15 min survey by scanning the QR code or ask your physio for a paper copy.

## CLUB CULTURE

### Adapted Gym

The benefits of exercise to our physical and mental wellbeing are well documented and proven by a recent study at NMC undertaken by Manchester Metropolitan University.

The NMC gym is the only one in Europe to be adapted for people with neuromuscular conditions. One-hour slots are available Monday to Friday with physios on hand to assist with transitioning, setting up equipment and developing training plans.

It is a place to build or maintain strength/stamina or help achieve a personal goal, such as weight loss without the intimidating atmosphere of a regular gym. More than that, it is a friendly and social space to build

friendships and share a sense of camaraderie.

Contact the physio team to book your gym session.



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## WHAT'S ON!

Wednesday 3rd July  
Holiday Workshop at NMC  
Travel Counsellor, Joanne Johnson

Friday 5th July  
Read and Connect book club  
11.30 at NMC

Wednesday 10th July  
Connect Up Drop In

Wednesday 10th July  
Tai Chi at NMC  
Contact Physiotherapy

Saturday 13th July  
Live in the Park  
Arley Hall  
Tickets from Fundraising

Date TBC – July  
Trip to National Waterways Museum  
Ellesmere Port

Wednesday 17th July  
Tai Chi at NMC  
Contact Physiotherapy

Wednesday 24th July  
Tai Chi at NMC  
Contact Physiotherapy

Friday 26th July  
Connect Up Drop In at NMC

Wednesday 31st July  
Tai Chi at NMC  
Contact Physiotherapy

Friday 2nd August  
Read and Connect book club  
11.30 at NMC

Thursday 8th August  
Fine Art - wax art and mark making @  
NMC  
Contact Kay Briggs

Tuesday 13th August  
Vehicle Demo Day at NMC

Wednesday 15th August  
Fatigue Management Workshop at NMC

Interested in any of the events or  
activities? Please see Andrea or contacts  
listed. Email [andrea.duckworth@nmcentre.com](mailto:andrea.duckworth@nmcentre.com)

## TEAM & SUPPORTER NEWS!

Mamma Mia - here the fundraising team go again.... another great event, this time sing along cinema event in Marbury Park raised over £3,400.

Congratulations to Teresa Tansey on completing the London Marathon and doubling her fundraising target raising over £3,000 for the NMC.

Thank you to all that supported the Charity Racing Lunch at Haydock Park in May and raised an astonishing £34,043 profit for NMC! Thanks in particular to Annie Fildes, Kate Preston and their friends and family for organising this event.

Community Fundraiser Jennifer Lea leaves us in June to begin a career in Marketing. Jenny will be sorely missed by staff and volunteers. Good luck Jenny, you should be proud of your achievements and thanks for all you have done.

NMC's Recognition Award scheme is open to everyone in our community. Submit your nomination to Lorraine Woolley along with the NMC value this person displays – see display in reception for more info.



Happy 80th Birthday to Bob Blaney from all at the NMC. Bob has been volunteering twice a week for the past 15 years clocking up over 1,500 days in the physiotherapy department!



## CONTACTS AND FEEDBACK

This newsletter is for the whole of the NMC community.

Whether you attend twice a week or once a year for treatment, for work, for training, as a service user, employee, carer, family member, supporter or friend then your views are important to us. For any comments or suggestions please contact Sarah Lalieu at [sarah.lalieu@nmcentre.com](mailto:sarah.lalieu@nmcentre.com)



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