



**Spring 2017**  
**Edition 36**

**In this edition...**



**New York Here We Come**

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Cover page photograph:  
Drone image of the NMC  
taken by Mike Brown

# Events Diary

## Swing Band and BBQ Cruise

Thursday 18th May



Aboard the Lady Diana, Chester's most prestigious vessel. Tickets are £22.50, which includes a sumptuous Sailor's BBQ and entertainment by Go Country, a renowned North-West Swing Band.

## Wine Tasting and Spuntini

Friday 16th June



An evening of wine tasting, with paired spuntini (appetisers), culminating in a delicious homemade tiramisu at Chester's hottest new wine café - Veeno. From 8pm onwards, tickets are £25 and includes all tasting and food for the evening.

## Wag n' Walk Chester

Saturday 17th June



Our annual Wag n' Walk at favourite Westminster Park Chester. Starts at midday, includes fantastic goody bag and prizes awarded to best dressed dog, best behaved dog and most money raised.

## An Evening of Jazz

Wednesday 28th June



Our annual jazz concert at the Eaton Estate, held by kind permission of the Duke of Westminster. Welcoming Mart Rodger Manchester Jazz, a 7-piece traditional Jazz band. Tickets are £18, which includes a delicious cheese buffet kindly

donated by Godfrey Williams Cheese Ltd, plus a glass of wine. There will also be a cash bar available throughout.

## Live in the Park

Saturday 15th July



Arley Hall is the stunning backdrop for our outdoor concert, where you can picnic before we bring you tributes to some of the greatest acts of all time! Don't miss out on Early Bird tickets at £19.50 for adults or £14.50 for children, available until the end of April

only. This year's line-up is: Bob Drury as Neil Diamond, performing with full band, Jackie Marie as Diana Ross, and Mod Revue - a Mod/Ska tribute to Madness, The Kinks, The Jam and many more!

# Editorial

Stuck at home with a broken ankle, I am eagerly looking forward to seeing the completion of the improvements to the NeuroMuscular Centre.

The building work is finished and facilities like the new gym and extended physio area greatly enhance the environment for everyone visiting. Hopefully the staff can now reap the rewards of their tolerant and professional approach to seamlessly managing the disruptions. I am sure that it will take a little time to complete the finishing touches and to fully appreciate the benefits of the new facilities.

In January we held the first One Voice Live event in the comfortable new lounge area of the NeuroMuscular Centre. We are grateful to everyone who came and shared their holiday experiences and anxieties with us, or just browsed the materials we had on display. During the week we had discussions about cruises, a popular option for many, overseas holidays and the recurrent concerns over air travel, holiday destinations where hoists are available, amongst other issues and we are especially grateful to those of you who have contributed holiday articles for this or offered for future

Jon McVey Editor

editions of One Voice. It was also pleasing to introduce people who had previously little awareness of the publication to One Voice.

At the event we had printed out all the Holiday articles that had been in past editions, including related issues such as insurance. In all over 70 articles demonstrated the wealth of knowledge and experience that has been shared through One Voice over the years.

It was an event that we intend to repeat in line with the themes of future editions.

There are also many other articles of interest in this edition and we are again grateful for everyone who has contributed. I am also grateful for the excellent work of the first-rate editorial team.

## NMC News in Brief

Beverley will be offering more appointments for her treatments such as aromatherapy, reflexology and manual lymphatic drainage on a Tuesday, Wednesday and Thursday from May 2017.

If you would like to make an appointment or would like further information please speak to Beverley on 07756 853089

The NMC held a very successful week of craft workshops in the retreat making a whole range of crafty creations - look out for more workshops in June 2017.

Please look out for events taking place at the NMC during Carers week June 12 -18th . Please contact Denise who would welcome any ideas of events you would like to happen.

"We are again grateful for everyone who has contributed"





**M**y wife has always wanted to go to New York, we have been to Florida but never the Big Apple.

We discussed our holidays and thought lets go for it. I have never taken a wheelchair on a plane before, but I booked my power chair on and away we went. I booked business class, and was worried about getting out of the seats. My condition is a weakening of the thighs and arms so it is difficult to rise from a sitting position. I have an up easy seat assist which I put in my power chair and I used this on the aircraft seat. It was a bit uncomfortable but I managed the 7hr journey ok.

On arrival at JFK I was met with my chair and assisted through homeland security. We had booked an adapted transfer vehicle for me and my chair, and taken to our hotel in Times Square. We were amazed at Times Square, the lights, noise etc . The accessible room in the Hilton, where we were staying was nothing special, only 1 pull down grab rail at the side of the toilet, disappointing, but I managed with my wife's help.

The following morning we went across to the local Diner, for breakfast, wow more like

breakfast, lunch and tea all on one plate. We signed up for an open top bus tour 3 days for the price of 2. On checking this I found that most of the Buses had an automatic ramp that came out of the bus entrance for wheelchairs prams etc. This made life easy and we visited the Rockefeller Centre, Grand Central Station, and Central Park. We visited the John Lennon Memorial Strawberry Fields in Central Park, which was very moving. The tour also took us to the Empire State Building and we enjoyed the views from the top. I was advised to book the trip to the Statue Of Liberty and Ellis Island in the UK which I did and it was a good job i did as the queues for the Ferry went on for ever.

Another visit was to the Ground Zero memorial and this is a must for anyone visiting New York. We also managed to take in 3 Broadway Shows courtesy of reduced ticket prices via the half price ticket booth on Times Square. We were told to go to the front of the queue which we did and so had first pick of the shows.

We both fully enjoyed the trip, the locals were very respectful of me in my power chair and always insisted I went to the front of the "Line" as they call the queue. The only disappointment for me was that they didn't have separate disabled toilets. They had disabled toilets, sure but these were either in the men's or ladies, and this was a problem when I needed assistance from my wife, we had to get a security guard to stand in front of the main door and not let anyone in until we had come out.

# One Voice LIVE Event

Always wanting to try something a little different, the One Voice team held a 'One Voice Live' event with a specific focus on days out and holidays. Members of the One Voice team took it in turn to man a stall in the new carers area with the latest edition of One Voice on display as well as booklets jam packed with articles and recommendations for days out in the UK as well as holidays abroad. We were amazed at the number of places the NeuroMuscular Centre community has been to and the articles collected over the years – all from previous issues of One Voice.

You may have seen the booklets in the carers area – if not, have a look through next time you're at NeuroMuscular Centre – a treasure trove full of info! We all need a break – why not have a flick through the recommendations to help put your mind at ease and give one of the breaks a go? Following a question that we were not able to answer, we would be really delighted to hear from anyone who has any knowledge of or recommendations for accessible coach tours.

We thoroughly enjoyed the week, the October weather was kind to us and apart from the traffic chaos everything went well despite our previous concerns and we can recommend the trip.

Where next to you might add, well we have booked a 2 week cruise in the Baltic ending up in St Petersburg in July so watch this space.



Some other recommendations that came out of the One Voice Live event were as follows:

**<http://www.brickhousecottages.co.uk/>**

8 accessible cottages (7 of which have ceiling hoists) varying in size from 2 to 4 bedrooms – set in Lancashire

**<http://www.chuc.org.uk/>**

Ceiling hoist users club – a great resource for anyone who uses a ceiling hoist to find about facilities with ceiling hoists fitted, support people who are looking at ceiling hoist installation, and a virtual meeting place for support and information sharing

**<http://www.treworgans.co.uk/>**

Converted cottages set in mid-Cornwall with fully wheelchair accessible accommodation including wheel in en-suite wet rooms, profiling beds with pressure relieving mattresses and portable electric hoists.

**<http://www.mdi.ie/home-from-home.html>**

A self catering 4 bedroom facility in Dublin, Ireland called 'home from home' and available to Muscular Dystrophy Ireland members and their families.



Set in scenic countryside on the East coast of the Isle of Anglesey. Located in a tranquil and quiet setting well away from any roads, making it extremely suitable for safe family holidays, yet only 5 minutes from several sandy beaches and stunning coastal walks.



Last year we purchased a caravan to travel on our holidays and short breaks during this year.

I have been to Home Farm a couple of times and I feel I must share this little gem of a place.

We try to locate our caravan near the disabled facilities, which are lovely and clean - the bathroom I visited, consisted of a shower area, toilet and sink. It is very spacious and very warm. They do provide a chair to sit on whilst showering but I would enquire about a sturdier chair if you require this.

On booking, I would confirm that all your needs are met. There have been times I have not done this at locations, and it's a stress you don't need whilst trying to enjoy your holiday.

#### Park Facilities

- Reception with an extensive supply of tourist literature plus a basic essentials and accessory shop
- Wifi

- Luxury award winning toilets - with free hot showers, hair dryers, separate disabled and toddlers and baby areas
- A fully equipped laundry room, with automatic washer, drier and iron
- Dish-washing sinks with free hot water.
- Electric hook-ups (16 amp)
- Safety surfaced outdoor/indoor adventure play area with TV and pool tables
- Outdoor recreation and ball game area
- Tennis Court
- Pitches ranging from grass to gravel - and from basic electric to the fully serviced pitches
- Extensive off-site exercise area for dogs
- Free ice pack service
- Motorhome service station
- Park monitored CCTV system
- Secure barrier entry/exit
- Tourer storage with tow on/off facility

As a family, we enjoy the luxury of the quiet and rural setting.

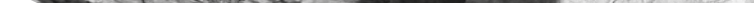






# Alicante Holiday August 2016

by Dawn Wilbur



## Hi lovely people!

I'm Dawn...a little bit about my life with the Neuromuscular Centre which has played a major role for the past 22 years .... in a positive way, I hasten to add. I moved to Cheshire from Kent (my husband and I did not know a soul in Cheshire – scary!) and fortunately discovered the NMC - situated only 4 miles away! Lynne Groves, Gordon Styles, Woolley and Cundall family ("the originals") soon made us feel welcome and had me organized with physiotherapy sessions (cannot express how euphoric those treatments felt considering I had not received any physiotherapy for 19 years prior!)....hydrotherapy, office work, fundraising events and incredible, lifelong, friendships soon blossomed :) with many, many more amazing friends connected to this unique, innovative centre of excellence!

Anyway, if anyone is still awake! .....I'd like to tell you the practicalities/niceties of my holiday experience to Alicante in August 2016; from a mother of a teenager (woteva!) point of view ... oh, also, forgot to mention! I use a dual controlled, powered wheelchair for mobility and hoists for transfers – here goes...

Alicante is the capital of the Costa Blanca with a mixture of historic buildings, beautiful beaches and serene harbour.

A superb shopping centre with a huge choice of fashion shops, department stores, restaurants, and bars. 90% of the Cathedral can be viewed from a chilled, seated, eye level. Santa Barbara Castle overlooks spectacular views of the City and Mediterranean Sea - accessible via a levelled tunnel and manned lift. Beaches have wooden slatted ramps for wheelchair/pushchair access and one beach has special aqua-chairs to take you in to the sea.

We stayed at a Melia Hotel TRYP Alicante Gran Sol - accessible rooms which catered for medium sized wheelchairs, lifts were not very particularly spacious, restaurant and all employees were extremely helpful when required.

### **MobilityEquipmentHireDirect.com**

T: 0800 994 9000 hired a portable hoist for hotel which was in situ on arrival.

### **WheelchairAccessibleHolidayTaxis.com**

T: 0800 622 6000 transfers ran smoothly: driver extremely helpful (took my headrest on the airplane)... dread being bobbed around in the back of a taxi like a nodding canine.

Manchester T3 changing room is at departures only (as far as I know) gate 53 around or that area. I am flying in June so I am trying to liaise with airport access team to provide a portable hoist for arrivals.

# Never a Dull Moment when we Fly by Derek Garner

and I finished up with two seats on the middle block of four the other two were unoccupied by accident or design, so my wife could lay down and have a sleep.


It was obvious to me that Qantas had told their staff at all points where I was due to be, of my disability. This is really all I have ever asked airline companies to do but Qantas actually have done it and I will use them again and would certainly recommend them.

The BA shuttle from Manchester was 90 minutes late leaving so we missed our Qantas connexion at Heathrow. Fortunately we were eventually offered a Virgin Atlantic flight to Auckland via Shanghai.

When we got to the plane my wife was told that they had found two seats together and we were put into business class. Ten hours in luxury, my how the other half live. We had a very pleasant trip I can assure you.

I have been to New Plymouth in New Zealand five times and the last leg from Auckland is in a twin prop small plane accessed from the runway. They transfer me from my chair onto the aisle chair on the runway then push me into a cage attached to a fork lift truck. They then raise the cage to the entrance of the plane and push me in. Sounds odd but it does work very well. Reverse the procedure at New Plymouth. Apart from losing both our suitcases, the flight there and back were as good as it gets if you are in a wheelchair. I can't praise Qantas enough for their attention to detail.

Upgraded to Business class, presented with champagne and a large single malt, hoisted on a fork lift truck, lost cases, missed flights. Never a dull moment when we fly.

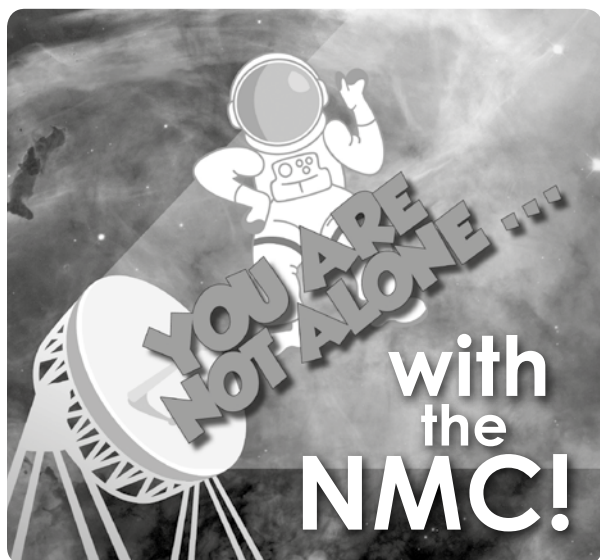


I have just returned from my fifth holiday in New Zealand visiting my son and his family.

I have always had problems with the transfer to and from my wheelchair to and from the aircraft seat and have suffered as a result and have always spoken to the companies at length to explain my needs with very limited success. This time I picked Qantas as a result of a website promoting wheelchair friendly travel. I spoke to Qantas staff and explained my situation and also my interest in their new Eagle hoist. At every stop on my journey I was met by staff who had obviously been told about my flight and were expecting me. I was handled with courtesy and respect and was looked after at all times.

Several staff members pointed out to me, unprompted, that they no longer used the hoist as two strong men were more efficient, which proved to be the case. Dubai was my worry after a bad experience there some years ago but they were excellent with one man allocated to my care during the time I was there. At Heathrow a special transporter machine was brought to the plane and I was moved from the plane via this machine from Term 3 to Term 5 by Gary and Omar. Brilliant. In the flight from Sydney to Heathrow on an Airbus 380 my wife





Dan Cundall our Head of Design and Print and his wife Karen gave a brilliant and thought provoking presentation 'Is there anybody there?'

A talk about the history of Jodrell Bank captured the imagination of many and we learned of the connection of the NMC in its Winsford location to Jodrell Bank. In fact that piece of knowledge enabled one happy family to return home with a prize bottle!

“...we hope you enjoyed it and feel ‘You are not alone ...with the NMC”

Talks by Dr Mark Roberts, Consultant Neurologist, Our own NMC Specialist Physiotherapist Jonathan Smith and Dr Chris Morse MMU researcher, shared the latest knowledge and inspired great interest in the management of neuromuscular conditions.

A day of happy memories and for those who wanted a photo to capture the moment our Photographer Ian offered some out of this world backgrounds.

A day for everyone to enjoy Time and Space .... we hope you enjoyed it and feel ‘You are not alone ...with the NMC’

(The event funded by Cheshire East council follows the success of the Living with Muscular Dystrophy Symposium last year.)

On Saturday 18th March 2017, 92 people many new to the NMC, shared ‘a very enjoyable day’ at Jodrell Bank Discovery Centre in Cheshire.

In the beautiful and relaxed setting of Jodrell Bank there was a super opportunity for people with neuromuscular conditions, their family, carers and friends to have time and space for themselves.

The NeuroMuscular Centre team were in the Events Space, full of enthusiasm answering questions and demonstrating the variety of services which we offer - a relaxing massage, a fitness challenge, a chance to try skills in a football wheelchair or enter a design competition.





# Assessment of Fitness to Drive

**Gary Jones**  
Centre Manager

Opening of an accredited driving assessment service for the Cheshire and Wirral region.

With increasing demand for drivers to undertake assessment of their Fitness to Drive following onset of cognitive or physical changes that could impact upon driving ability, a new accredited driving assessment service will begin operation in March 2017 to serve the Cheshire and Wirral regions.

Supported by The Department for Transport this new venture will be staffed by a team of experienced Occupational Therapists and Driving Advisers to ensure the most complete and robust assessment of cognitive, visual and physical abilities in relation to an individuals' practical Fitness to Drive.

As an accredited member of Driving Mobility ([www.Drivingmobility.org.uk](http://www.Drivingmobility.org.uk)), Chester Driveability is able to deliver assessments on behalf of DVLA, Motability and health professionals who are advising on the Fitness to Drive of individual patients.

Chester Driveability will be operated by The Wales Mobility and Driving Assessment Service ([www.wmdas.co.uk](http://www.wmdas.co.uk)) who have over 25 years' experience of assessment of Fitness to Drive on behalf of DVLA, health professionals and individual service users.

## Gordon's Ireland Challenge

Cycling the MizMal is the Irish equivalent of Britain's Land's End to John O'Groats, but with rugged coastline, unique landscapes and lively pubs. This is the colossal fundraising challenge Gordon Styles has set himself this summer marking 26 years working at the NMC. For part of the way he will be joined by Matthew, assuming he can keep up!

The following is an extract from Gordon's JustGiving page:

"I love this place. I come to work every day to work with, and for, my friends. I am very privileged. The Physiotherapy department continues to get busier with over 1100 families who are affected by muscular dystrophy

having been in contact with our service. 250+ are now regular patients.

...The MizMal is an enormous challenge - cycling from the South Westerly most point in Ireland to the most Northerly point, a distance of 820 km (512 miles). My current highest single day mileage is 62, and I've only twice ever managed that distance. Every day, except the last one, on MizMal is longer varying from 75 miles to 107miles." To find his page and further information about their progress visit [Justgiving.com](http://Justgiving.com) and search for Gordon Styles or Matthew Lanham. We wish him and Matthew well and look forward to reporting on their adventure later in the year."



# Chester Wins European Access City Award 2017

**Radio 4 interview with Andrea Duckworth**

## **Glycogen Storage Disease (GSD) support group**

People attending the NeuroMuscular Centre have numerous, but typically rare conditions. There are other focused support groups that offer something different and complimentary to the NMC. One such group is the Association for Glycogen Storage Diseases UK.

The group was formed thirty years ago in 1986 by two mothers who both had a child with a rare Glycogen Storage Disease (GSD). The group has grown over the years and has funded early research in to treatments and therapies. The Association is run, informed and supported by its members and they aim to provide a warm welcome to anyone diagnosed with a GSD including McArdles and Pompe. As with many neuromuscular conditions, the chances are they have had a long and difficult journey to diagnosis. The group has a Pompe Support Team, a group of people with Pompe who are willing to provide a listening ear or talk about common experiences. For more information visit [www.agsd.org.uk](http://www.agsd.org.uk).

As a regular user of DIAL West Cheshire's Shopmobility Service, I was privileged to be interviewed by Andrew Fletcher, from Radio 4 for the programme You and Yours.

Quite simply, without this service and all the access points to the City Walls, ramps and dropped kerbs, I would be unable to get around the City.

To hear the full interview  
<http://www.bbc.co.uk/programmes/b086kxzd#play>

## **Hynt - Access to theatres and Art Centres in Wales**

Hynt is a new national access scheme that works with theatres and arts centres in Wales to make sure there is a consistent offer available for visitors with an impairment or specific access requirement, and their carers or personal assistants. The site will tell you all you need to know about Hynt: who it's for; what it provides; and how to become a member.

Members are entitled to a free-of-charge ticket for their personal assistant or carer when attending performances at any of the Hynt theatres or arts centres.

Visit [www.hynt.co.uk](http://www.hynt.co.uk) to search venues shows and accessibility.  
contact: [info@hynt.co.uk](mailto:info@hynt.co.uk)





“These are very exciting times for us and the future is looking bright!”

**W**e have been training regularly for over two months now, it's going really well, everyone is enjoying it and developing well.

I have also enjoyed coaching the players, it has been a privilege and it is very fulfilling seeing them improve, develop and grow. Not only as players but as people as well, each week we train I have noticed a considerable increase in everyone's confidence and in myself also. Being part of a football team also benefits everyone socially; we have all become good friends and I don't think I just talk for myself here, but I look forward to each session. To have a catch up and banter with friends and have a kick about.

We have got eight players including myself that train regularly. Sessions consist of getting used to the wheelchairs, first by weaving in and out of cones with and without the ball. Learning to hit the ball for passing and shooting. Learning to take a touch and then hitting the ball. This is then put into practice during different drills such as; tennis, where we split in to two teams and each team works together to hit the ball over the baseline, then piggy in the middle, where we make a big circle around the hall and have to pass the ball between us trying to keep it away from the defender in the middle and then we play a game, where we work together to score against a goalkeeper.

The NMC have strong links with Manchester Metropolitan University (MMU), who have been working with the physiotherapy team for a while carrying out research on Muscular Dystrophy. Due to these connections they are letting us use their sports hall for training and have allowed us to place a storage container to store all our equipment.

Once we knew we had a place to train we started fundraising for the container and equipment, sports wheelchairs, goal posts and footballs. The fundraising went really well and we were able to order the equipment. Once we had all of this in place and we had five sports wheelchairs we could commence training and I could start coaching the players. We had our first AGM the other week, where we discussed the club moving forward.

Everything is going to plan. We plan to enter the North West championship regional league in October, which will give us a few months to be ready. We also plan to organise a few friendly matches, these matches will be our first competitively. We are in the process of getting a kit; we have decided that it will be blue with an orange stripe across. We have

had discussions with MMU and we are going to have them as our shirt sponsor, to mark our thanks and gratitude for all their help. Another good thing to come out from us creating a football team is the research opportunities for Matt from MMU and his colleagues, on people with Muscular

Dystrophy participating in sport, and how it has a positive effect on our health and wellbeing.

If you are interested in joining please contact Bryn [bryn.edwards@nmcentre.com](mailto:bryn.edwards@nmcentre.com), James [james.taubman@nmcentre.com](mailto:james.taubman@nmcentre.com) or myself [mark.chapman@nmcentre.com](mailto:mark.chapman@nmcentre.com).

# Making the NeuroMuscular Centre Grounds Beautiful -Volunteers Needed!

by Moyra Byron

As we speak, spring is fast approaching. The building works at the centre are coming to an end, with fantastic results, and we are now looking at the next big challenge.

The grounds belonging to the centre are very large, but have sadly had to be neglected while the works have been carried out. But all that is to change, as donations have been given which will enable the centre to purchase a greenhouse and hopefully also some raised beds. They are to be situated to the rear of the centre, between the sheds and the fence bordering the school and the new housing, which is quite a large area to be filled, although it means that there will be some shade from buildings. The area can be seen from the new gym, so people can watch its progress whilst exercising. We are also hoping to have several water butts installed across the grounds to aid with watering during the hot summer months (always the optimists!).



It is hoped to get as many people as possible involved in this new project and so we are asking all gardeners – and budding gardeners – for their input. We need to know what people would like to grow, and are suggesting things like vegetables and herbs, as well as flowers if possible. But we need to know which ones – and how to do it!! If you have a greenhouse yourself, or have some knowledge of growing these items, or would like to offer help of any sort, then we need to hear from you.

The greenhouse is to be wheelchair friendly, and the raised beds will be of such a height to be easily accessible, so there are no excuses!!!! If you are able to offer some input, then please contact either Moyra Byron who is available at the centre most Tuesdays, or alternatively Denise Boyall. We would be happy to listen to any comments and suggestions.



# A Drone at the NMC

by Mike Brown

After my FSD kicked in some fifteen years ago I lost my job in the hospital, and concentrated on my work as a professional photographer.

Many years and many weddings and portraits later, the condition was also to relieve me of that job too as the camera became too heavy to carry, and my legs did not want the workout any more. I turned to taking landscape images, as I had all the kit, and I could take my time setting up on a tripod, and perhaps do ten or twenty a day instead of a thousand. But I was also limited to where my stick or wheels could take me until along came drones. There can be hardly anyone who has not heard of them, if not seen them. But a camera drone would allow me to go where I could not with my legs, and still take the images I wanted to. It would also allow me to take my image taking to greater heights, literally.

The choosing of a drone and the legalities of it all could complete an article all on its own, so I will not go in to it here, but a chance conversation whilst at the NMC led me to photograph the building and its surrounds from the air. A "mission" as they are now popularly

called, requires planning and luck. Planning what images you want to take, planning how you will take them, and of course planning around the weather. That is also where the luck comes in. The drone I have, a DJI Phantom 3Pro, will fly in winds up to around 15 knots. The lower the wind the better the pictures though. Lighting is important too. As you will see later. On top of that other things need to be checked and planned for. Is there any aerial activity nearby? Are there any power cables or trees? Are there any prohibited zones like schools or nuclear power stations?



On the day of the "mission", the weather was very kind with patchy sun and little wind. Early fog had dissipated. However, there were a couple of problems before I could fly. The school next door firstly. They were most kind and co operative when informed about the flight , and requested an image from me. Secondly, there was a restriction on flying because of a nearby airfield, and I do not mean Speke or Manchester. I had permission to fly no higher than 120m, and always within sight.

So I trundled the drone in its converted suitcase on wheels down to the summer house, pulled up a chair and assembled it all. Yes it can all be done sitting down. Taking off from the wooden walkway and then off to take the pictures. First the still images and then the movies. Some of the images are here, and others can be seen at <https://mikeeaa6.myportfolio.com/disabled-photographer>



# Spinraza in SMA

Spinraza (INN Neurinosen) is a drug produced and marketed by Biogen. It is the first pharmacological therapy ever to be given broad approval for use in the treatment of Spinal Muscular Atrophy (SMA).

Individuals with SMA experience a loss of motor neurons - the nerve cells responsible for the generation of impulses which produce movement in the limbs and body - in the spinal cord. This is due to a genetic defect affecting the SMN1 gene which produces the Survival Motor Neuron Protein (SMNP).

Over time, insufficient levels of SMNP lead to a decline in the number of motor neurons within the spinal cord, resulting a loss of movement, muscle weakness, and reduced function and independence. Individuals with SMA retain some movement due to the presence of a less powerful version of the SMN1 gene called SMN2 (Scientists like to keep things simple!) Spinraza, when injected directly into the central nervous system, effectively converts



the less powerful SMN2 gene into SMN1, which produces normal amounts of SMNP and therefore prevents loss of motor neurons and the functional issues that come with muscle weakness in SMA. For anyone feeling confused at this point, that's the science bit over, and the outcome is that this is 'so far, so good' for Spinraza as a treatment for SMA!

Therapeutic drugs have to pass through a multitude of hoops before they can be approved for license to use on actual human beings and, so far, Spinraza has managed to satisfy the criteria for safety and effectiveness. So much so that in December 2016 it was granted approval from the Food and Drug Administration in the USA for use in SMA, and additional funding incentive was provided.

An article published in the Lancet in 2016 demonstrated the effects of Spinraza on a group of SMA infants <7 months old, noting improvements in motor function and survival rates in the majority of participants ([http://thelancet.com/journals/lancet/article/PIIS0140-6736\(16\)31408-8/abstract](http://thelancet.com/journals/lancet/article/PIIS0140-6736(16)31408-8/abstract))



Signing up with the Priority Services Register for older and disabled people available in England entitles you to a range of support such as advance notice if your supply is going to be interrupted and priority reconnection if your supply is interrupted. If they cannot connect you they will provide alternative facilities for cooking and heating if your supply is interrupted. If you own your own home you may be entitled to annual gas safety checks and they can also provide advice about being more energy-efficient. If

reading your meter is difficult they will move your meter free of charge or provide a free quarterly meter reading and if it helps copies of the bill can be sent to a relative, carer or friend. They will register you with a password protection scheme to keep you safe and protect you from cold callers. To sign up to the PSR you will need to contact your supplier. Remember if you have different suppliers for gas and electricity, you'll need to call them both and you'll need to register again if you change your energy supplier.



# Juice Diet

by Mark Chapman

For the last 4 years I've been on a juice diet on and off. For the weeks when I'm on the juices I just have a juice for my breakfast and lunch, then soup and a sandwich for tea.

Over the 4 years I have lost 3 stone, which makes me feel so much better I no longer have to worry about how I look and my clothes fit better.

Most of the juices contain avocado, beetroot or banana as the main ingredient because that's what fills you up. For the breakfast juice I usually have one with a banana, raspberries, blackberries and yoghurt. That's good for breakfast as it's light and it's a good start to the day like cereal and cereal bars.

There are loads of juice recipes out there, I use a recipe book by Jason Vale who is known as the Juice Master.

My favourite juices are;

- Carrot, orange and mint.
- Beetroot, blackberries, apple and lime.
- Avocado, kale, cucumber, apple and lime.
- Pear, parsnip, apple and lime.

Many of the recipes contain lemon or lime, this is so that the juices

stay fresh because the citric acid in the lemons and limes prevents the juice from oxidising, it also helps make the juice taste good.

Since I've been doing the diet my health and well-being have improved, touching wood I haven't had a chest infection or a bad cold in that time.

All the vitamins and minerals within the fruit and vegetables used in the juices have boosted my immune system; this with the weight loss has made me a lot more confident and happy with myself. The juices have given me more energy. I never feel bloated because the juices are nice and light but they are still filling and you aren't left feeling hungry. My skin and hair is healthier, it's a lot smoother, feels and looks stronger.



# Becoming Mr Sleek



by Peter Marley

I decided to concentrate on my weight loss after my relationship ended. I also had a diabetic check up and was told that I may have to go on insulin. This made me determined to lose the weight I needed. I was 24st 12lb at the time.

To start with, I lost two stone alone with cutting out treats such as crisps, sweets, biscuits & chocolate. I was asked to go along to Slimming World to support a good friend of mine and then decided to join myself!

I joined in February 2016 weighing 22st 12lb and set a target to lose 5st with Slimming World (I reached this target within 12 months so 7st loss in all).



The support I have received from the group has been amazing! There have been some great weight losses within the group which has been an inspiration to me.

I have been voted "Young at Heart Slimmer of the Year", "Man of the Year" and "Mr Sleek" of the group!

At the time of this interview I have lost over 7st and would like to get close to my 16st target - then I would have lost a total 9 stone!

I'm finding that I'm able to move more freely, and physio have said I have more flexibility in my legs. This has give me more confidence in myself.

# Getting<sup>up</sup> Again



by Jon McVey

I fall frequently, usually the fall isn't the biggest problem for me, it's getting up. I get around well enough using walking sticks, if a bit slow. but I don't seem to have muscles in the right places to be of any use in getting me off the ground. This is where a clever inflating device called a Mangar Camel comes to my assistance.

Until I got my Mangar Camel, if I fell outside the only option I had was to call an ambulance. I have had to do this when I fell on the drive and was stuck and unable to get off the ground but it seemed that there should be a better solution. I am about 6'4" and none too scrawny, my wife is a lot smaller and although she is remarkably strong, lifting me is really not a feasible option.

Fortunately with the help of an occupational therapist I was able to get a Mangar Camel, although the process wasn't straightforward as it was outside their normal purchasing practice. The Camel is basically a series of inflatable bags and a battery operated pump. It is laid out on the ground so that I can slide onto it.

The pump inflates the bags one at a time until I am raised into a sitting position. This can be inflated quite high which is an advantage as I'm tall. There is a smaller version called an Elk carried in Ambulances which does the same job, but the Camel has the advantage that it is a bit bigger and has a back support so I'm a bit steadier especially when there is one operator. Also being wider it is easier to push up from or transfer safely to my wheelchair. It is small and portable enough that it can be used anywhere in our house or drive and we can put it in the car when we go away.

Falling is literally a bit of a pain in the backside, but the important thing is to get up again. The Mangar Camel at least gives me confidence that I will be able to do this reasonably quickly and easily.



# Useful Websites

## Knowsley Wildflower Centre

They state visitors are very welcome to bring a carer to assist them free – but to make the best of your visit, please contact them in advance [www.nwc.org.uk](http://www.nwc.org.uk)

## National Trust

Their admission policy admits a necessary companion, or carer free of charge. 'Access for All Admit One Card' can be applied for and allows a carer free entry to support a person with a disability.

## National Express

Their Disabled Coachcard offers a great way to save 1/3 on standard fares to hundreds of UK towns, cities and airports. The majority of the fleet have a passenger lift, but you should contact them at least 36 hours before travelling. [www.nationalexpress.com/offers/coachcards/disabled-coachcard.aspx](http://www.nationalexpress.com/offers/coachcards/disabled-coachcard.aspx)

## Toll Concessions

You may be able to pay a reduced rate or nothing at some river crossings, bridges and tunnels if you're disabled. In most cases, you have to apply in advance to get a concession. [www.gov.uk/driving-medical-conditions/toll-concessions](http://www.gov.uk/driving-medical-conditions/toll-concessions)

## Rough Guide to Accessible Britain

A free, online guide including over 200 inspiring ideas for worry-free days out, reviews, hints and tips by disabled visitors. Provides lots of accessibility information including disabled parking [www.accessibleguide.co.uk](http://www.accessibleguide.co.uk)



## Bruce Trust

Specially adapted canal holidays on the on the Kennet and Avon Canal, which flows through Berkshire and Wiltshire [www.bruce-trust.org.uk](http://www.bruce-trust.org.uk)

# Useful Products

## Hands free hairdryer stands

If you have difficulty holding a hairdryer this convenient stand holds the hairdryer steady with a flexible neck that can be adjusted to any angle from its tabletop base. An alternative version has a flexible arm and a strong sucker that can stick to your bathroom mirror.



## Shampoo Hair Funnel

Designed for washing hair in an upright position if you have difficulty tilting your head back.



## Wheelchair Umbrella

Being in a wheelchair it is easy to get caught out in a rain shower or in bright sun with no shade, but with this compact umbrella shelter is always at hand.

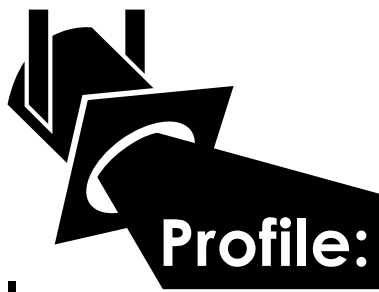


## TP-Link Smart Plug HS100 Wi-Fi

This can be used from a smart phone or Alexa to operate lights or other appliances at home.



Our thanks go to Jane Bradley and Stephen Clough for these suggestions.



Profile:

# Chris Wade

I came to know about the NeuroMuscular Centre after a visit to my hospital consultant, and from there he referred me.

I was feeling quite depressed at the time and lacked confidence. I was also having sleep problems and therefore would stay awake playing computer games. Not an ideal situation. I have been now attending the NMC for five years and it has given me more than I could ever imagine.

I had an assessment with Helen, a physiotherapist at the centre at the time and now receive physio on a regular basis which really helps.

I had a flare for art and design at high school and gained my GCSE. I also started on a two year National Diploma course but unfortunately only completed a year of it as it was expensive and I felt there was a lack of understanding of my MD.

I have done voluntary work for the council to help build my confidence. I also did a year course in Design and Print at More Training printers in Stoke on Trent.

After finding out about what the centre offered I went on a year course, level one design. I was having lots of problems in my personal life so doing this course took me a lot of motivation, Dee and Kay were very supportive of me.

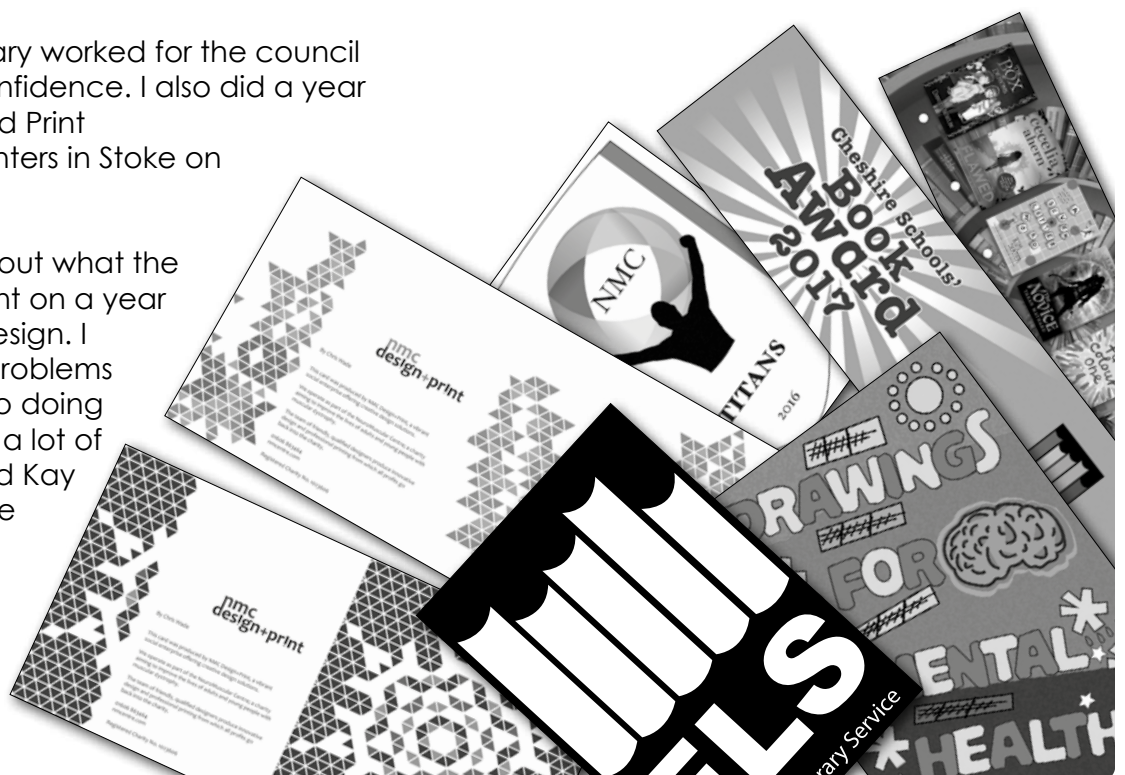
I have a motto of "mind over matter" and I passed! I took much inspiration from Kay. I also had the support of my fiancé Emily, we have been together for four years.



I was interested in moving in to the design and print side of things and was offered a week trial to re-evaluate. I came to the end of my trial and was offered a place in design and print! This was a great move forward for me and made me realize how valuable the NMC is.

I had input to the Christmas cards in 2016 and my ideas were used which was a real compliment to me. My design was also chosen from a handful of designs for the education library service. I also designed the NMC Titans logo.

Emily has been there for me through it all and I feel more involved.



# Dates for your Diary

## NMC's Upcoming Events!

- Swing Band and BBQ Cruise - Thursday, 18th May
- Wine Tasting and Spuntini - Friday, 16th June
- Wag n' Walk Chester - Saturday, 17th June
- An Evening of Jazz - Wednesday, 28th June
- Live in the Park - Saturday, 15th July
- Nantwich Big Day Out - Sunday 30th July
- Glenaffric Brewery Tasting - August

Please look out for the next One Voice Live event, Carers week activities in June and Bushcraft in the summer.

Follow the NMC facebook page [www.facebook.com/NMCCentre](http://www.facebook.com/NMCCentre) for a helpful way to keep up to date with current news.

## Other Forthcoming Events

[www.mobilityroadshow.co.uk](http://www.mobilityroadshow.co.uk)  
The 2017 Mobility Roadshow will be held at NAEC Stoneleigh. Sign up now and find out who is exhibiting, exciting news and what to do on the day.



## PHOTOGRAPHY WORKSHOP COMING SOON TO THE NMC!

FOR MORE INFO: POP INTO NMC TRAINING OR CALL KAY 01606 863464  
OR EMAIL [DEE.VALKERING@NMCENTRE.COM](mailto:DEE.VALKERING@NMCENTRE.COM)

## Wheelchair For Sale



### Jazzy

- Select 6
- Powered Chair
- Right hand controls
- Seat height adjustable (can be raised)
- Comes with charger (new battery installed in Oct 2016)



Worth £600 was £1200 new (price subject to offers).

Please contact Jo on 07422 506357.

## Editorial Team

Moyra Byron, Mark Chapman, Karen Pritchard, Sanjay Vaja and Jon McVey

## Next Edition

Following the completion of the new build at the Neuromuscular Centre we want to highlight the new developments and the services offered at the centre. We would like to hear about your experiences of using the centre.

Thank you to everyone who has contributed to this edition!

## Finally

We welcome any articles or suggestions on these or other topics please note that the deadline for all articles for the Summer edition is the 27th May. Please email: [jon.mcvey@nmcentre.com](mailto:jon.mcvey@nmcentre.com)

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