



ONE VOICE

Summer 2017
Edition 37

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Cover page photograph:
Gordon and MizMal Team

Coming Soon...

The NMC Photography Competition

The competition will open on 1st September and close on 31st October and is open to NMC Service Users, staff, carers, family and supporters.

There will be 4 categories:

- Family and people
- Pets and animals
- Landscapes and Architecture
- "View from a Chair"

All entries to be original, unmanipulated digital photos that have not been entered into any other competitions. Cost £3 per entry or £5 for two. Prizes to be announced.

Contact Claire James or Karen Pritchard at the NMC for more information. Call 01606 861733 or email claire.james@nmcentre.com

Muscle Month

Following the success of last year's Spaceathlon, this year's Muscle Month will take place in September and will have a Formula 1 theme. Our Service Users will be challenged and sponsored to take part in activity and collectively will be trying to cover the distance of 3 Formula 1 courses, Monza, Italy; Singapore (these are the two Grands Prix taking place in September) plus the UK's very own Silverstone, a total of almost 922km. You can adapt your activity to fit in with your physio appointments and your physio will be able to advise on goals you can set. You may wish to walk using the cross trainer, cycle using the pedals or assisted arm pedals, swim in the hydro pool or your local pool, row using the rowing machine or come up with your own idea. If you are interested in signing up, please speak to your physio to arrange your chosen activity then sign up with Claire in the Fundraising Office or email claire.james@nmcentre.com.

There will be other Formula 1 activities taking place across the month including a "Fantasy F1 league" and a Chequered Flag 'Guess the Square' game – the aim is to have

something for everyone regardless of whether or not you enjoy F1!

Watch out for sign-up sheets coming soon, or if you don't attend the centre regularly but would like to take part from home, please contact Fundraising on 01606 861733.

Pampering and Prosecco with Molton Brown

Thursday 21st September

We are thrilled that Molton Brown in Chester are hosting a fundraising evening for NMC. Join us from 6pm, where you will be greeted with a glass of fizz and a selection of canapes, before being treated to a pampering session by the lovely ladies of Molton Brown.

Tickets are £15, which includes unlimited prosecco, canapes and a fabulous goody bag full of Molton Brown miniatures to take home.

Autumn Dinner

Friday 29th September

A gastronomic feast awaits you at 1539 Restaurant, with a decadent Drinks Reception and three-course menu. 1539 provides the perfect setting for an evening of fine dining and dancing with Live music and a luxury auction.

Tickets are £45 per person, including welcome drink and three-course dinner.

Spirit of Christmas 2017

Friday 24th November

A truly magical evening that awaits you at Chester Cathedral on Friday 24th November, ensuring the festive season starts with a sparkle for the great and good of Cheshire. Matthew Kelly invites you to The NeuroMuscular Centre's 22nd Spirit of Christmas, the annual concert of festive readings and music. We will post details of the line up as and when we have further information for you.

Editorial

Jon McVey
Editor

I happened to be at the NMC during the recent Open Day. The doors of the new seating area were open, there was a pleasant breeze and the place was buzzing.

For many it was their first visit and those I spoke to were amazed and inspired by the range of things that happen at the NMC and the beautiful new environment. I spoke with a few who were inspired and amazed by the range of activities that happened at the centre, although one found the toilet doors and locks a little confusing.

In this edition we are highlighting some of the benefits that the new build has brought to the physio department, the gym, training, the new Design + Print department as well as the other communal or training areas and additional toilets. This though, is only a small reflection of what the NeuroMuscular Centre offers and there is so much more that supports this. Much work may not be as immediately apparent but is an essential part of the NMC.



Having recently been unable to drive after a fall I have reason to be very grateful

for the transport section. Each day a team of mini buses come in and out of the centre and without which the centre would be inaccessible to many. There is also a new fundraising office for the team that does such an incredible job of bringing in the funds that have enabled the new build and underpin all the work done by the centre. They are also responsible for organising all the events that are enjoyed by so many and raise the profile of the NMC in the wider community. The grounds are maintained by a small group of volunteers, including One Voice's Moyra and it is a substantial job keeping the meadow in control and the flower beds looking beautiful. Denise can offer advice and information on a wide range of issues, but there is also the shared experiences and support of others at the NMC.

In this edition we are also covering topics such as maintaining a healthy and enjoyable social life with a chronic condition, the developments in a drug called Spinraza for people with Spinal Muscular Atrophy, using an Echo Dot for help at home and acquiring a new powerchair and much more.

I can't finish without a mention of Gordon and his team of 14 cyclists and two support crew for their amazing feat of cycling the length of Ireland. The challenge started in Mizen Head in the far south west of Ireland and finished 520 miles and six days later at Malin Head, the most northerly point. The team also included other staff from the NMC and raised a massive amount. If you would like to find out more about the challenge there are lots of pictures on the NMC Facebook page www.facebook.com/NMCCentre or for this and other fundraising stories, www.justgiving.com/nmccentre.

"I can't finish without a mention of Gordon and his team of 14 cyclists and two support crew for their amazing feat of cycling the length of Ireland"



Physiotherapy Department

by Gill Storey

The builders have now left us and the new extended NMC is completed. During the 9 months of building work patients, carers, physiotherapists and others have worked side by side, and not a single day of treatment has been lost which is quite remarkable.

The physio department has doubled in size and we now have a new specialised adapted gym and an extra treatment room. We have recently employed two new graduate physiotherapists in order to maximise the use of the new department and gym. This means that we will be able to provide more active exercise to a wider range of patients, increase the amount of first assessments we see and also the number of regular appointment slots.

The fundraising team have successfully sourced funding for new disability access equipment which includes:

- A wheelchair accessible rower
- 3 assisted arm and leg cycles
- 2 exercise bikes
- A seated crosstrainer (that you can be hoisted into)
- A standing crosstrainer
- Wii for balance and weight distribution
- Theraband resistance station
- Cable weight station



In the future we are planning to train a physiotherapist to do cardiopulmonary classes at the centre to be able to improve the heart and lung fitness of our patients. The training is accredited and approved by the British Heart Foundation.

Complementary Therapy

Beverley Langley, our complementary therapist, has increased her days at NMC and now is available on Wednesdays, Thursdays and also on alternate Tuesdays to provide complementary therapies and manual lymphatic drainage to our patients and carers. We have also purchased a Hivamat machine that is used for the treatment of oedema. Beverley also has a notice stand in the lounge area to show any available slots for the day.

Please note that all treatments for service users, staff and carers are free of charge. Treatments currently offered are massage, aromatherapy massage, reflexology, and manual lymphatic drainage.

Please contact Beverley on: 07756 853 089.



Men in the Shed

There have also been challenging times for the 'men in the shed'. It has taken time to relocate the 'shed' and to completely change the workshop layout. They have built a large wooden shed for storage at the side of the workshop, and have also been useful putting up shelves and cupboards in the new NMC building, not forgetting their help installing the new gym equipment. The new foyer now has a lovely new coffee table with their compliments. They have been busy making a beautiful obelisk as a focal point in the grounds, and are about to make planters for the new allotment project which will be wheelchair accessible. So they have not been idle, and are looking forward to challenges ahead. If you would like to join, please ask at reception.





New room

The training department has gone through lots of exciting developments in the last couple of months. We have currently moved into a new, larger training room. This will give us the possibility to expand our work stations and deliver training to more students at any one time. It also gives us the opportunity to run more courses and/or workshops along side each other.

More courses on offer

NMC Training has expanded their course offer to Life Skills, including English & Maths and personal skills, Animation, Digital Music and a soon to be started Photography workshop. Currently we run Graphic design and Digital Music courses at the same time. It is great to see how the graphic design students are also keen to try the digital music course once they see their peers working on a piece of music. The digital music course is a fun course for anyone who enjoys music and would like to compose a piece of music themselves. Candidates work on a computer with a piece of music software called "Garageband". This easy to use program allows users to put together music from pre-prepared loops in a variety of styles. Newcomers will be guided through the early stages of making something simple, but sounding good. Equally, users with more experience are coached through more advanced skills and using more complex combinations of music.

New tutors

We would like to officially welcome Steve Gaffney and Chris Burden as new members of the training team. Steve Gaffney is an experienced tutor and talented musician. Steve delivers Life Skills and Digital Music on Mondays and Tuesdays. Chris Burden graduated with a BA in Animation at Edge Hill University last year and currently delivers a 20 week Animation course, which is held once a fortnight on a Monday.

Taster sessions for ALL ages

The courses at NMC Training are for ALL ages and no previous experience is necessary. Would you like to try any of the courses? Feel free to come along for a taster session and gain new skills in a friendly and informal environment.

Suggestions for new courses/workshops welcome

We welcome everyone with suggestions on other skills they would like to gain as we are currently looking for more ideas on a range of workshops/courses.

Or do you have a particular skill which you would love to pass on to other people? Please do pop into training and have a chat with us as we are open to delivering a wide range of workshops/courses. You can also email Dee dee.valkering@nmcentre.com



Animation

by Chris Burden

I have played games on many different games consoles. I was fascinated by the way they had been designed. This interest developed while I was in Secondary School, but there was a lack of software in school and the teachers at school only taught I.T.

The school's career advisor was aware of the NMC and the types of computer study that were available there, and eventually I attended the NMC 1 day per week over a period of three years. It was here where my horizons widened! I became adept at designing and producing posters, leaflets etc. Upon leaving school I went to Hereward Residential F.E. College, which was primarily for disabled people. It was here where my graphic skills went to a new level, and I was working from briefs and working to deadlines. It was at Hereward that I got certificates in design and graphics.

I stayed at Hereward for three years. I have to say I enjoyed every minute of my time there, not only learning about graphics, but I learnt how to live independently, and the social life was excellent. After leaving Hereward I



returned to my family home, and Knowsley Council appointed a social worker (Ruth Jones) to me. She persuaded me to continue my studies. I visited a few local F.E. colleges, Knowsley Community College and Hugh Baird College in the borough of Sefton. I chose Hugh Baird College because it had a wider range of courses that would add to my graphic skills. The course was Art & Design leading to a H.N.D. The course was a 'condensed one year course', but I completed it over two years. The reason why I completed the course over two years was because my work rate was quite slow due to my disability, and my tutor wanted to assess what equipment and software I could use to help me complete the course. It was the teaching assistant at Hugh Baird who got me to try creating animation. I produced a short animation and I also developed directing skills which was useful in producing diary type videos depicting everyday activities. I had to produce a portfolio of work in support of my H.N.D. At the end of the course all the students displayed their portfolios to the general public.

I went to Hugh Baird with no intention of doing a degree in Animation, but whilst on the course the tutors used gentle persuasion to get me to do the degree course. It helped that I enjoyed the H.N.D. Course in Art and Design, so I applied for an animation degree course at Edge Hill University.

Continued Overleaf...

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One of the criteria for the degree course was G.C.S.E. in English language. I studied for this in parallel with my H.N.D. Course. I was accepted by Edge Hill onto the animation degree course. I lived on campus throughout my degree. I learnt how to produce animation to a professional standard and learnt how to write scripts and introduce the necessary elements that go into producing an animation.

For my final project I had to produce a promotional video for a company. So I contacted Matthew Lanham, the Chief Executive at the NMC, and discussed producing a video promoting the Centre and to install it on their website to attract new clients.

Upon Graduation I contacted Dee Valkering (Head of Training at the NMC) to suggest teaching my animation skills to any of her students who may have been interested in learning about the subject. I presented a 'tester workshop' to gauge the level of interest in the course, and there appeared to be a keen interest from the students. So now I am teaching one lesson per fortnight at the NMC!

My life at the NMC has come full circle from a student to a teacher! At the end of the course the students will have produced a ten seconds animation. Different students work at different paces, which is understandable, but all the students appear to enjoy being on the course.

Animation Course at NMC

by Andrew Woodvine

On the Animation course my experience, at first, was I thought it was boring. But as I pressed on, I got to know Chris and what animation entailed, and now I'm enjoying it so much that I've started animating at home! So far I've achieved 7 out of 10

seconds of my animation - it's taken a while but I'm pleased with what I've done.

I would recommend this class to other people because I felt that I was given freedom to use any program and any technique to complete my work. This is unlike previous courses I've done where you're sometimes limited to what has been set in a brief, or by the tutor. I felt happier choosing how I went about animating. I like doing the course at the NMC because it's a familiar place as I also attend for physio there and know a few people. That makes it more comfortable as sometimes it can be difficult talking to new people, but as I say the NMC is a familiar place so it makes talking to people easier. I also feel I've made friends on the course so that makes going more fun. By the end of this course I hope to gain some knowledge and skills in Photoshop as well as animation and I hope to have maybe gained some friends. All in all I've thoroughly enjoyed the course and would do it again.

Do you fancy creating an animation like Andy? Would you like to do a taster session? Please go and see Kay in the training department or drop us an email: dee.valkering@nmcentre.com



Design + Print

by Steve Gaffney

Comments about the new working environment

I really enjoy the new lighter, brighter environment for Design and Print. We have good natural light, which will be tempered by the new blinds...when we get them! I find the softer lighting a bit kinder on my eyes too. Its been really cool to be able to switch them on and off zonally. People like to work in different lighting setups and that helps enormously with that.

I like the layout too... fortunately we had Dan's input into the re-vamp and he has a great eye for interior design that's not only aesthetically pleasing, but more importantly fit for purpose.

Sunflower Project

by Toni Abram



I have run The Big Sunflower Project for seven years now to raise awareness of centronuclear and myotubular myopathy. You can read about the project at <https://thebigsunflowerproject.wordpress.com/>.

In my experience, there isn't a single way to grow sunflowers - people tend to use different methods and have varying degrees of success. However, I find that starting them off on my kitchen window sill and introducing them to the outside world slowly works quite well. You could of course start them off in your greenhouse (or I have some in my shed this year) and allow them time outside during the day, if that is possible, before popping them inside again over night.

I have grown sunflowers both in pots and in my garden borders (although both ways they start out in pots). Sunflowers seedlings are very tasty to all manner of things and planting them directly into a border has never worked well for me. You will likely need to protect them - a 'cut off' plastic bottle placed over the top of your sunflowers are good for this.

Greenhouse Project

The greenhouse was funded by Bags of Help - Tesco. If you would be involved in the greenhouse project or helping in the gardens, please ask at reception.



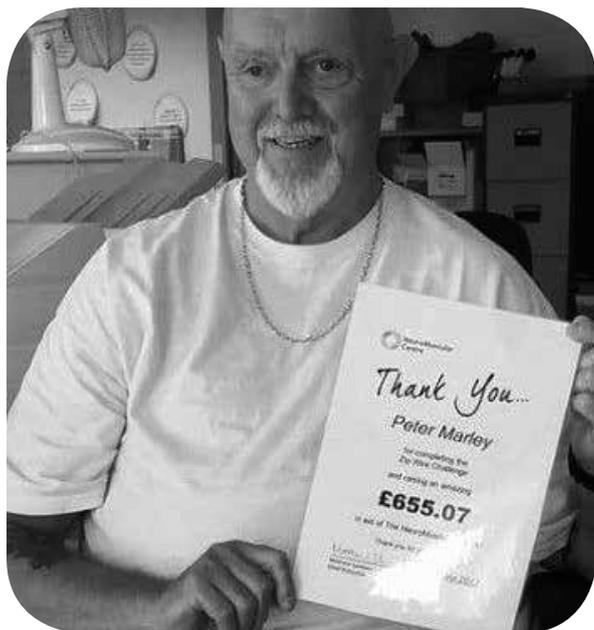
Research at the NMC in collaboration with Manchester Metropolitan University.

We are looking for people with MD who are able to walk 10 steps with or without walking aids to talk part in an exercise training study at the neuromuscular centre. If are aged between 18-65 years and interested in taking part please contact Dr. Emma Bostock emma.bostok@mmu.ac.uk

Life Begins at 60

by Peter
Marley

My name is Peter Marley and I have been attending the NMC since 2011.



I turned 60 in January this year and for my birthday my daughter Sarah bought me a voucher for the Velocity Zipwire - the longest and fastest in the northern hemisphere! I had wanted to do this for some years but had always been too heavy at almost 25st. So, last year I started to lose weight, and eventually on the 29th April, and 7.5st lighter!, I found myself in a quarry in Snowdonia.

The whole experience was fantastic and the staff could not do enough to help me. As I cannot walk very far, I was transported to the start by Land Rover, and they were there again to take me back down. My good friend Karen Pritchard (NMC user/worker), her husband Alan, their son Evan and Dini the dog came to support me.

I know a few people from the centre have done this now and I would recommend the experience to anyone - it was a fantastic day. And as an added bonus I was raising money through sponsorship for the NMC and I raised a total of over £650!

Support within the NeuroMuscular Centre

by Denise Boyall

Living with a neuromuscular condition can present many challenges to daily life at home, when enjoying social activities, at work, at school or university, when travelling or even when sleeping.

Within the NeuroMuscular Centre are a wealth of people with experiences, knowledge and ideas to share.

Here are some of the ways you can be involved in giving or receiving support to help you to make the best choices when faced with those challenges:

- Arrange a visit to the NMC - see the people and the facilities it offers. Please ring or email Denise or Matthew on 01606 860911.
- Use the NMC website for current events and to search for information from previous editions of One Voice.
- Browse the information in the lounge area.
- Book an appointment for a session of Complementary therapy.
- Consider taking part in one of the NMC well being courses such as Mindfulness
- Become involved in one of the NMC clubs, such as gardening, woodwork or craft and share your skills or learn new skills.
- People at the NMC can offer practical and emotional support as NeuroMuscular conditions change over time.
- Peers can help guide young people moving from life at school to life in the 'adult' world, and activities such as Bushcraft are an amazing way to develop independent life skills.
- When employment needs change, a discussion with the NMC designers or training team may help you to consider new directions and ideas.
- The NMC has an experienced care team and has many shared experiences from people arranging support and care.
- Financial issues can be a source of great anxiety. Please do not worry alone, there are people here at the NMC who can help you to complete forms, write letters of support or help you to contact the appropriate organisations.



NMC

Boat Trip 2017 by Sarah Lalieu

On the 6th June a group of 10 intrepid explorers, (including 3 generations of one family) embarked on an epic adventure to navigate (part) of the beautiful Llangollen Canal aboard the 'Shropshire Lad', one of the Lyneal Trust's accessible boats.

A somewhat disappointing weather forecast did little to dampen our spirits, after all it is said that 'there is no such thing as bad weather, just unsuitable clothing' and so appropriately attired in 6 layers of clothes we embarked. There was plenty of room on board, a good size cabin, accessible loo, kitchenette and front deck. We had a wheelchair and mobility scooter on board and the lifting platform made light work of transferring everyone from the deck into the cabin.

On leaving Lyneal Wharf Denise fired up the stove for morning coffee and homemade lemon cake. We cruised towards the town of Ellesmere through a tranquil verdant corridor. If you can picture 'Tolkien style Middle-Earth' with ducklings then you're part way there!

After a couple of hours pleasant cruising we arrived at Ellesmere yard. The Yard is owned by the Canal & River Trust – the charity with responsibility for 2,000 miles of historic waterways across England and Wales. <http://www.canalrivertrust.org.uk/>

Ellesmere Yard was built in 1805 and much of the site is listed grade II*. As an operational

yard, it is not normally open to the public but we were able to gain permission to moor up and visit Rowan Taylor, resident blacksmith. It was lovely and warm inside and Rowan gave us a fascinating insight into the historic importance of the forge and demonstrated some of his work using traditional techniques.

Back on board it was time for a lunch or rather a feast of biblical proportions. Fully sated we headed off again at a heady 3mph towards the end of the Llangollen Canal at Frankton Junction where it joins the Montgomery Canal. The 'Monty' as it is affectionally know is a canal currently under restoration and is a haven for wildlife and rare plants. After a mightily impressive 3-point turn manoeuvre we began our journey back.

During the day, most people took a turn at the tiller, there is also an option of a steering wheel for seated steering and before we knew it was time for afternoon tea this time with delicious ginger cake! We arrived back at the Lyneal Trust at about 4pm to much brighter weather conditions (down to just the 4 layers of clothes by then), all in all a most enjoyable day.

For more information on hiring a Lyneal Trust boat: <http://www.lyneal-trust.org.uk/>





“...so far, Spinraza has managed to satisfy the criteria for safety and effectiveness”

Spinraza & SMA

by Jonathon Smith

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 in 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 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)

Socialising when you have a Chronic Condition

by Karen Pritchard

Maintaining friendships is such a rewarding experience, but living with a Chronic condition and pain can be very difficult.

Friendships play such an important part in people's health and well-being. It can be very difficult to find opportunities to make friendships, so socialising and getting out and about is vital to our well-being.

It takes much confidence to find opportunities for friendship or social groups to join. We feel a need to play a part in society. It is so important to be given the same opportunities to make friends as everybody else.

Although it's difficult to remain positive on bad days we must learn to turn to friends as a source of support.

More often than not they can relate to our problems. At the other end of the spectrum – resolving conflict can seriously help our pain as the more we worry and stress, the more distressing pain is. Letting people know your limitations can also help as if you can't do something, at least they understand the reasons. Most importantly be kind to ourselves and try to embrace the positives

Living with chronic pain can be tough both physically and emotionally. It is easy to skip activities like visits to the gym, swimming that uses up vital energy which we may need to store for other daily tasks. However, any exercise has many benefits and has been

shown to reduce pain perception, increase mobility, improve strength and balance and even reduce stress and tiredness.

For parents, it can be difficult to let your child out from your protective care and their safety bubble, but it is so important that they get out, make friends, and experience as much as they can. MD can sap your confidence - if you let it - and before you know it, you're stuck at home. I've been there. Have a read of some of the things our readers of One Voice get up to - with a bit of planning, anything is possible. Don't forget, you're not alone - you've got the NMC community who will help and support you

if there's something you want to do but don't know where to start.

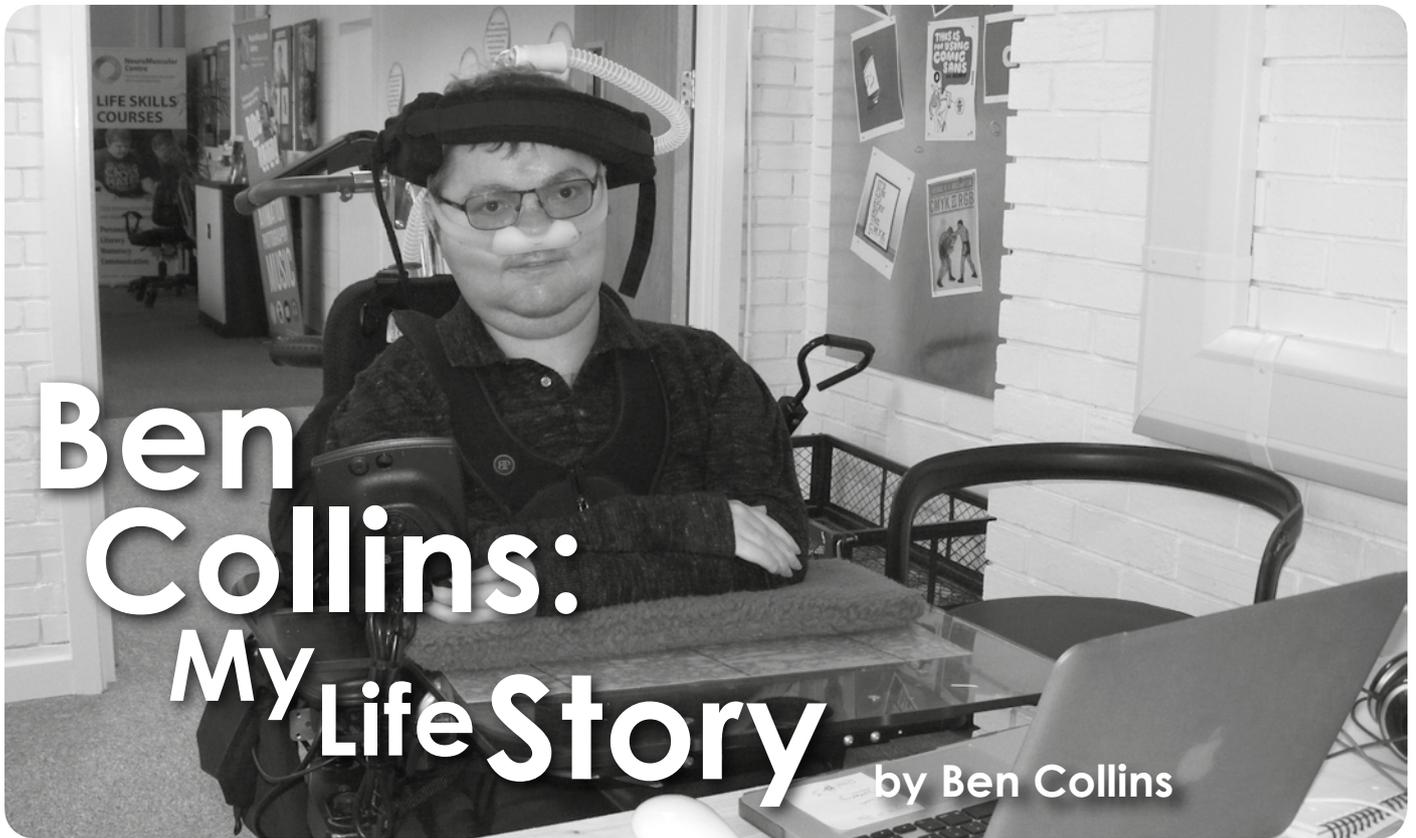


A Centre user describes.....

"My friends knew something wasn't quite right but they didn't dare ask me as they didn't think I was ready to talk about it. When eventually I did tell them, I discovered they'd been really worried behind my back

- because they care - no other reason. They didn't leave and run away like I thought they would - the opposite in fact."

"I find by being out and about, people stare at me. That was my worry about being in a chair. But I soon realised it was rarely out of pity (which I assumed it would be) but out of 'good on you getting out and about' kind of inspiration. We are all unique and have many gifts and talents - sometimes we forget."



My name is Ben Collins and this is my life story. I am 29 years old and have Duchenne Muscular Dystrophy.

The doctors found I had this when I was 18 months old. At this time I lived with my birth family. I had a very bad time with things happening to me which shouldn't happen to anyone, especially a little boy.

When I was 2 years old I went to stay with another family for part of each week. Bad things still kept happening so I went to stay there all the time when I was 5. Later on, the Judge at Court said I could stay there forever. That was good.

My new Mum and Dad, Carol and Philip, looked after me well and so did my new sister



and brother, Rachel and Tom. When I was looked after properly and loved, I learnt new things. With lots of physio I learnt to walk when I was 3¼ years old. Later I learnt to ride a tricycle and climb a slide and play on swings. I liked playing football with my brother Tom. When I was 7 years my muscles started to get very weak and I needed an electric wheelchair and when I was 8 years old I couldn't walk anymore. I used a standing frame everyday and had even more physio to stretch my arms and legs that I couldn't move on my own.

We still went on lots of holidays. I went abroad a lot and my favourite was when we used to camp in France. I liked going to my local primary school, The Wyche, and everyone was kind and helped me a lot. I went on school trips and staff carried me where my wheelchair couldn't go. When I was 11 years I had to have a big operation because my spine had gone crooked and I needed rods in it to keep me straight. Later on I went to my secondary school, Shavington High. Mum had to have lots of meetings and write lots of letters before I

could go. I told them I was an ordinary boy who had weak muscles and would not go to special school just because of this and having some learning difficulties I shouldn't be treated differently.

When I was 13 my body started to go very wrong with lots of things not working any more. Some days I could hardly eat and would choke on my food. I had a gastrostomy tube fitted into my stomach to feed me when I couldn't manage to eat enough.

My lungs got weak. I went to hospital for a sleep study but I had a respiratory arrest. I was resuscitated and put on life support. I was in intensive care for 2 months. All the time I just wanted to go home.

By this time Dad didn't live with us any more.

When I came out of hospital, my brother and sister still helped Mum to look after me, when they could, but they were both working. I needed even more care.

I needed carers to help me get up and bathe me and put me to bed as I was too big for Mum to manage on her own. I needed carers to look after me at night while Mum went to bed. I now used a ventilator.

I went back to my mainstream school along with my ventilator, suction machine, oxygen and tube feeding equipment. On my first visit back I banged my wheelchair through the door and said; "I'm still alive, I'm not dead yet!"

After this I was very poorly a lot with bad chest infections and I had to miss a lot of school but teachers and friends used to visit me at home. I also went to Reaseheath College one day a week from school along with my friends to learn about animal care. I liked this.

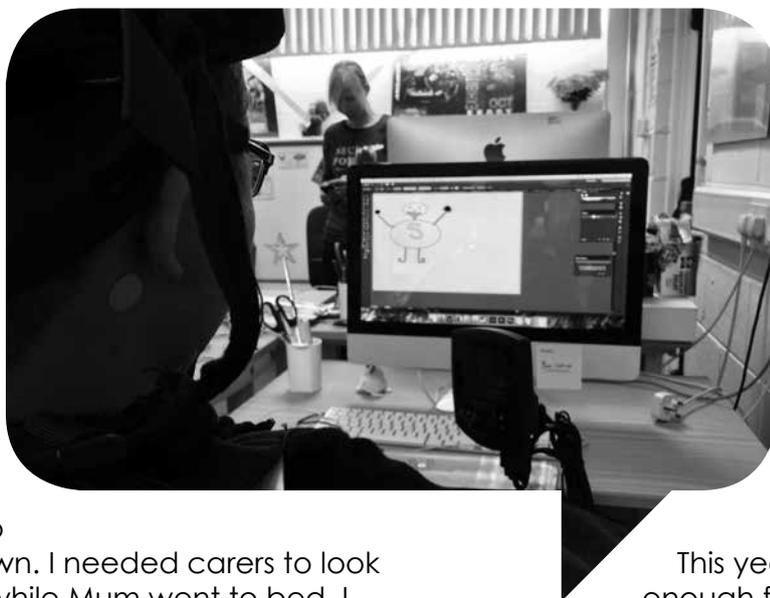
Then when I was old enough to leave school I went to another college for 2 days. It was a disaster so I left. My old school took me

back for an extra year and I took a double GCSE. Nobody thought I could pass it but I did. Then I went to the YMCA to do some courses. I enjoyed this but then I had to stop going because there was no more funding.

For the next 10 years, there were no courses for me to go to. I have been at home with family and carers. My family are very important to me. My sister Rachel and brother-in-law Steve, my niece Lola, nephew Lewis, my brother Tom, his wife Angela and my nephews Joseph and Isaac and of course, most important, my Mum. My brother-in-law Steve is now one of my main carers.

I have also had a lot of health problems and been very ill at times and everyone thought I was going to die. But I didn't, I'm like a cat with nine lives.

Unfortunately this meant I was no longer under Children's Services and there were no adult services for me. I was referred to the NMC and received weekly physiotherapy which I am still having even now. However, I have enjoyed going on outings and short holidays, my favourites being disability skiing and Chester Races.



This year my health improved enough for me to go out more and I went to the NMC for the "bushcraft" and "sports" activities. This was great and since the summer I have been going to the centre as a volunteer. I would like to do more activities and courses there but it costs a lot of money and it depends when they can afford them.

It is nice when I am well to have somewhere to go instead of staying at home as this is boring. Thank you all for listening to my story.

If you are an unaccompanied disabled driver it can be very difficult getting the help at petrol stations. The situation has been made even more difficult by the introduction of chip and pin as this has made paying very difficult for drivers who cannot easily get out of their vehicle, as standard card terminals cannot be used on the forecourt.

Useful Websites



myhailo.co.uk

Simply press the button on your MyHailo fob to alert filling station staff that you need assistance. This is a rebranding of the Contacta system we reported on in a previous edition. If you have a Contacta fob it will work just the same.

This system has been adopted by Sainsburys, Asda, Tesco and Cooperative service stations

service-call.net

This system uses an infrared transmitter and has the benefit of there being a very large number of participating stations.

fuelservice.org - recommended by Heather Murrant

This is a smartphone app that will let you find a petrol station know in advance of arrival if there is a person available to help you at the petrol station before you arrive. If you don't use a smartphone there is a text messaging service you can use. It has plenty of stations across the country, and the nearest to the centre are at Middlewich, Northwich and Sandiway.



If you receive the enhanced rate for mobility for PIP or the higher rate for mobility for DLA then you are eligible to apply for exemption of Road Tax.

If however you receive the standard rate mobility component of PIP then you are eligible to apply for a 50% reduction.

To claim the 50% reduction the vehicle must be :

- Registered in the disabled person's name or their nominated driver's name.
- It must only be used for the disabled person's personal needs. That means

the vehicle can't be used by the nominated driver for their own personal use.

- You can only have one vehicle tax exemption or reduction at any one time
- You can apply for the 50% reduction if you get the Standard Rate mobility component of Personal Independence Payment (PIP)

If you are entitled to the 50% discount, then you can ONLY obtain this by sending the appropriate paperwork to DVLA, Swansea, SA99 1DZ.

For more information visit: www.gov.uk/financial-help-disabled/vehicles-and-transport

Changing the Perception of Home Care for people with Muscular Dystrophy

by **Ben Selby, Managing
Director of Right at Home
South Cheshire.**

Having worked in community and home care services for 15 years I'm truly excited to have now set up my own care company, Right at Home South Cheshire. We are a home care provider based in Crewe, and the way we operate is very different to the vast majority of home care services.

My main motivation for starting the company was based on a poor experience with my Grandad when he needed home care. Unfortunately, what he experienced was irregular times; short visits; Carers were often strangers, not well trained, and they were numerous. Not surprisingly, home care didn't work for him so we ensure we don't make any of those mistakes. Our key differences are:

- Carers are always introduced to Clients
- We match our Carers to our Clients using one page profiles
- We keep the number of Carers visiting as low as possible
- Preferred minimum visit time of 1 Hour
- Our clients choose their times, and those times are regular

- We provide our Carers with an excellent baseline Induction, followed by specialist training when it is needed (more info below)

I stumbled across the NeuroMuscular Centre in 2016 whilst doing some market research prior to starting Right at Home, and was really struck by everyone I met and the culture of the place just felt amazing. Having spoken to a number of the staff and many of the visitors who come to the centre for physio, support, and to socialise it became apparent to me that there was a real lack of confidence in home care companies to provide care and support services.

This is why we have started to work with staff at the NeuroMuscular Centre to work towards having a team of staff who we can confidently call neuromuscular specialists. So far we have worked with Physios at the centre to deliver a specialised training session to a group of our Carers, covering many key areas including:

- An introduction to Muscular Dystrophy; the different types and how they affect the individual
- Specific Moving and Handling techniques
- Basic Physiotherapy techniques
- Oral hygiene and mouth suctioning
- An introduction to gastrostomy tubes
- Releasing air from the stomach
- Ventilator mask and head gear

We are now building a library of resources at our office, where Carers can pop in and continue to build and develop their knowledge. We know there is so much to learn but we are hungry for knowledge and we have a group of Carers who really want to become specialists.

If you'd like to know more or if you wish to arrange a no obligation, free care consultation, please don't hesitate to get in touch with Kirsty or Ben on 01270 257347 or email southcheshire@rightathomeuk.com

My New Powerchair

by Jane Bradley

I had a power chair provided by wheelchair services but it just was not suitable and because Ralph had had surgery and recovering from cancer we really needed a chair with a riser function, Wolverhampton services will never fund a riser power chair so I had to look elsewhere and this is where NMC was invaluable.



Denise arranged for me to try wheelchairs and for Eric and Dave Headford to come to the NMC with a selection of power chairs and they were able to find one with everything I needed and even add features I didn't know were available to suit my needs exactly. Once that was decided I then needed to find what if any charitable grants were available. Once

again Denise came to my aid. She printed out a list of charities online I could approach she actually gave me a list with 30 on!!!

I worked my way through them and found some were just for children and teenagers and some were just for people living in certain areas of the Country but I was able to find 5 I could approach as a starting point.

I also went on a site called "Turn To Us" online and under the section "Grantsearch" was able to find a few more. I contacted the charities and asked for application forms you can either do them online or ask for forms to be posted.

When I first got the forms I found them a little daunting so I took my time and filled them in a bit at a time!! They do ask for income and savings but really that is fair as then the funds can go to those who really need it. Also Denise was with me every step of the way and always at the end of the phone when I got stuck I really could not have done it without her and I know she would do the same for any of the NMC patients.

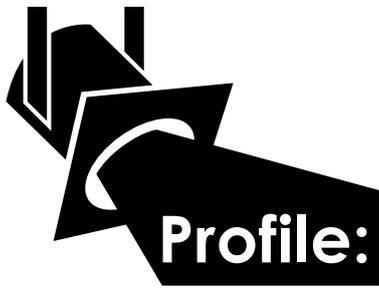
So the wonderful results were that I got all the funding for my £8,746.00 Quickie Salsa M2 Mini !!!

The funding came as follows
IHA Independence at Home £500
Act Foundation £2,000
Florence Nightingale £2,264.00
Tishie Yong Foundation £1,500
Joseph Patrick Trust £2,500

All of these charities are easy to find online. I made contact with a Brenda Yong at the Tishie Yong Foundation and she is a lovely helpful lady. Also Ann Griffiths at the Florence Nightingale Trust was very helpful.

I was quite overwhelmed by the generosity of these charities as I really didn't expect to get all the funding and I am forever grateful. I also made a point of writing and thanking them all for their help which they then thanked me for thanking them so that was nice!

And again my thanks go to Denise for all her support and everyone at NMC who do so much for all their patients what would we do without you all!



Profile: Tony Robinson

I have been attending the NeuroMuscular Centre for over a year which has been a great form of support to me. I live in Stoke Heath, Market Drayton, and come to NMC for physiotherapy every other Monday and I have hydro once a month.

In the past I had owned my own tyre factory, and it was there I had an accident with a grinder some years ago in which I lost strength in my hand and fingers, my MD was also affecting me more and more.

My pain has been more manageable since attending NMC and with active exercise combined with hydro therapy I have cut back on my pain medication. I was taking 1 Naproxen, 4 Tramadol and also 9 Gabapentin a day. To be now off all these medications is a fantastic achievement personally. Exercises at the base of my back particularly help me.

My Muscular Dystrophy has yet to be diagnosed. I have been a "model" patient at the Robert Jones and Agnes Hunt Orthopaedic hospital for 12 years, attending the special muscle clinic on a Saturday morning and have recently had muscle biopsies taken - I'm currently waiting on the results which should shed some light on my type of neuromuscular disorder. I have no family history but probably looking back, I did have symptoms as a child



I was struggling at home with my toilet and bathroom needs. I had previously fitted my own double shower but, there was a step into it and it eventually became unsafe for me to use as my needs had changed. I also relied heavily on my stair lift which was breaking down more often than not. I eventually made contact with social services and asked for some help. I hesitated at first, because I felt tremendous guilt, as after enquiring about my financial situation, I didn't need to contribute to the work they needed to do to keep me safe in my own home. So many other people have to contribute and it took me a while to adjust to how life was for me and not others. The work was completed to my bathroom and I feel much safer. It is a big relief to me and has changed my life and kept my independence to do things. The work on my bathroom took four days and the stair lift half a day as did the toilet. All the work was completed within a two week period.

I feel much happier in myself these days and, enjoying singing in my spare time. I recently raised some funds for the hospital I attend which was a real boost to my confidence. My two dogs Rosie (age 6) and Harry (age 2), are my motivation and inspire me to get out of bed in the mornings. I enjoy taking them out as this gives me a purpose. I will continue to attend the NMC as it is such an inspiring place to be and has really helped me.

Useful Products

by Mark Chapman

Echo Dot

I got an Amazon Echo Dot for Christmas and I love it, it's made my life so much easier. Amazon Echo Dot is a hands-free, voice-controlled device with a small built-in speaker - it can also connect to your speakers or headphones over Bluetooth or an audio cable to play stereo sound to any speakers you choose. Echo Dot connects to the Alexa Voice Service to play music, provide information, news, sports scores, weather and audiobooks. The Echo Dot is always learning and keeps being updated with more features and accessories being added every month.

If you sign up to Amazon Prime, members can also ask Alexa to order eligible products they've ordered before and many Prime products. All you have to do is ask.

Echo Dot can hear you from across the room - even in noisy environments or while playing music. When you want to use Echo Dot, just say the wake word "Alexa" and Echo Dot responds.

You can buy the Amazon Echo or the Echo Dot. The Echo has an in-built speaker, but is unable to connect to other speakers and at £150 is a bit on the expensive side. The Echo Dot on the other hand can connect to any other speakers and at £49 is a lot more reasonable.

It allows me play music and turn the radio on without me having to ask someone to do it for me. All I have to do is say "Alexa, play..." and voilà it starts playing. It virtually has almost every song you can think of. It not only lets me play music but it allows me to control my lights and my TV. I had to buy Philips Hue lights and a Logitech Harmony Hub extra, which connects to my wi-fi and the Echo so that I can turn my lights and TV on and off with just my voice. It cost me a bit to get it all set up but it is well worth it because it has given me independence, just being able to control things by myself its amazing how much confidence it gives you.

Dates for your Diary

NMC's Upcoming Events!

- Stall at Nantwich Food Festival - 1st – 3rd Sept
- Pampering and Prosecco at Molton Brown, Chester - 21st Sept
- Autumn Dinner at 1539 - 29th Sept
- Ladies Lunch - 8th Nov
- Spirit of Christmas - 24th Nov

Editorial Team

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

Thank you to everyone who has helped and contributed to this edition!

Next Edition

The theme for the next edition is "Things to do during the winter months". We will be having a One Voice Live event about this theme in September or October. The date will be posted on the One Voice notice board in the seating area, so please come and talk with us there.

Finally

We welcome any articles or suggestions on these or other topics. Please note that the deadline for all articles for the Autumn edition is Friday 13th October.

Please email: jon.mcvey@nmcentre.com

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