



The Unimaginable Pandemic Year NMC's Social Accounts 2020

Contents



03 Welcome to our Social Accounts

04 Living Through the Pandemic

06 How did NMC Respond and Navigate these Challenging Times?

08 Chief Executive Gives Thanks

09 30 Years of the NeuroMuscular Centre

10 Size and Scope of NMC Community

12 What are Neuromuscular Conditions?

13 How do we Compile our Social Accounts?

14 Mission, Objectives and Values

16 Support

24 Connect Up

34 Physiotherapy

43 NMC Design+Print

56 Training and Development

64 NMC Finances and Covid-19

68 Transition

90 Conclusions



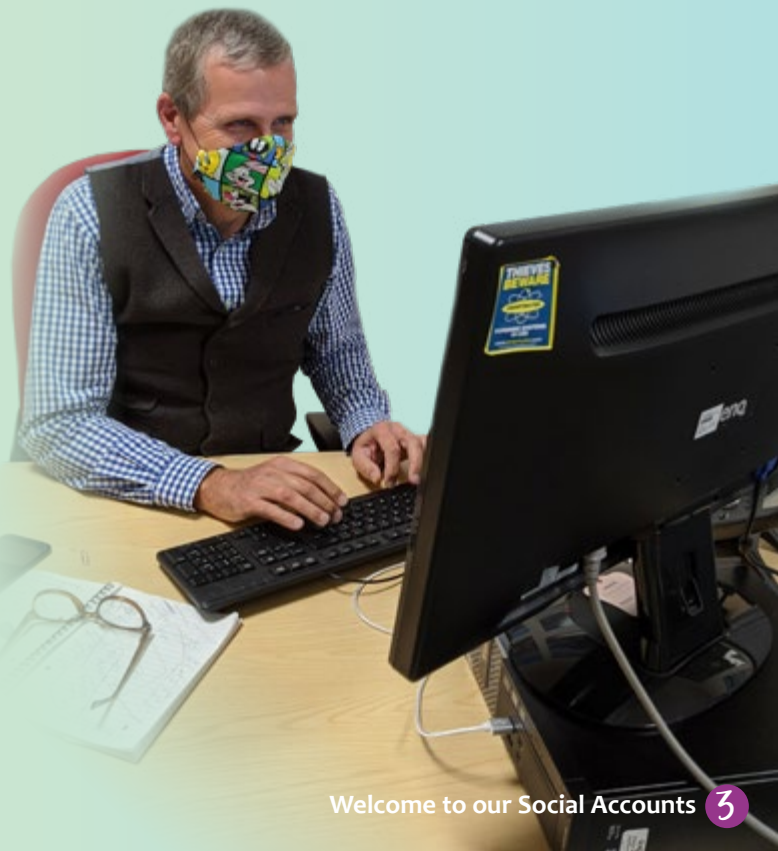
Welcome to our Social Accounts

Our Social Accounts are totally different this year. We have chosen to simply tell the story of what we have done.

The story of how that response has sought to meet the needs of our community of people affected by muscular dystrophy and neuromuscular conditions in new ways that respond to very new circumstances.

Our aims and objectives as a charity have always been at the heart of everything we have done or tried to do. We hope to demonstrate that in the Social Accounts.

Above all we hope that having read these Social Accounts you feel you understand the scale, size and nature of the impact of NMC in this extraordinary year. We have used a variety of tools and individual challenges to seek to measure and show that impact. For example, we asked a group of our community to create a work of art to express NMC's impact on their lives this year. We have never used tools and techniques like this in creating past Social Accounts, but we felt this year that seeking feedback from people should be fun and creative. We concluded that filling in forms and surveys was not conducive to enhancing our ambitions to be a positive force on individual wellbeing in tough times.



Living through the pandemic

It is important when reading these Social Accounts, or indeed any history that is written of the pandemic, that we stress how uncertain we were at each stage about how the future would pan out. We should try to remember that each week held different surprises and challenges. We all believed that the March/April wave of infections would pass and that would be the trigger for normality to return.

Some aspects of life and societal change in 2020 that are worth remembering;

- When many in the NMC community were asked to shield at home no one could have predicted for how long that would go on and how fears and anxieties developed among many of those shielding about how to re-integrate when that period expired.
- We had no idea how long children would be off school.
- Washing hands and staying 2 metres away from other people became the nation's priorities.



- April saw empty skies with all planes grounded. Empty roads with hardly anyone going anywhere.
- We clapped on our doorsteps for those who wrestled with caring for those suffering with the virus, and for those who bravely worked to keep us safe.

- Rules in Wales started to diverge from those in England which we hadn't expected. In time over the summer people would be told they couldn't travel between the two nations with some very limited exceptions.

- We wondered where and why all the toilet rolls in the land seemed to have been snapped up.

- We all learned how Zoom was to change our habits when meeting friends, family, or workmates.



- Second only to toilet rolls was an insatiable (and initially unmet) overnight demand for Personal Protective Equipment (PPE).

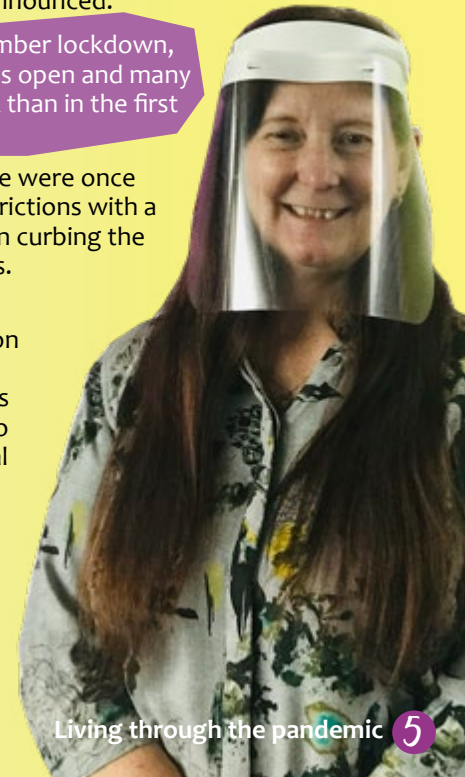


- We adjusted to a very different approach to shopping – no longer a leisure activity but now an unwelcome and uncomfortable chore. For many there was a period of uncertainty and frustration as the cogs and wheels of the supermarket home delivery services slowly clicked into action.
- Many people were furloughed or had people in the household who were furloughed. People had reduced income, and many had money worries.
- A daily hour of exercise was allowed – our little bit of freedom and fresh air eagerly snapped up by a captive population.
- Each day we were bombarded with graphs and statistics and we made various personal judgements about whether things were getting better or worse.
- Restrictions were eased from the end of July and August and this seemed to offer many a chance to relax a bit and enjoy just a little of what they had been missing. A few ventured on holidays and “Eat out to help out” encouraged many to dine out for the first time in months.
- September saw signs of the virus returning in force although few were planning for the full blown second wave that materialised.
- Mask wearing became the unimaginable new norm.

- There were tiers with complicated levels of restrictions that were interpreted and understood to different degrees.



- A much publicised “Rule of 6” was launched to restrict our social contacts.
- There was the end of the furlough scheme in October and then, after it had finished a surprise extension to March 2021 was announced.
- There was the November lockdown, this time with schools open and many more people in work than in the first lockdown.
- In early December we were once again in tiers for restrictions with a strong focus again on curbing the pubs and restaurants.
- Christmas plans and arrangements took on new significance and challenges as families and friends sought to live within the special rules on gatherings over the festive period.
- 2020 ended with the announcement of a 3rd full lockdown



How did the
NMC
respond to, and navigate



these
challenging times?

When we all went to bed after, perhaps, a glass of bubbly last New Year's Eve 2019, we were, as always full of good intentions, bold plans and great hope and optimism for 2020.

Never in our most outlandish dreams did anyone imagine that 2020 would unfold in the way it has.

NMC had enjoyed an extraordinarily successful 2019. There were so many new things going on, so many new people joining our community, so much energy and vibrancy and vitality.

Our finances were strong and our levels of confidence and optimism for 2020 and beyond were high. It seems a lifetime

ago when the Centre was buzzing with the excitement of our monthly vibrant Welcome Days for new people. Connect Up was the focus for regular social gatherings, activities and trips. The car park was full to overflowing and Physio was routinely seeing well over 300 people a week for treatment.

Then overnight pretty much everything stopped EXCEPT.....

The love, warmth, friendship, expertise, determination, skill, and sense of close community! We had all that in abundance and it has carried us through. It has taught us new things and it has enabled us to still be optimistic and realistic about the shape of NMC in months and years to come.

Fundraising events were, one by one, cancelled as rules and people's fears made social gatherings a no-go area. Our income streams were hugely challenged. It was extremely

worrying, and it remains uncertain and concerning. But inventiveness, some very tough decisions to cut cost, a shared determination and generosity has seen us through.

Although we were forced to change the way we did things at work (and at home and with our friends/families), it was not all negative. We embraced new attitudes, values, and approaches. Many of these will be good societal shifts and great new skills, and many seem likely to be sustained post pandemic.

The period of the pandemic crisis was broadly split into 4 phases at NMC. It is important to stress that the Centre has stayed open throughout. We only shut for a few days at the end of August to facilitate a complete deep clean prior to physiotherapy restarting.

Our 4 Phases

- 1 Keeping in touch, providing advice, and urgent help
- 2 Enabling virtual and real social connections
- 3 Physiotherapy and exercise
- 4 Reshaping the charity for changed times



How did NMC respond and navigate these challenging times? **7**

Chief Executive gives thanks



My warmest thanks to all our loyal and lovely supporters, our volunteers, our staff, and our fantastic community.

You have all played a part in getting us through the crisis to this point. NMC is strongly placed to cope with, thrive on, and bounce back from all these challenges and obstacles. There are more tough months ahead, but one thing is crystal clear; our work is needed like never before. Our role in people's lives has never been more clearly demonstrated and so we just must get through this, and we will.





30^{years} of the NeuroMuscular Centre

NMC is now in its 31st year of providing our unique combination of life enhancing opportunities and support for people affected by neuromuscular conditions. We had exciting plans to celebrate our 30th birthday milestone in April 2020 but all that had to be shelved because of the pandemic.

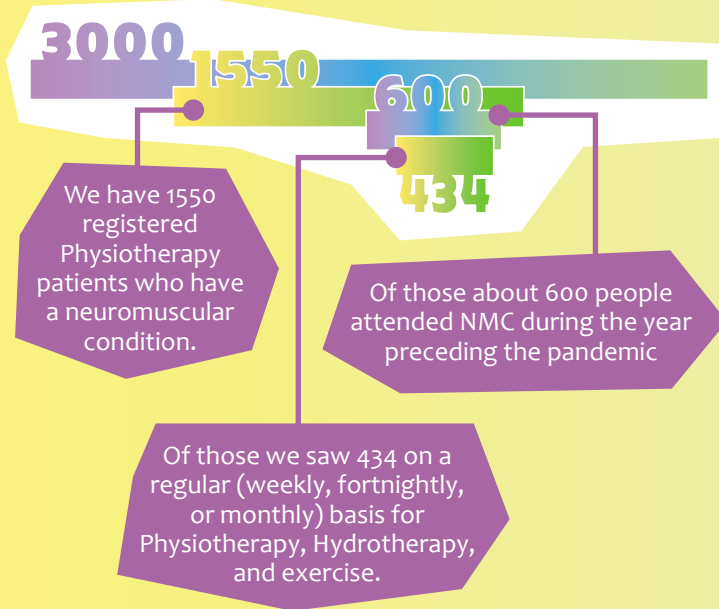
The NMC was 'born' in 1990 out of a dearth of services and opportunities for (predominantly young) adults with neuromuscular conditions including muscular dystrophy. Affected families

feared the lack of service and support. It was a determination to address this, combined with an equal resolve to create opportunities and enable fulfilling and productive lives, for those living with these conditions, that led to the foundation of NMC.

This new independent charity began to offer specialist Physiotherapy services on a very small scale, funded initially by one of the first Comic Relief Grants. Demand for services grew steadily and so too did NMC's resources.

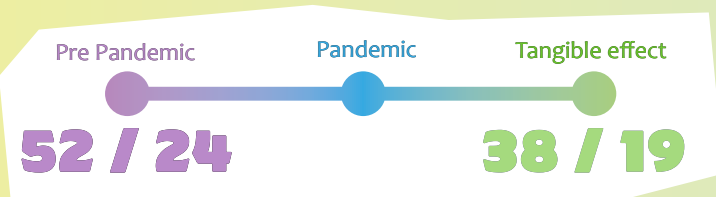
Size and scope of NMC community today

NMC is a community that totals over 3000 people.



We estimate that we tangibly and demonstrably support 700 Carers of individuals with a neuromuscular condition (this figure is almost certainly much higher) and that we have a close relationship with 300 of those Carers. It is difficult to accurately measure the reach of our support to Carers, many of whom do not actually attend the Centre on a regular basis but are perhaps supported remotely by phone or through the NMC's provision of breaks for those with neuromuscular conditions.

NMC Staff numbers



NMC has a total staff team of 38, of whom 19 have a neuromuscular condition. Last year we had 52 members of our staff team and 24 staff members with neuromuscular conditions. A very sad and tangible effect of the pandemic has been our need to reduce the size of our staff team.

The reduction in size of the team was achieved largely by not filling vacancies as they arose and enabling in one case an extended secondment. But we had to also make 5 team members redundant and that was a dreadfully sad time for us all.

47 people with a neuromuscular condition tried out or undertaken Training with the NMC in the year prior to pandemic.

The 350 volunteers that support the NMC by giving their time, energy, skill, and expertise are also very much an essential element of our community. Sadly we have had very limited scope to draw on their skills and energies during the pandemic.

In normal times we have people come from all over the UK, from a wide variety of backgrounds and circumstances. We also have a small number who come to us from continental Europe, and even further afield, on a regular basis – highlighting the absence of comparable services elsewhere in the UK and Europe.



Whilst NMC has a largely adult focus, over the last 7 years we have introduced Short Breaks and Support services for younger teenagers to help them, and their families, successfully navigate the changes often referred to as 'Transition'.

Transition describes the move from childhood to the adult world. This often includes changes to key clinical, educational, and social work support.

More than 30 years on from the founding of NMC, there remains a dearth of Specialist Neuromuscular Physiotherapy service within the NHS. What NMC offers, in terms of our Physiotherapy service, is a lifetime provision. We are there for an individual through all the different stages of the condition. Demand for all NMC's services continues to grow, highlighting the gaps in public service provision for people with neuromuscular conditions. There appear to be growing challenges getting help and support from Social Services, NHS, DWP and housing provision. Creating a great quality of life for those with neuromuscular conditions and those close to them is challenging.

What are neuromuscular conditions?

Neuromuscular conditions (which include the muscular dystrophies) are a group of disorders characterised by progressive muscle weakness and loss of muscle tissue.

These are relentless conditions with progressive and ongoing deterioration of the muscles. They are usually of genetic origin (hereditary).

Onset varies; birth, childhood or adulthood. At NMC we see a lot of people for whom the condition has only become disabling in adulthood.

There are more than 150 forms of neuromuscular condition. We work with the definition and range of conditions used by Muscular Dystrophy Association of Canada because leading clinicians with whom we work feel that it is appropriate, and it has the most comprehensive and expanded list.

Some of those conditions most commonly seen at NMC are;

- Spinal muscular atrophy
- Charcot Marie Tooth (peripheral neuropathy)

- Facioscapulohumeral dystrophy
- Myotonic dystrophy
- Limb girdle Muscular Dystrophy
- Duchenne Muscular Dystrophy
- Becker Muscular Dystrophy

They affect both genders and all ages, except the last 2 on the list above which almost always affect males only.


There is no cure at the moment, but Physiotherapy delays the degenerative process and deconditioning of the muscles.

Physiotherapy can help people stay stronger for longer, maintain flexibility and treat pain sometimes associated with the condition. Practical help and support can help people stay positive and maintain good all-round well-being. More than 70,000 people in the UK have a neuromuscular condition. We estimate that 40,000 of those are adults over 18. This estimate is based on the knowledge and experience of the NMC clinical team and sense-checked with leading Clinicians in the field nationally.

How do we compile our Social Accounts?

Unlike financial accounts, there are fewer definitive figures to which we can refer. Social Accounting is a subtler process where the views of our stakeholders are the prime source of information. In the previous 13 years of NMC completing an annual set of Social Accounts we have collected feedback via questionnaires which aim to elicit responses relating to specific areas we are targeting in any year. We normally change the targeted areas from year to year to get a complete picture over a three to four-year period.

This year we have not done surveys or questionnaires. We sensed there was no appetite for what might well be perceived to be dull surveys. We felt that everyone has needed a boost this year; an opportunity to do something enjoyable and filling in survey forms felt like the antithesis of that. As a result of these thoughts, and very much as a one off, we have tried alternative innovative approaches to get feedback and thoughts about NMC's impact. We asked our Graphic Design students, for example, to produce a piece of artwork that encapsulated their feelings towards NMC and how they felt we had impacted on their pandemic life experience.



**...we have tried
alternative innovative
approaches to get
feedback about
NMC's impact**

We have sought perspectives from a range of key stakeholders and figures in and around the organisation and incorporated them to form a documented history of NMC's activities, responses, feelings, and impact in the pandemic period of 2020.

We hope that this change of tempo and approach will complement our normal Social Accounting methodology and approach. We hope you will glean a real sense of our year and how our community felt individually and collectively about the role of our charity in their physical and mental health and wellbeing, as well as their wider enjoyment of life in general.

This set of Social Accounts relate to the period March 2020 to December 2020.

The narrative of the Accounts is written by several authors. Our whole approach to Social Accounting is to embed it in our daily working lives and so contributing elements of to the Accounts each year is part of many people's role here. The contributions are gently edited so that the whole document reflects a certain degree of NMC 'house style' but equally the reader will detect different styles as they move from section to section. We hope this gives character and personality and does not confuse or irritate.

NMC Mission, Objectives and Values

Mission

NMC works together to support people affected by muscular dystrophy, creating an environment where full potential and optimal well-being can be achieved through employment, training and physiotherapy.

Objectives

- To enable adults with neuromuscular conditions to maintain or improve their physical, mental, and emotional well-being.
- To provide a range of services, opportunities, and support to improve the quality of lives for individuals affected both directly and indirectly by neuromuscular conditions.
- To provide adults with neuromuscular conditions with opportunities to lead fulfilling and economically productive lives
- To enable people with neuromuscular conditions to expand and fulfill their potential

Values

The NMC has 8 values. These were last reviewed and relaunched to our community two years ago.

1. We are a caring organisation with an open management style which values and respects individuals
2. We enjoy what we do, creating a warm, welcoming, and positive environment
3. We are an inclusive community which is informed, influenced, and guided by people with neuromuscular conditions
4. We create and maintain an environment where disability is no barrier to achievement
5. We are innovative, creative, and ambitious
6. We celebrate our successes and achievements
7. We believe it is important to create a high level of understanding of what we do in the wider community
8. We have the highest ethical and professional values and standards

Simply knowing we were here and that we remained open throughout was reported by many in our community as the single most important source of hope in their lives



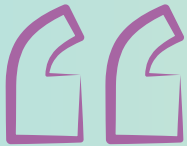


Support

FEB 2020

Life before Covid came

Denise Boyall (Head of Support and Training) reflects on the year as it has unfolded for those in NMC's community



...our community had more of the qualities of resilience, organising, mutual support and the ability to adapt than many others

Reflecting on life within the NMC community in February 2020, memories are of a vibrancy, an excitement and ambition at the centre. 2019 had been a successful year with new opportunities, many personal achievements and energy was high.

2020 arrived with great hopes for a memorable 30th year.

It will end as one of the most memorable years in the NMCs history.

Plans were abundant, a mixture of events for celebration and fun combined with opportunities for challenging life impacting activities. A dream to acquire an NMC house was in its early stages of fulfilment.

With an abundance of calm social interactions, chatter, laughter and a warmth of friendly care and concern



NMC was able to offer a warm welcome to 40 people per day and 10 new people each month.

“There’s always so much going on. It’s truly amazing, helpful, joyful and heart-warming! Not to mention great fun!” This summarises the thoughts of someone with a neuromuscular condition describing the NMC.

The problems being faced by NMC were the sort of good problems for any community to have;

- How can we make more spaces in the car park?
- How can we cope with such a large group participating in the DoE expedition?
- How can we ensure new people are being welcomed in the best way possible?
- How to extend support to more families and carers?

Social isolation and the negative impact which this can have on people was a theme of national debate and discussion. For over 2 years the NMC had been researching the impact which a neuromuscular condition had on people’s opportunities to enjoy the amount of involvement in social and community life they would wish for. Experiences of our community showed barriers to social inclusion to be broadly 3-fold:

- 1 Personal such as pain, fatigue, low energy levels, low confidence, anxieties about going out alone, and financial.
- 2 Environmental concerns about practical difficulties of accessibility.
- 3 Societal attitudes, attitudes of family and friends and how others in the wider community would respond to them.

The NMC Connect Up project to reduce social isolation was being shaped to give strength to more people to collectively overcome these barriers and plan social opportunities within the NMC and beyond in local communities.



MAR & APR 2020

A country in lockdown

Overnight the country is locked down, everyone is experiencing restrictions, barriers, and a loss of freedom. Everything is having to be planned, spontaneity is not an option and fear is controlling everyone's actions.

Some parallels are showing with the descriptions which people have given when asked about the ways their lives are impacted by living with a neuromuscular condition.

Social isolation and shielding from human contact – now the things to do and being advised by Government and NHS as a priority for health. Only a few days earlier the national agenda had been to ensure people were never socially isolated from contact with others due to the harm caused to the quality of peoples' lives.

Suddenly everyone was restricted, a level playing field for all, but on this occasion perhaps our community had more of the qualities of resilience, organising, mutual support, and the ability to adapt, than many others.

Amongst the tragic headlines and sadness of the unfolding pandemic, Social media focused on ways society was caring for each other. The NMC community, used to caring and sharing, turned to our own social media platforms to extend contact with each other and make a significant impact on people as these comments show:

It lifts my spirits to see a group of people that are all so willing to help and support one another, we really do have a special community.

We are all there for each other and such a wonderful community

I think the way we have all come together virtually is amazing. The support is overwhelming.

I find ongoing encouragement and support has had a much-needed positive effect on my anxiety and wellbeing. It means a lot to know that they (NMC) are there as they are often the only social contact I have.

Although the NMC building was lonely with only a small number of people entering its doors, its phone lines, computers, and iPads were buzzing.

As the NMC team ‘adopted’ families to keep contact with, it seemed the physical restrictions of travelling and socialising were impacting less on those with muscular dystrophy than might have been anticipated. Keeping safe and healthy was the priority, solving the practical dilemmas of food deliveries, whether to retain care teams or rely solely on family care were greater sources of concern.

For the IT savvy in the community this was a time of playing to strengths and the use of technology for Zoom and Teams meetings was welcomed positively as physical access barriers were removed. For others this was a daunting prospect to consider.

The NMC GameChangers (young people in the Transition and Training teams) were particularly keen to ensure people could continue to participate in their work and social activities whilst not able to physically meet at the NMC. Having a sense of purpose has had a very significant impact at a time of uncertainty and change.



AUG 2020



Coming out of lockdown 1

Society moves on again except...

Along with the new Covid terminology of social isolation, social distancing and, in these unprecedented times, came a new word to describe people with long term health conditions – vulnerable! One impact of this, as the first lockdown ended, was that many viewed the opportunity to re-enter a ‘social distanced’ society with a great sense of anxiety and fear.

Not everyone felt safe or able to participate in the local daily exercise being advised. Renewing social contact, which had been so desperately lacking, became a fearful prospect for many people. Instead of friends being a force for good they suddenly became a potential threat with the risk of sharing a most unwelcome virus.

The beautiful weather, NMC meadow and trust of the NMC community combined to remove some of these anxieties and enable the first opportunity for people to return to NMC and meet in small groups. These were enriching and

emotional visits for everyone. For many it was the first time they had left their own homes since March. Social distancing, temperature checks and masks might have changed the style of welcome people received, but it did not affect the power of being amongst friends and the number of smiles behind the masks in the meadow.

Many family’s dynamics changed during lockdown. Many were furloughed and the change to home working and closed schools meant homes saw families sharing more time together. For some this was enriching, but the restrictions also brought tensions and pressures especially when families chose to limit the number of people coming into their homes to provide care and took over this role themselves.

Fatigue and frustration were taking a toll and cracks appearing in some relationships. The united societal view of ‘we’re all in this together’ was changing. Those with ‘vulnerable’ health were encouraged to remain very vigilant and continue to shield themselves as much as possible while others were enjoying new freedoms including time on - (sometimes packed) - beaches.

Talking Therapies have been offered at the NMC for a couple of years with opportunities for anyone with a neuromuscular condition or their family members to spend private time talking to someone impartial to their life challenges. Social distancing and shielding took away the opportunity to continue physical meetings but the impact

of this support was known to be too important to lose. Adapting their approach, Listening Ear (who work with NMC) changed to phone calls, **zoom** or Facetime to offer a much-needed listening ear and support the new challenges arising from the vicious virus.

AUTUMN 2020

Return to work with masks

After five months of restricted living, working from home and home schooling, society 're-opens' with the return to school and university. Masks are the new 'must have' fashion accessory and NMC crafters once again rise to the challenge by producing a fantastic array of handmade masks for every occasion.

The resilience, adaptability, and determination of the NMC community to overcome barriers is apparent in this quote: "I've loved learning about other people's passions and hobbies - I get a buzz from others joy and enthusiasm and it's encouraged me to try out a few new hobbies or research new topics too."

Returning to more opportunities to mix with people at the NMC has had a very positive impact on people and these comments show that the time spent 'virtually' mixing with others has strengthened and enabled new friendships to form.

I don't think we would have crossed paths much if we had been in the Centre. It's lovely to catch up at art club, mindfulness and staff meetings and form a new friendship in these strange times

I've had the opportunity to get to know so many new people on this group and I hope that I can now call many of them friends.

I only said yesterday it's been great all the things throughout so far, getting to know people, doing challenges, learning new things. I've loved it.

When the Connect Up project was introduced to the NMC in 2018 one of its great achievement was to hold a series of workshops to explore the impact of a long-term health condition on working life. At this time, the group described the major impacts of a restricted working life was a feeling of low self-esteem, lack of purpose and narrowing social involvement.

Throughout 2020 many of the NMC community have adapted their working lives to use technology to work from home.



As we faced a second lockdown, we have learned a great deal. The NMC had embraced the on-line world and plan to keep a mixture of online and real as we go forward.

We knew how to approach this 'new' lockdown routine, we knew the slogans of 'hands face space' and once again 'we're were all in it together again.'

Less fear this time, more acceptance with a hope of a vaccine. Still challenges, still frustrations, anger and personal pain and sadness.

Here is a selection of comments from our younger members of the community sharing a hope and optimism that the year has also brought them some new experiences, friendship, and fun:

I was thinking earlier how our wonderful NMC Community will continue to support us, and each other, during Lockdown no 2! Looking forward to NMC activities this month.

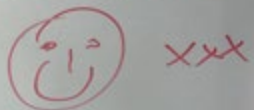
The SpeakEasy sessions are about getting together with other people in the group and talking with each other and playing out scenarios that will help us in the future like talking on the phone to important people, also we do speaking presentations to the group. By doing the sessions it will make me feel more confident about speaking in public, as I do get stage fright when speaking in a large group.

The SpeakEasy facilitator felt it would be difficult to replicate the Face-to-face experience using video conferencing, but our young people persevered by having a brainstorm and putting something together that would work. I can honestly say that video conferencing worked out better than face-to-face because some of our participants were more comfortable and came along in leaps and bounds literally. It was a phenomenon.

Learning about self;

The video conferences were good, we had so many laughs! I think this helped me to keep being social because I tend to reclude myself. I feel like I may have been more social during lockdown than I would have before.

WERE OPEN FOR
VIRTUAL HUGS
AND KISSES



Pleasure of helping others;

Live in The House was groundbreaking for NMC. This was an online music festival and turned into a fundraiser too, generating over £1,000 and this is all credit to the NMC Gamechangers. Personally, it provided a positive distraction from isolation and I can't wait for next year's festival!

I really enjoy the Tuesday chats to it has been lovely to see people, I have enjoyed making my snoods and mitts. the people who have had them have benefit, and helping the NMC with the donations from the sale.

I have previous experience designing webpages especially during the development of the NMC website, but these Live in The House pages allowed me to be more creative and achieve something on my own. I enjoyed designing a webpage around the festival and carrying out feedback from the group. Being part of a team with everyone completing tasks set around each other's strengths.



Connect Up

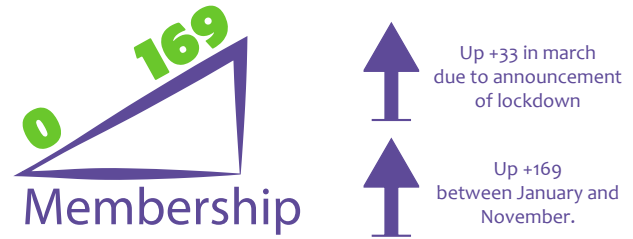
This is the NMC project that aims to reduce social isolation. The challenges of the pandemic brought renewed focus on the essential need for this work.

What did Connect Up organise and do in their efforts to provide structure, social connection and nurture friendship? The lockdown imposed to control the spread of the covid-19 virus has proved challenging for all and especially for many of our participants already impacted by social isolation, and also within the clinically vulnerable shielded group. However, this has provided some new opportunities to try new ways of working. To ensure our community were able to stay connected during the lockdown period we have

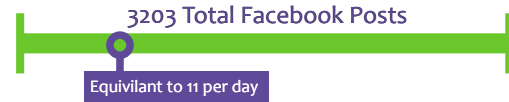
continued to provide opportunities online via our Facebook group and also continued to contact people via e-mail and telephone.

The overall statistics for the Facebook group for 2020 are as follows:

Membership 0 in January to 169 by November. There was a sharp rise in membership from 33 in March aligned to the announcement of the lockdown.



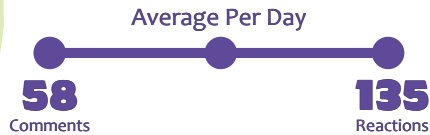
There have been a total of 3203 posts, equivalent to 11 per day



Posts have generated 16906 comments and 39110 positive reactions.



That is an average of 58 comments and 135 reactions per day respectively.
During 2020 there were an average of 140 active members each day.



In addition, 90 people participated in organised activities. The total number of engagements across all activities was 295 (multiple attendance at weekly clubs etc)

We set out with the aim of engaging as many participants as possible in a wide variety of activities.

A weekly programme of events and themes for each day has been established and provides an opportunity for people to meet in the virtual world as well as providing a routine and incentive for others to break up their week.

MON Art Club is a 45 min zoom meeting every other week. Art and craft related posts made each Monday to encourage people to get involved and share their creative makes from painting to cross stich, knitting, pottery and crochet amongst others.

TUE Gardening - a very detailed and interesting blog full of hints and tips is now available online. It includes information to help people in their own gardens as well as updates about the NMC Garden. New articles every Tuesday and encourage conversations about gardens, flowers, growing veg, bird watching and generating good engagement.

Our Tuesday Chat online coffee morning brings people together to share ideas and catch up with friends.

WED At 11.30 each week the NMC Therapies team provide an online exercise class and offer advice on any queries people might have to stay fit during lockdown.

THUR A **Zoom** crossword group meets every Thursday morning to tackle a quick and cryptic crossword and provide an opportunity for a chat over a cup of coffee.

Thursday is also our day for focusing on mental health and a series of mindful mediations have been produced and shared including some guided mediation events.

FRI

Friday is dedicated to food. A blog has been established to share ideas and themes have included healthy eating, cake and cocktails, recipes for substituting ingredients during the lockdown flour famine. An online picnic and afternoon tea were held via **zoom** to enable people to connect.

Our Read and Connect book Club also meets once a month on Friday via **zoom** and this has proved so successful that we intend to continue to offer an online opportunity to participate when lockdown is over.

WEEKEND

The weekend is about fun and games. The NMC design team and students have created colouring in sheets and crosswords, which we shared on the website and posted out to the group. Online quizzes have been shared by an increasingly large number of people which has been good to see.

There are also a range of one-off activities providing opportunities for participation. These are as diverse as a Macarena challenge in celebration of the NMC's 30th birthday, a postcard design competition, poetry group, penpals whereby people are matched to send letters and e-mails to each other, a tai chi DVD mailed out and other DVDs from the NMC collection available to borrow during lockdown.

The result has been that despite being apart we have

enabled people to maintain contact and this has been demonstrated in some positive feedback including the following from our Facebook group:





'It's nice to know that I still have a connection to NMC here as I miss my friends so much. I've loved Pete's quotes the gardening pics and all the cute pets. Lockdown takes its toll and coming here helps....'

'I have really enjoyed getting to know people, sharing experiences, hobbies and interests.

Great banter, had fun at the Bingo, Gordon's quiz. Enjoyed doing a poem and some limericks, following Pete's tasty treats. It has encouraged me to take photos of what's growing in my garden. I feel that even though we have not seen each other in the flesh we are so connected virtually! A great platform for friendship, food and fun Thankyou NMC xx'

'I've enjoyed getting to know people I don't always get to meet at the NMC visits and getting to know what they enjoy doing and hobbies, likes and dislikes, I feel like I've got an insight into everyone's lives. It's been brilliant for this lockdown'

'Friendly faces on Zoom, friendly chats on the phone. Posts that keep you going and make you smile. Always a listening ear...knowing there are people that care. Thank you xx'

Due to the Covid pandemic our initial plans have had to change and we've developed new ways to enable our community to come together for social engagement and to connect with their peers.

We have established a private Facebook group to provide a focus for sharing information, advice, activities, discussion and support for our NMC community.

Comments received from members of the NMC community when asked about the impact of Connect Up during the pandemic:

'I've been enjoying interacting with people in the general facebook group chat - friday food, silly memes etc and I've also really enjoyed getting involved in zoom book club. Thank you all for making it possible!'

*'Peter Marley's delicious fudge - a summer highlight'
'Thanks for keeping us cheerful'*

'We are all there for each other and such a wonderful community xx'

*'It's all appreciated'
'Positivity keeps us on track'*

'I only said yesterday it's been great all the things throughout so far getting to know people doing challenges, learning new things I've loved it x'

'I don't think we would have crossed paths much if we had been in the centre. It's lovely to catch up at art club, mindfulness and staff meetings and form a new friendship in these strange times'

'There's always so much going on. It's truly amazing, helpful, joyful and heart-warming! Not to mention great fun!'

'I was thinking earlier how our wonderful NMC Community will continue to support us and each other during Lockdown no 2! Looking forward to NMC activities this month. Thankyou'

'I have loved writing the blog and have learnt lots from doing it too. X'

'I think the way we have all come together virtually is amazing. The support is overwhelming.'

'It lifts my spirits to see a group of people that are all so willing to help and support one another...'

'I have thoroughly enjoyed and valued the virtual company of others in the NMC Community. I feel I have got to know people a lot more during lockdown through general chatter, cooking, and gardening club... Massive thanks to everyone who has worked so hard to keep the NMC Virtual Community going.'

Connect Up provides a first trip out

During August and September we were able to invite small groups of people (in line with government guidelines) to visit the NMC for socially distanced meet ups in the NMC meadow.

A total of 78 people took the opportunity to visit and the overwhelming response was very positive. People commented on how much they had enjoyed being back at the NMC and for many of the visitors it was their first trip out for several months.

Comments received included:

'It was lovely to meet up with friends'

'Enjoyed our visit, good to have a trundle round the grounds'

'Looking forward to being more involved, will give anything a go!'

'Count me in on future activities'

We held some 'one-off' events, including a bingo evening that proved very popular with 30 people from our NMC community and their friends and family taking part.



Fishing Club

One of the thriving elements of the Connect Up programme has been the Fishing Club. During the pandemic they took the opportunities that arose to go fishing in a safe and socially distanced environment.

“In August and September we were able to hold 2 fishing events at a local fishery. 6 people attended each session and thoroughly enjoyed their day in the sunshine. What follows is Shaun’s account of the day and the impact on him;

It is 9.30am, the warm sunshine is already glistening through the trees and shimmering across the surface of the pool between the reeds. Suddenly, a fish breaks the surface with the flick of a tail and the excitement and anticipation of the day is already starting to build! Who will draw the best peg, and who will catch the biggest fish? The launch of the NMC Fishing Club has been absolutely fantastic and brilliant enjoyment for us all!! It is a wonderful opportunity to be with, and make new friends, and a truly

great way to spend the day. There is nothing better than being out in the fresh air and close to nature, and the catching of a fish is just the bonus!

The smile on my face says it all with the landing of this fantastic mirror carp!!

The conversation over lunch about the one that got away and the excitement for the afternoon and who may land the biggest catch of the day, what could be better!

It is a great way to improve your mental and physical wellbeing, and it has certainly helped me to de-stress and just being near water seems to lower the anxiety levels, and instils a sense of calm!

It is surprising just how much of an exercise workout it also gives you and it certainly helps improve your fitness. The constant casing off and winding back in,



especially with the success of a hooked fish, and, with the battle that ensues to make sure it is landed successfully, I find it really does engage the shoulders, back, arms and my core by the end of the day!

The opportunity of just being outside in the fresh air on a lovely warm day and taking notice of the beautiful environment around you really improves your sense of wellbeing, and level of concentration and appreciation of the fabulous wildlife around.

None of this would be possible without the support of NMC, and the wonderful help and support of everyone involved in organising and arranging each event, the preparation and serving of refreshments on the day, and the angling club volunteers who personally support us through the day and offering their own expertise.

These events have taken me back to my childhood days and have personally helped me in developing my own fishing skills. They have also inspired me to now go fishing more regularly, and I am now planning to purchase my own fishing equipment.

It clearly takes a lot of very hard work and effort to plan, prepare, and organise each fishing event and it is very much appreciated!!

These fishing days have had an extremely positive impact on me and I am always looking forward to the next organised event. I just hope and pray that we can continue to hold more fishing events in the future!!”



It is a wonderful opportunity to be with, and make new friends, and a truly great way to spend the day





Physiotherapy

Bryn Edwards, Therapies Manager, reflects on the impact of the pandemic on physiotherapy, and the impact of the Physio Team on NMC's community

The NMC therapies team has always been one to overcome difficulties and remain at the forefront of treatment of those with neuromuscular conditions. 2020 presented the biggest challenges we have had to face since the start of the NMC in 1990.

The NMC therapies team had been seeing 600+ appointments every month for those in our community. We would be providing hands on therapy, exercise and activity, advice and assistance with assessments. The gym would be full, 5 people, working hard, music pumping. There would be a buzz coming from the department with all treatment "plinths" in use and conversations being bounced around the room. Those using our service would make strong,

long lasting friendships going to the gym together and following it up with a cup of tea. NMC Therapies department was a warm, welcoming, friendly place.

As we entered spring, the team was riding a wave of this energy. With multiple new team members more service users were getting treatment than in previous years. On March 16th all of that came to a very sudden halt. The NMC decided that the vulnerability of our community to this new virus meant we could not continue to deliver our service. Overnight our regular 500 service users had no provision of treatment. Overnight a team of therapists were unable to do what they knew and loved best. And one week later the rest of the country followed. We were lost, our community was lost.

We had to find a way to stay in contact and support the NMC community which was the focus of **Phase 1**. The ingenuity of the team immediately became apparent. It was decided that all of our service users should be assigned into an NMC Virtual Family with a NMC staff member as family leader. The role of these individuals initially was to identify those in crisis and address it where possible. It also allowed us to give health and fitness advice over the phone. People were so grateful for this, in a time of huge uncertainty the

NMC remained constant. Many other health services were put on hold with their staff being redeployed to focus on the COVID-19 pandemic, people were not being spoken to or heard regarding their condition. The regular contact from NMC could consist of an educational discussion over stretches but equally it could be a friendly chat to see how people are doing. During the first lockdown we were that friendly voice on the phone.

The next step was setting up a much-improved virtual presence. NMC Therapies already had a somewhat successful series of videos on stretching and massage (available on YouTube), but to ensure our community had something to keep them motivated and active in the first national lockdown. We filmed a series of workout videos catering to all levels and focusing on all body areas. We also started doing a weekly live workout on Facebook with a variety of our staff taking on the role of Mr Motivator! This was a completely new approach for the NMC and proved to be extremely successful. The ability to talk to a group of NMC community members every week during an exercise session was invaluable. Each session was real fun, both working out muscle groups with the exercises and the respiratory system through laughter.



It also provided an anchor for each week, there was a real excitement and anticipation for each session. It increased our reach also. We have viewers on our Facebook videos from Turkey, New Zealand, Israel! There are over 8200 views on workout videos alone. NMC is a Centre small in physical stature which has always had huge national impact, this has now expanded further, our services were more accessible than ever.

This phase ran until May and proved to be essential in many ways. As with many people around the country, the mental wellbeing of the NMC community was suffering. The idea of any more face to face treatments in 2020 was laughable and keeping in touch with so many people was not easy, but for many it was the only interaction they were looking forward to each week. We were able to identify those who were in desperate need of support and act on that with skilled and specialised colleagues across the charity.

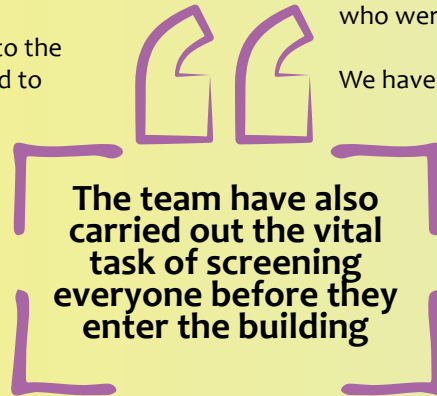


We addressed numerous injuries and changes in symptoms. We provided advice and possible solutions meaning injuries would begin rehabilitating, and individuals could resume function promptly.

One of the impacts of our approach was that people who may (in normal times) have only had occasional visits to NMC and may not have been as well connected to the rest of the community, were now getting a level of support equal to their need in both a physical and psychosocial aspect. We learnt about our community allowing for a better tailored service suiting the needs of as many as possible.

Phase 2 started in June and ran through to the end of August. At this point there seemed to be a distinct dip in morale amongst our community. We had been in lockdown for 12 weeks; people were more uncertain of their own (and the charity's) future than at the start. The Therapies team however had a glimpse of hope. We knew that by using the tools provided by professional societies, we could treat people again when we deemed it was needed. This encouraged us and allowed us to share this positivity with our community. We would be able to return to what we were passionate about, and simultaneously give the people the service that they were desperate for; face to face treatment. With this shift, we would be able to have more impact again.

During this period the world became accustomed to Zoom calls, and we had settled into a way of working which was completely virtual. We knew we had to get more information from our service users in preparation for returning to physical appointments so decided to carry out a virtual assessment for all of our community. We asked in in depth questions about physical and mental health, as well as ensuring a support system was available to those who were shielding.



The team have also carried out the vital task of screening everyone before they enter the building

We have always had regular yearly or 6 monthly assessments but there always some individuals who miss it and slip through the net. In 2019 we carried out 198 re-assessments in the year. Now we wanted to do three hundred in just one month! A gargantuan task that required four member of staff working long intense hours every day. It was draining, but virtual meeting allowed us to see many people for the first time since the start of the pandemic.

It allowed the members of the team to greet people with a wave and a smile which really helped lift their spirits and was crucial in our effort to re-motivate individuals. Carrying out the assessments in this way highlighted an even greater number of people in desperate need for help and allowed us to prioritise those who need face to face input most urgently. For those who did not need face to

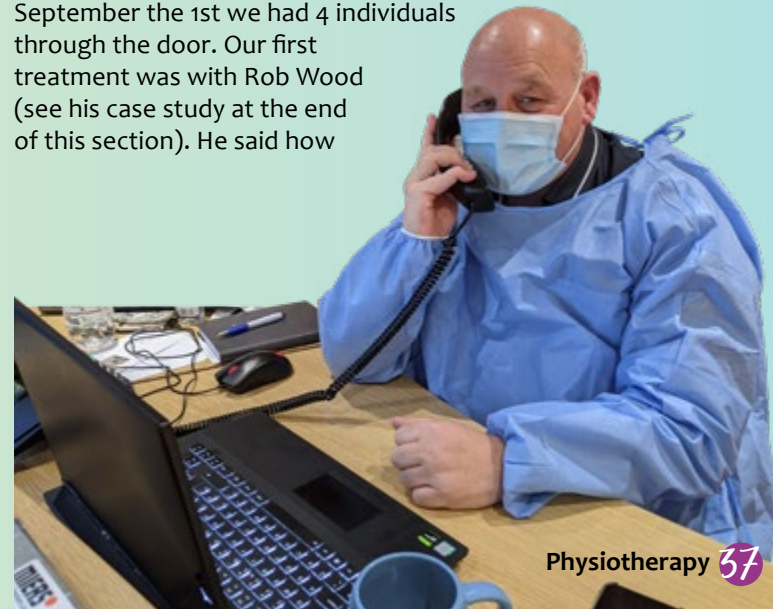
face appointments we were able to organise **zoom** calls to discuss exercise or rehab from injury and set up home exercise plans. This allowed a faster response rate than what they could have expected for a physical appointment. We achieved our goal. In 5 weeks, we carried out 450 reassessments. More individuals in our community had been reached in a single month than ever before. For some it was life changing.

We were able to assist with severe mental health crisis, relationship breakdown, homelessness, aid in rehab following injury and surgery. Despite not being able to see anyone in the Centre the team, with help from many others in the Centre, had just as much if not more impact on people's lives. In the period of not seeing anyone in the Centre we had 17,000+ virtual interactions. Nearly double the number of appointments (9400) we saw in the 18/19 financial year had virtual interactions in a 5-month period. Phenomenal considering the change of work, reduced staff, and team fatigue.

We formulated a plan to allow entry to the Centre with minimal risk of any cross contamination. NMC is a unique place with unique factors to consider so we were not able to draw on published advice or protocols. We planned for weekly staff testing, PPE provision, maximum numbers in each area, and how the building would be divided to allow distancing. We established a plan where both the treating staff and visiting service users were happy this was going

to be safe. We would use separate treatment pods instead of our usual warm, open department. We would be in full PPE and must keep distanced, instead of people seeing our beaming smiles and have that comforting touch. The team would be split into two sub teams to ensure minimal cross contamination and to create a backup team in case of illness. We would be tested weekly for COVID-19 and temperature scanned on entry with all service users being questioned and scanned prior to entry. The NMC was less obviously a warm welcoming Centre where you could meet and socialise or do a gym workout with others.

Phase 3 was restarting face to face. On September the 1st we had 4 individuals through the door. Our first treatment was with Rob Wood (see his case study at the end of this section). He said how



important the appointment to come into NMC was to him, and how privileged he felt being in. He told us there were no areas he could find where the comfort or safety could be improved. This gave us a real boost and the confidence to slowly increase the numbers of individuals through the door, reaching as many people as possible. At this stage we set a goal of seeing every person who wanted an appointment before closing for Christmas in December. The virtual aspects continued but at a reduced rate. We had 30 virtual appointments in September but 101 physical appointments. This felt huge. We were once again interacting with our community in the best way we knew. People from the community always left smiling, feeling better about

themselves and more knowledgeable on how to help themselves at home.

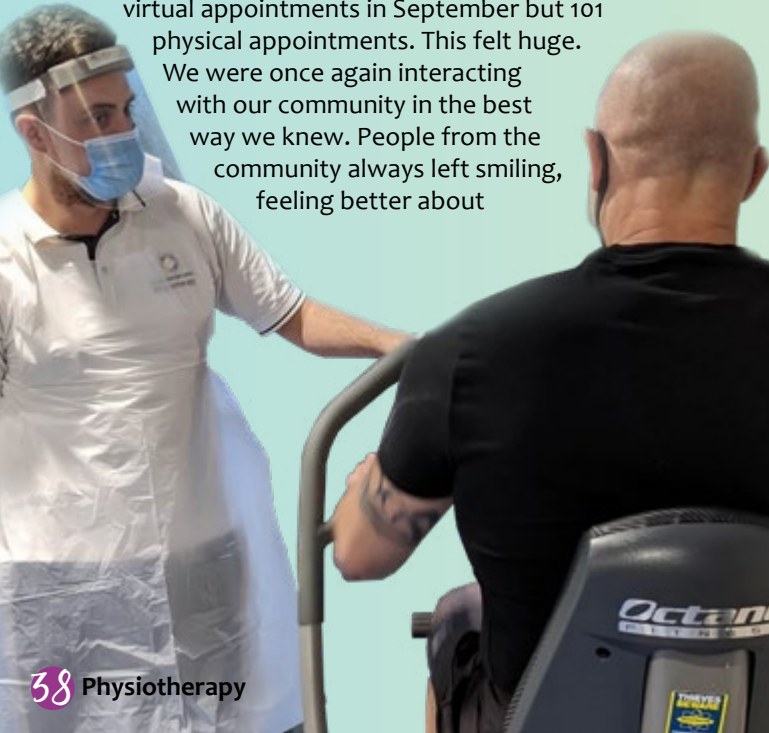
In October we brought the full team back in for the first time since March. At the same time, we started using the gym for one-to-one sessions again. We had 141 appointments in the Centre.

We have been able to alter our practice to better reflect clinical need, service user desire, and the most recent research.

In November we underwent a physical transformation to better match the new way of working. Our gym was extended allowing better use of the available space and increasing the distance between equipment. The department was set out to allow multiple people in at a time whilst still having appropriate measures in place. This allowed 251 appointments to be carried out safely in the NMC.

In December we started gym group sessions again offering 20 a week.

The team have been racing forwards since September. Often acting before NHS neuromuscular clinic teams. We were praised by respected professionals and nationally renowned clinical experts for the safety, pace and thoughtfulness of our actions. By mid-December we had a face-to-face appointment with 98.5% of our service users.



A huge thank you to the NMC Therapy Team who worked so hard over this period. They have shown amazing energy throughout, giving 100% to caring, contacting, assessing, encouraging, treating, and running exercise classes.

Without these incredible people the NMC would not be providing therapy. The team have also carried out the vital task of screening everyone before they enter the building. This kept us all safe and crucially kept the virus out of NMC. The whole team have given more of their time, effort, and energy than any other year and I am grateful to have had them by my side throughout this. It has been tough for everyone at the NMC, and I am proud of the effort they have put in this year and everything they have achieved.



I previously came to the NMC for therapy every two weeks. When the country went into lockdown, I was unable to do this and as a result my muscles started to feel stiffer and I was getting more pain. I had an assessment with the therapies team in July over Zoom and they discussed my overall health, answered my questions about getting pedals at home and demonstrated the stretches I could do. I do these every day and have felt much better.

Consequently, I decided to order the pedals and at a subsequent zoom meeting was advised on how to get the best advantages from it. It was great to have the physiotherapist observing. Daily pedaling helps my physical and mental health enormously!

It has been very helpful to connect up with people who know me well and understand my needs.

Andrew
NMC Physio Regular

Activity levels for NMC physiotherapy in 2020

Current Registered Patients **1685**
 Current Active Patients **495**
 Cancelled Appointments since June **79**
 DNA since June **8**
 Phone Consultations **715**
 Online assessments **456**
 Virtual Advice **316**
 Zoom Exercise Users **80**
 Facebook Exercise Views **8200**
 Youtube Physio Views **6840**
 Youtube Pilates Views **633**

Total Virtual Interactions **17240**

| | Monthly Appointment Totals | Physical Treatments Totals |
|-------------|----------------------------|----------------------------|
| January | 601 | 601 |
| February | 563 | 563 |
| March | 295 | 295 |
| April / May | 0 | 0 |
| June | 22 | 0 |
| July | 352 | 0 |
| August | 67 | 0 |
| September | 131 | 101 |
| October | 165 | 144 |
| November | 266 | 251 |
| December | 121 | 121 |

Totals
2459 **1950**

Rob Wood's Personal Account

What did it feel like when NMC reopened for Physio treatments on 1st September after 5 and half months of no hands-on treatment?

Our first person back for treatment was Rob Wood. Rob had been a long time NMC user and his family have always been heavily involved in other aspects of Centre life. This is what he said about returning:



Firstly, can I start by thanking you sincerely for allowing me, however it was decided, to be the first

person back to the NMC for treatment since the lockdown began. I felt incredibly humbled to have such an opportunity, which was very much needed - even if I was a little nervous about how it would all work, given that I can count on both hands the number of times I have left the house over the past 6 months.

Right from arriving into the car park, it was clear that the NMC had taken a lot of thought and consideration into preparing the building in a safe manner for both staff and patients. The signage outside of the entrance was clear and informative, a great reassuring factor from the first moment of physical contact with the organisation / buildings.

Whilst I completely appreciate that you have no control on the weather, it was quite a shock to see shortly after parking up, Gordon approaching the car in his shorts

and PPE that revealed far more of his legs than I could have prepared for!

Jokes aside, Gordon gave us a friendly welcome and was clearly able to ensure that before leaving our vehicle, it was safe for both patient and staff members for the appointment to take place. He explained clearly that the normal route to the treatment room was not being used and guided me down the side of the building to where I would wait only briefly for a side door into the new treatment area.

Ashleigh was also extremely welcoming and made it very clear right from the start how the appointment would work and safety measures in place for all involved, enabling me to lose any worry I had about entering a new environment as someone who is classed as “high risk”. The appointment with Ashleigh went very well, she wanted to know how I was coping, any problems I had encountered and allowed me to advise her on what I felt would give me the best results from attending the physio session.

Afterwards, the route back to the car and to avoid coming into contact with anyone else was well explained and designed, so all in all I cannot identify any issues that would need to be thought through to improve the experience (other than covering up Gordon’s legs perhaps!!) and I hope that my feedback can be used if required or requested, to be passed onto any other patients who may be worried about attending the NMC in the near future.



Very sadly, Rob died just a few weeks after coming into the Centre of causes unrelated to his neuromuscular condition or COVID-19, but his account will stay with us all as a testament to the efforts the NMC team had put in to keep him safe. It is included with the kind permission of his family.



NMC Design+Print

Dan Cundall, Head of Design sets the scene and gives his personal perspective on 2020, NMC Design+Print, and the impact of the pandemic

Watching

the wave of Covid-19 slowly sweep westwards in the beginning of 2020 was a deeply concerning period. Could the country escape it?

In the back of my mind, I started to wonder what might happen if we couldn't.

Within a couple of months these sketchy ideas had to become reality. Risk was our driving force. Risk to the team, and to reputation and the company itself.

With the nature of Design+Print's team, the majority have a neuromuscular condition, an underlying condition that ultimately led us to be fully shielded. Personally, I need

to use portable ventilator to aid my breathing making me quite vulnerable. Being known as a sociable office, it was hard to close our doors to visiting customers, but that was our first step. Whatever the cost we had to keep safe.

My decision to work from home had been building but a call from my stepson, who lives in London, urged me to stay at home as, in the voice of an apocalyptic movie, 'it's crazy down here and its spreading!' The next day in work was our last as the team quickly followed my lead.

Our reputation is very dear to us, we have spent many years slowly building our position in the community the last thing we wanted to do was leave any customer in need. A long-term aim was to explore remote working, so this



was the ideal opportunity to put it into action. Each team member, armed with remote server access, took their Mac home and we rolled up our sleeves. Our sales manager, who had some office access, took the quarterback role, and handed off projects to each one of us.

Home working was a success. Our local customers who needed us had access to us and we didn't let them down. The community have had their local heroes' calendar, covid prevention leaflets and sport club logo to name but a few.

As the national lockdown took hold, many of our customers melted away as they also closed their doors and our orderbook became empty. Also, at this time the charity fundraising team were cancelling events and income was slowing. Were we entering a worrying state of mind, how long could a charity support an unproductive company?

We were busy as lockdown began providing many varied materials for the NMC as a whole. At first hand we witnessed all the mini projects that were put in place for our charity community; it was so reassuring to see this professional and fun response emerge and give the design team first-hand access the wider work of NMC, establishing relationships at a time of isolation.

As time moved on, our customers gradually started to return. From April to July turnover doubled month on month. Currently we are achieving consistent levels of

income with no decline during lockdown two. We have a way to go still, but we can rebuild from a strong foundation.

Currently we are still working from home but as the vaccination programme unfolds, we can slowly make our careful return.

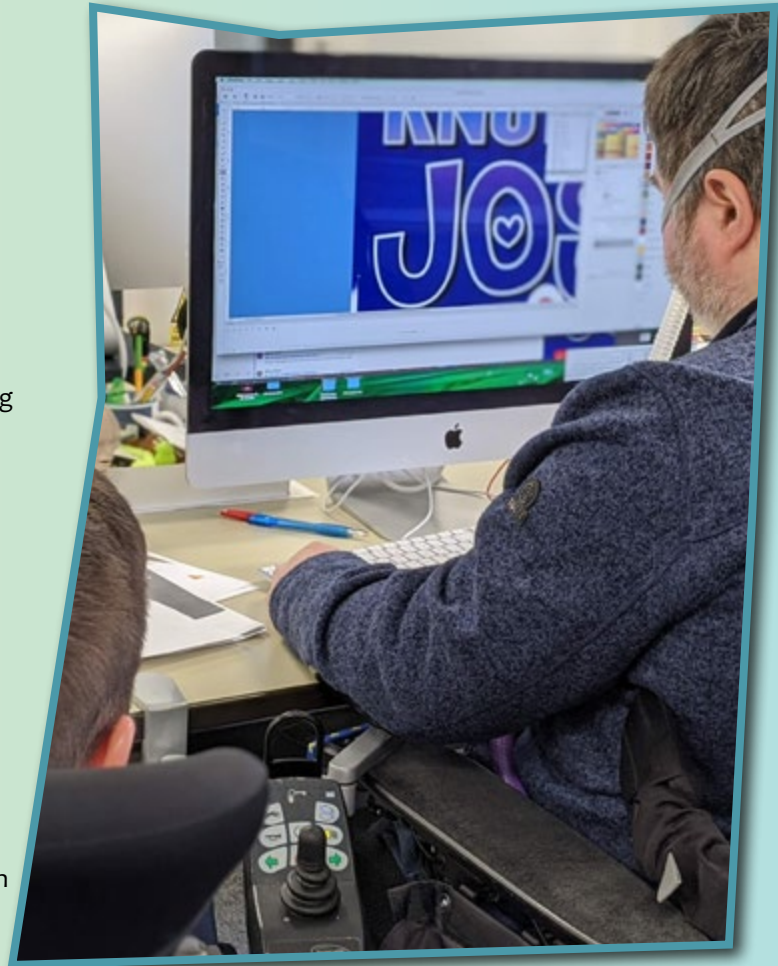
*Our position
going into the
pandemic*

NMC Design+Print is a social enterprise offering creative graphic design and professional printing services and we employ 11 members of staff, 9 of whom have neuromuscular conditions. But we are not just a graphic design and printing company; we are a team of individuals, right at the very heart of the NeuroMuscular Centre, with big social aims. We are driven by the desire to promote the talents of graphic designers with muscular dystrophy, or similar neuromuscular conditions, and show wider society that disability does not have to pose a barrier to a successful career in the creative industry.

- We want to inspire young people with disabilities, leading by example, to give them the confidence and motivation to pursue their own career aspirations.
- We want to connect to our local community, as a friendly, reliable, and knowledgeable supplier or partner. Both to promote the talents of people with MD within our local community, and to support local people to help our area grow, thrive, and prosper.
- We want to give back to the NeuroMuscular Centre, and its service users, by contributing our profits to the running costs of the charity.
- We want to share our experiences of living and working with neuromuscular conditions to others within our community. Shared knowledge, support and advice allows us to prosper as a group, and as individuals.

Many of our goals revolve around community and shared experience, so the onset of the pandemic was a big concern. As we began to shelter, and step back from face-to-face interaction, we worried about the impact it would have on our business, our team members and the NMC community.

Many of our team members are in the high-risk category so, as a group, we made the decision to prioritise our staff members and a large portion of our team decided to work from home to protect themselves from Coronavirus. Within the following two weeks the whole country went into lockdown.



Our experiences of working through the pandemic

We have faced new challenges and had to find new ways of working to keep up and running. But we have also discovered a strengthened sense of purpose and commitment to the bonds within our team, our role within the NMC, and our relationship with our local community.

Communication

Our primary methods of communication had to change quickly with the onset of the pandemic. We have always prided ourselves on our ability to work as a team and seen our co-operative approach to working as one of our biggest strengths and a vital component of operating an organisation with many part-time members of staff. Before this year, our proximity to one another within the office had enabled

us to discuss upcoming and ongoing jobs, use one another as a sound board for creative ideas, and provide feedback, support and mentoring with ease. Distance and home working introduced a big hurdle!

The solutions lay within the introduction of new technologies, and our desire to stay together and support one another as a team. Microsoft Teams and Zoom have allowed us to hold regular team meetings and provide technical support and mentoring to newer members of staff. Office 365 with inbuilt webmail and SharePoint cloud storage, as well as a new NAS (Network Attached Storage) which works like a remote server and is compatible with both Apple and Microsoft software, has enabled key members of the team to access files from home and then transfer necessary information from the server between team members. And distribution of computing equipment usually kept on site has allowed all team members to stay up to date with industry standard software.

Most importantly, we have made a commitment to one another and recognised the value of regular interaction. Co-operative working sessions over Teams have allowed designers to work in pairs on larger jobs, such as logo design, to share ideas and concepts and push one another to be more creative. Senior members of the team have made themselves available to provide feedback and encouragement daily via Teams, email or phone.

Thanks to this new way of working, we have been able to have more frequent meetings than ever before. Prior to the pandemic, gathering the whole team together on a regular basis proved to be quite problematic. Most members of the team are part time, due to health requirements, and rely on NMC transport to get to work. Therefore, it is rare that everyone is on site at the same time. Having to meet virtually, from the comfort of our own homes, has meant that gathering the team together has been a much simpler task! The support of video conferencing will make regular meetings a possibility when we are back in the building too, allowing those who are not present to engage with the members of the team who are on site.

Community

Past impact surveys completed by NMC community members have continually identified facilitation of community, peer to peer support, and a sympathetic ear as one of the key roles of the NMC. Our desire to connect with one another and support the Centre and its community members has proven to be vital over recent months. As a team, NMC Design+Print members reach out to one another on both a professional, social and emotional level. We offer encouragement, compassion and understanding to one another and this has helped to motivate us in a multitude of ways.

Our newest member of the Team, Jake said:

Lockdown has been difficult for everyone; I am no exception. It has been lonely and sometimes very boring with no social interaction other than my family. Working at Design+Print has been my saviour, my go to activity when times were tough.

The weekly design meetings on zoom / teams and WhatsApp group chats has kept me in touch with my colleagues during lockdown stopping me from becoming socially isolated, also continuing the office feel all be it virtually.

The collection of activities from all around the Centre shows a great depth of support and community feel within the NMC. Without the NMC none of this social interaction would be possible and I would have no interaction with anyone other than family for over 6 months.



Jake
Designer

Another, long standing, member of staff agrees:

It's great to be in contact via the zoom app and teams, I've even set up a virtual meeting myself! It is so nice to see others from the NMC and to also keep up to date to what's happening in and around NMC.

Karen
Designer



Providing Purpose

We have always understood the value of meaningful employment and the importance of having purpose. During the pandemic, the work that we are passionate about has become a lifeline to many members of the team.

Head of Design, Dan Cundall comments:

This has been an unprecedented period of our lives and has tested us all in many ways. To have NMC in your corner has offered confidence, fun, reassurance, friendship, and pride in how we made the best of 2020. Design+Print has given us a focus, kept us active, helped our customers and given something back to the charity we would be lost without.

Designer Peter adds:

The work has kept my mind occupied and not thinking about Covid! It has helped me greatly, if I didn't have my design work to look forward to then I would be staying in bed a lot more which would not be good for me.

10
/ 10

staff members asked stated that being part of NMC Design+Print had a positive impact on them. 8 stating that it had a definite impact, with the other 2 saying yes to some degree.

10
/ 10

staff members also agreed that they felt supported by their team and other staff members. Again, 8 stated that this was the case, whilst the other two answered yes to some degree.

Jake agreed and said:

Working allowed me to maintain some sort of routine, something to get out of bed for. The challenging jobs really got my brain ticking over allowing me to express my creative design ideas and forgetting about the pandemic.

We have also come to appreciate the emotional outlet that the creative nature of our job allows. We asked, 'Does being creative help you to express your thoughts and feelings?' We received the following responses from members of our team:

Yes, very much so. On the odd occasion that I didn't have any work to do, I was looking for design tutorials online.

Creativity is a helpful tool to help through the darkest of days, it helps as a distraction from dark thoughts.



All staff members agreed that they had learnt new skills and techniques whilst working for the company whilst 6 saying that this happened regularly.

Connecting with Customers

Unsurprisingly, the first lockdown saw a dramatic reduction in business. Though this was worrying, the ability to focus more time and attention on the charity itself has proven to be valuable and rewarding. The lull also allowed us to support our local town council in the design and production of thousands of information leaflets about the outbreak of Coronavirus. These were circulated throughout Winsford and informed local people how to stay safe and what rules to follow.

Sarah Bacegalupo, Support Officer (Events & Projects) at Winsford Town Council stated:

NMC created Winsford Town Council's COVID-19 leaflet they designed and printed this promptly, we were amazed by how quickly NMC produced this work. They offer innovative ideas and creative solutions. Along with the guidance they provide from start to finish, their response time and their patience have provided us with peace of mind in knowing we have a team dedicated to taking care of our needs.

As restrictions eased, we were happy to see the number of customers steadily increase. Our reputation as a reliable and community focused business, and our efforts to form strong customer relationships, has proved to be invaluable. Although, like any business, we aim to make money (which we then put back into the NMC), we also want to support local people and help them get as much from their design or printed materials as possible. We take the time and effort to offer advice, help and tips to customers producing their own artwork, recommend the most economical approach to print for those with a tight budget, and offer a friendly and efficient customer service to help combat any issues that arise.

Mia Yearsley approached us during the first lockdown to ask us to help brand her new business, which will offer football coaching for young children in schools, pre-schools and at private parties. Mia says,

I love my football and it has been a dream of mine to open my own football coaching company.

Although she had to delay delivery of her service due to coronavirus restrictions, Mia was keen to get her name out and make connections with local people in Winsford. Knowing that the pandemic was making things very difficult for new business start-ups, we wanted to guide Mia through the logo creation processes and offer as much help and support as possible:

Throughout the whole process of creating my logo the Design+Print team were patient and understanding about everything I wanted for my design and brought it to life. They helped me out so much during this pandemic, the support given me, and responsiveness was really beneficial.

Mia Yearsley MY All Stars

Another job that we have taken great pride in this year was with long-time customer, Friends of Winsford Town Park. The group have strong roots within the Winsford community and are committed to improving the town's green spaces and bringing people together. They liaise closely with other local community groups and the town council to try to promote the local area and create more opportunities for its residents. Their annual calendar had a special focus this year; to thank key workers from the local community. We liaised with Chairman John Malam to involve the customer in each step of the journey to create a piece of design that felt truly collaborative.



The Friends of Winsford Town Park worked with the NMC Design+Print team on the Official Winsford 2021 calendar, which features portrait photos of keyworkers who have kept the Winsford community safe and Winsford open for business during the pandemic.

The calendar is a community-led initiative, and the Friends wanted to keep it as local to Winsford as possible: the NMC Design+Print team were the perfect fit.

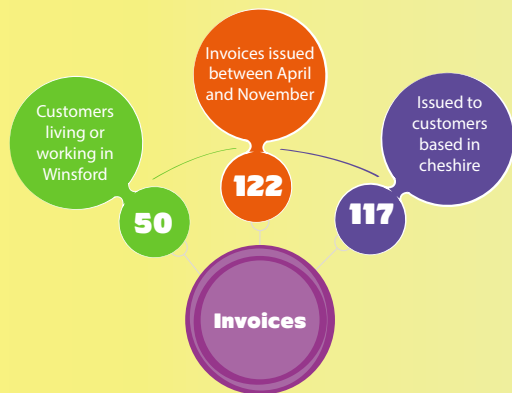
We could not have hoped for a better team to work with, and quickly found that “distance working” from our respective homes was no barrier to communication.

The outcome is much more than a calendar: it is a record of this exceptional year, honouring some of the many unsung heroes of the Winsford community. The NMC is part of the Winsford community, and the Design+Print team are to be praised for the part they have played in creating this very special calendar.

John Malam

Chairman of Friends of Winsford Town Park

Being unable to work face to face with customers has forced us to focus on how we talk about ongoing projects to make sure that we gather all the information required and keep the customer fully informed. Video calls on Zoom have been a great help, and this has been supplemented by regular emails, phone calls and samples sent out in the post. We hope to continue offering video calls going forward. It increases the level of accessibility and will allow us to include members of the team who are not on site, or customers from further afield, to give a greater input.



Clients include key organisations within our town such as Winsford Town Council, Cheshire Fire and Rescue and Friends of Winsford Town Park. We believe that this is a clear reflection of the strength of the relationships that we have forged with local people, and those that they are connected to.

Our team as part of the wider NMC community

The quiet period of business that we experienced during the first lock down allowed us to give more time and attention to supporting the other departments within the NMC. Staying in touch with service users and finding ways to offer virtual aid, community engagement and activities became the primary focus. With our attention turning toward social media groups and telephone support, as well as newsletters, information leaflets and cards with messages of support for those with less inclination for IT, the demand for fast and impactful design was high.

Alongside the production of a wide variety of designed or printed materials for the charity, multiple members of the design team were instrumental in the setup, monitoring and content creation of the NMC Online with Connect Up Group, were part of the NMC Spirit of Christmas and Live In The House planning groups, which supported the set up and delivery of each event, and have helped to provide one to one support for other members of the NMC Community by helping to run the support line during.

Having the opportunity to become more involved with the day-to-day activities of the charity gave us purpose and direction during uncertain times. It also helped us to form

new connections and relationships with the people most important to the NMC, our service users. This greater level of integration has been beneficial for all parties. We have been able to use our skill sets to help the NMC offer new clubs, such as the NMC Art Group, produce thoughtful and timely information materials to help the support team reach out to people in need, and have been able to offer a listening ear to people that needed a friendly voice down the phone. But, it's given something back to us as well, and it goes far beyond a sense of community and a network of supportive people. The groups that we have been involved in have taught us new skills, allowed us to access mindfulness and wellbeing activities, and have given us a constructive outlet for anxiety or a daunting expanse of time that we did not know how to fill.

Karen explains:

I've had contact with the NMC craft club, and they provided me some materials to make some bracelets to sell. This helped me immensely, especially when i found that they had sold some! I feel I have contributed and would like to continue with this should it prove popular and constructive to raising funds.

We used this time as an opportunity to get to know the people around us, outside of our team bubble, and have learned about the incredible wealth and diversity of skills, interests, and abilities that our community possess. We have been able to work with some of these individuals to expand our own offering as a design company. NMC regular and local artist, Traceyanne, agreed to work with us to create the NMC 2020 Christmas Card. Her understanding of the Centre as a service user, and ability as a fine artist proved to be a great match with our design focused team and the cards created have become our best ever seller and over 1500 cards!

Traceyanne commented that,

It was an honour to be asked

but it was a fantastic experience for us too and has shown how we can engage, support and benefit from talents throughout the NMC.

One of our younger designers commented:

The NMC has kept me busy and connected to our community. During the shielding period it was nice to get numerous calls from Ali asking how I was doing during that difficult time. The Connect Up Facebook group has also been a fantastic addition to the NMC community, a virtual center experience that no other community can match. The GameChangers team has also kept me busy and given me the opportunity to help organise the 'Live in the House' virtual event but also get involved in social activities like the weekly quiz meetings.

Jake

Our worries about broken communication, caused by the pandemic, did not come to fruition. In fact, we have a better understanding of the other department that make up the NMC and are far more aware of the successes, stresses, and strains that each have been under. We are more aware of the needs of service users, and the hurdles tackled by our therapies team and support worker to surpass them. Interdepartmental working, particularly for the staff members that have been on site, has been a great and unexpected outcome. We feel more equipped to deliver on the ethos and aims of the NeuroMuscular Centre, and can the great strength, motivation and level of achievement that can be reached when we work to support one another.

Looking to the Future

Change comes with reflection and we have learned a lot about the structure of our own company and become more aware of our motivations. Whilst some members of staff have seen their job as a lifeline and a creative outlet that they enjoy and look forward too, others saw the lull as a welcome break.

Early in the setup of NMC Design+Print, one of the main aims of the company was to offer job roles to people with muscular dystrophy. Whilst many staff members flourished,

some discovered that design was not a true passion for them but could not see any alternative opportunities beyond the walls of the NMC. This is reflected by the following finding from a recent poll of staff members: When asked if they found their work fulfilling or rewarding, 7 out of 10 said that their work is always fulfilling, whilst another 3 said sometimes. 1 of these individuals went on to comment that it was the nature of their job, rather than the organisation itself, that lead to them not always feeling fulfilled.

Society, overall, is changing and more education and job opportunities are opening up for people with disabilities. But, the NMC has changed and evolved too. With more physical space, and a growth in service users and finances over recent years, the Centre has been able to run new projects and offer new opportunities. The interdepartmental approach that we have taken during the pandemic has shown us a bounty of new roles and positions within the Centre itself. Some members of our team have already begun to experiment by working alongside and offering support to our web designer, the transition team, and charity events teams.

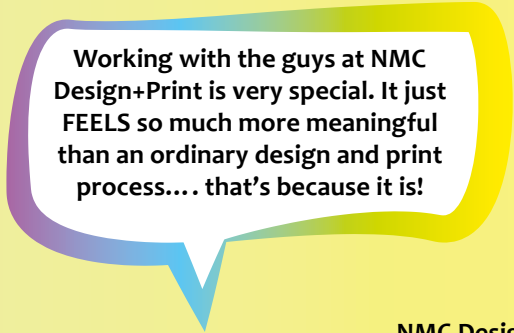
Though we are still keen to promote graphic design as a fantastic career path for people with muscular dystrophy, we are excited by the prospect of offering alternative opportunities too.

We have also had to face the sadness that comes with losing staff members to redundancy. The changes within the Centre have created new roles, but also made others inviable. As a close-knit unit, losing two team members felt like a huge loss. However, the understanding of these individuals, and team wide desire to put the success of the Centre first was great balm.

Rather than causing despondency, the losses have helped to redirect and strengthen our sense of purpose and dedication to the aim of the NeuroMuscular Centre; to improve the wellbeing of individuals and families with neuromuscular conditions.

Beyond all other concerns, we are proud to be part of this charity, and are more motivated than ever to represent the value, talent, and drive of our community.

We think that our vision has been perfectly summed up by our long-term customer, Donna Okell:



Working with the guys at NMC Design+Print is very special. It just FEELS so much more meaningful than an ordinary design and print process.... that's because it is!



Training and Development

NMC's Tutor Kay Briggs shares her reflections

NMC

Training & Development provides an accessible range of workshops and courses specifically designed to suit those with a neuromuscular condition.

All those with a neuromuscular condition are eligible to enrol & study and there are no restrictions on age or experience level. We offer taster sessions that give students the opportunity to test out the courses before they enrol. We have two knowledgeable tutors that provide year-round guidance, with a professional transition and admin team to support you every step of the way.

The courses have been designed to adapt to everyone's needs and circumstances. Some courses have the option of home study and can work at their own pace, in the comfort of their own surroundings and receive support via Zoom and Teamviewer. All the course websites are password protected and course materials are delivered through easy-

to-follow video tutorials and work sheets, that are updated regularly. We pride ourselves on supporting each student individually to enable them to work at their own pace with the aim of ensuring no one ever "falls behind" because of a period of absence due to ill-health for example.

The pandemic has brought a new range of challenges for Training. We have used this as an opportunity to evaluate how we deliver training and improve our services. We have continued to develop a wider range of courses and workshops to suit everyone's taste. New workshops have included art, mindfulness, and self-hypnosis. Students have been finding new social activities to be involved in and new ways to connect with others. Everyone has become more active on social media, in community groups or found new hobbies and interests. This has led to new friendships and connections forming, with a mutual appreciation for the opportunities that are available.

With support from the Design and Print team we have continued to put together the new Level 3 graphic design

course that will be available in 2021. The course will offer a work placement module, interview skills, professional large-scale printing and communicating with a client. We want to prepare students for a work environment and make the transition from student life over into the workplace a smooth and comfortable journey. By allowing students to gradually build up their professional design skills while being introduced to a professional work environment. The training team are also working closely with the Head of Design to combine the Level 1 & 2 courses in Graphic design to deliver a more effective and updated set of design skills. 2020 has highlighted that software skills are just one aspect of any course. Strong communication, drive, and creative passion also play crucial roles.

Our 3D printing club has blossomed along with their technical skills. They started by making straws, woodland insects, phone holders and wheelchair parts, but as the year progressed the demand for 3D Printed PPE supports became stronger. This meant their experiment skill set needed to be enhanced. The team have successfully created Face Shields and Surgical Mask Straps that have been made from food hygiene safe filament. Working independently at home meant all members had to make more decisions independently. Time as a team was more valuable, subsequently this has strengthened the team's bond between members dramatically.



Working from home has meant that training needed to be

flexible and adapt to demand. Some courses were not able to be delivered remotely. In June we created a new virtual workshop called Mindfulness. We wanted to focus on mental wellbeing and encourage a friendly, safe environment for everyone to share their thoughts. Mindfulness involves breathing methods, guided imagery, and other practices to relax the body and mind and help reduce stress. Each week we delivered meditations that highlighted a variety of different styles of Mindfulness. We also shared useful information about the practice of Mindfulness and promoted the many ways it can be incorporated into daily activities. By August we were pleased to be able to deliver Live sessions where people could take part in group meditations. In total we were forty-two people actively involved with our Mindfulness workshop.

This year twenty-eight people have entered the training suite to work with a member of the team to explore their expectations and ideas of how participating in a training course or workshop would impact on their lives. Thirteen people decided to continue their course working through the home study program through lockdown. Three new students have enrolled onto courses. Four students celebrated at the start of the year as they completed their Graphic design course. The sense of team spirit and determination this year has been overwhelming even when times have been challenging. We will get you to your goal, nothing is a barrier when it comes to learning. As a community we have grown stronger and will continue to do so.

The Mindfulness sessions were very good and well thought out and the delivery well executed. I found the time used was a good way to take some time out to relax and because and the themes good, for example the chocolate session. Kay has a lovely soothing voice and each session I found really beneficial in helping me cope with both my muscular dystrophy and Cancer symptoms. Kay very kindly sent me some CD's which I put onto my iPod device so I can listen to them while in bed. I particularly liked the Sleep meditation which I use most nights to aid sleeping. I look forward to further sessions that may help relieve my pain that may be used in conjunction with my prescription drugs.

Vivienne

An artwork to illustrate NMC's impact

Here's the brief students were given when asked to produce a piece of art to illustrate the impact of NMC on them as a person during the pandemic;

I would like you to create a piece of artwork that will express your feelings and opinions about the NMC. You can use any medium that you like. You can incorporate colours from this colour chart.



If you agree with a statement, add the corresponding colour into your artwork. If you disagree with a statement, then please do not include the colour. Make sure that you add the colours for all the statements that you agree with. Please do not add additional colours to your artwork.

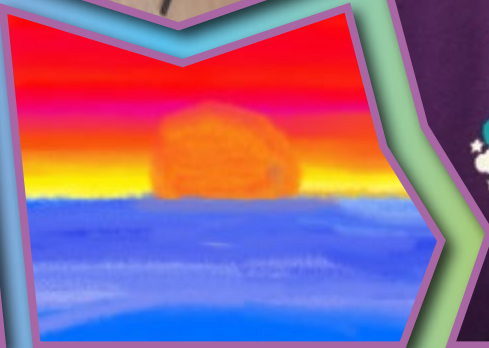
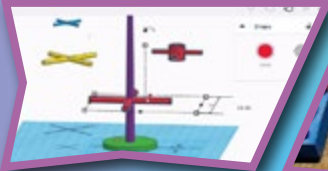
Types of media that you could use:

- Music software (you may wish to take a screenshot and the colours to this).
- Written text, such as a poem.
- A hand drawing or painting.
- A digital drawing.
- Animation.
- 3D printing.
- A hand-crafted item.

Your thoughts and opinions are very important to the NeuroMuscular Centre so please take part in this project. If you have any questions, please let me know. I very much look forward to seeing your creations.

The 3D Print Club has had a really positive affect on myself and all of us, especially in lockdown. It's been an essential weekly focus and social for me and really helps connect socially with the NMC, despite our focus on printing. From my perspective it's amazing to see a group who came along to an afternoon in the NMC in June 2018, completely new to the world of 3D printing to being 3D printer experts and owners in their own homes while still interacting with each other. Learning new knowledge and making together does empower you I think even if 3D printing may seem a little obscure; in reality it helps you connect to the world and get intimate with new materials and ways of being creative and engaging. Kay has been great in supporting this fledgling community which I think will go from strength to strength. It's been hugely beneficial to my mental and physical wellbeing

Ross
3D Print Club



What ^{our} students and workshop participants said

Although I was worried about attempting to carry on studying from home with my graphic design foundation course, I was greatly surprised at how much hands-on help was available through the design tutor. Zoom meetings were arranged when help was needed and that also helped to keep me motivated throughout these challenging times - even when technology was not always on our side! It has taught me that I can work to deadlines unaided which will be valuable in an employment setting.

Julie
Graphic Design Course Level 1

The NMC have done me proud, kept me busy, kept my mind sound. Stayed in touch - I loved that very much. Helped me set my goals. I completed my Level 3 Graphic Design course in 2020. NMC are the best!

Velvet
Graphic Design Level 3

The NMC 3D Printing Club had only been up and running a short while when Covid 19 caused the whole country to go into lockdown. Being part of the Club during this time has given me something to focus on and keep me busy. I was relatively new to 3D Printing and had a lot to learn as I had bought myself a printer and was keen to get to grips with it, being able to interact with the other club members and pick their brains via online weekly meetings has been a great help and it is something I look forward to as we continually bounce ideas off each other, discuss problems we have encountered, and generally have a great two hour (sometimes more) "get together". I now feel quite confident in my 3D Printing abilities and have stripped, modified, upgraded, and rebuilt my printer none of which I would have considered without the help and support of my 3D Printing Club friends.

Chris

3D Printing Club

The mindfulness sessions every Thursday were really helpful in controlling some of my anxiety especially during lockdown when I was mostly at home alone. It gave me a focus where I could take the time once a week to relax and try to practice new techniques. My sleep improved greatly, and I found that I could control my eating habits too. It was also a nice space to meet new people from the centre, who I couldn't have met in person to discuss our worries.

Julie

Mindfulness Workshops



participants agreed that talking part in a Mindfulness session has helped them find time for themselves and they have benefited from this. Five out of eight said they had learned a lot about the practice of Mindfulness and the different techniques. People also reported a reduction in stress levels after taking part in a meditation and some noticed an improvement in their sleep pattern.



NMC Finances and Covid-19

What was the position before Covid-19?

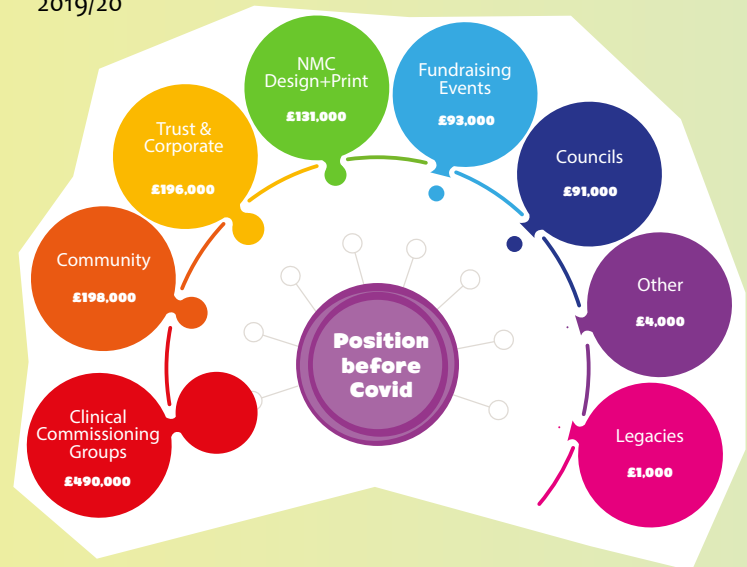
In recent years, the NMC's financial performance has been excellent.

Except for one year in which we reported a very small deficit, the last ten years have brought manageable growth that has allowed us to invest in delivering more service, developing the range of services we offer, and improving the facilities in which we provide them.

A key element of NMC's financial success has been the diversity of its sources of income. It helped us emerge

largely unscathed from the financial crash of 2008 and has proven to be a sustainable model as we've not been overly reliant on one particular type of funding.

The following chart shows the make-up of NMC's income in 2019/20



NMC began 2020 in a healthy financial position with aspirations of further service and infrastructure development.

How did Covid-19 affect NMC's income generation?

Inevitably the pandemic has had a profound effect on NMC's funding streams. The initial national lockdown in March immediately put in jeopardy at least 60% of the funding from the chart above.

Our funding from the NHS comes in two forms; grants which make up 25% and activity based which makes up 75% of the total. Grant funders have maintained the level of funding agreed in our contract before restrictions came in. Funding through activity collapsed as individuals stopped attending the Centre for hands-on treatment.

Most of NMC Design+Print's staff had to shield during the first phase, so on-site working was impossible. Customer demand quickly dried up though, so the workforce had very little to do during the Spring.

Our largest event, our Summer concert Live in the Park at Arley Hall & Gardens, due to be held in July had to be cancelled, after initially being postponed to September.

Sponsored runs, Quizzes, Gin Tasting evenings - anything planned to be held at a single venue with numerous attendees had to be scrapped.

What was the NMC's response?

The production of weekly cashflow projections in the early stages of the lockdown allowed NMC to plan for various scenarios of differing lengths in order to mitigate the impact of the pandemic.

At the time of lockdown, NMC had five vacancies in its staff. These roles were not filled to save money. We have otherwise been very frugal, spending 50% of what was originally budgeted on non-salaried expenditure.

The NMC welcomed the Government's Coronavirus Job Retention Scheme (CJRS). It seems wildly unrealistic with hindsight, but our hope at the time was that the crisis would last until the end of Summer at the latest, and we would indeed retain all jobs before normality resumed. Sadly, as the situation worsened it became evident that some job roles were no longer required, and we were forced to make redundancies.

The introduction of flexible furlough on 1st July 2020 allowed the reintroduction of service provision, albeit in alternative ways. Clinical intervention through digital technologies meant chargeable activity, while most importantly serving our clients. This period gave the Physiotherapy team the opportunity to reassess clients before restarting on-site treatment in September.

NMC Design+Print was able to provide limited services in the early part of lockdown as most members of the team are not salaried, therefore were not furloughed. A very quiet first quarter of the year was followed by increased activity as salaried staff here were also able to benefit from flexible furlough. Zoom meetings with customers have enabled a much more collaborative approach, but although that technology eliminates physical distance to an extent, there has been much more focus on serving local businesses, groups, charities, and councils.

Fundraising events had to move online due to the restrictions of movement and social distancing rules. Small scale events such as a quiz, bingo and dog show were held, with the morale of NMC's community being the priority rather than fundraising. The focus however shifted in planning the Virtual Spirit of Christmas to replace our flagship event, the Spirit of Christmas, held annually at Chester Cathedral. It was an enormous success, making a surplus comparable with previous years, and introducing the Centre to new audiences as far afield as

Scotland, Ireland, Germany, America, Canada, Australia and New Zealand. It's entirely possible that the virtual event could run alongside the real one in the future.

NMC is blessed to have an exceptional Trust & Corporate fundraiser, who also deals with Council contracts. In addition to maintaining the usual fundraising targets, £100k has been raised to help the Centre cope with the impact of Covid-19. This was made up of £16k in the first quarter, as an emergency response to the collapse of other income streams, and £84k in the next two quarters to fund the reshaped services and roles to help us meet and embrace the new challenges of the post pandemic world.





The chart above shows the make-up of NMC's income to the end of December 2020. The difference from 2019/20 is marked. The CJRS has helped us significantly, being our largest single source of income. That and our traditional, charitable fundraising endeavours have safeguarded the Centre's finances while traded income has been heavily reduced this year.

What does the future hold?

The NMC will be in a good position when some sort of normality returns. The CJRS is currently planned to run until the end of April. We don't anticipate being able to run our physiotherapy service at full capacity by then, but it will be significantly increased from current levels.

While our earned income from the NHS, Design+Print sales and Fundraising Events has been much reduced in 2020/21, it will recover greatly in the next financial year, reducing the pressure on fundraised income, and helping fill the gap the absence of furlough support will leave.

There may be more challenges securing fundraised income with the potential of Covid-fatigue setting in, and the consequences of the enormity of support given in the immediate aftermath being felt. Given our track record of securing diverse, sustainable income streams, we can be confident going forward.



Transition

Social Accounts Impact Statements

Younger members of the NMC community were asked to select a word that summarised the impact of NMC on their lives through the pandemic. Here's what they said;

— Constellation —

I think everyone has come together like amazing stars they are and have tried their best to give help and hope to everyone.

Ellie

— Invaluable —

If I had to choose one word to describe the NMC during this pandemic it would be invaluable. For me, this year has been extremely difficult as I've struggled to cope with health issues as well as lockdown. Very often the NMC has been the only communication I had with the outside world and I was grateful to receive a text message, an email, a phone call or a video chat from them. I also find the ongoing encouragement and support has had a much-needed positive effect on my anxiety and wellbeing. It means a lot to know that they are there as they are often the only Social contact I have.

Anonymous

Unity

As we have kept each other positive no just in terms of friendship but working as a team bouncing off each other with ideas and being a supportive unit whilst having fun.

James

Belonging

The NMC is a place where I feel like I belong and that we are not alone. Working in a team where everyone is accepted, and the focus is on ability not disability is truly something to be treasured. There is a real sense of community spirit, that we all belong together and there is always a bucket load of people ready to help with anything.

Amy

Togetherness

During the Covid19 pandemic the NMC has provided many services to me. I have felt a real togetherness within the community. When times were challenging and sometimes lonely, I knew I could rely on the NMC community to cheer me up. Everyone has come together during these difficult times and supported each other, including myself. The NMC has allowed me to stay positive, by completing certain group projects to take my mind of the pandemic and focus on working together to achieve great things. Another factor the Centre has provided me is Increased confidence in myself to communicate more confidently before lockdown, without this I would be incredibly lonely. Overall, I feel part of a fantastic organisation that has a real togetherness to support as many people as possible.

Jake

Lorraine Woolley, NMC's Transition Officer explains the projects NMC offered, and the young people involved give personal reflections on the impact of those projects during the pandemic;

When

the pandemic began March 2020, I never dreamt for one moment that we would still be here now working to diversify and overcome all the barriers it created. Life already has its challenges for our young people, and they have had to dig deep to continue through this pandemic with the same enthusiasm and optimism for the future that they had before. It has been a testament to their characters the way they have embraced every opportunity put before them. They have also come together with camaraderie for each other and have genuinely looked out for one and other alerting each other when individuals have been struggling. I've seen nothing but the very best in people and I have also seen testing times where people have had to deal with difficult situations in isolation.

Initially, I wondered what on earth I could do to continue my work when I started working from home. It did not take me long to realise that my role was going to be vital in making sure everybody had a purpose to fulfil even though they were stuck indoors. It was also vital to keep everybody's mental well-being in mind making sure they have hope

and giving them a vision Beyond Covid 19 when everything seemed so hopeless. This is something that is important to continue doing as we are far from out of this horrid situation.

There have been various projects that I have been involved with and allocated roles with the NMC team for our young people tapping into their strengths and trying to keep them involved and motivated.

Our first project was Pick Me Up Postcards which was to bring the NMC community together giving people the opportunity to design a postcard with inspirational quotes. It was a competition that reached across the community to all ages to become involved. We had over 40 entries and lots of people submitted artwork and inspirational quotes. Ellie, Amy, Kay, Ali, Millie, and I have worked together since April on this project and we are now just starting to reap some financial rewards for the NMC which is a bonus considering we just wanted people to have something to do to take their minds off the pandemic.



Pick Me Up Postcards

Pick Me Up Postcards was one of our first projects since lockdown had taken place. I enjoyed it as it made me work with different people, which gave me a different perspective on things. I learnt to voice my opinions more during our Pick Me Up Postcard meetings, which is beneficial for me. Again, it has helped me to become more independent and host meetings independently, for example, the meeting we had yesterday I continued to ask questions that I thought needed to ask and I was not anxious about asking them.

Ellie



Pick Me Up Postcards gave a brilliant sense of purpose and focus during lockdown which really helped with mental wellbeing. Working alongside brilliant people was a confidence boost and all-round greatness! It was satisfying to be helping the NMC and community.

Amy

The Pick Me Up Postcard Competition was really fun to be a part of as it gave me something nice to do while stuck in my house due to Lockdown, it also gave me the chance to use my Photoshop skills to create my Postcard design which was good because I love being on Photoshop. I felt there was a good balance to the competition because you could design your Postcard whichever way you wanted to, and I think the Competition happened at the right moment in Lockdown as I was starting to feel really bored and a bit down about being stuck at home all the time, but the competition gave me something positive to focus on which massively improved my wellbeing.

Josh

SpeakEasy

SpeakEasy was very much a face-to-face workshop that has been spearheaded by NMC volunteer Ellie whose official role is Transition Admin. Ellie has led this workshop as part of her Duke of Edinburgh new skill module and she has done an amazing job I'm making it a great success and that has superseded everything I expected of her. This workshop it was interrupted once again by the pandemic. Ellie, Amy and I set up a meeting with the workshop presenter Ian Linton who is a Creative Director.

On initial contract Ian felt it would be difficult to replicate the Face-to-face experience using video conferencing, but our young people persevered by having a brainstorm and putting something together that would work. I can honestly say that video conferencing worked out better than face-to-face because some of our participants were more comfortable and came along leaps and bounds literally. It was a phenomenal success and very well attended. Initially, Ellie requested my presence on the conference. She was very happy for me to be in the background with no camera and muted microphone. Eventually, she was happy for me to leave her to it and she really made a great success of this workshop and continues to do so.

SpeakEasy has been great so far, it's great fun to do (someone is always laughing) and a fantastic way to build confidence. The activities we've done have really helped build my confidence talking in front of a group and especially talking on the phone which I've had to do a lot now! It's been fantastic to see everyone and given a focus to break up the week whilst being a lovely accompaniment to the other projects and activities.

Amy

The SpeakEasy sessions are about getting together with other people in the group and talking with each other and playing out scenarios that will help us in the future like talking on the phone to important people, also we do speaking presentations to the group. By doing the sessions it will make me feel more confident about speaking in public, as I do get stage fright when speaking in a large group.

Xander

My favourite part of these workshops was helping and seeing the younger guys develop skills and it was an honour to be part of this. It also helped me to improve some of my communication and presentation skills and it was also fun.

James

My name is Dillon and I have attended the Speakeasy workshop for 12 weeks. I've worked with a group of 9 other people on building confidence and speaking in public. Before this I found it difficult to speak in front of others that I didn't know as I have selective mutism. Every week we did small exercises to build up to doing a presentation to present in front of the group. We had to choose a subject we were interested in and I chose the film Guardians of the Galaxy. I used keynote software on my laptop to put together the presentation and learnt how add video clips and music. Then I had to present this to the group using my voice and we did this on zoom due to being in lockdown. Doing this workshop has really built my confidence to talk to others and I've got to know new people and they got to know me a bit better.

Dillon

SpeakEasy was the first workshop that I created from start to finish, it has given me more confidence than I could have even asked for! I think this is due to me joining in on the workshop as well as creating it. At first, SpeakEasy was located on NMC grounds, but because Lockdown I had to adapt it quickly. We went from doing SpeakEasy in-person to using Zoom a virtual video call. It has surprisingly got smoothly well, which is better than I could have anticipated.

I have become more independent regarding the planning and organising, for example, this week, I had a situation where we needed to change date/time to SpeakEasy to fit around some individuals ASAP and due to Lorraine being on Annual leave I had to resolve the issue independently. I have gained a variety of skills throughout participating in SpeakEasy and looking back I have enjoyed it.

Elie

Quiz

When lockdown began, I spoke to as many young people as I could to get ideas to do something social each week that will keep everybody alert and in contact. After deliberation they decided a quiz would be quite good. There has been good attendance and every single week it has gone ahead either way even when I was not able to host it. Everyone has hosted the quiz on Zoom at some point as the weeks have gone by. They have all become quite competitive in a friendly way and I have literally belly laughed with the youngsters over the weeks. I have just become entertainment value every week with my ridiculous answers!

One of our Duke of Edinburgh participants Josh now runs that quiz as his volunteering module. He is now hosting get independently every week from emailing participants, booking the scheduled meeting, running the quiz and keeping in touch. He has become a real asset and his confidence has gone from strength to strength.

The quiz was so much fun! It was a great opportunity to socialise and boost wellbeing. It helped increase my confidence with talking in front of a group and feeling ok to answer questions wrong in front of people without feeling embarrassed.

Amy

During the peak of lockdown, I was invited to a weekly Quiz. This included finding my own 10 Quiz questions each week and asking someone to answer them. For variety we tried asking someone different each week. This was my first experience with zoom meetings so to start of with I was quite nervous and did not know what to expect. I am also not very confidence speaking in public so again this was challenging in the beginning. Over the weeks I started to get more confident and asking the questions was much easier, the Quiz provided some social interaction during the week. The Quiz allowed me to become more confident during future zoom meetings like Live in the house.

Jake

The quiz is definitely a highlight of the week we all enjoy challenging each other and it's brought out the competitive side in people, especially me and you learn some new and interesting facts and it's resulted in some confidence boosts for many participating.

James

Helping with and being a part of the Zoom Quiz has been really exciting and fun, it has given me the chance to get to know other people who also attend the Neuromuscular Centre which has been really nice and given me something good o be able to do as it's not been really easy to get out and do things with COVID-19 and Lockdown which has been important for my wellbeing as I'm not just stuck doing nothing every afternoon.

Helping run the quiz is also helping with my Duke of Edinburgh Award as it is contributing to the Volunteering section of the award which I had to change from what I had originally planned to do for the section due to COVID-19 restrictions, being apart of the quiz has really helped improve my confidence as I'm not very confident talking to others that I don't know very well but now I feel a lot more confident talking to everyone who is a part of the quiz.

Josh

Live in the House

NMC GameChangers Youth panel came together to work on a project called Live in The House which was a virtual event to substitute the Live in the Park outdoor tribute band concert that was sadly cancelled due to the pandemic. They worked as a team with the support of the amazing NMC Design and Print and the overall NMC community. They collectively put together this event which consisted of music, poetry, animation and art to celebrate creativity. There was an auction, fancy dress, podcast and a draw. Live in The House was amazing. Jake, James, Ellie, Amy, Mark C and Andrew did an amazing job.

Live in The House was a fantastic opportunity to develop confidence in my own decisions. It felt lovely to be part of something big and I had a sense of belonging as we worked in a team. It gave a focus and goal, which is something isolation was trying to take away! It was great fun to be part of – especially working with such amazing people.

Amy

Being straightforward the Live in The House project wasn't my favourite. I do not think my whole heart was into it, but I did still learn a few things from it. For example, I was extremely busy with homelife, due to babysitting my two nephews during the lockdown and I had to balance looking after them and work, which I have not had to do before. It was hard, I think that is why I didn't enjoy Live in The House, because my mind was always on my nephews, wondering if they were okay etc. However, I still managed to do both at the same time, whether I enjoyed Live in The House or not I still participated in helping, which to me is a big thing. I would normally quit something that I don't enjoy, so it has taught me perseverance.

Ellie

It was so good overseeing this event. The team was so professional, and everyone had a skill that they brought to the table. Amy, Ellie, Jake, Mark, Andy, Luke and many others who had smaller roles were key to the festival's success.

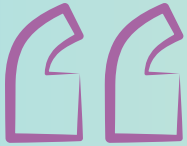
It was ground-breaking for the NMC and turned into a fundraiser generating over £1,000 and this is all credit to the NMC Gamechangers. Personally, it provided a positive distraction from isolation and I can't wait for next year's festival!

James



I really enjoyed the Live in The House Festival and it gave me something to really enjoy in the evening. I thought it was really nice that I was able to see so many talented people with their different acts and I was glad I could do a small part and contribute towards the festival by showcasing some of my Photoshop work in a video which was good. I felt the whole festival was really planned out and I thought there was a good balance of different acts to watch and other things like a Quiz to participate in. Even though lockdown had been lifted by the time the festival took place it still helped with my wellbeing as it gave me something nice and fun to do and cheered me up lots after a boring and depressing lockdown.

Josh



The regular meetings kept me in touch with the gang, it helped keep a weekly routine that was missing during lockdown. I think the meetings kept everyone organised and on track during Live in the house project.

Designing the Festival webpages

Contacted iPlayer HD to increase the video bandwidth. I personally emailed the company pleading for more bandwidth! This provided me with reassurance everything would be okay to host the video content. I felt this provided me with some professional experience I would not have gained without the festival.

Purchased the paid version of iPlayer HD.

Again, this provided me with some technical experience in the web design field that I will be able to use in the future. From Researching to actual implementation.

I have previous experience designing webpages especially during the development of the NMC website, but these Live in the House pages allowed me to be more creative and achieve something on my own. I enjoyed designing a webpage around the festival and carrying out feedback from the group. Being part of a team with everyone completing tasks set around each other's strengths.

Added the webpages to the main NMC website.

This was more of a technical job but nevertheless still needed to be done. Until the Festival came along, I did not know how to do this. This task required research for me to carry this out, again gaining valuable experience I can take into future projects.

Worked with Mark to receive the video content and upload the videos to the festival webpages. This required teamwork and organisation between me and Mark to get the relevant videos to upload to the website. We had to plan our time wisely to ensure the videos could be uploaded to the website in time for the festival. This included regular emailing and messaging due to lockdown.

On hand to assist with any technical issues during the festival. This included answering any questions or finding the answer to problems. I enjoy problem solving so it was nice to be on hand to help anyway I could.

Designed 2 versions of the flyer, one for social media and another full-size document. I improved my Graphic Design skills by creating a flyer from a specific brief to the final article. The best part of designing the flyer was everybody appreciated my work and it felt good to complete something successful during lockdown.

Jake 

Virtual Nights Out

The weekend and evenings have been the most difficult times particularly for those who would normally be socialising together or out and about with their friends and family. We developed Virtual Nights Out which was very successful. Young people came together and chatted, sang, shared in music interests, and have a tippie. It was just time to come together and talk about all sorts of things. People talked about their worries, conditions and they helped each other. These were lovely social nights enjoyed by all those who attended.

This was a great space to just enjoy yourself and introduced me to new friends and was a great way of getting to know someone better and took your mind off lockdown.

James

The virtual nights out have been a fantastic way of socialising and developing friendships. We always have a laugh and chat about anything and everything, it's the next best thing to seeing everyone in person and fighting off loneliness as well as a great addition to the projects.

Amy

These were good, we had so many laughs! I think this helped me to keep being social because I tend to recluse myself. I feel like I may have been more social during lockdown than I would have before!

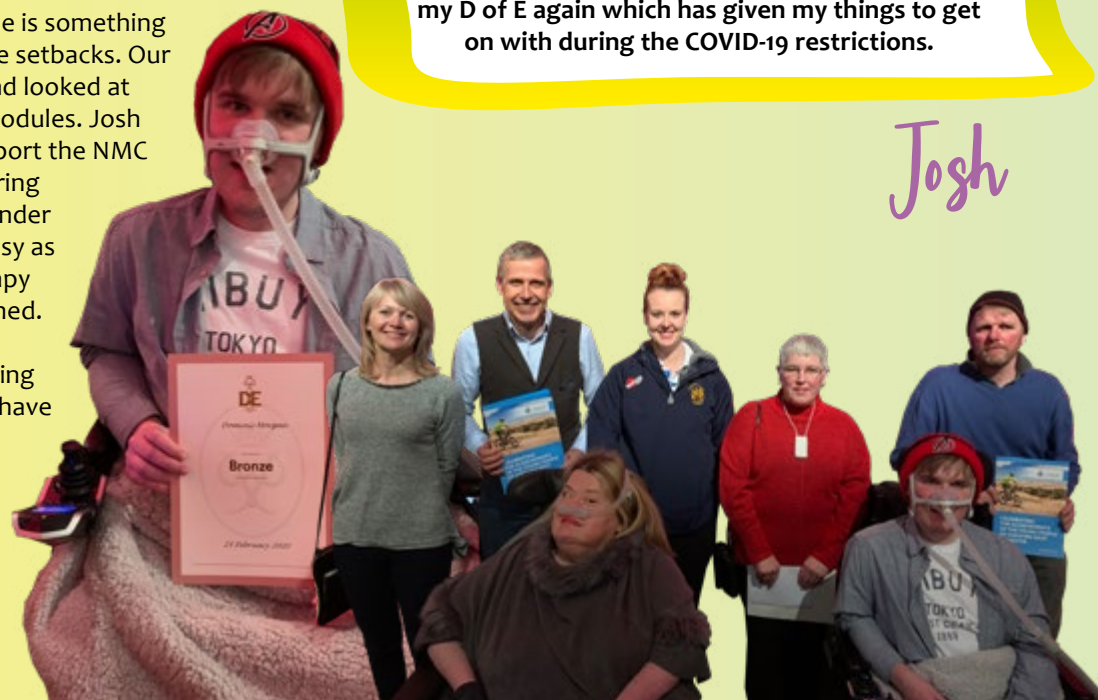
Ellie

Duke of Edinburgh Award Scheme

I found the Duke of Edinburgh 1 to 1's very helpful as before the 1 to 1's I was a bit unsure about how I was going to be able to start doing my D of E again. After having them I now have a clear plan in mind of what I'm doing for it and I am managing to get back doing my D of E sections again. I definitely feel the balance was right with having a 1 to 1 every week or so as I was able to stay up to date with everything. The 1 to 1's have helped with my wellbeing to as I have been able to start with my D of E again which has given my things to get on with during the COVID-19 restrictions.

Josh

Duke of Edinburgh Award scheme is something that I wanted to continue despite setbacks. Our young people have diversified and looked at other options to complete the modules. Josh changed his volunteering to support the NMC quiz. Ellie has done her volunteering for NMC fundraising projects. Xander changed his new skill to SpeakEasy as he could not work with the therapy dog team as he had initially planned. Ellie also continued to do her physical challenge at home working with the physiotherapist team. I have had regular one-to-one sessions with as many youngsters as possible and will continue to do this as they all want to complete as much as they possibly can.





Measures of Impact

We have included feedback from 3 young members of the NMC community (Amy, Andrew and Josh) to a variety of projects and development opportunities that were offered during the pandemic. These projects were all spearheaded by Lorraine Wooley our Transition Officer. Other young people were involved but not all felt able to feedback. We are confident that the experience of impact of these 3 people is reflective of most involved.

Josh

Pick Me Up Postcards

When you started this project how was your confidence?



How did you feel when lockdown began?



When this project it was completed did your confidence increase?



Did this project help you to overcome the impact of lockdown?



Live in the House

When you started this project how was your confidence?



When this project it was completed did your confidence increase?



How did you feel when lockdown began?



Did this project help you to overcome the impact of lockdown?



When you started this project how was your confidence?



When this project it was completed did your confidence increase?



How did you feel when lockdown began?



Did this project help you to overcome the impact of lockdown?



Quiz

Andrew

Duke of Edinburgh

When you started this project how was your confidence?



When this project it was completed did your confidence increase?



* Current confidence as course not yet completed

How did you feel when lockdown began?



Did this project help you to overcome the impact of lockdown?



Live in the House

When you started this project how was your confidence?



When this project it was completed did your confidence increase?



How did you feel when lockdown began?



Did this project help you to overcome the impact of lockdown?



Amy

Pick Me Up Postcards

Quiz

When you started this project how was your confidence?



When this project it was completed did your confidence increase?



When you started this project how was your confidence?



When this project it was completed did your confidence increase?



How did you feel when lockdown began?



Did this project help you to overcome the impact of lockdown?



Live in the House

When you started this project how was your confidence?



When this project it was completed did your confidence increase?



How did you feel when lockdown began?



Did this project help you to overcome the impact of lockdown?



When you started this project how was your confidence?



When this project it was completed did your confidence increase?



How did you feel when lockdown began?



Did this project help you to overcome the impact of lockdown?



Quiz

Speak Easy

When you started this project how was your confidence?



When this project it was completed did your confidence increase?



How did you feel when lockdown began?



Did this project help you to overcome the impact of lockdown?



Virtual Night Out

When you started this project how was your confidence?



When this project it was completed did your confidence increase?



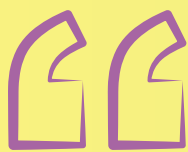
How did you feel when lockdown began?



Did this project help you to overcome the impact of lockdown?



Amy describes what life in lockdown would have been like without the NMC...



The NMC is a place where I feel like I belong and that we are not alone, even in lockdown and throughout the pandemic so far. Working in a team where everyone is accepted and the focus is on ability not disability is truly something to be treasured. Without the NMC I honestly don't think I'd still be here. I've struggled a lot with my mental health in the past and the NMC has given me the support, confidence, purpose and social side of things that I desperately needed.

I started at the NMC about two years ago and have been volunteering as Transition Support for over a year plus during the pandemic and it has honestly been incredible. I have taken part and helped in quite a few of the events since I started. These include Live in The House, Pick Me Up Postcards, SpeakEasy, Virtual Spirit of Christmas and more.



Live in The House was a fantastic opportunity to develop confidence in my own decisions. It felt lovely to be part of something big and I had a sense of belonging as we worked in a team. It gave a focus and a goal, which is something isolation was trying to take away. This was very similar with Pick Me Up Postcards and especially Virtual Spirit of Christmas most of all. These gave a brilliant sense of purpose and focus during lockdown which really helped with my mental wellbeing and gave me something to look forward to.

Working alongside such brilliant people was a confidence boost in itself and being able to help the NMC and community was all round amazing! I've gained so much confidence and feel like I'm becoming the person I want to be because of the incredible NMC.

I honestly don't know what I would have been doing without the NMC especially as my other volunteering has stopped with the pandemic. The NMC has kept me going

and I cannot express how incredibly grateful I am for the opportunities and everything the NMC does. Without the NMC I would be lost with no purpose with my mental and physical well-being suffering greatly. I wouldn't be keeping up with exercise as the physios wouldn't be there for support and motivation so as a result my condition would have severely deteriorated. I wouldn't have a reason to get out of bed or anything meaningful to focus on and as a result I would have spiralled with very poor mental health. The NMC was and very much still is absolutely fantastic during the pandemic to keep moral high and loneliness at bay. Despite the normal events and a few new things having to switch to being online, they were all successful. I really dislike comparing one thing to another but, I have to say, the NMC was miles ahead of a lot of organisations in terms of communication, keeping support going and still providing activities and social interaction albeit online. The NMC has reacted and adapted incredibly well to the pandemic which goes to show how phenomenal the team of staff are and the true passion they have for the community and what the NMC stands for.

The NMC is a vital part of so many people's lives, including mine, it brings people together and puts a smile on the faces of hundreds of people, which is especially important during these difficult times.

Amy





Conclusions

As the concluding thoughts are being written we are in full national Lockdown #3 in the midst of a cold and wet January.

It does not feel like there is a great deal to look forward to but NMC is still feeling buoyant. There is still a lot of creative and kind energy in the team. Plans are emerging for real get togethers outside in our delightful grounds. We have already ordered a large marquee/gazebo to enable NMC to go outside for much of our community life in spring and summer 2021.

Just these simple acts and thoughts about getting dates in the diary – things we can all look forward to, feels like the most important energising and positive thing we can be doing.

2020 has been hard work. So much of the year has been spent agonising over striking the right balance between helping as many people as much as possible, ensuring that

those who do attend the Centre do so confidently, along with keeping everyone safe from the virus. We reflect that we have struck that balance about right. The virus has never entered NMC and our community, whilst frustrated by restrictions and reduced service, have been universally understanding and supportive of the measures we have taken.

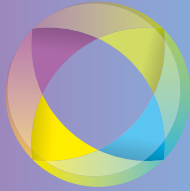
Whilst we reflect proudly on our year, we ask ourselves what has been our most impactful achievement amongst all the positive work that has been done?

We think it is best summed up by saying that we kept people afloat through the darkest and most difficult of times. People's physical and mental health was sorely tested and in many cases people struggled. NMC has been successful in keeping individuals and families "bobbling along" as our Chief Executive describes it. That is not to say there have not been individuals who have thrived during the pandemic – there have, but for most it has been challenging. Simply knowing we were here and that we remained open throughout was reported by many in our community as the single most important source of hope in their lives.

With so much responsibility on our collective shoulders our duty is very clear. We must remain energised. We must remain responsive to people's needs and we must continue to function and flourish as an organisation. It is simply too important to countenance anything else.



The NMC is a place
where I feel like I
belong and that we
are not alone



NeuroMuscular Centre

Woodford Lane West, Winsford, Cheshire, CW7 4EH

01606 860911

matthew.lanham@nmcentre.com

www.nmcentre.com

Registered Charity No. 1023606

Produced by NMC Design + Print • Tel 01606 863464

A social enterprise forming part of The NeuroMuscular Centre,
working with people with neuromuscular conditions



GRAPHIC DESIGN+PRINT MANAGEMENT
Part of The NeuroMuscular Centre