

Get Active Toolkit: Neurological Conditions

A toolkit for organisations wishing to support people living with neurological conditions to be physically active.

This toolkit will be useful for a broad range of people from a person living with a condition to a commissioner of health, wellbeing and leisure services as well as anyone delivering these services. We believe the toolkit could also be applied to a range of other long-term conditions.

It explains how the Neuro Therapy Centre developed this project in West Cheshire with many partners. This is how the steering group for the project achieved this. Read the evaluation and outcome [report](#) to see the results.

If you are trying to get this type of project or activity off the ground we hope this guide will be useful.

The project partners were:

- Neuro Therapy Centre
- Brio Leisure
- Walton Centre (focused on the Therapies Team)
- Parkinson's UK
- MS Society
- Sheffield Hallam University



You are welcome to read the whole toolkit. We have identified sections of the toolkit below that may be of particular interest to certain audiences:

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What did the Access to Exercise Project set out to do?

The project funded by the Sport England Life Changes programme aimed to:

- Provide accessible and varied activities and spaces for people living with neurological conditions to develop exercise and movement.
- **This was done by providing:**
 - Accessible exercise options in Brio leisure sites and the Neuro Therapy Centre
 - Training for exercise professionals through a partnership with [WRIGHT Foundation CIC](#)
 - The project ran from May 2018 and was extended until October 2022 due to the impact of the pandemic.
 - During and after the pandemic people could access opportunities and support digitally and over the phone.

What the project actually delivered

- Opportunities to move and exercise even during covid through digital options with one person commenting about the lockdown:
- ‘Great big thankyou to the Neuro Therapy Centre and all staff for all they have done during the last year it has really helped me to keep going and keep moving.’
- Established exercise opportunities in Brio leisure sites prior to lockdown which only started up again in April 2022 after Brio leisure opened fully in September 2021.
- The project also established an accredited course for exercise professionals as detailed above.

Learning Points

Important learning points prior to the commencement of the project:

- Focus groups and the steering group involved three people living with conditions in the design
- A steering group that all partners attended including representatives of people living with conditions (attendance from the health trust partner proved difficult to maintain through the life of the project, and hybrid meetings should be considered to facilitate participation).

The project aimed to address the concerns and barriers raised by people in the focus groups, this included:

‘Worst thing you can do is not move enough, this place helps you keep moving.’

‘If you could sort something out nearer to home that would be great.’

‘Lack of training of leisure service staff in neuro conditions would affect confidence of people using the service.’

‘The biggest thing I’ve lost (with MS) is my confidence.’



What is a Neurological Condition?

“A neurological condition is any condition that affects the brain, spine and/or nerves. Because these systems control your mind and body, neurological conditions can affect the way you think and feel and interact with the world. Neurological conditions can affect anyone at any age.” - Neuro Alliance

One in six people in the UK lives with a neurological condition.

There are over 600 known neurological conditions and this number is increasing all the time as diagnosis improves. Doctors, researchers and clinicians sometimes find it helpful to group neurological conditions together in four main categories:



Sudden onset conditions, like stroke, traumatic brain injury, spinal injury, meningitis or Guillain-Barre Syndrome

Intermittent conditions, like epilepsy, migraine or cavernoma

Progressive conditions, like Parkinson's disease, dementia, motor neurone disease or ataxia

Stable with changing needs, like Tourette's syndrome, narcolepsy, fibromyalgia, transverse myelitis and cerebral palsy.

This project worked mainly with people with progressive conditions and some people with stable with changing needs conditions. As the work develops from this point there are discussions to include people living with other neurological conditions where exercise and wellbeing needs are not being met.

Forming a Partnership

The partnership came together because the idea of increasing access to exercise and movement opportunities for people living with a neurological condition was:

- Important to everyone in the partnership and fitted with their goals
- All partners recognised there was a gap and wanted to work together to develop a response.
- People living with conditions had stated the benefits and also the difficulties of accessing current services.



This gave the partnership time to:

- Get to know each other better in particular how the respective organisations worked including identifying who the right people were to sit on the steering group
- Provided time to develop links with Sheffield Hallam University, as the research partner
- Provided an opportunity to trial access at Brio leisure through welcome events and trialling one aqua class at Ellesmere Port.
- Most importantly developing engagement with people living with neurological conditions to identify the blocks and barriers people experienced when trying to access community leisure facilities.



Learning Points

Give time to form the partnership developing relationships and aligning with goals of different partners.

Ensure the partnership has clear ways in which to engage with people for whom the service is being developed, including people sitting on the steering group.

Brio Leisure:

“ This partnership approach has had a positive impact on the lives of those living with neurological conditions within Cheshire West and Chester, providing them with access to high-quality facilities and to a range of physical activity and rehabilitation services.

This collaboration represents a wonderful example of how a number of organisations can come together to co-design solutions together to make a positive impact on the health and well-being of individuals within their community.

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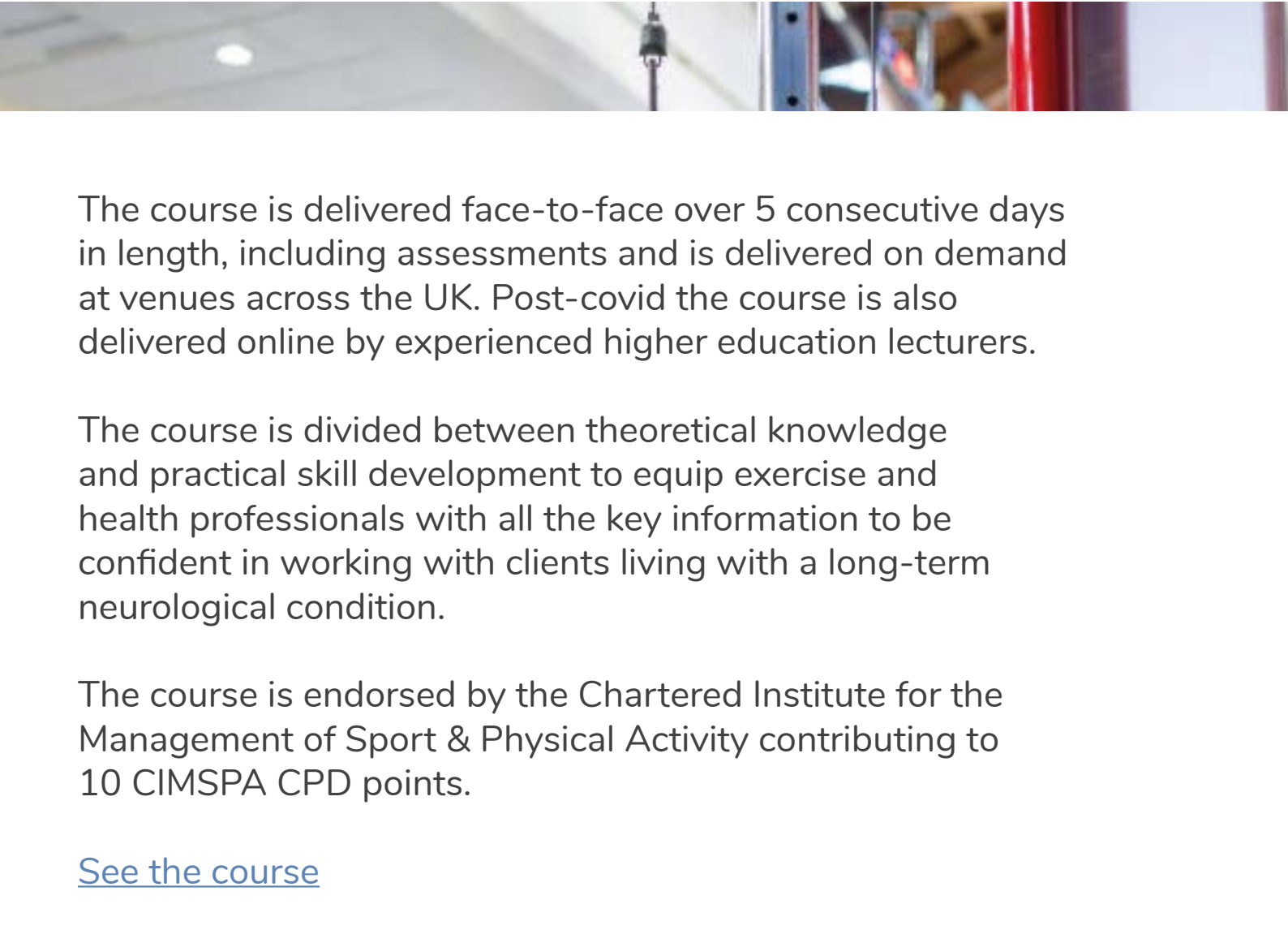
Training for Exercise Professionals

“ Amazing course with amazing lecturers. Clear, friendly delivery of material. Inclusive approach. I have learned so much from this experience. ”



The course was put in place to address the barrier people living with neurological conditions identified about being uncertain in the skills and understanding of leisure service staff around neurological conditions.

The course and qualification development was overseen by the WRIGHT Foundation CIC, a training provider who offer Exercise Referral and Specialist Long-Term Health Condition qualifications for the fitness industry, and who already provide training to staff at Brio Leisure. The course was developed with Keele University, a leader in Rehabilitation Science.

A woman with blonde hair, wearing a red tank top and black leggings, is seated in a wheelchair in a gym. She is performing a seated row exercise using a cable machine. She is pulling the handle towards her chest with both hands. The background shows other gym equipment and a bright, well-lit environment.

The course is delivered face-to-face over 5 consecutive days in length, including assessments and is delivered on demand at venues across the UK. Post-covid the course is also delivered online by experienced higher education lecturers.

The course is divided between theoretical knowledge and practical skill development to equip exercise and health professionals with all the key information to be confident in working with clients living with a long-term neurological condition.

The course is endorsed by the Chartered Institute for the Management of Sport & Physical Activity contributing to 10 CIMSPA CPD points.

[See the course](#)



first course ran in January 2019. 173 professionals have been trained across the UK (at time of writing) and a survey of our students in 2021 found that amongst 32 respondents:

- 667 people with neurological conditions had been supported
- 92% of students cited referral directly from health care services and support groups, including NHS, GPs, Parkinson's UK, MS centres and neuro physiotherapists.

The project also worked to establish a networking group of the people trained, although this has proved difficult to re-establish post-covid. The network when it met provided opportunities to:

- ask questions of neuro physiotherapists about particular people they were working with.
- discuss together the development of the service they offered and share what had worked in the setting they work in.
- share ideas and thoughts about how to increase referrals





Learning Points

- Managers and where possible strategic managers in a leisure service need to support and enable staff to be freed up to complete the training.
- Although staff can use the training with many people they come into contact with in a leisure service it is beneficial to get agreement at a strategic level and from senior managers in the leisure service so the people trained can do targeted delivery to people with neurological conditions.
- It is helpful although not essential for staff to have links with a local therapies team and to build a partnership. This supports ongoing learning for the people trained and has the potential to build up use of the services offered from people who access physio services.
- It is important to work towards 3-4 staff at least being trained within a leisure service provider at any one time to maintain continuity in the event of staff departure.

Learning Points

- A requirement of the course is that the person must have completed the GP referral level 3 training course for exercise professionals, this can be a barrier to accessing the course. It may be necessary to increase the number of people who have completed this level 3 course in any organisation that wants to access this training.
- People completing the qualification and developing opportunities and resources for people living with neurological conditions increases awareness amongst all staff of this group's needs. This is positive and to be encouraged and will mean support can come from a range of staff some of whom won't have completed the training and will use the skills and expertise to adapt classes and opportunities to individuals ability.





Thoughts from participants:

“ Really interesting and inspiring delivery of sometimes forgotten conditions when delivering exercise. ”

“ I thought this course was extremely professionally run by two immensely knowledgeable, kind and helpful tutors. Our group and the tutors brought in real life examples which helped with the immersion of the course content and I absolutely enjoyed the whole course. Thanks again. ”

Developing Referrals

The project tried a number of ways to develop referrals none of which apart from the self-referral route and to some extent referrals from GPs were very successful in securing referrals.

Health Care

To encourage referrals from health care staff the project:

- Met with and presented to specialist nurse teams in the acute neurological centre that provided services across Mersey and Cheshire – Walton Centre. These meetings took place several times up to the end of 2019.
- Targeted information for health care professionals supporting an understanding of the referral process were created.
- The health care professional information was sent round the West Cheshire GP bulletin and other local health care contacts. Very few referrals came through the primary route, this led to independent interviews conducted by Sheffield Hallam University with Walton Centre staff and the following was identified as potential barriers:
 - The staff did not see large numbers of people living with neuro conditions from the West Cheshire area.
 - A lack of time to have the discussion/make the referral.
 - Concerns that a referral amounted to an endorsement of the service
 - Concerns that people had to pay for the service.
- In response to this the project rewrote the information for health care staff to address some of these concerns, and revised the referral form.

Alternative Referral Routes and Self-Referrals

People were encouraged to make use of the service by the project communicating with local charities and networks as well as through word of mouth. The following contact points were developed:

- Targeted information for people living with neurological conditions to encourage self-referrals. These were sent to local neuro groups meeting in the West Cheshire area including Huntington's, Ataxia, MS, Parkinson's, Fibromyalgia and other local networks as well as circulating to local charities such as Disability Positive.
- Engagement with the local GP referral scheme service via Brio health improvement worker employed by the project. This meant people who were referred into the GP referral scheme who were living with a neurological condition could be picked up.



Learning Points

- Establish contact early on with potential referral partners in the NHS preferably before the project starts.
- Don't assume by providing information that referrals will be received.
- Make the referral process from health care staff as easy as possible whilst ensuring GDPR requirements are complied with. The referral process is currently being streamlined again in discussion with Walton NHS staff.
- Don't give up if referrals from health care in particular are hard to secure. We were informed by the researcher for the project that this was a common experience with other health care charities in other sectors struggling to secure referrals.



There is a renewed focus on the role of the [voluntary sector in health care](#) with the ICSs – see next steps below.

‘That’s why integrated care systems (ICSs) must look and feel different from the past by embracing the VCSE sector like never before. VCSE bodies should be able to build on the work they are undertaking and be treated as key partners in the delivery of health and care.’

Local groups and networks need to receive the information about the project you are setting up or the support you offer with regular updates. The communication should flow with an opportunity for feedback via surveys and focus groups.



Leisure Services

Opportunities and Challenges

The partnership with Brio Leisure was a natural one to develop because of their commitment to developing fully accessible services.

This is underpinned in Brio leisure by a welcoming environment for all which all staff are supported in delivering through training and learning. In addition, as Brio Leisure is a not-for-profit organisation the focus on community needs and concerns is balanced with the need to develop sustainable services. Some development points from the project:

- Up until April 2021 a member of the Access to Exercise project team was based in and managed by Brio Leisure. This proved important in developing conversations and presenting to staff teams on the project. It also increased referrals into the scheme.
- The welcome sessions run in Brio Leisure were well supported by exercise professionals in Brio Leisure who listened carefully and responded to the needs of people living with neurological conditions.



- Examples of the ability to listen to needs and respond appropriately as a service included:
 - Waiving the requirement to pay for a session if you cancel on the day, in recognition of the fact that many people living with neurological conditions do not know what they will feel like that day or what they can achieve until the itself.
 - Putting clips for walking sticks pool side so they are easy to access when the person gets out of the water.
 - Giving wheelchairs poolside access to facilitate inclusion in aqua therapy.
 - The design of the newer Brio Leisure sites had been thought through in terms of accessibility e.g. lifts that lower people into the pool which a wheelchair could be wheeled onto and plenty of space and large changing rooms with one changing room with a hoist built in.
- The worker in place at Brio was important and needed to be supported by a senior and more strategic member of staff in Brio Leisure. This proved more difficult to secure as the staff allocated at a senior level changed several times due to changes in roles and staff departure, and obviously was impacted by the lockdowns and closures.
- Several targeted classes for people living with neurological conditions were started prior to covid,, and work was undertaken to make these sustainable. These were shut down during covid and were supported in restarting from September 2021 when Brio fully opened again. There are now six classes with sustainable numbers attending although promotion and encouragement to attend needs to continue.
- Support from physios to help leisure staff understand how to adapt their approach for people living with neurological conditions.

There have been many positive comments now the classes are back up and running:

“ I have attended a couple of the Neuro Therapy classes on Friday afternoons at 1pm. At my first class I was asked what my abilities were and Donna, the instructor, has been working with myself and others to improve our strength in the areas we require. All of this is slow movements and use of stretch bands and Pilate soft balls. This is a lovely, small class and everyone goes at their own pace.

My movement has improved steadily with her guidance and my confidence has been built as I had been reluctant to attend any exercise classes as embarrassed. Donna is a very good instructor and I am grateful to her for her help and support.

”

Learning Points

- Identify and secure a marketing contact early on in the project development to support joint communication and social media to develop. In part because of covid which led to structural and staff changes this has proved difficult for this project.
- Need to develop communications and marketing about the offer beyond usual contacts linking in with local neuro charity groups around MS, Parkinson's, Huntington's etc.
- A post based in the leisure service is useful to increase the knowledge of staff teams and support referrals into the service.
- They need to be well supported by consistent management which was not always the case for the worker although this was impacted by covid and lockdowns. Also it is important to work through and ensure different terms and conditions for the leisure service staff don't impact on project delivery e.g. length of contract, etc.
- Regular meetings with centre managers in particular post-lockdown proved important to secure an understanding of the work and actions to develop the numbers of people attending the classes.
- Think about the times that classes are put on so that people aren't put off because of issues of fatigue - later afternoon, and early morning and directly over lunch time can be difficult for people to attend.
- Gathering vignettes/video stories from participants to include in promotion of the services offered is a positive way to advertise.
- The goal in working with leisure services is to make the classes set up sustainable, this is an ongoing commitment in relation to marketing of the offer.

Member with MS:

“ Since I’ve been attending the Brio Centre, I’ve noticed a big improvement in myself, in fact I’ve felt alive for the first time in a long while. I was new to exercise but the classes have improved my circulation and this is improving my confidence and my desire to try new things at the Centre and beyond. ”



Member with Parkinson’s disease:

“ The instructor is brilliant and she thinks about the types of exercises to suit my condition. The classes have had an amazing impact on my life. This type of exercise is perfect. I have no worries about falling down. This is now my world and I love it. ”



Covid and Digital Options Developed

It is fair to say that covid and a lockdown appeared nowhere on the project risk register prior to 2020. The project team was able to regroup on zoom fairly quickly and discuss options and agree that offering a digital option during lockdown was positive and hopefully would be beneficial.

The following points were important to developing this offer:

- A decision was taken in March 2020 that the project would broaden its offer with support as well as access digitally to exercise opportunities. The offer of support and exercise opportunities began to be delivered from April.
- The digital exercise offer included live classes people could join and a range of videos people could use to keep active.
- The support was offered via regular phone calls to all participants although this proved difficult to achieve as the Brio member of staff was initially furloughed, so time was lost in maintaining this contact during the first lockdown.
- People were also able to access one-to-one digital sessions with physios and instructors at the Neuro Therapy Centre if they felt that would be beneficial or the support call identified this as important.
- A risk and health and safety assessment was completed for this new offer to ensure effective delivery and the health and safety of participants
- Surveys were conducted twice by the researcher to find out the benefits and difficulties of using the digital service Social only classes were trialled including quizzes, etc.

Learning Points

- It was necessary to ensure Wi-Fi and internet support signals were as strong as they could be to prevent buffering and freezing during live classes.
- It was also important to provide support to people so they could use zoom effectively.
- **The surveys conducted showed:**
 - Most but not all project participants were happy to switch to digital and enjoyed the social aspect as much as the physical.
 - Participants needed to identify a large clear area in the home to take part in the classes.
 - People appreciated having a focused way to keep moving while at home.
 - Most people who wanted to were with some support able to use the digital classes.
 - Post lockdown some but not all people valued having the choice to access a digital class on days when they felt less like travelling to the Neuro Therapy Centre.
 - Most people post lockdowns appreciated having the option to meet people face-to-face stating that socialising just 'flows better face to face'.
 - Digital meetings have made it much easier for the health partner to attend the steering group.



Evaluation



The purpose of this section is not to go through all the findings of the [evaluation report](#) of the project.

This section details how the evaluation was set up to deliver on its primary aim which was to understand to what extent the Access to Exercise project effectively supports and sustains people with neurological conditions into an active lifestyle.

Our approach

A well-planned and carefully executed evaluation will reap more benefits for all stakeholders than an evaluation that is thrown together hastily and retrospectively.

The evaluation of the Access to Exercise programme aimed to overcome these challenges by adopting:

- the use of validated tools of measurement
- recognised methods of data analysis and interpretation. That said, it was also important to be mindful of the fluid nature of the Access to Exercise programme, and as such, the evaluation worked within a pragmatic framework.

The evaluation included in practice:

a mixed-method design which was three years in duration with both quantitative and qualitative data being collected to give a more comprehensive overview and help address the different elements of the research question. [Figure 2 illustrates the AtoE pathway.](#)

The Access to Exercise participants were given questionnaires at four-time points within 12 months, including; baseline, 3 months, 6 months, and 12 months (completion). Interviews were conducted with project delivery staff and health professionals.

The quantitative outcomes collected were: physical activity levels, engagement in sport, mental well-being, self-efficacy, and social and community development. Sport England specified all questionnaires.

Learning from the Evaluation

- As you begin developing an idea, engage with academic research teams as early as possible. This will ensure they are part of the development process. For this project Sheffield Hallam University staff were involved in discussions for approximately 18 months before the project began.
- Test out the tools you are going to use with some potential participants. The tool we used around exercise behaviour (linked to Sport England requirements) was quite restrictive and made participants feel they hadn't achieved that much when they had increased activity over the recording period.
- Don't only focus on activity, mobility, and exercise in outcome measurement. Wellbeing scores are equally if not more important to record in terms of impact on quality of life.


Conclusion and Further Contact with the Project

Everyone involved would like to say a massive thank you to all the partners who made the this project possible. Really positively the work is now progressing through ongoing commitment from the partners and some new partners following funding from the Community Fund.

If you want to stay in touch, or there is an area of the work you would like to know more about, please send your details on the form below. We will respond to your request for further information and if you have agreed your name will be kept on a mailing list used to send further updates and workshops/webinars linked to this area of work.

We hope you will have success in delivering exercise and activity using some of the pointers above. We'll finish with a quote from someone living with a neurological condition, this and other comments inspired the steering group to keep going to develop these opportunities:

[Contact Form - Keep in Touch](#)



“ Once you have grieved (having received diagnosis)... exercise. ”