



# ARCBITE

Brokering Innovation Through Evidence

## Supporting access to activities to enhance wellbeing and reduce social isolation in patients living with motor neurone disease (MND)

### Background:

Up to 5,000 people live with Motor neurone disease (MND) in the UK at any one time. It is a complex neurological condition that can affect an individual physically, cognitively and psychologically, it is life-shortening and there is no cure. People living with MND have emphasised the importance of psychological support and wellbeing in helping them manage their condition. Occupational therapy is a client-centred health profession concerned with the use of occupation to promote health and wellbeing. Participation in our chosen occupations can provide a sense of happiness, satisfaction and connection with others, which are key elements in maintaining a person's sense of wellbeing. Occupational therapists have expertise in balancing risk and addressing barriers to participation. Social prescribing has seen growing momentum recently and has been referenced heavily in the NHS Long Term Plan and the implementation of Personalised Care. It has been defined as a formal process of referring patients with largely socioeconomic and psychosocial issues to a link worker, to co-design a plan to improve their health and wellbeing. The link worker facilitates engagement in occupations based within the individual's local community this might include volunteering, accessing educational courses, attending social clubs, joining in with reading groups or art classes. This project brings together the expertise of occupational therapy and social prescribing link workers to address the well-being needs of people living with MND in the Liverpool and Sefton area.

### What was the aim of the project?

The project aimed to identify suitable community based activities to support psychological wellbeing for a cohort of people living with MND in Sefton and Liverpool. The project led by an occupational therapist worked alongside social prescribing services to enable the

person with MND to participate in their chosen occupations. The project would identify the pre-implementation barriers and facilitators from the perspective of a) patients and b) people referring and link workers. The project would consider how facilitators identified can be enhanced, and barriers overcome.

### What did we do?

Participants were recruited by The Walton Centre multidisciplinary team (MDT), community therapy teams, council based occupational therapists and local MNDA Association Visitors. Participants were contacted by the project lead and a home visit was completed alongside a link worker. Participants were asked to complete an interest checklist prior to the visit to help facilitate conversation about their chosen occupations. Link workers provided their expertise in relation to their knowledge of local activities as well as additional support with issues such as benefits. The project lead provided expertise in relation to identifying potential barriers and supporting problem solving as to how these would be overcome. This included accessibility of the environment, the availability of appropriate seating and liaising with community services about wheelchair needs.

### How did we involve people?

Three public advisors supported the project, two of whom had lived experience of supporting a family member with MND and continue to advocate for people living with MND. The third represented the third sector and provider of support services including wellbeing activities specifically for people living with neurological conditions.

Allied Health Professionals (AHPs) were asked to complete questionnaires prior to the commencement of



the project to establish their confidence using and referring to wellbeing activities.

Participants were asked to participate in interviews during the post intervention review and gave their insights into participating in the project and how they felt using community based wellbeing activities would or would not benefit people living with MND.

Link workers and wellbeing activity providers were asked to provide their experiences of participating in the project, their role in enabling a person with MND to participate in their chosen occupations and any future training or development needs.

### What we found and what does this mean?

This pilot study demonstrated that plwMND (people living with Motor Neurone Disease) value participation and would want to engage in community based activities. Those plwMND who were experiencing mild symptomology and minimal changes to their level of independence were able to access community based activities and reported a positive impact on their wellbeing. The plwMND with more complex needs in particular reduced mobility, which prevented their participation. Barriers included transport, equipment provision, lack of company to support participation and lack of confidence using mobility aids in a community environment. These same barriers were highlighted by the link workers during their interviews. Link workers valued the opportunity to work with an occupational therapist and the opportunity to work in partnership. AHPs reported a lack of knowledge of community activities and wanted to know more about what was available. Based on these findings it is recommended that social prescribing pathways should be considered bringing together the expertise of AHPs and link workers to enable plwMND to access community activities and to prevent further health inequalities. In order to address wider barriers to participation a whole system approach is required including the consideration of local infrastructure.

### What Next?

Further research is required to determine how best to implement social prescribing for people with neurological conditions such as MND to prevent increased health inequalities for this group of people with long-term conditions. This pilot project will

continue to gather data and explore how best to support partnership building between link worker services and AHP services. Findings from this project will be shared with Liverpool and Sefton CCGs and Councils to raise awareness of the current barriers to participation for people living with a long term neurological condition like MND.

### Who was involved – partners?

- Citizens Advice Liverpool – Ways to Wellbeing
- Living Well Sefton
- North and South Sefton Community Therapists
- Liverpool Community Therapists
- Liverpool Council Occupational Therapists
- The Walton Centre MND MDT
- MNDA
- The Brain Charity

### What is NIHR CLAHRC / ARC North West Coast?

The Applied Research Collaboration North West Coast (ARC NWC) superseded CLAHRC NWC in September 2019. It is a partnership between universities, NHS, public, etc.

Its mission is to undertake applied research to improve public health, wellbeing, quality of care & reduce health inequalities across the North West Coast region.

<https://arc-nwc.nihr.ac.uk/>