

# Communicating wellbeing and quality of life in Motor Neurone Disease to Multidisciplinary Teams



Collaboration for Leadership in Applied Health Research and Care North West Coast

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## Background

Increasing evidence shows that services for people with Motor Neurone Disease (MND) need to address strategies to enhance psychological and social care in addition to physical needs<sup>1</sup>.

This project aims to educate staff about the importance of psychological and social wellbeing in Quality of Life (QoL) to people with MND, joining these with recent findings of the Trajectories of Outcome in Neurological Conditions (TONiC) research<sup>2</sup> via a one-off workshop. This work also takes into account the need to impact on reducing inequalities in health. As the Marmot review (2010) detailed, this is not just a nice thing to do, but a matter of social justice<sup>3</sup>

## Method

A research steering Committee was established early in the research process to inform the study design, implementation and data-analysis. This consisted of; two public health advisers, MND Occupational therapist, neuropsychologist, MND regional care and development adviser, nurse clinician and a community based speech and language therapist.

A mix of clinical healthcare professionals working with people with MND were recruited via a snowball technique. The workshop included talks about MND and QoL, and the link to health inequalities. After the talks, staff were divided into four groups moving between different topics for discussion (awareness and knowledge of MND; skills and practicalities in MND; acceptance of beliefs and motivation for change in MND; health inequalities). Most of the workshop discussion topics were based upon the NICE guidelines and changing practice<sup>4</sup>

The group work was arranged in a world café approach, whereby each group added information to the previous group. Participants were asked to complete a pre-workshop questionnaire to assess baseline knowledge on QoL, followed up with a post-workshop questionnaire two weeks later and a 10-minute telephone interview after a further two weeks.



## Results

**The following results will demonstrate the analysis to date of the workshop pre-questionnaire and the group work. The post-workshop questionnaire and interview data analysis is ongoing.**

Nineteen people attended the workshop, including dieticians, physiotherapists, psychologists, assistive technology representatives, occupational therapists from health and social care, speech and language therapists and palliative care nurses.

## Results

Clinicians had a high degree of experience with MND (mean 12.5 years), and expressed a diverse range of interests in MND issues, primarily involving physical care and supporting people with MND and their families.

When focusing on QoL, holistic and cohesive work was emphasised. The TONiC study was well known to the majority of attendees (53%). Two people were aware of outcomes to date and outlined how TONiC findings apply to their practice.

## Workshop Themes and Analysis

Main Themes	Sub Themes
Collaborative Working	Team Enhancement MDT Rainbow Caring MDT Rainbow Support
Specialist Links	Journey to Experts Pathway needs psychology
Referral Links	Enhance Referral process Quality Referral Right time right place referral Self Referral
Knowledge Base	Learning barriers Enhancing specialised MND Knowledge Sharing the knowledge with generalists Sharing pathway knowledge
Experience	The learning trajectory Confidence to manage MND Others matter
Providing pwMND information	Enlightened informing Better working
Creative methods of working	Service flexibility Developing new horizons
Promote understanding throughout trajectory	Condition adjustment Service flexibility Right time right place
Promote individuality of pwMND & family	Keeping on track Right approach for pwMND Making more of what we've got Barriers to living with MND
Pathway predicaments	Right timing right people Pathway Inertia Chronological Care The postcode lottery Pathway building
TONiC QoL	Resonance QoL vs finances

Team helping younger people. They communicate with peers and family through mobile phone & social media

Empower patients to access services

Other agencies lack understanding of MND

One way of providing info at diagnosis may result in health inequality

Tap into voluntary sector

Demystify wellbeing and psychological support

Financial burden not only attached to lower socioeconomic areas

Lack of current pathways for care for psychological input

## Workshop Themes and Analysis

The themes demonstrate many different aspects which were categorised. The need for 'joined up' information on local services in general and specific to motor neurone disease was emphasised and repeated in many of the category themes as was the need for appropriate psychological services.

## Discussion

The next step is to compare the views of the pre-workshop questionnaire with data from the post-workshop questionnaire and interviews, to understand how TONiC findings can be implemented. The lack of acknowledgement of social issues in the MND team interests, and importance to QoL, may need to be addressed in practice.

## Future Plans

- To take forward the concept of needing a local 'information repository' for patients, carers, families and professionals
- To collaborate with other voluntary and statutory organisations who have an interest in local information directories such as the Brain Charity Liverpool.
- To collaborate with existing projects that hold similarities with this project such as 'The Sefton Project'.
- To devise an implementation plan through PPP3 application
- To induct the newly appointed MND project lead

## References

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