

Models of Care in Motor Neurone Disease

Final report to the Motor Neurone Disease Association

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Introduction

Motor neurone disease (MND) is a progressive neurodegenerative disease of the upper and lower motor neurones that leads to weakness and wasting of muscles, loss of mobility in the limbs, difficulties with speech, and difficulties with swallowing and breathing. People with MND may also present with non-motor symptoms, one of the most common being cognitive change. People with MND may experience changes in thinking, reasoning and behaviour. For many people the changes are subtle and have little or no effect on daily life, however a small number develop frontotemporal dementia and need additional support.

In the UK there are up to 5,000 people living with MND at any one time. MND can affect adults of all ages but is usually diagnosed in those over the age of 40, with the highest incidence occurring between the ages of 50 and 70, and men are more affected than woman. Life expectancy can vary considerably with some people living for up to 10 years, however half of all people with the disease die within 14 months of diagnosis.

The MND Association is the only national organisation supporting people affected by MND in Wales, England and Northern Ireland, with approximately 90 volunteer led branches and 3,000 volunteers. The MND Association plays an active role in campaigning on a range of issues concerning MND and is also focused on MND care and research across the UK.

Background to the research

The Office for Public Management (OPM) was commissioned by the MND Association to research and identify different models of care for people with MND to be used to develop a clear vision for planning, commissioning and delivering high quality multidisciplinary services for people with MND. The aim of this work is to equip the Association to provide clear influencing messages to audiences at all levels, in order to secure progress towards well-understood and well-evidenced models of care for people with MND.

Throughout this report the term 'model of care' will refer to the way health and social care services are delivered and set up to provide care for people with MND throughout the course of the disease. It incorporates the types of activities and services delivered to provide care and support to people with MND, the location and setting in which the activities and services are delivered, the teams and professionals involved, and the way in which these teams and professionals interact. Specifically, this project aims to understand:

- The nature of existing models of MND care - who is involved (e.g. NHS, social services, carers), what the settings are, and what role each plays;
- How care is coordinated, and how health, social care and other services are working together;
- What works well and what are the benefits of different models of care;
- How the models of care are commissioned, paid for and delivered;

- Issues for people with MND with existing models of care, and what could be improved.

The announcement of NHS England's New Care Models Programme post-dated the design of this study, and this study therefore does not intend to answer how those New Care Models should be designed, however future work should consider how current MND care models tie in with the New Care Models.

Research activities undertaken

This project utilised a variety of research methods and activities to explore and identify the types of models of care that currently exist for people with MND, and to identify the benefits, outcomes, challenges, and views from those delivering and receiving services.

Light touch review

A rapid evidence review was carried out to map out what is currently known about models of MND care. To assist with the 'light touch' review, the MND Association provided OPM with a list of documents about current models of care for MND, the MND Care Centre and Care Network programme, and general information about MND in the UK. Additional information was also obtained by OPM from online searches for relevant literature and materials.

Call for evidence

OPM issued a call for evidence to hear directly from those involved in the delivery of MND care. This involved two online surveys:

- A call for evidence targeted to MND Care Centres and Care Networks.
- A general call for evidence for all health and social care professionals involved in delivering care for people with MND. In total, there were 54 respondents: 39 were based in England, 12 in Wales, and 1 respondent was jointly based in both England and Wales. Two respondents did not specify where they were based.

Interviews

Building on the call for evidence, individual telephone interviews were carried out to explore further some of the issues and findings that were identified from the call for. In particular, this involved exploring the relationship between different services (for example, Care Centres, hospices, hospitals, and community services), how care is coordinated, and the level of MND specialism. Interviews with a sample of MND Association Regional Care Development Advisors (RCDAs) were also carried out to identify potential case studies.

Twenty participants were interviewed. The participants were from a variety of backgrounds and settings, including those from MND Care Centres and Networks, hospitals, community teams, and hospices. A full list of participants is in Appendix 1.

Case studies

Five case studies were chosen following the interviews and discussions with RCDAs, and the aim was to focus on a variety of different models of care. The case studies involved a number of elements, including focus groups, interviews, telephone interviews and informal face-to-face interviews with patients and carers. The rationale for each case study is briefly summarised below:

- **West Suffolk:** The purpose of this case study was to look into MND clinics outside of MND Care Centres, as is present in West Suffolk.
- **North Wales:** Interviews identified that MND care in North Wales was fragmented with many seeking care elsewhere, including in England; however MND MDTs had been established across the region. This case study was also chosen to provide a Welsh context to MND care.
- **Bromley:** Interviews identified there was a case for establishing a care coordinator for rare and rapidly progressing neurological conditions to be in Bromley. This case study therefore aimed to identify issues with care coordination, especially in the context of London.
- **Oxford MND Care and Research Centre:** The purpose of this case study was to look into the MND Care Centre model of care.
- **Milton Keynes:** The focus of this case study was on the interaction between the Oxford MND Care and Research Centre and local services in Milton Keynes, and how people with MND are cared for locally outside of the Care Centre clinics.
- **Peninsula MND Care Network:** The purpose of this case study was to look into the MND Care Network model of care.

A full list of research activities for the case studies is provided in Appendix 2.

Section 1: Models of care in the UK

Background

This section provides an overview of the various models of care for people with MND, and the topics and issues identified from the different research activities. This section only briefly touches upon the MND Care Centre and Care Networks, as they will be covered in-depth in Section 2 of this report.

The following section is based on the findings from the light touch review, the general call for evidence, and the interviews. Findings from the case studies will also be mentioned as many of the topics and issues identified from the case studies were also identified in the call for evidence and interviews. In total, 20 telephone interviews were carried out and there were 54 respondents to the general call for evidence. Respondents were from a mixture of professions and disciplines. The most common role was occupational therapist (21%), followed by physiotherapist and palliative care consultant (19%), and neurologist who specialises in MND (15%). Only 1 MND specialist nurse and 2 neurology specialist nurses completed the call for evidence. Respondents were asked what setting they work in, with 46 respondents answering this. Almost a half (48%) worked in a hospital. Nine respondents further said they worked in a hospital with a dedicated MND clinic, and seven said they worked in a hospital with a general neurology clinic. Just over a third (37%) worked in the community. Although the respondents to the call for evidence were only a very small sample of people who provide care for people with MND, and were not equally spread by geography, care setting, discipline, and profession, the call for evidence does provide a glimpse as to what services and models of care are out there.

Multidisciplinary teams

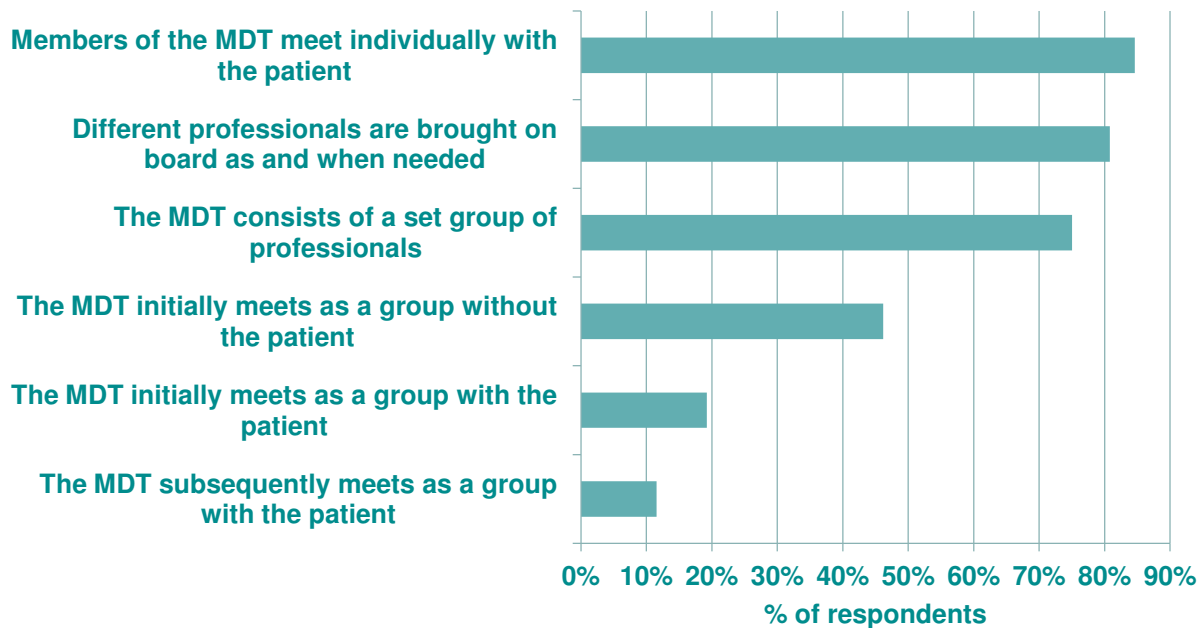
Multidisciplinary care is essential for supporting and caring for people with MND, with some evidence of the effectiveness of this approach. The NICE guideline¹ for non-invasive ventilation in MND patients states that a multidisciplinary team (MDT) should coordinate and provide ongoing management and treatment for people with MND. At the time of writing this report, NICE were in the process of drafting guidelines and quality standards for MND.

Fifty-two respondents from the call for evidence stated that their model of care involved the presence of a MDT, and one respondent stated that they are currently in the process of setting up a MDT. The composition and structure of the MDTs varies greatly. In some cases the MDT consists of a set group of individuals that meet each time, and in other cases additional professionals are brought in as and when needed. In addition to the MDT meetings, almost a

¹ Please note that at the time of writing this report, NICE were in the process of drafting a guideline and quality standard for MND

quarter stated that the MDT collectively sees the patient in a clinic setting. Some stated this is a specific MND clinic and others said this takes the form of a hospice day care service.

Figure 1: How does the delivery of person centred care involve a multidisciplinary team?

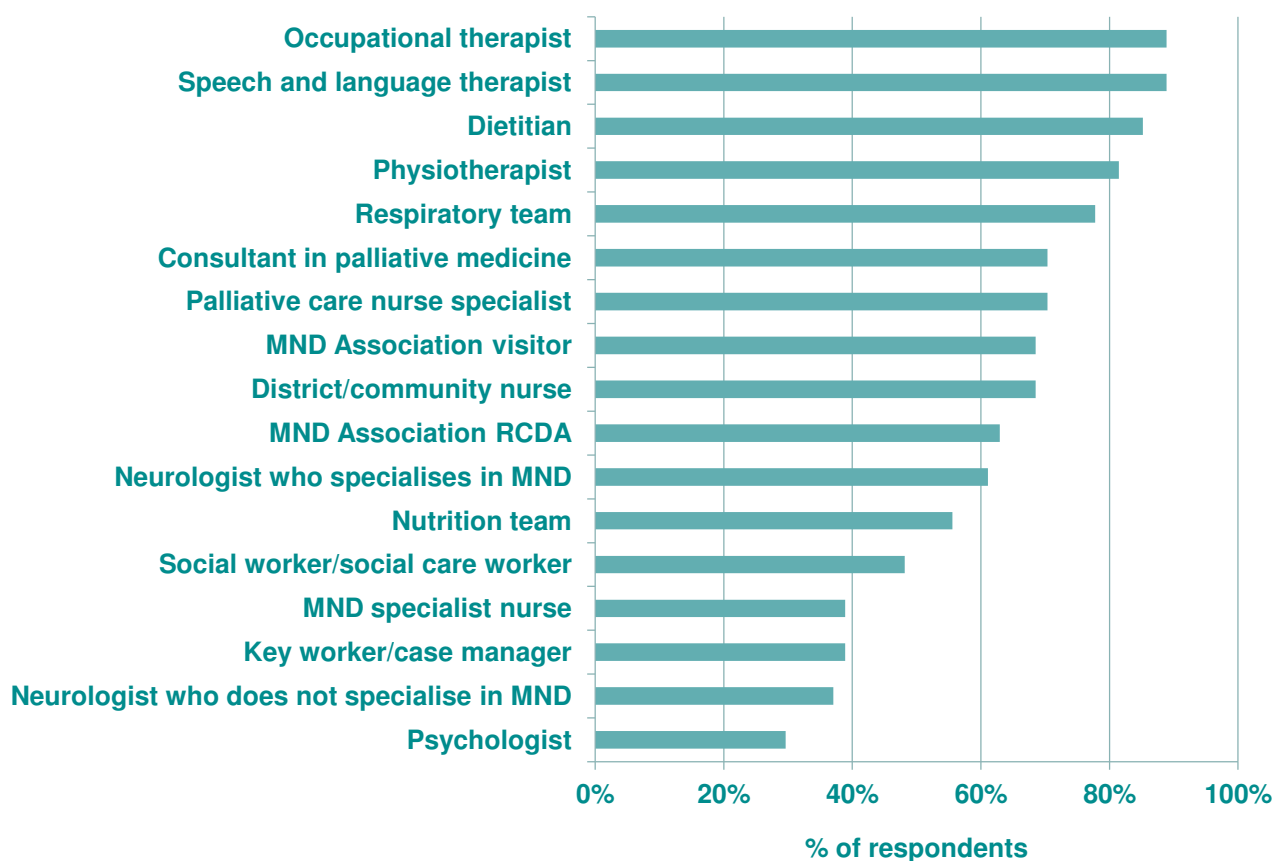


The NICE guideline for non-invasive ventilation in MND patient states that a multidisciplinary team (MDT) should coordinate and provide ongoing management and treatment for people with MND. It states that:

“The team should include a neurologist, a respiratory physician, an MND specialist nurse, a respiratory specialist nurse, a specialist respiratory physiotherapist, a respiratory physiologist, a specialist in palliative care and a speech and language therapist”

Respondents to the call for evidence listed the range of health and social care professionals involved in the MDTs that provide care for people with MND. Respondents commonly reported the presence of occupational therapists (OT), speech and language therapists (SLT), dieticians, district/community nurses, respiratory teams, and palliative care teams. The NICE guideline for non-invasive ventilation in MND patients also states that the team should be led by a health professional with a specific interest in MND. Seventy percent said there was some form of MND specialism involved, either through the presence of an MND specialist nurse, an MND neurologist, or both. The majority said there was also input from the MND Association, either through a Regional Care Development Advisor (RCDA) or Association Visitor. Only 30% of respondents reported that there was input from a psychologist, which was an issue identified by some participants during the interviews and case studies.

Figure 2: Who is involved in the delivery of MND care?



It was also apparent from the interviews and case studies that the types of MDT arrangements vary. In some cases they were solely MDT meetings with professionals and in other cases they included MND clinics for patients attend. The size and number of MDT meetings also varies. Many have good input and attendance from community teams, hospitals, and hospices; however a few reported little input from hospitals. Some also reported good input from neurology, palliative care, occupational therapy, social care, etc., however others did not. Most MDTs are led by a neurologist, usually with an interest in MND, or an MND specialist nurse, however some don't have any input from neurology at all. Some instead have strong input from palliative care. For example in North Wales there are three MDTs covering three different areas, each of which are run by a palliative care consultant. Some MND clinics which are held in hospices are also run by a palliative care consultant. Referrals to MDTs are usually made by a GP or neurologist.

The call for evidence, interviews and case studies highlighted the benefits of having MDTs. The MDT meetings provide an opportunity to update professionals on newly diagnosed patients and to discuss those already on the caseload, for example what professionals have recently seen somebody with MND, what professionals need to see somebody with MND, what needs people have, etc. It is also a space to generally discuss MND care and developments and to raise awareness of issues. Many participants saw the great value of having MDTs as they improve links between different services and ease care coordination. A number of people commented that MDTs offer excellent opportunities for networking and building relationships with other health and social care professionals, allowing people to get to know each other and to know who to contact in

emergencies and when dealing with complex patients. A few further reflected that having good relationship with professionals, particularly those who they would otherwise rarely see, makes it easier and more comfortable asking for advice. In addition, some commented on the importance of having somebody from the MND Association (e.g. a RCDA or Association Visitor) attending MDT meetings and MND clinics to inform patients and professionals of the range of services and support available.

Although all professionals valued having MDTs, and acknowledged the benefits listed above, there were some who reported difficulties in holding MDT meetings and MND clinics. The main issues are around time and resources, and this is often underpins the frequency at which MDT meetings are held. For example, many MDTs meet once a month whereas others are unable to do so and meet less frequently. Some professionals also suggested it may be frightening for people with MND to see multiple professionals in one go at a clinic. Others suggested that some people with MND also do not like being in a situation where they see other people whose illness has progressed further. This was a view expressed by a few people with MND.

“Many professionals seeing together may be frightening for the patient. Additionally, it would be waste of time and resources of the professionals if they are not needed”

Many highlighted that there is no one-size-fits-all model of care and some areas have adapted in order to work towards the same standards of services and to allow everybody to receive the same level of care, for example by turning to virtual MDTs and clinics. Areas in the north of Powys are scarcely populated, with few people with MND. They are also not easily accessible due to the geography of the area, which subsequently would result in long travelling times for both professionals and people with MND. Adapting to this, virtual MND clinics and MDTs in these areas have been set up which happen via telephone conference and include a palliative care team, occupational therapists, speech and language therapists, dieticians, physiotherapists, district nurses and social workers all based from different locations. Similarly, the Oxford MND Care Centre offers consultations via Skype or FaceTime for people with MND who are unable to attend the Care Centre or who just want to talk about any specific issues at short notice.

In addition to virtual MDTs, one participant mentioned that on a few occasions they have recommended holding MDT meetings in patients' homes. This is something the participant was aware of when previously working as a social carer, however it was noted that some professionals may be unwilling to see patients in their homes. This was primarily due to views on clinical practice, as the interviewee stated that some health professionals firmly believe in hospital based clinics as opposed to those in patients' homes, but was also due to time constraints and difficulties organising the meetings. Although unable to offer MDT meetings in the community, a number of interview and case study participants highlighted that they perform multidisciplinary home visits, i.e. joint visits by a nurse and OT, or nurse and physiotherapist, for example. In many cases this is usually only reserved for urgent and complex cases that require a multidisciplinary approach, as a joint visit is often not needed for most people with MND. Time constraints and difficulties scheduling the visits also discourage more frequent joint visits.

Care pathways and guidelines

Care pathways and guidelines map out the patient journey and process to be followed by health and social care services in the treatment and care of a patient with a particular condition or with particular needs. They embed best-practice guidelines and protocols, and are multidisciplinary. The light touch review identified a variety of care pathways specifically for MND. At the time of writing this report there are currently two NICE care pathways and guidelines for people with MND: treatment with non-invasive ventilation, and guidance on the use of Riluzole for the treatment of MND. At the time of writing this report, NICE was also in the process of drafting clinical guidelines and quality standards for people with MND, which will incorporate the current guideline on non-invasive ventilation.

Although MND Scotland is separate from the MND Association in England, Wales, and Northern Ireland, it should also be noted that in 2009 Health Improvement Scotland published the Clinical Standards for Neurological Health Services (NHS Scotland)². This provides a set of standards for neurological health services in Scotland, with Standard 11 focussing on access to specialist motor neurone disease services:

- Standard statement 11: *“An effective and comprehensive motor neurone disease service is available and offered across all NHS boards.”*
- Statement 11.3 further states: *“The NHS board provides rapid access to demonstrably effective care pathways covering all aspects of the illness, including links to specialist palliative care and respiratory medicine, gastrostomy services and social services.”*

In 2012, Health Improvement Scotland carried out a peer review evaluation to assess the NHS boards’ progress towards implementing the standards listed above. Findings of this review, and the models of care for people with MND in Scotland, are detailed in Appendix 3.

The light touch review identified very few multidisciplinary care pathways for MND, as many were symptom or service specific. Locally, some MND specific care pathways were identified, with comprehensive ones in Dorset, as well as Leicestershire and Rutland:

- The Dorset pathways for people living with MND were set up in 2012 in conjunction with the MND Association and acute trusts across Dorset to improve the care for people living with MND by implementing a joined up, cross-organisation approach that responds to its various stages; from diagnosis through to end of life care. Four pathways have been set up. These include a holistic Care Pathway for People Living with Motor Neurone Disease in Dorset as well as separate pathways for nutrition, respiratory, and End of Life care. These provide professionals with a detailed care plan, ensuring that care is co-ordinated throughout the journey of the

² Clinical Standards for Neurological Health Services (2009) - http://www.healthcareimprovementscotland.org/programmes/long_term_conditions/neurological_health_services/neurological_standards.aspx

disease, and that symptoms are spotted and treated as early on as possible. The pathways were drawn up with all commissioners and service providers involved in the management and care of MND.

- The Leicestershire and Rutland Motor Neurone Disease Palliative and Supportive Care Pathway Project is run by the Leicestershire and Rutland MND Supportive and Palliative Care Group at LOROS Hospice. This involves a MDT clinic with specialist doctors, specialist nurses and visitors from the local MND Association. As part of this project, The Leicestershire and Rutland MND Supportive and Palliative Care Group has also developed nine care pathways for people with MND in the area. The pathways include: a pathway for the cough assist machine, pathway for preparing to withdraw Non-Invasive Ventilation (NIV), referral pathway for speech & language therapy, enteral feeding, naso-gastric tube placement, PEG tube placement, RIG tube placement pathway, riluzole supply, and a referral pathway for respiratory assessment/intervention.

A number of care pathways developed by the Motor Neurone Disease Association or MND Scotland were identified. Some of these are service specific pathways such as the MND Association Wheelchair Service, the MND Scotland Equipment Loan Service, the MND Association Respiratory Management Pathway, and the MND Association Augmentative and Alternative Communication (AAC) pathway. Others are more general and broad and include the MND Scotland Integrated Care Pathway and the MND Association Year of Care Pathway. Elsewhere, a few MND Care Centres have developed care pathways, with most focussing on specific areas of care.

Coordination of care

The 2013 Improving MND Care survey found that 78% of respondents said they had a named person in either health or social services who is responsible for coordinating their care and support. However, the call for evidence, interviews, and case studies suggest that care coordination varies considerably. Less than half of the respondents to the call for evidence said there is a key worker/coordinator role for patients with MND. The call for evidence and interviews expanded on the types of care coordinators. The only instances of there being a specific MND coordinator are the MND Care Centres, each of which has a Care Coordinator. Additionally there are a few examples of care coordinators based in the community with considerable experience with MND as well as other neurological conditions. These include a Coordinator for Rare and Rapidly Progressing Neurological Conditions in Hertfordshire, a Clinical Nurse Specialist for Rare Neurological Conditions in West Berkshire, and a Neurological Conditions Clinical Specialist in Milton Keynes. These roles were all said to be strongly valued by staff and patients, and should be replicated elsewhere as they facilitated strong links with different services. Having these roles was said to simplify care for both patients and professionals as they all benefit from a coordinated

service with regular communication, with good understanding of everybody else's role. A report on services for people with neurological conditions³ suggests that specialist nurses can help to improve patient care and the coordination of health and social services resulting in reduced hospital admissions. Evaluations of some of these posts show the impacts on people with MND and the wider health system:

- The specialist neurological coordinator in Hertfordshire is part of Hertfordshire Community NHS Trust Neurological Services and was introduced in 2012 as part of the *My Needs Now* pilot in response to patient feedback which reported inconsistent, fragmented and unresponsive care provision, and a lack of coordination across different agencies and teams. An evaluation^{4,5} of the post have demonstrated impacts in both patient outcomes as well as cost savings. Between November 2012 and Oct 2013 the post reduced number of hospital admissions, and 168 admissions were avoided, saving an estimated £504,000. Patients in contact with the coordinator were 98% less likely to be admitted to hospital, with estimated NHS savings of £220,000 per year. The average length of stay at hospital was reduced by 32% and there was an increase in the number of people dying in their preferred place. Patients and carers provided very positive feedback about the post, indicating that it has helped them to receive timely access to specialist knowledge and care, and enhanced quality of life.
- The West Berkshire Clinical Nurse Specialist for Rare Neurological Conditions post was established in 2005 to work with patients across the Berkshire West area who have rare complex neurological conditions. The neurodegenerative diseases included were: MND, Huntington's Disease, Myasthenia Gravis, Multiple Systems Atrophy, Progressive Supranuclear Palsy, Post-Polio Syndrome and Ataxia. MND is the most common condition. An evaluation⁶ of the post in 2007 found that patients and carers reported greater satisfaction with health services and high satisfaction with the post. The high level of satisfaction was reflected in the fact that all thought the clinical nurse specialist made a real difference and should be available to everyone affected by a rare neurological illness. Among many things, it provided rapid and timely access to specialist knowledge and services and reduced the length of time patients with rare neurological conditions were in hospital. The post was also highly cost-effective. Cost savings from the reduction in bed stay more than covered the cost of the post. Evidence from other NHS staff, including the

³ National Audit Office (2011) Services for people with neurological conditions - <https://www.nao.org.uk/wp-content/uploads/2011/12/10121586.pdf>

⁴ Hertfordshire Community NHS Trust (2012) My Needs Now Project

⁵ MND Clinical Specialist Co-ordinator – Hertfordshire. 12 month report for the John Ellerman Foundation – (Nov 2012-Oct 2013)

⁶ Quinn, A (2007). Evaluation of a new post: the West Berkshire Clinical Nurse Specialist for Rare Neurological Conditions. University of Reading.

neurology and neurorehabilitation consultants, indicated that the CNS role freed their time to offer further services to those with neurological conditions as well as providing an additional service to patients and carers.

The coordinator, whether Care Centre Coordinator or specialist nurse, is usually informed immediately of any newly diagnosed or suspected patients with MND, and in most cases would make first contact within a week or two after diagnosis. This usually involves a home visit in a comfortable setting where the coordinator will carry out a holistic assessment of their physical and social needs and an assessment of their home and needs for equipment and home adaptations. The coordinator also informs the patient of the MND Association, support groups, Care Centres, and local services and contacts, etc. The coordinator would then make relevant referrals, and from that point on would be the single point of contact. The coordinator may perform subsequent home visits when needed or when requested by the patients, but in some cases the coordinator plays a 'third party' role between the patient and services and has little face-to-face contact after the initial visit. The patient is often copied into emails/letters between professionals so that they are aware of all the people who will provide care/may at some point provide care. One person said that this is preferable to giving the patient a leaflet with all the services/contacts on it.

In most cases, however, there is no formal coordinator. Some noted that the first member of the MDT to make contact with the patient acts as the key point of contact from then on, which in the majority of cases is maintained throughout the patient's disease progression; however they are not actively involved in coordination. Some participants mentioned that there is no overall coordinator/key worker, but that each specific team or service, such as physiotherapy or speech and language therapy, would have a key point of contact. This was said to work well as long as they can coordinate between themselves. However, some interviewees acknowledged that a single care coordinated is still preferred and that it is important to have somebody who can move across teams and services. In other cases people with MND are provided with contact details for different members of the MDT, and that patients can contact these members as and when needed. For example, Social Services OTs in Bromley have created a leaflet with contact details of all health and social care professionals who somebody with MND may have need of.

Aside from the coordinator role, for the areas that have one, MDT meetings were reported as being the primary channel for care coordination. Over half of the respondents to the call for evidence said that care is coordinated through regular MDT meetings, the benefits of which have been discussed previously. Regular communication by email and telephone was discussed, along with the use of shared information systems and patient records, however many people acknowledge the issues with accessing and sharing information, and the lack of shared systems.

However, some respondents openly highlighted that care coordination is poor in their area. These people reported that there was no care coordinator or single point of contact and no clear process of coordination with much of it being ad hoc and confusing. In some areas this was due to the geographical location. For example, one interview participant highlighted that

"The team is very close and are in regular contact via email regarding patients on a weekly basis. In addition we use a clinical database which is helpful to know if a patient has been in touch with another member of the team"

there is very poor care coordination in some areas of South London. One reason for this is that there are too many services, too many patients, and too many points of contact which ultimately leads to poor continuity of care as patients may attend multiple hospitals and services, with poor communication between them all. The participant commented that securing a coordinator role is crucial, and that this would greatly improve care coordination, particularly between hospitals and community teams.

Links between different services

Links and communication between hospitals, care centres, community services, and hospices vary, but on the whole the majority of participants reported good communication and working relationships. Links between different community teams were said to work particularly well by a few participants, as well as between community teams and hospices. A few participants said there is still separation between community and acute services, however a number of participants reported excellent links between community teams and Care Centres.

As mentioned, many participants valued MDT meetings as they facilitate working relationships with health and social care professionals from a variety of services. MDTs were said to be a key factor in facilitating links between different services and team. Many people said it allows individuals to see and get to know people they previously would not have come across. Some commented that

“We have good links following recognition from regular MDT meetings”

holding MDTs in hospitals and inviting people from community teams and hospices is particularly effective as it is the only time where they would meet face to face. The same was said for holding clinics in hospices.

In most cases communication between different services and professionals was said to be informal and done via telephone, email, and letters. When constructing emails and writing letters, some said they would copy in the whole MDT and those involved in MND care so that all professionals are aware of the patient. This was said to work well as a means of communication and coordination. A few also commented on the benefits of being co-located with other teams. For example, one participant from a community neurorehabilitation team said that they are co-located on site with the palliative care team, which has led to a good relationship between the two and facilitates collaborative working. Another participant said they were previously co-located with wheelchair services which meant they were able to keep a stock of chairs in the building so that they could get them to patients quickly, however now they are not co-located which has led to delays in patients receiving wheelchairs.

There are a few unique cases, for example the link between community teams in North Wales and the Walton Centre in Liverpool. As there are no Care Centres and specialist neurological services in North Wales, many patients (as well as those from other areas of Wales and Isle of Man) attend the Care Centre in Liverpool. Additionally, neurologists from the Walton Centre run general neurology clinics in North Wales. There are generally good links between community services in North Wales and the Walton Centre; however participants from both highlighted some difficulties with this, such as delays in referrals and different IT systems.

Care setting and MND specialism

The interviews explored differences between different care settings. Most participants discussed the importance of providing care for people with MND in the community and in people's home as many patients, particularly as the disease progresses, may be unable to attend a Care Centre or MND clinic. Many felt that MND care should lean towards community services as opposed to acute care, and a number reported that the majority of care occurs in the community.

Many still acknowledged the need for MND Care Centres for MND clinics and specialist care that cannot be performed in the community (e.g. respiratory assessment, PEG etc.), and valued Care Centres as a source of advice and support when needed. One person mentioned that there are outreach clinics from the Bart's MND Care Centre, saying that this offers an alternative to patients travelling into central London to attend the Care Centre. Hospices were discussed by a number of participants as very useful and effective settings. Many said conditions can be monitored better at hospices as opposed to at home, and that hospices help a lot in-between MDT meetings, and offer a good environment and level of care.

The level of MND specialism varies across the different models of care. A lot of MND specialism is evidently present at the Care Centres, but less so in district hospitals and community teams. The interviews highlighted different views regarding the need for MND specialism. Some participants expressed the importance of having an MND specialist nurse or team members who are experienced with MND. Some also thought that having some MND specialism is necessary to 'up-skill' more general professionals, and this was said to be common for those who had a lot of experience with

"It would be better if we had more presence in the community from qualified MND specialist" - Carer

"There are people waiting on things that I really should be dealing with but I can't. I try to prioritise MND at the expense of others. It's a balancing act and there's always somebody losing out"

MND. One neurological clinical nurse specialist said they would benefit from an MND specialist post in their area, and that this would not only benefit MND patients, but also those without MND. The participant said that they get some intense periods with MND patients that require a lot of attention and time. As a result these MND patients are then prioritised over other patients, who in turn get pushed aside. The participant said that having an MND specific nurse would avoid this from happening, as the MND nurse would focus solely on MND patients and other nurses would focus on other patients with neurological conditions. An interview with the spouse of somebody with MND

said that her husband had been attending a Care Centre but there came a point where they were unable to continue attending. The person with MND had greatly benefited from the MND specialist at the Care Centre, however the MND specialist nurse was unable to do home visits, and as such they lacked this MND specialism in the community. One person, however, suggested that the day-to-day care for people with MND does not require much MND specialism.

Some expressed that it would be more beneficial to have an MND care coordinator position over an MND nurse specialist, stating that MND specialism is essential when coordinating care. There needs to be experienced, but not necessarily MND specialist, staff in the community who can communicate and liaise with the range of services and teams. As mentioned previously, this project did not identify any community MND specialists outside of the Care Centres/Networks. Instead, rare neurological conditions specialists are more prevalent, such as the Coordinator for Rare and Rapidly Progressing Neurological Conditions in Hertfordshire, the Clinical Nurse Specialist for Rare Neurological Conditions in West Berkshire, and the Neurological Conditions Clinical Specialist in Milton Keynes. Some were in favour of grouping MND with other rare and long-term neurological conditions, such as Huntington's, and PSP. A main reason for this is that it would increase the caseload and provide the team/service with a greater voice and more influence for commissioning and campaigning. It may also avoid competition between different neurological conditions, for example between Parkinson's, Multiple Sclerosis, and MND, when securing specialist nurses. A more linked-up and wider neurological approach was suggested.

"It needs somebody who knows MND who can say 'that's not right, that won't work with somebody with MND'" - Carer

Lastly, some participants also talked about MDT forums for professionals to get information and advice regarding MND care. In some cases these are primarily online forums, notably the MND Association Professionals Forum. However respondents mentioned that they attend face-to-face meetings, some of which are MND specific, whereas others are discipline specific. For example, in the Thames Valley area there is a group of neurological specialist nurses that meet regularly to discuss MND and other rare and rapidly progressing neurological conditions. In Suffolk there is a group of SLTs that meet to discuss issues that may be relevant to people with MND. Similarly, the interviews and case studies highlighted numerous educational events and study days focussing on MND, which may be said were highly beneficial for those with little experience with MND.

Outcomes

Respondents to the call for evidence were asked what they perceive to be the main benefits of the model of care. Fifty-three respondents answered this question. The most commonly perceived benefit was the professional support (89%), followed by good management of patients' symptoms (85%), and allowing patients to remain safely and adequately cared for at home, and to die in the place of their choosing (85%). Some respondents commented on other benefits. These included advanced care planning, early introduction to hospice services, having a central point of contact, and, good joint working across multiple teams.

Figure 3: What do you perceive to be the main benefits of the model of care you work in?



Respondents were asked if there are any aspects of the model of care that they think should be replicated elsewhere. Most of these focussed on MDT clinics and the one stop shop approach, as well as the involvement of professionals from teams and settings (hospices, community teams, hospitals, etc.) at MDT clinics and meetings. Some people commented on the importance of MDTs seeing patients in the community as opposed to hospitals. The presence of a key worker/coordinator role was mentioned, with one person commenting that it is important to proactively manage a case and not just react in an emergency. A few respondents also commented on the use of technology, such as Skype consultations for those who are unable to attend a clinic.

Funding and commissioning of services

The light touch review found that there is considerable and ongoing confusion at CCG level about commissioning responsibilities for local neurology services. This confusion is the product of the lack of clarity on the question of what is commissioned nationally by NHS England and what is commissioned locally by CCGs. The current Manual for Prescribed Specialised Services and the Neurosciences Service Specification for specialised neurology contradict each other on this point. The latter in particular can be, and has been misinterpreted by CCGs to mean that they have no neurological commissioning responsibilities. There is also growing evidence that due to the confusion around the division in neurological commissioning responsibilities and the lack of neurology accountability and incentive at CCG level, services and treatments that are the

commissioning responsibility of CCGs are not being commissioned. This was also highlighted in call for evidence and interviews and professionals were confused as to who commissions services for people with MND. Participants also highlighted the lack of understanding of MND by commissioners, who do not recognise how complex MND is and how important it is for interaction between multiple services.

An important finding from the research was that many MDTs and clinics are not formally commissioned and funded by the NHS. For example, in East Anglia there are MND clinics in Ipswich, Kings Lynn, and West Suffolk. These are said to work very well and are well coordinated, however they are not funded and not formally commissioned and have been set up by neurologists and other health professionals with support from the RCDA. This has been reported elsewhere, and in many cases these may be down to the goodwill and enthusiasm of a few key individuals. If these key people leave then the MDTs may not be able to function as effectively or may simply not continue. Many expressed the need for MDTs and clinics to be fully picked up and commissioned by the NHS. Many of the MND Care Centres and Networks, which will be covered in Section 2, are also not formally commissioned by either NHS England or CCGs, and in most cases the MND Association fully funds the position of Care Centre Coordinator. This is despite NHS England being formally obliged to commission specialist multidisciplinary MND clinics with include a specialist neurologist and a specialist nurse/care coordinator, as set out in the Neurosciences Service Specification. The service specification states that *‘All services for people with motor neurone disease should be commissioned as a specialised service’*.

Universities also fund some services, particularly in Care Centres that are within university hospitals. Some neurologists at those Care Centres are fully employed by a university. For example the 2 honorary consultant neurologists at the Oxford MND Care Centre are fully employed by the University of Oxford but carry out clinical duties and run the MND clinics. Across England, clinical academics (honorary consultants) are employed by a Higher Education institution in a research and teaching capacity and also hold honorary contracts with a local NHS organisation to undertake clinical duties and responsibilities, commensurate with consultant level staff in the NHS. Their contracts include Programmed Activities which are scheduled periods, nominally equivalent to four hours, during which they undertake contractual clinical services.

Challenges

A number of challenges were identified when it comes to MND care. Care coordination was said to be a key issue, and was identified in the call for evidence, interviews, case studies, and light touch review. Some professionals highlighted difficulties communicating with different teams and

“I spent so much time and effort liaising with the services trying to find out what was going on and when”

services, and being updated on patients. In some case this was down to the lack of shared IT systems and in other cases it was simply due to the complexity of services for people with MND and the involvement of multiple disciplines and teams, and the uncertainty over who was providing what aspects of care, and when. From the patient and carer side, there are issues with knowing what services are out there and who to contact.

The 2013 MND Improving Care Survey identified some issues with referral and diagnosis times. Seventy-eight percent of respondents waited one month or more from when they first consulted their GP until they were referred to a Neurologist. Fifty-seven percent had to wait a further month or more until they were actually seen by a neurologist, and 70% of respondents waited one month or more from when they saw a neurologist until they were given a diagnosis of MND. Adding to this, the Neurological Alliance state of neurological services in the UK report found that 44% of people with MND had to wait 6 to 12 months before being able to see their neurological specialist for the first time from when they first noticed their symptoms. The Neurological Alliance report also found that 43% of individuals with MND experienced problems or delays in accessing the services or treatment they needed. This included GPs not having knowledge or awareness of the signs and implications of MND, which resulted in delayed diagnosis, and a lack of urgency in transitioning from primary to specialist appointments and care. Due to the rapid progression of MND and the short life expectancy, timely referral and intervention is essential for effective care and management of MND.

An issue identified from the call for evidence, interviews, and case studies is that some people with MND who want to attend an MND clinic are unable to do so, which may be due to long travel distances or the physical effort in attending, and that the same level of care is not always provided in the community. Additionally, one participant said that clinics have time constraints and professionals do not have enough time to see all patients during a clinic, and as such they may have to prioritise patients by need.

Some participants reported challenges when working with health professionals. One person commented that some less experienced health professionals sometimes prefer to hold onto their patients instead of referring them to a Care Centre or specialist team, and that some are unaware of all the services for people with MND. One person also said that people with MND who receive their care from general neurology clinics do not have access to professionals who are specialised in MND and as

“One of the main challenges we face as a team is the rurality of the area in which we work. If the patient is unable to attend clinic it is more difficult coordinate care”

“I get the impression sometimes that I’ve broken through all expectations regarding my lifespan...I do think because of that people take the foot off the accelerator and I’m ok”

such the lack of knowledge of MND prevents patients from building a relationship of trust with the professionals they encounter. One participant also commented on poor working relationships with different disciplines, and that some professionals may be reluctant to get advice from community services or from the MND Association and RCDAs. Additionally, one person said that there is less input from the MND Association in acute settings, for example there is less attendance of RCDAs and Association Visitors to clinics and MDTs compared to in the community and hospices.

A key issue reported in a few interviews was that patients are not always kept on caseloads, for example if a patient’s condition has been stable for 6 months or so. They expressed the importance of keeping all MND patients on the caseload and performing

regular check-ups. One person with MND, whose condition is very slowly progressing and who has been living with MND since 2007, felt as if there is sometimes less focus on people with a 'stable condition'. He understood and agreed that there should be more focus on newly diagnosed people, but expressed that there needs constant attention and focus on all people with MND.

Challenges with diagnosis were brought up in one of the focus groups, primarily around people with undiagnosed MND being sent to the wrong specialist. This was often said to happen to patients who would present with swallowing problems and who would subsequently be referred to ENT, or elder patients who would be referred to a stroke clinic. This is also a problem for healthy, middle-aged people who may receive unnecessary surgery because they were referred to the wrong professionals, for example somebody with a loss of mobility in their limbs who is referred to an orthopaedic surgeon. The participant stated that the Red Flag diagnosis tool distributed to GPs by the MND Association has been helpful in improving diagnosis of MND, however this is still a recurring issue.

Other challenges included the lack of integration between health and social care, lack of shared IT systems, difficulties with Continuing Healthcare (notably the difficult assessment/application process), and difficulties obtaining equipment.

West Suffolk – case study

Background

This case study focuses on the West Suffolk Disability Resource Centre (DRC) in Bury St Edmunds, which provides a care service for people with MND registered with a GP in West Suffolk. The DRC runs a monthly MND clinic whereby people with MND can meet a multidisciplinary team of health professionals as well as representatives from the MND Association. Currently there are roughly 25 people with MND on their caseload.

The care process

In West Suffolk people with suspected neurological conditions are referred to the neurology department at West Suffolk Hospital where they will be triaged by one of four consultant neurologists. Those with non-urgent conditions may have to wait up to 8 weeks for a diagnosis whereas those with suspected MND will be rapidly referred to the Addenbrooke's MND Care Centre in Cambridge. People with suspected MND may also be referred directly to Addenbrooke's by their GP. Those who live closer to Ipswich or Norwich may instead be sent to Ipswich Hospital or Norfolk and Norwich University Hospital for diagnosis. The consultant neurologist who leads the MND clinic at the DRC attends the newly diagnosed clinic at the Addenbrooke's MND Care Centre and will see roughly half of the people from West Suffolk who have been sent for a diagnosis. Once diagnosis has been made, the consultant neurologist will then set up an appointment at the DRC clinic, copying in the two neurological specialist nurses. Other consultant neurologists at Addenbrooke's, however, may not automatically arrange an appointment at the DRC clinic. A letter will also be sent out to the GP informing them of the patient's diagnosis and whether they will be attending the MND clinic at the DRC.

MND clinic and multidisciplinary team

A monthly MND clinic is held at the Disability Resource Centre and occasionally extra clinics are run if needed. Five patients are seen in each clinic and the frequency at which people with MND attend varies. Most generally attend 2 or 3 times a year, but for some this may be 6 times a year. The clinic is run by a MDT which includes a consultant neurologist from West Suffolk hospital and Addenbrooke's, two neurological specialist nurses, dieticians, SLTs, and occasionally physiotherapists from the local hospice (St Nicholas Hospice). Patients have booked appointments where they may see the whole MDT. An Association Visitor is also present during the clinic and will talk to patients, families, and carers in-between appointments. After each clinic the MDT will meet to discuss all patients on their caseload, including those who did not attend the clinic. At this clinic they will also discuss service development matters such as whether or not they will join the Trajectories of Outcome in Neurological Conditions study (TONIC – a national study which aims to examine the quality of life in patients with neurological conditions including MND), or whether they will start referring to palliative care sooner, etc. In addition the MND Association run quarterly meetings at the DRC which is attended by the RCDA and Association Visitors. The MDT can

attend, and this provides a space for the RCDA and Association Visitors to pass on any patient-specific issues to the MDT, as well as allowing the MDT to keep up-to-date with what the MND Association is doing.

In-between clinics the neurological specialist nurses, and sometimes the consultant neurologist, will perform home visits and will assess the patient's condition as well as their home situation, and will identify any needs or issues. They will then refer onwards to other community services, such as OT, physiotherapy or social services as needs be. A speech and language therapist may sometimes do joint visits with OTs, and a nutritional support nurse based at West Suffolk hospital also does home visits. Patients who attend the DRC are given the choice to be referred to the Respiratory Support and Sleep Centre at Papworth hospital, and the large majority of patients will choose to do so. Support groups have recently been set up for people with MND and their carers, which both groups find very useful.

Addenbrooke's MND Care Centre

Most people with MND in West Suffolk will have attended the Addenbrooke's Care Centre for a diagnosis and some patients, although few, continue attending the Addenbrooke's Care Centre. In these cases it is often the patient's choice to attend, with many going in hope that the Care Centre will provide better care and will provide something that the local services can't give them. Some may also attend thinking that they will be able to take part in clinical trials, however in some cases people from the edge of the county are referred to the Care Centre from the start. What often happens is that when people with MND get worse and become less mobile then they stop

"If you happen to live in a city where there is a MND Care Centre, so it is your local place, then I think that is the ideal scenario... but not if you live 30 or 40 miles away from that Care Centre"

attending the Care Centre and instead attend the DRC clinic, as the DRC is easier to attend, has easier access, and has better parking. Generally the view among the focus group participants was that care is best served in the community and with local services, although they acknowledge the advantages of Care Centres and the work they have done around spreading awareness of MND. Patients who do

attend the Care Centre tend to be under the supervision of only one consultant neurologist, either at Addenbrooke's or DRC, and not both.

West Suffolk

Inputs

Key staff

- ✓ Consultant neurologist
- ✓ 2 x Specialist neurology nurses
- ✓ Speech and language therapist
- ✓ Dietician

Annual staff costs (based on estimated time allocated to MND care): **£31,188**

In-kind investment by others

- ✓ MND Association Visitor attends MND clinic
- ✓ Hospice team member attends MDT meetings

Facilities

- ✓ Clinic space at West Suffolk Disability Resource Centre
- ✓ Travel expenditure

The service

Caseload

- ✓ 25 people with MND on current caseload (as of 11/15)
- ✓ 10 new referrals in 2015

MND clinic and MDT

- ✓ Monthly MND clinic at West Suffolk Disability Resource Centre. 11 clinics in 2015 (no clinic in August). Can run ad hoc clinics if high demand
- ✓ 5 people with MND attend each clinic (55 attendees in 2015) Most attend every 2 or 3 months
- ✓ Monthly MDT meeting after clinic
- ✓ Home visits and follow up calls by neurological specialist nurses
- ✓ Bimonthly MND support group attended by neurological specialist nurses

Other local services

- ✓ Day centre at St Nicholas hospice
- ✓ Respiratory service at Papworth Hospital
- ✓ Enteral feeding at West Suffolk Hospital

Outcomes

For people with MND

- ✓ Easy access to clinic
- ✓ Able to avoid travelling to a district hospital
- ✓ Friendly and relaxed environment
- ✓ Flexible - able to reschedule clinics at short notice
- ✓ Reassurance that they can be seen at home
- ✓ Able to see multiple professionals at once
- ✓ Reduced number of appointments

For professionals

- ✓ MND clinic has led to easier care coordination and greater awareness of patients
- ✓ Improved working relationships and understanding of professionals involved
- ✓ Co-location with services results in good links and communication

Links with other services and care coordination

The DRC generally has strong links with local services. They have particularly good links with St Nicholas Hospice as many people with MND will attend the hospice day centre. The hospice also has physios, OTs, and a complementary therapy team that can offer do home visits, which for some people may provide a less frightening alternative to visiting the hospice. A representative from the hospice attends the MDT meetings after the MND clinic, and will feed back to the palliative care team and take note of any issues or actions to be dealt on their end. The DRC and hospice also have a shared electronic records system, which facilitates sharing of information and care coordination. In general, the DRC will hold off when it comes to palliative care and will not refer patients to palliative care services straight away. They will wait until the appropriate time for each individual person as some patients find it so hard to accept their diagnosis and do not think they are at the stage of requiring end of life care.

The specialist nurses at the DRC have very good links with the nurses at Addenbrooke's and are frequently in contact regarding West Suffolk patients. The DRC holds a steering group meeting with Addenbrooke's every 6 months where representatives from the Care Centre can discuss West Suffolk patients and voice any issues or concerns. The DRC also has good links with Ipswich hospital, and they will check up on patients who attend there.

Although there is no specific care coordinator, much of the coordination is done by the two neurological specialist nurses who take a lead on each patient individually and know what is going on. During the focus group participants expressed that there was no real need for a specific care coordinator as they only have 25 MND patients on their caseload, which was said to be manageable, although if they had more patients then they would need a coordinator and would prefer more MND specialism in the team. Each professional will update others when they come into contact with a patient, and will make steps to avoid duplication and unnecessary home visits. "I don't think we need a coordinator." "We're specialist nurses so that's what we do". Some of the care coordination is additionally done by the consultant neurologist's secretary who keeps an up-to-date record of patients on their caseload.

"I don't think we need a coordinator...we're specialist nurses so that's what we do"

What works well?

The clinic itself was reported to be a major benefit of the West Suffolk set-up, and people with MND expressed the value of being able to see multiple professionals at once and reducing the number of individual appointments. Before the clinic was set up the consultant neurologist would only see people with MND from West Suffolk for 10 minutes after the Addenbrooke's follow-up clinic and would then have to send out around 7 individual emails to various people which was time consuming. Now that the clinic has been set up care coordination has said to have improved overall, and everybody knows each other and all of the patients. In addition

"Being able to go to go somebody's house in-between clinics is invaluable"

members of the MDT felt that some people with MND prefer attending the DRC as opposed to the Addenbrooke's Care Centre and other acute settings as the DRC has better parking, is easier to access, and has a more relaxed and friendly atmosphere where they build strong relationships with patients. Members of the MDT reported that there is very good turnout to the clinic and that they are very flexible as patients can easily reschedule appointments at short notice, which is not always possible at general neurology clinics. An important aspect of the DRC is that they can do home visits, often also at very short notice, for people who are unable to attend the clinic. The ability to do home visits was greatly valued.

An important and valuable aspect of the West Suffolk set up is that the neurological specialist nurses, OTs, physios, dieticians, and equipment and wheelchair services are co-located in the DRC and as such there are good links and constant communication between the different teams, and equipment can generally be obtained fairly quickly. In addition, the OTs and physios understand MND and the urgency of it. There are generally good links with the different health and social services, and MND is flagged as a priority condition across the board.

Challenges

One issue discussed in the focus group was the demand and pressure on local services, such as wheelchair services. Participants also mentioned the demand on the local hospice as it cannot always react to demand, i.e. there are sometimes too many patients needing too few beds. The MDT discussed the issue around providing sufficient care for people at home and providing support to families and carers, particularly towards the end of life. Conversely, it was noted that some families and people with MND may be reluctant to ask for help which then makes it difficult to anticipate patients' conditions, and when it comes to needing help they suddenly need a lot of help.

The difficulty getting patients onto research projects was highlighted in the focus group. Most research projects are concentrated in specialist centres so patients are required to travel to distant hospitals and MND Care Centres if they want to take part in research trials, which some are unable or unwilling to do. Delays receiving CHC funding were also reported.

Currently physiotherapists and OTs are not present at the MND clinic, although sometimes a physiotherapist from the hospice may attend, as there are no specialist OTs and physios in Suffolk and all are generic and cover smaller catchment areas. MDT members expressed an interest in having an OT and physio assigned to the MND clinic, and commented on the usefulness of having physios with more experience and specialism in MND.

Other comments

There is an annual study day for MND at West Suffolk hospital which is open to all professionals who may come across people with MND. This was initially organised as a one off event by Social Services as a means to raise awareness and education about MND among social workers, but this has now taken off and is well attended, with 80 attendees at the last event. There are a series of lectures in the morning which are then followed by smaller workshops, for example focussing on palliative care, SLT, advanced care planning. The focus group participants said that these events

have raised interest in MND among local health and social care professionals, and some health and social care professionals have observed the MND clinic to see how it works and to improve their knowledge of MND.

Milton Keynes – case study

Background

The model of care for people with MND in Milton Keynes is largely based in the community, with strong links with the Oxford MND Care Centre and local hospitals as and when needed. The central point of this model is the Neurological Conditions Clinical Specialist – a community-based coordinator, based at Bletchley Community Hospital, who provides a one stop shop for care for people with MND, Huntingdon's Disease, muscular dystrophy, ataxias, and other rare neurological conditions. The Neurological Conditions Clinical Specialist currently has a total caseload of 160, of which 25 are people with MND. The Neurological Conditions Clinical Specialist is part of a wider Milton Keynes Neurological Clinical Specialist Team – a multi-disciplinary community-based team with expertise in neurological conditions, physical disabilities and rehabilitation. This team consists of some disease-specific specialist nurses, such as a Multiple Sclerosis Clinical Specialist and a Parkinson's Disease Nurse Specialist. The Neurological Conditions Clinical Specialist is the key point of contact for people with MND in the Milton Keynes area from the point of diagnosis and plays the key role in coordinating care and linking in with local health and social care services, the palliative care team in the local hospice, and with the Oxford MND Care Centre.

Complementing the Neurological Conditions Clinical Specialist is the Milton Keynes Neurological Rehabilitation Service, which provides rehabilitation for people with neurological conditions. The services consists of a team of NHS professionals including physiotherapists, occupational therapists, speech and language therapists, psychologists and nurses, and covers people with MND registered with a GP in Milton Keynes.

The care process

Initial contact and diagnosis of MND is usually made through a consultant neurologist at Milton Keynes University Hospital, at which point the Neurological Conditions Clinical Specialist will be informed. The Neurological Conditions Clinical Specialist will then contact the person with MND and arranges a visit which is usually done within a few days of diagnosis. People with MND also have the opportunity to be seen at Bletchley Community Hospital, however most are seen in the community. During the visit the Neurological Conditions Clinical Specialist will perform routine assessments, discuss advance care planning and advance decision to refuse treatment, and provide information on MND. The Neurological Conditions Clinical Specialist will also provide contact details for other health and social care professionals as well as information on the MND Association, support groups, and MND Connect, and she will advise the patient to contact the MND Association. The Neurological Conditions Clinical Specialist will then refer the patient onwards to local services, primarily the Neurological Rehabilitation Service, and will provide some information on the patient, such as when they were diagnosed, who else they are seeing, and what their symptoms are. The Neurological Conditions Clinical Specialist will also inform the Regional Care Development Advisor of any new diagnoses and referrals.

People with MND are also informed early on of Oxford MND Care Centre⁷ and are given the option to attend. In some cases there are certain patients who the Neurological Conditions Clinical Specialist is particularly keen on visiting the Care Centre, such as those with respiratory or swallowing problems. Most people with MND in the Milton Keynes area attend the Care Centre, with some initially attending to receive a second opinion, however not all wish to attend and the main reason for this is the requirement to travel to Oxford. Those who do want to attend are then referred to the Care Centre by the Neurological Conditions Clinical Specialist, by either email or telephone.

One person with MND who took part in a telephone interview was diagnosed with MND in February 2013. His diagnosis was initially made in a local district general hospital by a specialist stroke neurologist who said there was an 80% chance he had MND, and who at the time informed him that he had 13 months to live. He subsequently attended the Oxford MND Care Centre in March for a follow up at which point his diagnosis was confirmed, in what he said was a more professional manner. From then on he attended the Care Centre every 3 months, and now attends every 6 months. One of the key benefits of going to the Care Centre is that they monitor his breathing which gives him reassurance that he can get an intervention at the right time and allows staff at the Care Centre to anticipate any problems before they fully arise. He commented that if he stayed at home he wouldn't receive interventions quickly enough. Another benefit is that people with MND are able to find out about the care available. For example the OT at the Care Centre referred him to a specialist computer OT – a service which he was previously unaware of.

*“To me the MND centres are very useful...they anticipate problems and keep you one step ahead. You need to be one step ahead with MND.” –
Person with MND*

Most of the regular care for people with MND in Milton Keynes is provided in the community, in peoples' homes, however some receive care as outpatients at Milton Keynes University Hospital. For example, the specialist neuro physiotherapist spends 2.5 days a week seeing patients in the community and then 2 days at the hospital. Generally speaking the criterion for community visits is that the patients are usually housebound and unable to attend outpatient appointments, however most people with MND will be seen at home even if they are able to access the outpatient service. People may often continue seeing their neurologist at Milton Keynes University Hospital, even if they attend the Oxford MND Care Centre.

*“I certainly think the MNDA meetings are really good practice and should be replicated by other branches...I think all affected people in MK should attend” –
Person with MND*

Monthly MND drop-ins are organised by the local Milton Keynes branch of the MND Association. These are open to

⁷ Please note the Oxford MND Care Centre will be focussed on in a separate case study in Section 2.

people with MND, carers and family and provide a space to meet other people, share experiences, and gain information. The Neurological Conditions Clinical Specialist attends most of these drop-ins and people living with MND are able to talk to her about any needs and problems that have arisen, after which the Neurological Conditions Clinical Specialist can then make referrals. These MND drop-ins are also attended by the Regional Care Development Advisor and sometimes an Occupational Therapist. Feedback from people with MND is that these meetings are particularly useful as they bring together health professionals in one place who can then see people MND at one time, which benefits people with MND but also saves time and resources for the professionals who attend. One person with MND commented on the benefits of being able to talk to carers and other people living MND, and that they can bring up issues with the Neurological Conditions Clinical Specialist which are then acted upon.

Rare neurological conditions multidisciplinary team

The Neurological Conditions Clinical Specialist runs a rare neurological conditions MDT meeting every 2 months. This is attended by a variety of health and social care professionals, which may include dieticians, physiotherapists, OTs, palliative care nurses, district nurses, and sometimes social workers. At these meetings all patients with rare neurological conditions are discussed, and not just the MND caseload although people with MND are the largest group and will be discussed first. Before the meeting the Neurological Conditions Clinical Specialist will send out an agenda and minutes of the last meeting. At the meeting all new referrals and people diagnosed with MND are discussed and highlighted to all MDT members. There is also an update on people with MND who have passed away and an update on the current caseload, as well as general issues and developments regarding MND care.

Communication and care coordination

The Neurological Conditions Clinical Specialist plays the key role in coordinating care and linking together different services. When the Neurological Conditions Clinical Specialist makes referrals the patient and all relevant professionals, including the GP, are copied in to any emails and/or letters. The Neurological Conditions Clinical Specialist is the central point of contact for patients and professionals. Interviews with health and social care professionals highlighted overall good links with local services, with one participant noting particularly strong links with the respiratory team and PEG team at Milton Keynes University Hospital. Nearly all contact between services and health and social care professionals is done by email. The Neurological Conditions Clinical Specialist has strong links with the MND Care Centre at Oxford and will frequently contact the Care Centre Coordinator regarding, and vice versa. However one therapist in Milton Keynes commented that communication with Oxford is not as easy as it is with the Neurological Conditions Clinical Specialist and other local teams. It was also reported that there are sometimes issues receiving clinic/care letters from the Care Centre, and it was suggested the large caseload and area that the Care Centre covers may be the reason underlying this. The Neurological Conditions Clinical Specialist also has strong links with the local MND Association branch.

Milton Keynes

Inputs

Main staff

- ✓ Neurological Conditions Clinical Specialist
- ✓ Administrative assistant (shared among 6 other clinical specialists)

Annual staff costs: **£51,662**

MDT staff

- ✓ Community dietician
- ✓ Community speech and language therapy
- ✓ Community occupational therapist
- ✓ Physiotherapy
- ✓ District nursing
- ✓ Palliative care CNS from hospice
- ✓ Social worker

Facilities

- ✓ Access to neuro-rehab unit at Bletchley Community Hospital
- ✓ Travel expenditure

The service

Caseload

- ✓ 160 in total on the Neurological Conditions Clinical Specialist's caseload (25 people with MND)

MND services

- ✓ Home visits by the Neurological Conditions Clinical Specialist
- ✓ Monthly drop-in organised by the MND Association attended by Neurological Conditions Clinical Specialist, RCDA, and sometimes other professionals
- ✓ Bi-monthly rare neurological conditions MDT meeting
- ✓ Milton Keynes Neurological Rehabilitation Service

Other services

- ✓ Inpatient and outpatient services at Milton Keynes University Hospital
- ✓ Oxford MND Care Centre

Outcomes

For people with MND

- ✓ Neurological Conditions Clinical Specialist provides a single point of contact for people with MND
- ✓ People with MND have the option to be seen in a multidisciplinary setting (Oxford) as well as at home
- ✓ Able to see multiple professionals at the MND drop-in
- ✓ Able to meet other people with MND/carers at the drop-ins
- ✓ Access to the Oxford MND Care Centre for specialist care

For professionals

- ✓ Neurological Conditions Clinical Specialist provides a single point of contact for professionals
- ✓ Neurological Conditions Clinical Specialist and MDT meetings facilitate communication and care coordination
- ✓ Strong links with the Oxford MND Care Centre

What works well

People with MND highlighted the usefulness of the MND drop-ins, providing a space to talk to other people with MND, carers, and families, as well as the Neurological Conditions Clinical Specialist, RCDA, and other professionals who attend. In this way it can be seen as acting as both a clinic and a social/support event. Strong links and access to the Oxford MND Care Centre is similarly highly valued by people with MND and professionals, and a unique feature in Milton Keynes is that the local MND Association branch will pay for taxi costs to transport people with MND to and from the Care Centre. One professional discussed the importance of having access to multidisciplinary drop-in clinics but also having the option for people to be seen at home or one-to-one, as a key issue with drop-ins is that some people do not want to see others who have MND. What works well in Milton Keynes is that people with MND can access both types of care, as many attend the MND drop-ins and the Oxford MND Care Centre, but then there is a good network of community teams that can offer one-to-one care at home.

One of the main aspects of the set up in Milton Keynes is the presence of the Neurological Conditions Clinical Specialist, with both professionals and people with MND highlighting the crucial benefits of this role. One of the main advantages of having this type of role is having the single point of contact, not only for people with MND but also for health and social care professionals in community teams, the hospital, the hospice, and the Oxford MND Care Centre. The Neurological Clinical Specialist Team was initially developed for this exact reason, because patients wanted a single point of contact.

“[The Neurological Conditions Clinical Specialist] is very good and I’m sure if I go elsewhere I wouldn’t receive the same service”
– person with MND

A strong aspect of the Milton Keynes set up is the excellent links and communication between various local services and community teams. One factor contributing to this is the fact that much of the MDT, notably the Neurological Rehabilitation Service Neurological Conditions Clinical Specialist, is co-located in Bletchley Community Hospital, which facilitates communication and working relationships. However one professional based in the hospital commented on the importance of having the *whole* MDT working in the same building, and that this should be best practice. The MDT meetings are also valued as they also facilitate communication care coordination, and allow people with urgent and complex cases of MND to be flagged up early on. Lastly, the Neurological Conditions Clinical Specialist commented that there is a very clear pathway in Milton Keynes, and that it is relatively simple and clear compared to other areas. A key reason for this is that the Neurological Conditions Clinical Specialist and MDT have a very clear catchment area that they cover.

“We mimic an MDT and do work like an MDT but it is not in the ideal circumstance – you need to be under the same roof”

Challenges and areas for improvement

An issue highlighted by one of the professionals was that spasticity management is only available at Oxford, which requires people with MND to travel to Oxford to access this service. However, some patients may be homebound and others may have to be transported lying down in an ambulance which some may find traumatic. They are currently trying to set up a good spasticity management team in Milton Keynes whereby people will be able to access this service from home or from Bletchley Community Hospital, however to date there have been no new developments. This is a key issue with specialist services and treatment, in Milton Keynes as well as other areas in the UK that require travelling to a Care Centre.

“You don’t want to be told that you have to go to Oxford to get certain care”

Other comments

The Neurological Conditions Clinical Specialist plays a key role in education around MND. She runs study days and gives talks at the hospice. She is also involved in district nursing teaching of MND and takes on nursing students on one-day placements. As the main point of contact for health and social care professionals, she is heavily involved in up-skilling professionals, particularly around specific treatments and areas such as PEG. The Neurological Conditions Clinical Specialist is part of a group of specialist neurological nurses across the Thames Valley area who meet up once a month and discuss MND. These meetings are also attended by the Oxford MND Care Centre Coordinator.

North Wales – case study

Background

Across Wales there are an estimated 250 people living with MND, yet services available for people with MND vary considerably:

- In South Wales, where the majority of people with MND in Wales reside, there is an MND Care Network which has expanded on the Cardiff MND Care Centre. This Network consists of two hubs, one in Swansea covering South West Wales and one in Cardiff covering South East Wales, as well as satellite clinics.
- In Mid Wales services are more fragmented and there are no district general hospitals. People with MND may receive their care in Cardiff, and many also cross over to Birmingham or Liverpool.
- In North Wales people with MND are generally seen in general district hospitals and in the community. As with Mid Wales, many people also attend the Liverpool MND Care Centre at the Walton Centre for Neurology and Neurosurgery, and as such there are strong cross-boundary links. In 2015 there were 68 people with MND in North Wales, 20 new diagnoses, and 22 deaths.

In April 2012 a North Wales Neurosciences Network was formally established by Betsi Cadwaladr University Health Board (BCUHB) to advise on the strategic clinical direction and delivery of neurological services in North Wales. The Network is made up of a range of statutory and non-statutory bodies including the NHS, patient and carer representatives, the Voluntary Sector, Social Services, The Walton Centre NHS Foundation Trust, and hospices in North Wales. The Network has adopted a whole system, partnership approach to the planning, commissioning and delivery of services in North Wales. By securing better integration across sectors, its vision is to drive transformation to ensure the delivery of safe, high quality and effective neurological services, to address issues such as the overuse and underuse of resources and to ensure that patients have access to the necessary information and support. The Network is also leading on the development of clinical pathways and standards of care which will deliver a consistently high quality service across North Wales.

The North Wales Neurosciences Network has since established 4 Disease Specific Advisory Groups (DSAG), with the first being the Motor Neurone Disease DSAG. The MND DSAG was established in October 2012 and is currently chaired by a consultant in palliative care. This DSAG came about from wanting a strategic planning group to ensure that every person with MND in North Wales would receive the same level of care. Initial feedback from people with MND at the time was that coordination between professionals could have been improved, including coordination between local services in North Wales and the Walton Centre. Feedback from health and social care professionals was also that coordination and communication could have been improved.

North Wales

Inputs

MDT staff

Each of the 3 MDTs consists of multiple professionals and cover multiple disciplines. All have input from local hospices

East and West MDTs are led by consultants in Palliative Medicine. Central MDT is led by a dietician

The North Wales RCDA is involved in all 3 MDTs and attends MDT meetings as well as clinics at the Walton Centre

The service

Caseload

- ✓ 68 people with MND in 2015
- ✓ 20 newly diagnosed. 22 deaths

MND MDTs

- ✓ 3 MND MDTs across North Wales. Monthly meetings
- ✓ East MDT led by a consultant in Palliative Medicine
- ✓ Central MDT led by a dietician
- ✓ West MDT led by a consultant in Palliative Medicine

Clinics

- ✓ Monthly MND clinic in West MDT area. Up to 6 people with MND attend each clinic and most attend quarterly
- ✓ Newly diagnosed MND clinic & follow-ups at Walton Centre
- ✓ General neurology clinics throughout North Wales
- ✓ General palliative care clinic in East MDT area

Other local services

- ✓ Day centres at local hospices

Outcomes

For people with MND

- ✓ Patient satisfaction with the MND MDTs
- ✓ Reassurance that they are known and discussed by multiple professionals, and that their care is being coordinated
- ✓ MND clinic in Bangor provides a one-stop-shop
- ✓ MDTs have shortened referral times

For professionals

- ✓ Positive feedback regarding the MND MDTs
- ✓ Improved interdisciplinary working and cooperation
- ✓ Greater support from professionals and understanding of each other's roles
- ✓ Improved communication and coordination of care, and reduced duplication

Care process

All specialist neurological services for people with MND in North Wales are provided by the Walton Centre. Consultant neurologists from the Walton Centre visit district general hospitals in North Wales where they may see people with MND in general neurology clinics. There are some disease specific clinics in North Wales, such as epilepsy and MS, but none specifically MND. In addition there are also disease specific neurological nurse specialists for epilepsy, MS, and Parkinson's, but likewise none for MND. People with MND in North Wales wanting MND-specific services must instead travel to the Walton Centre which holds an MND Care Centre.

Diagnosis is carried out by a Walton Centre neurologist in one of the general neurology clinics in North Wales. People with suspected MND, or those requiring a second opinion, are then referred to an MND neurologist which is undertaken at the Walton Centre itself. This is taken up by most people with MND in North Wales. The MND Care Centre at the Walton Centre receives a lot of referrals from North Wales and runs an MND newly diagnosed clinic twice a month. Patients who are diagnosed with MND are offered an appointment at this clinic within 4 weeks of diagnosis. This clinic is attended by a Consultant Neurologist specialising in MND, MND Nurse Specialist, Occupational Therapist, Speech and Language Therapist, Physiotherapist, and Welfare Benefits Adviser, as well as the RCDA for North Wales. Interviews with patients revealed that a key reason for going to the Walton Centre was that they thought the consultants had more experience with MND. The Walton Centre also runs once or twice monthly educational sessions for patients recently diagnosed with MND and their carers. These sessions provide useful additional information that could not be covered in the clinic due to lack of time and go more in-depth into what MND is, current research, lifestyle issues, the services offered at the Walton Centre, and the role of different professionals.

After the clinic people with MND are offered the opportunity to be seen by a general neurologist in their district general hospital in North Wales or to continue attending the Walton Centre where they may receive regular follow-ups with the MND neurologist and MND nurse specialist. Many people with MND in North Wales receive care locally, however many still regularly attend the Walton Centre. The MND Nurse Specialist can offer home visits however this is limited for patients who live in or around Liverpool due to time constraints and practicalities. Home visits are not available for people with MND in North Wales or elsewhere in England. Those who decided to receive care locally are then referred on to the relevant local services, and receive care in clinics, hospital, hospices or at home.

Many people with MND also receive multidisciplinary care from local hospices in North Wales. For example, a few people with MND who were interviewed stated that they attend the day care service from St Kintigern's Hospice. One of the people with MND attends weekly and has the opportunity to see a physiotherapist, occupational therapist, and social worker. She also highlighted that she is able to utilise a hospital transport service to take her to

“One of the advantages attending the hospice is being able to see different people. It allows me to avoid separate hospital appointments” – Person with MND

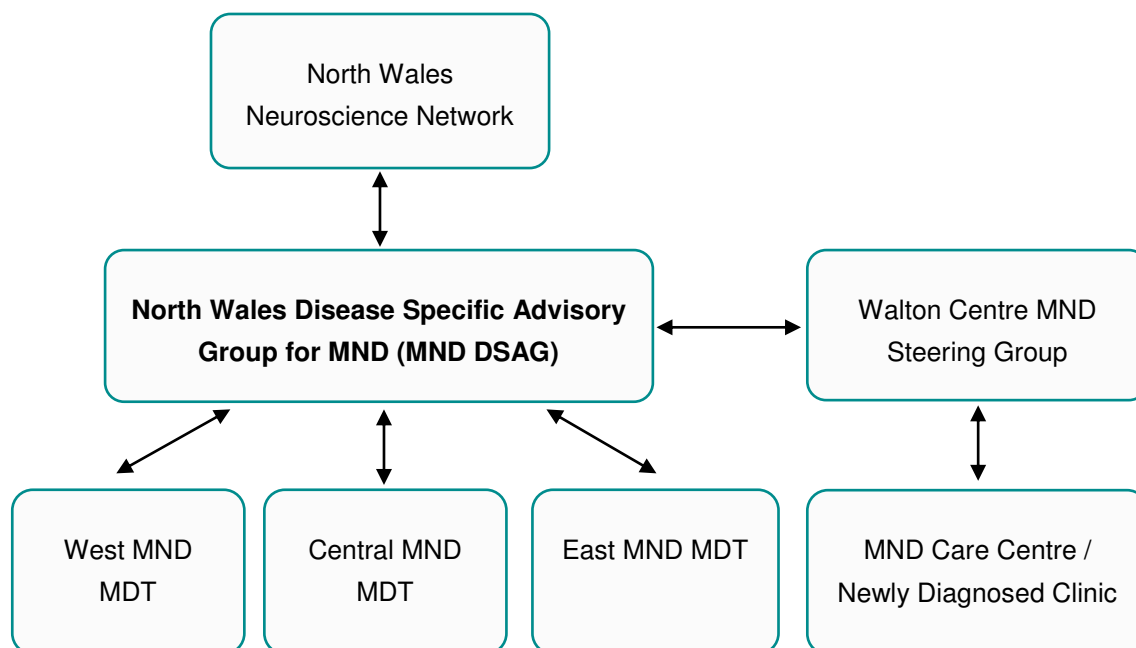
and from the hospice. Another person with MND said they attend the day centre at St David’s Hospice where he can see multiple professionals including a nurse, physiotherapist, and dietician. Hospices, and the range of service available at them, were valued by people with MND but also professionals, with one commenting that they help a lot in-between MDTs and clinics as they provide a good environment for monitoring peoples’ conditions and for allowing people with MND to raise issues and needs.

MND multidisciplinary teams

An important development over recent years is the establishment of three MND multidisciplinary teams across the Betsi Cadwaladr University Health Board (BCUHB) area in North Wales. These are named the East, Central, and West MDTs. These MDTs meet up every month, with the main aim being to improve planning and coordination of services for people living with MND in North Wales. The MDTs are supported and accountable to the MND DSAG and BCUBH, and are each run by a palliative care consultant. Each MDT meeting is attended by a range of health and social care professionals, and all have strong input from palliative care and local hospices. It should be noted that a ‘virtual’ MDT has been created in Montgomeryshire as it is too large for MDT members to travel and there are too few people with MND to make face-to-face meetings viable.

The MDTs play a crucial role in care coordination and each patient is discussed at the meetings. Information is passed on during the MDT meetings with consent from the patients and each discipline will report on their involvement with a patient and will recommend if the patient requires additional services. A key person, which for the Central MDT is a consultant, will be identified at each meeting and will coordinate the discussions and care and will ask relevant services to become involved when required. They will also chase up with any letters and feedback if required.

Figure 4: Impact map for North Wales



What works well?

The establishment of the MDTs has received positive feedback from professionals and patients alike, and these play a key role in coordination of care. Professionals have reported that the MDTs have improved interdisciplinary working and cooperation, improved communication, and avoided duplication. As a result of the meetings, patients are highlighted and issues are flagged up early on and everybody is aware of the issues of all patients. A key benefit is that the MDTs have simplified and quickened referrals by allowing professionals to refer directly to other individual professionals instead of going through a medical practitioner, which in turn ensures a timely management of the MND caseload. The MDTs also allow professionals to support each other and understand more

“Everyone knows what’s already been planned and sorted out without having to ring all the individual teams involved”

about each other’s roles. It allows professionals to get to know each other which makes it more comfortable asking for advice and support. This aspect of the MDTs, around relationships and networking, was said to be almost as important as the care coordination side of it.

The West MDT, which is based in Bangor, additionally runs a monthly MND clinic. People with MND usually attend on a quarterly basis, and on average 4 or 5 people with MND are seen at each clinic. The clinic ensures patients are reviewed every few months and at these clinics they are able to review respiratory function. The clinic is then followed by the MDT meeting whereby professionals can pass on all relevant information to different disciplines, and each discipline in turn is aware of what is required from them. For patients it also gives them the peace of mind that they are being reviewed and discussed on a regular basis and that they know who to call up if they have any issues.

Challenges

One of the key challenges in North Wales has been coordination of care. The establishment of the MDTs and DSAG have led to improvements in care coordination but some issues still persist. One issue highlighted is that there is still some poor communication between different services,

“It would be a lot easier if there was a coordinator in North Wales”

particularly between the community services in North Wales and the Walton Centre. The Walton Centre makes referrals to community services in North Wales, however respondents reported issues with this as there are often difficulties finding out who does what and who the patient is seeing locally. In

addition, the MND nurse specialist may see patients all across North Wales, spanning all 3 MDT areas, but does not attend any of the MDT meetings as it is outside their remit and impractical. Institutional differences between Wales and England, notably the difference in their NHS and social care services, pose further challenges. For

“I think it would be helpful if we had a Keyworker to contact if we were unsure about all the differing situations we were encountering, particularly when we are first diagnosed” – Person with MND

example, the Walton Centre does not have access to patient records for those living in North Wales due to different IT systems and administrative barriers, and as such they have to follow up with individual teams in North Wales which can cause delays. One person from the Walton Centre highlighted that coordination and links between North Wales and the Walton Centre would be greatly improved if there was a coordinator in North Wales. The need for a coordinator was also expressed by health professionals in North Wales and people with MND, so that they could have a single point of contact. It must be noted that the North Wales Neurosciences Network and MND DSAG, with help from the RCDA for North Wales, have recently secured funding from the MND Association for an MND care coordinator in North Wales, which will come into effect in 2016 and which is expected to make large improvements in care coordination. The main aims of the post will be to develop Primary Care links, act as a single point of contact for people affected by MND and professionals, and continue to develop links with the Walton team. The MND Association will fund the first two years of the post, on the understanding that it will then be picked up by the NHS.

One speech and language professional commented that there should be time and resources ring-fenced for people with MND, as people with MND are fast-changing and require regular communication. They suggested there should be a specialist SLT clinic for people with MND. One professional also commented on poor communication and duplication between health professionals and social care professionals and a poor understanding of the different services. Other challenges were around poor awareness of the MND MDTs among GPs, issues with travelling due to the large, rural areas, and the fact that some areas have a high percentage of Welsh speakers, but not all professionals can speak Welsh.

Bromley – case study

Background

Bromley is a borough in South London with a relatively high number of people with MND due to the slightly older population who live in Bromley. Most of the care for people with MND is delivered through mainstream community services and they have access to multiple hospitals, including the Princess Royal University Hospital and King's MND Care and Research Centre, as well as strong links with local hospices.

Care process

People with suspected MND are referred for diagnosis to the Princess Royal University Hospital, and are usually seen by a specific consultant neurologist with an interest in MND. Other neurologists may also pick up people with MND and then in most cases would refer on to the MND neurologist or King's. An advantage of King's is that people with MND can see a multidisciplinary team all in one place, however travelling and parking is often an issue. Although not geographically far, it can often take a long time to travel to King's, due to traffic and transport links. Bromley is also the largest borough in London and it may take over an hour to travel to King's via car or public transport for those who live in the south of the borough. As such, most attend the Princess Royal. Some people with MND, primarily those living near the boundary with nearby boroughs, may also attend other district general hospitals, for example those in Lewisham and Croydon.

“There does come a time where patients can't attend King's or it becomes too overwhelming”

Once diagnosed with MND, patients will be referred onwards to local services, most of which are mainstream community services. These include community health services provided by Bromley Healthcare, such as physiotherapists, health OTs, district nurses, SLT, and dieticians, and then Social Services OTs from Bromley Council. There is also a Bromley Specialist Community Rehabilitation Neurology (SCRehN) team which provides targeted specialist rehabilitation and specialist neurology nursing interventions for people with neurological conditions. However, despite community rehab teams in other areas covering people with MND, SCRehN do not often take on people with MND as they are instead more targeted on providing short term rehab services, for example for people who have had a stroke. They take on people for either 6 or 12 week strands on a more short-term approach, which professionals at the focus group said was not suitable for people with MND. Professionals suggested there should be a neuro community team with a different remit, to provide ongoing, long-term care that is required for people with MND.

“The neuro rehab team probably should see MND patients but they are set up for fast-through, whereas MND patients don't thrive in that kind of environment. They need ongoing input”

Specialist assessment, care, and medical procedures are carried out at King's, the Princess Royal, or Guys and St. Thomas'. Up until recently non-invasive ventilation (NIV) was set up at King's but the respiratory consultant has recently left and has not since been replaced. As such, the respiratory unit at Guys and St Thomas' is now used. A positive aspect of this is that Guys and St. Thomas' has an outreach unit, however a downside is that communication and response times are not as good. There is also a respiratory team at the Princess Royal where people with MND can potentially be set up with NIV, and respiratory tests can be performed at King's, however most routine assessments and recommendations would be put through to Guys and St Thomas'. Gastrostomies usually happen at King's but some patients who have been set up with NIV at Guys and St Thomas's can also receive gastrostomies there.

St Christopher's Hospice offers a range of services for people with MND in Bromley, at both the Sydenham site and the Orpington site, with most attending the Orpington site. Both sites offer a day service that people with MND can be referred to, where they can access physiotherapists and OTs. Dieticians and SLTs from Bromley Healthcare also attend. The hospice holds nursing clinics where people can book appointments with a clinical nurse specialist. These clinics are run separately from the day hospice. Some people may go to the day hospice and then see a clinic nurse whilst they are there, whereas others may only attend the hospice for the clinic appointments. The clinical nurse specialists do not offer home visits, but those unable to attend the hospice can be seen by a community team of homecare nurses who are also employed by St. Christopher's. People with MND who are mobile and able to attend the hospice are encouraged to do so instead of being seen at home, as one participant at the focus group said it gets people out of the house and into the hospice where they may then access other services that they would not have accessed otherwise.

MND clinic and multidisciplinary team

People with MND are also referred to a specialist MND clinic at the Princess Royal University Hospital which takes places the 1st Tuesday every month. This clinic is run by either the consultant neurologist with an interest in MND from the Princess Royal University Hospital or the MND nurse specialist from the King's MND Care Centre, or both. These are usually booked appointments but patients can sometimes request to attend at short notice. Every other month there is an MND MDT meeting which takes place after the MND clinic. All patients with an MND diagnosis, including those who did not attend the clinic that day, are discussed. The meetings provide a space to inform all professionals of recently diagnosed people who they may have not come across, and this is usually done by the MND neurologist. The MDT meeting was initially held every month, however this was thought to be too frequent and it now takes place every other month.

GPs will be sent clinic letters and individual professionals may contact GPs directly as and when needed, but generally speaking communication with GPs is kept to a minimum and is thought not to be necessary. Some therapists attend Gold Standard Framework meetings where they may discuss MND patients with GPs.

Bromley

Inputs

MDT staff

- ✓ Consultant neurologist
- ✓ MND specialist nurse
- ✓ Physiotherapist
- ✓ Speech and language therapist
- ✓ Social Services occupational therapist
- ✓ Wheelchair service lead
- ✓ Palliative care nurse

Facilities

- ✓ Clinic/MDT meeting space

The service

Caseload

- ✓ 23 people with MND in 2015
- ✓ 8-10 new referrals per annum

MND MDTs

- ✓ Weekly MND clinic at King's MND Care and Research Centre
- ✓ Monthly outreach clinic at Princess Royal University Hospital
- ✓ Bimonthly Bromley MND MDT

Other local services

- ✓ Specialist assessment, care, and procedures (e.g. NIV and gastrostomies) are carried out at either King's, PRUH, or Guys and St Thomas'
- ✓ Day service and nursing clinics at St Christopher's Hospice

Outcomes

For people with MND

- ✓ Patient satisfaction with the MND outreach clinic at PRUH
 - ✓ People with MND able to avoid travelling further to King's
- ✓ People with MND able to receive care from an MND specialist (either at King's or the outreach clinic)
- ✓ Access to multidisciplinary care at King's

For professionals

- ✓ Improved joint working between services and professionals
- ✓ Greater support from professionals and understanding of each other's roles
- ✓ Improved communication and coordination of care
- ✓ Having medical input at the MDT meetings

Care coordination

A key topic of conversation during the focus group was that of communication and care coordination. One of the biggest issues is the number of services that people with MND in Bromley may use and the overlap of catchment areas across boroughs, which is widespread throughout London, whereas outside of London there is often a hospital that everybody in that catchment area attends. There are multiple hospitals across South/South East London that people with MND may attend. For example, people with MND who live on the border with Lewisham may attend University Hospital Lewisham, however focus group participants highlighted poor communication between University Hospital Lewisham and the Princess Royal, and mainstream community services in Bromley. This then poses a problem when accessing patient information and clinic letters. Professionals at the focus group highlighted the confusion this causes, among

“We’re confused but think how confusing it is for the patients”

“I think the individuals themselves do their best but there are issues with the system” - Carer

themselves as well as the patients. From this, the focus group participants expressed a strong need for a care coordinator, suggesting that this would greatly improve coordination of care for people with MND in Bromley whilst also freeing up time for therapists that is currently spent on case management. They suggested it would likely be most appropriate and realistic for this care coordinator role to cover other rare neurological conditions as well, such as Huntington’s and PSP, in order to increase the caseload, while also acknowledging the time commitments, quick responsiveness, and resources needed to solely coordinate care for people with MND. Bromley CCG is currently looking at restructuring neurology services in Bromley and the need for a care coordinator for rarer rapidly progressing conditions has been highlighted by the RCDA for South London.

Carers of people with MND highlighted significant issues with care coordination, and the difficulties knowing what services there are, who does what, and who to contact. They commented that a lot of work was done on their behalf and that it is essential to have a key contact who knows MND and who knows the system.

“It feels a lot like you have to do everything yourself” - Carer

Currently any coordination is largely done out of goodwill and on an individual basis. The MDT plays a crucial role in the care coordination is not formally commissioned. Participants highlighted their concerns regarding the long-term sustainability of the MDT, questioning whether key individuals would be replaced if they left, and thus whether the MDT would continue running. A leaflet was put together by Social Services OTs which is given out to people with MND and provides contact details for health and social care professionals. However it was noted that there is still confusion and a lack of understanding of the services provided for people with MND.

The sharing of information and access to patient records various across the different services and professionals providing care for people with MND. The mainstream services within Bromley

Healthcare have a shared system where they can access patient records and notes. Other services, on the other hand, do not have access to this system. This includes Social Services OTs and St. Christopher's hospice, and professionals from these services instead have to phone up individual teams to get patient information, which was said to be time consuming. SLTs and dieticians from Bromley Healthcare who attend St. Christopher's Hospice are additionally able to access the hospice's system when on site, however this only works one way and the hospice cannot access the Bromley Healthcare system. The MND clinical nurse specialist from King's also faces difficulties accessing notes and is unable to access test results from the Princess Royal. Patient notes at the Princess Royal, including clinic letters, are on paper and are eventually uploaded at which point the MND clinical nurse specialist can access them, although there are delays in this.

There is a Single Point of Entry (SPE) form that GPs can use to make multiple referrals to community teams, but this cannot be used by the consultant neurologist. The consultant neurologist would instead send out a clinic letter to multiple professionals after each clinic, asking them to see the person with MND, which can be time consuming and can sometimes cause delays. There have been instances though where the consultant neurologist has been able to send a clinic letter to the GP, and the GP has then sent out a SPE form to all relevant teams.

What works well?

Those who attended the focus group commented on the importance of the MDT as it brings together all the professionals and has improved joint-working through networking and knowing who does what. It also facilitates coordination and communication and highlights patients that some people may be unaware of. An added benefit is that the MDT meeting is held after the MND clinics, and participants valued having the medical input from both the consultant neurologist and the MND clinical nurse specialist. Previously, before the MND clinical nurse specialist was involved in the MDT, there were instances where the consultant neurologist was unable to attend the MDT meetings which meant there was no medical update. Having both involved in the MDT always means there is medical input present at the meeting. The MND clinical nurse specialist also brings along clinic letters to the meetings and send out emails beforehand, which the others value, as it allows them to directly see the most up-to-date notes and developments.

“Our MDT is really valuable because even though we all sit in different pockets, we all come together with the one aim of that MND patient”

Interviews with carers highlighted the benefits of the clinics, at PRUH as well as King's, particularly with regard to the ability to see an MND clinical nurse. One carer said her husband attended King's but then there was a point where he was unable to attend. Due to the large area that King's covers, the MND clinical nurse specialist is unable to perform home visits to people with MND in Bromley. As such the carer commented that her husband was unable to receive the same level of care when not attending King's, and that there needs to be more presence in the community from a qualified MND specialist.

Challenges

As discussed previously, there are key challenges around the coordination of care, confusion of services, and access to information. An added challenge is that many professionals and teams sit in different offices, for example SLTs are based at the Beckenham Beacon whereas dieticians are based at the Beckenham Clinic. Teams also cover different areas, for example SLT covers the whole borough, whereas the health OTs, physios and district nurses form local teams and split into 6 areas, which is soon to become 3. It was also highlighted that there is regular re-configuration of community services in Bromley, whereas this tends to be more stable at the hospital.

Interviews with two carers highlighted issues with diagnosis and in both cases it took up to a year for their relative to be diagnosed, and in both cases they had to resort to private medical care. Other challenges were around equipment and care packages, and getting this funded and set up in a timely manner. In particular there are issues with obtaining equipment as it largely depends on the contracts between Bromley and the providers of equipment and what is on the list of available equipment. There have been cases where some specialist equipment has not been on the list of available and funded equipment and as such has had to be specially ordered and signed off, which has consequently led to delays.

Section 2: Care Centres

Background

The MND Association operates a programme of 17 MND Care Centres and 2 MND Care Networks across England, Wales and Northern Ireland. MND Care Centres are dedicated MND clinics with MDTs consisting of a range of professionals who come together to improve the standard of care for people living with MND. They monitor and advise on symptoms and provide support and information. Their main aim is to improve support and coordination of services for people living with MND. The MND Care Centres:

- Provide a single point of contact for all persons affected by or caring for a person with MND.
- Deliver a high standard of coordinated and integrated care to people with MND, linking people with MND into local and community based services, and the MND Association.
- Provide expertise in the management of MND.
- Provide educational opportunities for health and social care professionals, and disseminate good practice.

MND Care Networks are similar in many regards to Care Centres as they coordinate and support local health and social care organisations to deliver high quality care to people living with MND. The main difference is that the Networks do not have a physical 'centre' but instead utilise a range of clinics or outreach services to people's homes to provide access across a wide area. There are currently 2 MND Care Networks which cover large, generally less densely populated rural areas. These are the South West Peninsula Network (covering Devon and Cornwall) and the South Wales Network.

The MND Association part-fund Care Centres throughout England, Wales and Northern Ireland and in most cases fully fund the position of Care Centre Coordinator. The MND Association provides funding by a contract with the provider organisation; in England, the clinics are not formally commissioned by either NHS England or CCGs, which represents a direct subsidy of £1million to the NHS. As mentioned previously, this is despite NHS England being formally obliged to commission specialist multidisciplinary MND clinics which include a specialist neurologist and a specialist nurse/care coordinator, as set out in the Neurosciences Service Specification.

The following section is based on the literature review, telephone interviews with 4 Care Centre/Care Network coordinators, and an online call for evidence which was sent out to the Care Centres. In total, 16 Care Centre/Network coordinators completed the Care Centre call for evidence, representing 14 of the 19 MND Care Centres/Networks throughout the UK. A list of respondents is provided in Appendix 4.

Patient caseload

MND patient caseloads for the Care Centres/Networks ranges considerably from 68 to over 300 (See Appendix 5). The frequency at which patients attend varies. In some cases people with MND may attend a Care Centre for a one-off consultation or a second opinion, or to attend a newly diagnosed clinic, and then choose to receive their care more locally at a district hospital or in the community. Some people with MND who make a one-off visit to a Care Centre may do so because they live far away, and regular visits may not be practical. In other cases people with MND may attend regularly and may be entirely managed through the Care Centre clinic. Some respondents to the call for evidence said that patients attend every few months, and others said patients attend as and when needed. Many of the respondents said that patients are offered routine reviews every three months, commenting that this allows for anticipatory care planning. They also said that seeing a patient every three months is frequent enough to help the Care Centre to build trusting relationships with patients and their family.

Whether patients attend or not often depends on the patient's preferences and their ability to travel to the Centre. It often also depends upon their rate of disease progression, and those with slower progression may either be advised by the Centre that they do not need to attend regularly, or may decide themselves that they do not need to attend. The interviews and case studies explored the reasons why people attend a Care Centre. In many cases the main reason for attending is to access a 'one stop shop' service where people with MND can see multiple professionals at one go. People with MND often go to receive a confirmed diagnosis or second opinion, or to take part in research. Many also attend because they believe there is a higher level of MND specialism and experience among the Care Centre professionals, more so than outside of the Care Centre. This may be based on their own judgement, or that of other people with MND, or professionals. In some cases people with MND will be informed and advised to go to the Care Centre by a health and social care professional.

"We are ultimately needs led so we can and will see patients more or less frequently based upon their clinical need and/or preferences"

On the other hand people with MND may feel disinclined to attend. Interviews with professionals and people with MND highlighted that some people, particularly those who are newly diagnosed, are disinclined to attend as they do not want to see people with more advanced MND, and thus they do not want to see what their own condition will progress to. Importantly, one respondent to the call for evidence reported that not all people with MND are referred to a Care Centre, due to poor awareness among GPs. In addition, the respondent reported that some people with MND may not want to be referred as they do not fully understand what the Care Centre can offer them. In other cases, people with MND may not want to attend because of travel requirements or issues with parking, or the fact that some may be housebound and unable to attend a Care Centre. Instead, patients are often able to be seen at home by the Care Centre coordinator instead of attending the clinic. Some may also be seen at home in-between clinics. In most cases home visits would be for those who are unable to attend the clinic or have difficulty attending, or for those with

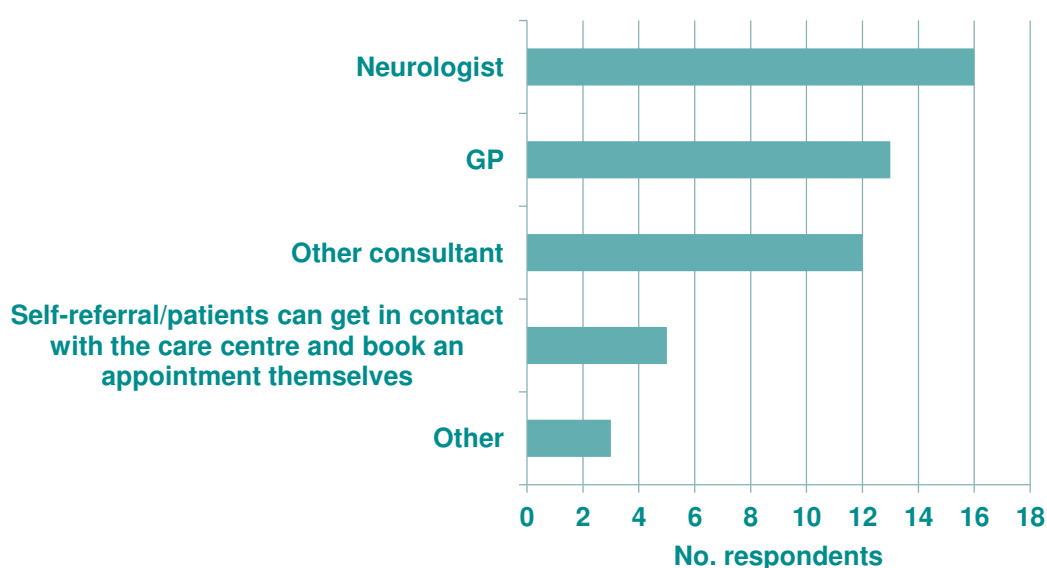
a faster rate of disease progression. There are inevitably cases where patients will be required to go to the Care Centre for more specialist care, such as respiratory assessment.

Respondents to the call for evidence were asked what other services patients receive care from, if they are not attending the Care Centre regularly. These include a variety of local services, most of which are in the community, such as community palliative care teams, neurology teams, physiotherapists, occupational therapists, community matron. Others may attend a local district hospital or general neurology clinic for follow-ups or will be seen at home by an MND specialist nurse.

Referrals

Respondents to the call for evidence were asked whether they see many patients or referrals from outside of their local area/county. Eleven respondents said they receive patients from outside of their area, and five said they do not. Some Care Centres accept referrals from large geographical areas. For example, the Bristol Care Centre receives a small number of patients from Devon, Cornwall and South Wales. This may be due to patient choice and preference, for example patients wanting to receive care from a larger tertiary centre, or choosing to transfer from another Care Centre. In other cases it may be due to the fact that there are no specialist MND services in the patient's local area. For example, the Liverpool Care Centre receives patients from North Wales and the Isle of Man as there are no Care Centres in these areas. Respondents from the Care Centres at the National Hospital for Neurology and Kings' College Hospital in London stated that they may receive patients from all over the UK. Respondents were also asked how patients are referred. In the majority of Care Centres, patients can be referred by either a neurologist, GP, or another consultant. Five of the respondents said patients can self-refer. 'Other' responses include MDT members, local community teams (for example SLT, OT, PT), and RCDAs.

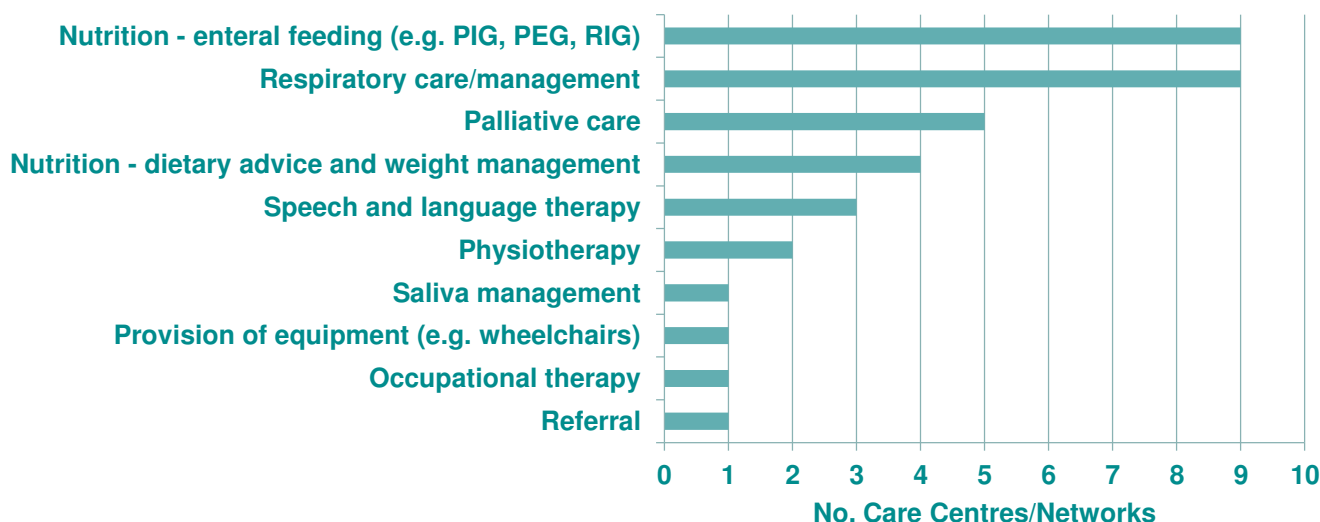
Figure 5: How are patients referred?



Care pathways

Half of the respondents stated that their Care Centre/Network has some formal care pathway(s) in place for people with MND. The most common care pathways were for enteral feeding and respiratory care/management. Some respondents further commented that community teams and other services may have care pathways, but not specifically for patients with MND. A few respondents said they are currently in the process of writing up formal pathways for MND patients.

Figure 6: Is there a care pathway?



MND clinics

The MND Care Centres/Networks vary greatly in the frequency and types of clinics that they offer (see Appendix 5 for an overview of the MND clinics offered from the Care Centres/Networks). The number of clinics ranges from 7 clinics a month to once a month. Half of the Care Centres/Networks hold weekly clinics and some may additionally hold ad hoc clinics if there is high demand. Not all services are concentrated in a single centre as some Care Centres hold outreach clinics across different areas. For example, Bart’s MND Care Centre runs 7 clinics a month across Bart’s Health NHS Trust, Barking, Havering and Redbridge University NHS Trust, and Basildon and Thurrock University Hospital NHS Trust. All of these clinics are attended by the MND Coordinator and a consultant neurologist, but the presence of other professionals, such as physiotherapists, OTs, and SLTs, varies. Likewise, the Southampton MND Care Centre offers clinics in Southampton as well as Portsmouth and Basingstoke. The Care Centre Coordinator commented on the benefits of offering outreach clinics and providing a ‘network/satellite’ model as opposed to concentrating care in one centre. The respondent reported that offering outreach clinics works well to ensure that care is embedded within local services. Some Care Centres offer non-multidisciplinary outreach clinics, i.e. they are only run by a MND specialist nurse or consultant neurologist. For example, King’s run a monthly nurse-led clinic at Princess Royal University Hospital. Other MND Care Centres run clinics in different settings. For example, in Preston there

are three monthly clinics based across six different local hospices. Care Centres may also offer different types of clinics. For example, the Manchester MND Care Centre holds newly diagnosed clinics as well as more frequent follow-up clinics. Middlesbrough holds a weekly MND clinic as well as a twice weekly general neurology clinic for suspected MND.

Additionally, respondents were asked what services are available to patients outside of the clinics. Most of the respondents stated that the Care Centre/Network coordinator is available during normal office hours and can be contacted when needed, however one respondent said that there is no cover when the coordinator is on leave. There are a variety of services available to patients outside of clinics. Home visits are arranged by some Care Centres. On-call neurology services and local MDTs can also be contacted.

Differences between Care Centres and other clinics

Respondents were asked about the main differences between their Care Centre and general neurology clinics, with the main difference being the level of MND focus and MND specialism in the Care Centres contrary to general neurology clinics where the neurologist does not have a specific interest in MND, as well as the presence of the MDT. Respondents commented that in Care Centres patients can see a range of professionals who are knowledgeable about MND and experienced in caring for people with MND, and these specialist professionals and teams can all be accessed in one location, and often in one sitting. Some people referred to the one stop shop approach. The presence of a Care Coordinator, who is a MND specialist nurse, is also a key difference between Care Centres and general neurology clinics. The Care Coordinator provides a single point of contact for people with MND as well as health and social care professionals. They offer advice and information on managing symptoms and discuss care options, and ensure that patients are referred to the appropriate professional within the multidisciplinary team and follow up care in the community is arranged. Overall, this in turn provides more holistic and specialist care, which is absent from general neurology clinics. More time is also given to patients as appointments are much longer.

Other differences and benefits of Care Centres include providing patients with a better understanding of the biology of the disease, access to research, more comprehensive assessment, and good links with support services such as those offered by the MND Association through the Association Visitors. They also act as a source of education and information around the management of MND for health and social care professionals.

Links with local services and coordination of care

MND Care Centres and Networks do not replace an individual's existing health and social care teams, but work in partnership with them to promote and develop effective service delivery. A key aim of the Care Centres is to improve the support and coordination of services for people living with MND, and to promote effective, integrated working between local health and social services. Respondents to the call for evidence were asked how their Care Centre works and interacts with

“The MND Coordinator attends local MND MDT’s where possible and links in with the RCDA’s to help facilitate seamless care over into the community and good communication”

local services, and how patient care is coordinated. This is largely done by the Care Centre Coordinator and involves regular updates and sharing of patient information via email, telephone, and letter, with all professionals involved so that they are informed of any patient appointments, assessment, treatment, etc. Many Care Centre Coordinators reported that they send out clinic letters to all professionals involved in a patient’s care, and in many cases the patient’s GP is informed. Many of the respondents also reported that MDT meetings facilitate coordination of care and some MDTs are

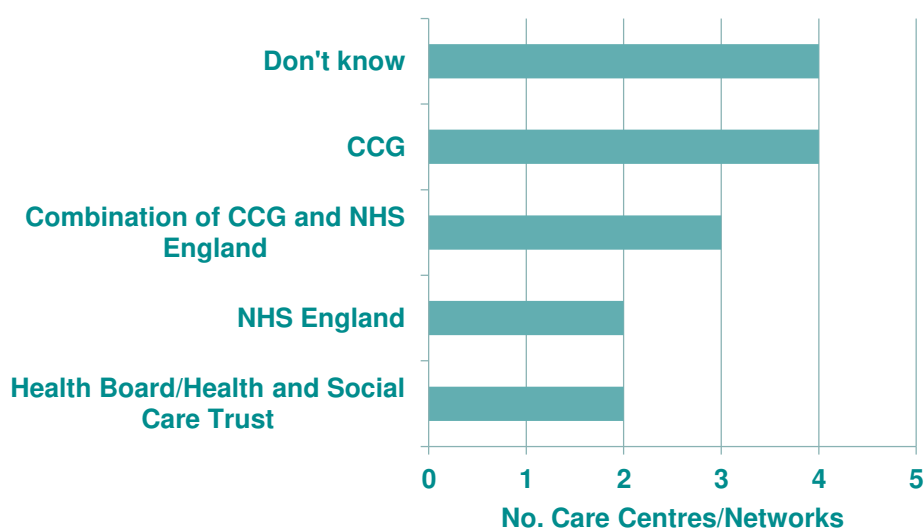
attended by professionals outside of the Care Centre, which further facilitates interaction with different services and sharing of patient information.

Some respondents mentioned access to patient information through a shared database. For example, one Care Centre Coordinator reported that they have access to the community health records in some areas, which greatly helps with communication.

Commissioning, funding, and planning

As mentioned previously, there is confusion in England as to who commissions MND care services. As shown in figure 7, four of the respondents reported that the services at their Care Centre are commissioned by CCGs, three said they are commissioned by both CCGs and NHS England, and two said they are commissioned by NHS England. Four respondents were unsure who commissioned the services at their Care Centre. The Care Centres/Networks in Northern Ireland and Wales are commissioned by their local Health and Social Care Trust and local Health Boards, respectively.

Figure 7: Who is responsible for commissioning services at your Care Centre?

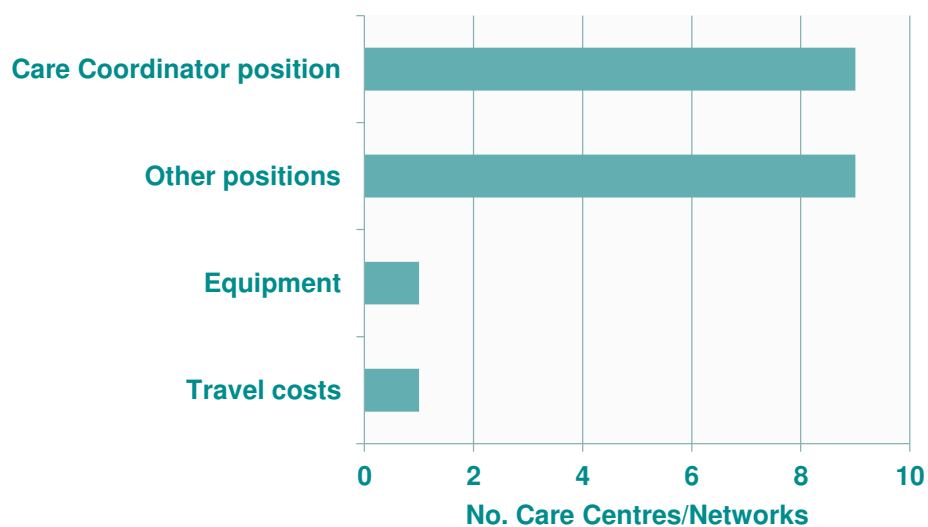


Care Centres/Networks are funded in collaboration between the MND Association and NHS, with some also funded partly by individual donations. Thirteen of the Care Centres/Networks from the

call for evidence receive some form of funding from the MND Association, with only one respondent saying that their Care Centre did not receive any funding from the MND Association. Funding from the MND Association is generally through 4-year grants. Four of the Care Centres/Networks receive funding from an NHS Trust (England), Health and Social Care Trust (Northern Ireland), or Health Board (Wales). Four of the Care Centres/Networks receive funding from CCGs, and four receive funding from NHS England.

The Association usually funds the Care Coordinator role within a Care Centre/Network (the Association itself is not a direct provider of these services), although in some cases this post has been picked up by the hospital trust and the Association may instead fund other aspects such as travel costs or other positions. As shown in Figure 8, nine Care Centres/Networks said that the MND Association funds the Care Coordinator position. Nine said the MND Association funds other positions, including a research nurse, benefits advisor, physiotherapist, dietician, respiratory technician, and occupational therapist. In some cases they MND Association part-funds positions or funds for specific services. For example, at the National Hospital the MND Association funds a 0.1 WTE dietician to provide a monthly MND PEG clinic. At the Preston MND Care Centre the MND Association funds a 0.2 WTE respiratory technician, 0.2 WTE physiotherapist and 0.4 WTE OT.

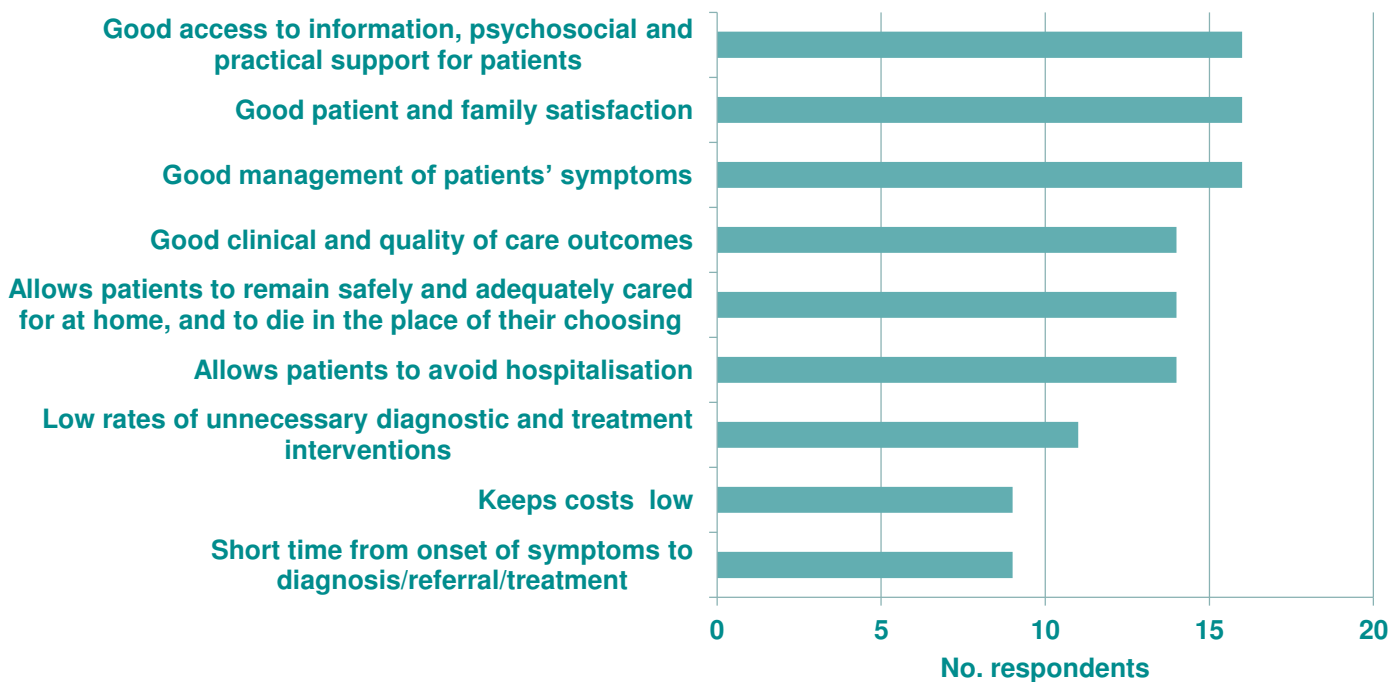
Figure 8: Which of the following does the MND Association fund?



Outcomes

Respondents were asked what they perceive to be the main benefits of the Care Centre. The most commonly stated outcomes were good access to information and support for patients, good patient and family satisfaction, and good management of patients' symptoms.

Figure 9: What do you perceive to be the main benefits of the Care Centre?



Respondents were asked if there are any aspects of their Care Centre that they think should be replicated elsewhere. Some commented on the MDT approach and the different clinics they hold, such as the newly diagnosed MND clinic in Liverpool and the joint NIV/MND clinics in Bristol. Others commented on the good links between different services. Other aspects that respondents thought should be replicated elsewhere included Skype clinics, access to research, access to psychology, and the ability to offer home visits by the MND Care Centre Coordinator/MND specialist nurse.

Challenges and areas for improvement

Respondents commented on some of the challenges that the Care Centres face, and general challenges in providing care for people with MND. The biggest challenges were around resources and funding of Care Centres. Respondents commented that there are not enough clinics, staff, and time to develop the service. In particular, some commented on the lack of resources for community teams as well as their lack of knowledge. One respondent also commented that there is a lack of specialist MND knowledge among community teams. Difficulties with social care funding, Continuing Healthcare and financial support to patients, and access to good care at home were also highlighted. Some respondents commented on the speed and delays in care, notably delays accessing equipment such as communication aids and adaptations.

“We are often faced with having to provide care and support which should be provided by community teams, which unfortunately community teams are unable to provide due to time, resources etc.”

Other challenges included poor integration between health and social care and a lack of continuity of care. Respondents subsequently commented on what aspects of the Care Centre they would like to improve. These included:

- Increased awareness of the Care Centre
- Longer clinic appointments and larger spaces for clinics to be held in, as well as providing more outreach clinics
- More staff/reduced caseloads so that patients get more individual attention
- Having a central base for the network (respondent from a Care Network)
- Admin support for Care Centre/Network coordinators
- Undertake more audits/reviews to improve service development
- Offer more advice and support regarding benefits
- Greater provision of psychological support

Oxford MND Care and Research Centre

Background

The Oxford MND Care and Research Centre is based in John Radcliffe Hospital and opened in 2002. It is one of 16 MND Care Centres throughout England. The Care Centre covers the Oxford area but also receives referrals from all over the UK, and in 2011/12 received 318 patients, 133 of which were new referrals. The clinic is run by two honorary consultant neurologists, both with over 10 years' experience specialising in MND, who are employed by the University of Oxford but hold honorary contracts with Oxford University Hospitals NHS Foundation Trust. In addition there is a Care Centre Coordinator who is fully funded by the MND Association.

This case study focusses on the Oxford MND Care Centre but will also how this interacts with local services throughout Oxford and the wider Thames Valley area.

The care process

Referrals to the MND Care Centre are made once there has been a diagnosis of MND. In Oxford and nearby areas the diagnosis is made by any neurologist, and most of the time this is not a neurologist specialising in MND. An estimated three quarters of MND diagnoses are done at a district general hospital. Once diagnosed, most neurologists would then refer the person with MND to the Care Centre and those who don't would likely refer the person with MND to a specialist nurse in the community. Referrals are also often made by specialist neurological nurses in the community who may have already had contact with the patient.

In many cases people with MND choose to attend the Care Centre to receive a second opinion or confirmation of their diagnosis, and many also attend specifically asking to take part in research and clinical trials. However, one of the participants in the focus group noted that some people with MND may be initially disappointed that there are no ongoing clinical trials at the time and therefore may not attend the Care Centre. In other cases people with MND may mistakenly assume that if they do not attend the clinic then they will not be asked to take part. All patients who express an interest in taking part in research are kept on record and are assessed for eligibility when new projects arise. Discussions from the focus group also highlighted that some people with MND are put off from attending as they would rather not see other people with MND, and how the condition deteriorates. As such, the Care Centre has separated the new patients' clinic from the follow-up clinic and newly diagnosed people, as well as those attending for the first time, may also request to wait in a separate waiting room from other first-time visitors.

Oxford MND Care and Research Centre

Inputs

Investment

- ✓ **Funding:** £210K MND Association grant from 10/14 – 10/18

Key staff

- ✓ 0.67 MND Care Centre Coordinator
- ✓ 0.25 Sleep and Ventilation Nurse
- ✓ 0.4 MND Occupational Therapist
- ✓ 2 x MND Neurologists/Care Centre directors

Annual staff cost: **£100,270**

Other staff

- ✓ Dietician
- ✓ Clinical Neuropsychologist
- ✓ Consultant gastroenterologist
- ✓ Enteral feeding nurse practitioner

Facilities

- ✓ Office space at John Radcliffe Hospital
- ✓ Travel allowance (for MND Association grant period): £5,000

The service

Caseload

- ✓ 318 patients on caseload (2011/12)
- ✓ 133 new referrals (2011/12)
- ✓ 185 follow up (2011/12)

MND services

- ✓ Weekly MDT MND clinic
- ✓ 50 home visits by Care Centre Coordinator in 2011/12 (20 patients seen at home)
- ✓ 15 multidisciplinary home visits in 2011/12 (15 patients seen at home)
- ✓ Family and friends support group every 2 months

Activities

- ✓ Steering group meetings: 2 per year
- ✓ Annual study day
- ✓ Frequently host visitors to the clinic for educational purposes

Outcomes

For people with MND

- ✓ Short waiting times: Average waiting times is 2 weeks – improved from previous audit
- ✓ Avoids unwanted hospital admissions (anecdotally from professionals)
- ✓ Provides holistic care
- ✓ Minimises the number of visits/appointments
- ✓ Higher levels of patient and care satisfaction: 89% of patients met standard of care – improved from previous audit
- ✓ More clinical time with consultants
- ✓ Anticipates problems and identifies needs/issues early on
- ✓ Able to take on higher risk PEG cases and reduce the risk of complication

For professionals

- ✓ Positive staff feedback on MND clinic
- ✓ Good communication and coordination of care

Figures obtained from 2 year progress report (2012) and MND Association grant application (2014).

MND clinic

First-time visitors, or those asking for a second opinion, will have an initial consultation with one of the MND neurologists, who will go over the patients' symptoms and perform a neurological examination. They then usually meet the Care Centre Coordinator who will carry out additional assessments. At subsequent visits people with MND have the opportunity to see an OT, physiotherapist, dietician, SLT, and neuropsychologist. People with MND also have the opportunity to see an MND Association Visitor during the clinic. After seeing the patient, a clinic letter will be sent out to the patients' GP, and the Care Centre Coordinator will make onwards referrals depending on what the person is presenting. For those who live outside of Oxford referrals will be made to the community specialist nurses throughout the Thames Valley area, that is, if the person with MND had not already been seen by their local specialist nurse. Patients who live in or around Oxford may be referred to local teams, such as neuro community nurses and community matrons for more short-term crisis situations. Some may be solely seen to at the Care Centre.

In addition to the clinics, the Care Centre can offer home visits for those who live locally, and the number and frequency of home visits depends on the individual patient. These can involve individual members of the team (often the Care Centre Coordinator) visiting a patient on their own or multidisciplinary home visits, known as 'Safari Visits', whereby two or more professionals visit a patient at home. Safari Visits are joint visits often carried out by the Care Centre Coordinator and OT, but can also include palliative care nurses from the local hospice - Sobel House Hospice - as well as other therapists and specialist nurses. Safari Visits tends to be only for patients with complex cases who require a MDT approach and each patient has on average 5 complex issues which need addressing. There have been some instances where the OT from the Care Centre has done joint visits with therapist/nurses in neighbouring areas, such as in Milton Keynes, although these would only be for very complex cases. The Care Centre increasingly offers Skype consultations which seem to meet patient and carer satisfaction, however to date there has not been a large uptake of this. One participant noted that Skype may sometimes be a poor medium for having difficult conversations, for example around end of life. In addition, not all patients may be able to access or use Skype. However feedback from patients was that they value this alternative and provides them with reassurance that they can keep in contact with the Care Centre in-between clinics or that they can contact somebody if they are unable to attend a clinic.

Every new patient who attends the clinic is offered the opportunity to attend Sobel House Hospice and regular and routine involvement with the hospice is encouraged from the start. Although patients are unable to access palliative care services during the clinic, one participant stated that palliative care is covered to an adequate standard by the MND neurologists. The Care Centre holds joint meetings with palliative care team and representatives from both attend shared workshops and conferences so there is a lot of collaboration and learning between the two disciplines. Palliative care involvement differs across the Thames Valley area. In some areas patients are referred to palliative care as soon as they have been diagnosed.

Care coordination

The Care Centre Coordinator takes a lead role in care coordination for patients who live locally, and will act as the main contact for patients and health professionals alike, including the palliative care team at the hospice. For people with MND who live outside of Oxford but attend the Care Centre, the local specialist nurse will take on responsibility for care coordination. For example, the Neurological Conditions Clinical Specialist in Milton Keynes will act as the main contact and coordinator for people with MND who live in Milton Keynes but who attend the Care Centre. There are strong links between the Care Centre Coordinator and neurological specialist nurses throughout the Thames Valley area, all of whom attend a monthly meeting to discuss MND. People with MND are able to access the Care Centre but maintain access to well-established and experienced local service in-between clinics, and the Care Centre makes it very clear to patients that they are not substituting for local care. Focus group participants expressed the importance of having a local, single point of contact (the specialist nurses) that can link in with Care Centre.

“You’ve got your specialist Care Centres but then you need to have your local satellites. You don’t want to replace one with the other”

Focus group participants highlighted very strong working relationships and good communication between the Care Centre Coordinator and specialist nurses in the Thames Valley area, however one area for improvement would be to ensure patients’ clinic letters are sent out to the relevant specialist nurse. A reason for not always doing so is that the Care Centre may not always know who the patient is seeing locally. It was suggested that the Association Visitors could ask patients at the clinics who they would like their clinic letter to be sent out to, so that all those involved in the patients care are informed.

What works well?

Participants during the focus group outlined that one of the main pieces of feedback they receive from patients is that patients are able to have a lot more one-to-one time with the consultant neurologists, more so than they would if they were to see a general neurologist at a district hospital. In addition, patients are seen by neurologists with a lot of experience in MND, something which the Care Centre is very much committed to keeping.

A key benefit of the Care Centre model is that people with MND have access to a range of services and professionals at the clinic, providing a one stop shop approach. People with MND and professionals are seen holistically and are able to discuss and sort out multiple issues in one go with multiple referrals made at once. The focus group participants also said it minimises number of visits and appointments that patients need. Importantly, the focus group participants said the clinics allow them to anticipate problems before they arise, for example respiratory problems and the need to insert a PEG, and keeps them one step ahead. They said this ultimately reduces unwanted hospital admissions, although it would be difficult to prove that hospital admissions are avoided using Hospital Episode Statistics data.

In conjunction with the main MND clinic the Care Centre also has a nutrition clinic which is run by the Care Centre Coordinator. During this clinic the Care Centre Coordinator will assess patients who require a PEG and will immediately flag any high risk cases. These will then be passed on to a gastroenterologist, through a 'goodwill arrangement', who will further assess whether a PEG can be inserted. This red flag system has meant that they are able to identify any high risk patients early, and thus take on more high-risk patients. A concern is that the involvement of the gastroenterologist is not funded and purely down to goodwill and, as such, this arrangement with the gastroenterologist would likely be lost if he were to go.

Lastly, participants highlighted the benefits of home visits and Safari Visits as it allows the team to provide multidisciplinary care to those unable to attend the clinic, or to those who have urgent complex issues. The 2nd year progress report highlighted that Safari Visits have been successful in resolving multiple complex issues and in one visit has been adequate to resolve the majority of problems, with subsequent issues being resolved over the phone.

Challenges and areas for improvement

An issue identified was that the Care Centre is not properly commissioned and funded, and the input of most of the key individuals is not funded by the NHS. As such, much of it is run on goodwill which raises concerns over uncertainty in the future. For example, both MND neurologists are paid for by the University of Oxford and if they were both to leave then they would not necessarily be

“How do you know where to go if we don't really know who's got the money and who's commissioning the service?”

replaced. Generally speaking the focus group participants were unsure as to who commissions MND services, and whether it comes under specialist commissioning. This in turn impacts on their ability to develop and improve services, as they are not sure who to target.

An issue across the Thames Valley area is the availability of some specialist services and equipment. For example in West Berkshire people with respiratory problems can be seen by local services in West Berkshire, but cannot be discharged with a ventilator and instead have to be transferred to Oxford to get one, which is sometimes too difficult to do as the patient may be unable to lie down in an ambulance. In one recent case a respiratory nurse was able to collect a ventilator from Oxford and take it to a patient at the Royal Berkshire Hospital, however there is nothing formally in place to deal with these crisis situations.

Some of the participants at the focus group highlighted issues with SLT. In Oxfordshire the current wait for an urgent appointment/visit is 12 weeks as there is a shortage of staff. In other areas SLT services were said to be slow at responding to referrals and would discharge patients after each appointment/visit. However this varied across the Thames Valley area, with some noting that they were very responsive and would do urgent swallowing assessment within days.

An issue with the Care Centre is the distance some people may have to travel, as well as difficulties parking. These combined may make visiting the Care Centre a full-day outing.

Other comments

The Care Centre plays a key role in education and training around MND care and holds annual study days. These have focussed generally on MND care as well as more specific areas such as palliative care. More informal education take place across the Thames Valley area, depending on what the need is locally. The Care Centre also plays a key role in up-skilling individuals and acts as a source of advice and information about MND and MND care throughout the region.

Lastly, the Care Centre is an established research centre with both MND neurologists part of the Nuffield Department of Clinical Neurosciences at the University of Oxford. They are a major centre for therapeutic trials and also offer patients the opportunity to participate in genetic and biomarker studies.

South West Peninsula MND Care Network

Background

The South West Peninsula MND Care Network was set up in 2008 and covers Devon, Cornwall and the Isles of Scilly. As of August 2014 the Network had a caseload of 130 people with MND, receiving 85 new referrals between August 2013 and August 2014.

At the heart of the Network is a Care Coordinator who provides a single point of contact for people with MND and professionals alike. The Care Coordinator is a Band 7 nurse employed by Plymouth Hospital Trust and is based in the Department of Neurology at Derriford Hospital, although the large majority of work is out in the community. The Care Coordinator plays a pivotal role in linking patients with MND to multidisciplinary teams, community services, and the MND Association. She liaises with 5 district general hospitals and the 21 consultant neurologists across the Peninsula who diagnose and support people with MND. The Care Coordinator is supported by an administrative assistant who is also employed by Plymouth Hospital Trust and based at Derriford Hospital. Additionally there are 3 co-directors who are consultant neurologists based at Torbay Hospital, Royal Cornwall Hospital, and Derriford Hospital. Currently the Network is funded by the MND Association up until August 2016.

This case study focusses on the whole Peninsula MND Care Network, but additionally focusses in-depth on the Torbay area from telephone interviews carried out with members of the MDT.

The care process

People suspected of having MND are referred to a general neurologist for diagnosis. If diagnosed, a referral letter is then sent to the Care Coordinator, who will attempt to make contact with the diagnosed person with MND within two weeks of receiving referral. The Care Coordinator will make a home visit which may last between 2 and 2.5 hours. At this visit they will go over the person's past medical history, diagnosis, symptoms, benefits, and perform an assessment of the person's living conditions and social situation. She will talk through the MND Association and the services and support available, offer to contact the RCDA, and will provide the MND Association's 'Living with MND' pack. At this initial meeting the Care Coordinator also discusses the Dementia and Neurodegenerative Diseases Research Network (DeNDRoN) and asks if the person with MND would like to be signed up, giving them the option of being involved with future research. DeNDRoN is a clinical research network that supports the set up and delivery of clinical research in the NHS in a range of diseases including MND.

After meeting a newly diagnosed person with MND, the Care Coordinator will write a detailed report which is copied to the patient, their GP, and any other professional involved in their care. The letter is also copied to the RCDA, provided consent is given. The Care Coordinator will then send out onward referrals to local community teams all of which are broader neurological teams with no specific MND focus. Similarly, there are various general neurology clinics across the Peninsula without a specific MND focus.

Peninsula MND Care Network

Inputs

Investment

- ✓ **Funding:** £289,681MND Association grant from 08/12 – 08/16 and £10,000 DeNDRon grant
- ✓ **Set up costs:** £1,000 (from MNDA grant)

Key staff

- ✓ 1 x FTE Network Coordinator
- ✓ 1 x 0.8 FTE Administrative Support
- ✓ 3 x Network Co-directors (Consultant neurologists each contributing 0.33 Programmed Activities per week)

Annual staff costs: **£80,571**

Other staff

- ✓ 1 x FTE RCDA

Facilities

- ✓ Office space at Derriford Hospital
- ✓ Travel expenditure: £1,360 (11,528 miles at 11.8p/mile)

The service

Caseload

- ✓ 130 PwMND on caseload (as of 08/14)
- ✓ 85 new referrals (2013/14)

MND MDTs

- ✓ 7 MDTs across the Peninsula
- ✓ Approx. 90% of PwMND managed via MDTs
- ✓ Coordinator attended 32 MDT meetings and 8 SIG meetings
- ✓ Monthly MND MDT clinic at Derriford Hospital
- ✓ Cornwall telephone/email clinic

Activities

- ✓ 128 home visits, 1567 phone calls, 3997 patient-related emails
- ✓ South West MND Conference
- ✓ GP/Professionals survey
- ✓ MDT survey

Outcomes

For people with MND

- ✓ Timely contact by Network Coordinator - 98% had first contact within 14 days of referral
- ✓ High satisfaction with Network Coordinator and home visits, and waiting times for home visits
- ✓ 57% of deaths at family, residential, or nursing home. 32% of deaths at hospital
- ✓ Improved symptom management and quality of care, and reduced avoidable hospital admissions (anecdotally from professionals)

For professionals

- ✓ Positive feedback with Network Coordinator
- ✓ Improved coordination and communication
- ✓ Single point of contact
- ✓ Reduces workload of other professionals

Figures obtained from 2013/14 report

Torbay

In Torbay there are a number of teams working together to provide care for people with MND, most of which are based in the community. Referrals are usually from a neurologist, GP, or sometimes the Care Coordinator, but other specialists may recommend referrals. For example, in cases where a SLT may see a patient they suspect to have MND, they will then contact the GP and ask for that patient to be referred to neurology. There is also a lot of cross-over between the teams and if they come across other issues outside of their discipline then they will contact those who need to know. For example, sometimes the community neurology physiotherapists would recommend that SLT or OT be involved, and vice versa. An overview of some of the services available for people with MND is provided below:

- There is a generic OT service, which comprises of two teams: a triage team and a long-term team. All people with MND are referred to the triage team, who will then prioritise patients according to need and will then deal with urgent, high risk cases, much of which is focussed around end of life care, rapid deterioration, transferring people out of bed or off the toilet. They then have a long-term team which will provide long-term interventions and adaptations.
- There are 4 community SLTs who primarily see people with MND in their homes but also run generic SLT clinics that people with MND may attend.
- There is a team of community neurology physiotherapists who primarily see people with MND in their home. The neurology physiotherapists will often do joint visits with the OTs when working with complex people with MND to identify the most appropriate intervention.
- Palliative care for people with MND is arranged across 3 settings, each with a specialist palliative care consultant: one is primarily based in the community, one in the hospital, and the other in an inpatient unit at Rowcroft Hospice.

As highlighted, there is no MND specialism in the Torbay area aside from the Care Coordinator. Some teams have a particular neurological focus, such as neurology physiotherapy team, however others are generic mainstream services.

In many cases after each professional sees a person with MND they will send out an email to all MDT members who the person is also seeing. If appropriate they will also send out an email the patient themselves.

Multidisciplinary teams

MDT meetings are held throughout the region in East Cornwall, Cornwall, Torbay, Plymouth, Exeter, South Hams, and North Devon. They vary slightly in each area, in terms of who attends, the location of the meetings, and the duration, but overall the meetings are held regularly and are attended by representatives from different disciplines across catchment area. Each meeting is facilitated by the Care Coordinator who afterward circulates minutes of the meeting to all relevant

professionals. The Care Coordinator also transfers a copy to patient notes. At the meetings each person with MND is briefly discussed to ensure appropriate disciplines and professionals are involved and up-to-date, make referrals, discuss appropriate timing of interventions such as PEG and NIV, and identify any potential problems to prevent emergency admissions to hospital. The meetings play a key role in care coordination and help clarify who is leading on what aspect of care.

The person with MND does not attend the meeting, but a key professional at the meeting is identified to feed back to the person. The meetings also provide a regular forum for staff discussion and act as a staff supervision/support medium. The MDT meetings are well attended and feedback is positive. Individuals report they have clearer information about the people with MND in their area, increasing knowledge about MND (e.g. the importance of referring for PEG early before respiratory function is compromised) and they have greater confidence of who to refer to thus streamlining communication.

Torbay

In Torbay there is a MDT meeting every 2 months based at Rowcroft Hospice. The meeting is divided into 2 groups according to the patients' geographical location as some MDT members only cover certain areas, thus this setup means some members do not have to attend the whole meeting. Each MDT meeting is usually attended by the Care Network Coordinator, consultant neurologist, consultant in palliative care, nurse consultant in domiciliary ventilation, nurse specialist in enteral feeding, dietician, SLT, community neuro physiotherapist, and OT. One representative from the neurology physiotherapy and SLT teams will attend the MDT meeting but who that is may vary and they often take it in turn to attend, depending on who has the most MND patients on their caseload at the time.

The meeting is patient focused and they talk through what is happening for each patient. Whoever has had contact with the patient will provide an update on the current status of the patient's condition and the care they have received, as well as any current needs or concerns. This varies from patient to patient and those with more stable conditions will be discussed briefly. They also update on new referrals and deaths and will talk about the cause of death and whether there were any issues that the MDT could learn from to avoid in the future. As with all MDTs in the region, the Network Care Coordinator plays a pivotal role in the Torbay MDT meetings by carrying out all the admin work associated with it, such as sending out minutes of the meeting to all professionals. Other members of the Torbay MDT commented that they don't individually have the admin time and that the MDT and MDT meetings couldn't survive without the input from the Care Coordinator.

Specific teams may also have individual MDT meetings or may informally discuss patients as a group, particularly with regard to complex and rapidly deteriorating cases. For example, the community OTs, SLTs, and neurology physiotherapists, who collectively form the community neurology team, have weekly MDTs for all their patients with a neurological condition. Each MDT meeting will have a specific focus and will vary each week. On the whole, they usually have a specific MDT meeting for their MND patients once a month.

What works well?

Interviews with members of the Torbay MDT highlighted the importance the Care Coordinator plays. They noted how the Care Coordinator is very responsive and provides crucial links between different teams and services. She also acts as a key source of information and advice and is the key point of contact that MDT members and patients can turn to. Additionally, the Care Coordinator holds study/information days for health and social care professionals outside and within the MDT which are useful for in an educational aspect but also provide a place to share concerns and discuss areas for improvement.

“The Care Coordinator role is very valuable. She has links with all the different services and brings everyone in”

A crucial aspect of the Peninsula MND Care Network is the MDT meetings across the region. Members of the Torbay MDT highlighted the importance of these meetings as they keep everyone up-to-date on people with MND in the area and provide a space to collectively discuss care, make referrals, identify any problems, and share information and news related to MND care. A major benefit of these meetings is also that they allow working relationships to form, maintain and strengthen links between different teams, and allow everybody to understanding what each other’s role is and what challenges they face. This aspect was said to be equally as important as discussing people with MND. Although the MDT meeting is strongly valued by health and social care professionals, one interviewee commented that one of the problems is that people with MND can change significantly in-between MDT meetings. As such, there is a lot of contact between MDT members outside of the meeting. For example, if somebody comes across a complex patient or a patient whose condition has deteriorated rapidly then they will contact members of the MDT to inform them of this, and copy the team into referrals.

*“The MDT has really made it easy. If you see somebody with MND and they have an issue then you know who to call” –
Consultant, palliative care*

Challenges

One of the main challenges that the Peninsula MND Care Network faces is the large geographical area it covers. This is particularly challenging for the Care Coordinator as, despite her flexible use of time, a large portion is spent travelling to and from home visits which subsequently impacts on clinical and administrative time. For example, a visit to see a person with MND in distant areas can take up a whole day. As such, the Care Coordinator and members of the MDT expressed an interest in obtaining another Care Coordinator and splitting up the geographical area so that each Care Coordinator would cover a smaller area which would in turn reduce travel time and allow more home visits and more clinical time with patients.

Discussions with members of the MDT identified that there are potentially a huge amount of health and social care staff to work with and that the different areas across the Peninsula all have different organisational structures, staffing, and processes. Even within MDT areas there are a

number of professionals involved from different settings, which can make communication an issue. Differences in IT systems were also highlighted as an issue, both across and within MDTs. For example, in Torbay the palliative care team have a shared electronic record between the hospital, inpatient unit, and community team, and the OTs and neurology physiotherapists have a separate shared system, however there is no shared system service-wide with all teams providing care for people with MND.

Participants highlighted issues with future care planning and the funding issues and difficulty obtaining equipment at the right time, for example communication aids such as Eye-Gaze. Other issues highlighted by participants included uncertainty regarding the commissioning of the Care Network and current financial constraints within health and social care budgets.

Other comments

Some of the MDT members expressed their opinions of the Care Centre and Care Network models of care. They acknowledged the benefits of the Care Centre/ MND clinic approach as a one stop shop where people with MND can see multiple professionals in one day. One of the MDT members noted that she previously worked as a registrar in palliative medicine elsewhere in the England where they held an MND clinic. She commented on the usefulness of this set up particularly as it allowed patients to see professionals regularly and allowed them to form relationships and become familiar with each other, many months before

“I think we’ve made the best of the geography and resources we’ve got” –
Consultant, palliative care

“The idea of having a MND centre is great but it would mean patients would have to travel far. Later on in the condition they can’t do this” –
SLT

patients were admitted for palliative care. Although recognising the benefits of such clinics, some of the participants however noted the challenges that arise with this model of care and the difficulties replicating it in the Peninsula due to the size of the area and the travel requirements. They commented on the need for people with MND to be seen in their homes in the later stages of their condition.

Conclusions

The call for evidence, interviews, and case studies identified a variety in the models of care for people with MND. They varied in the size and composition of MDTs, the location of services, and the key individuals involved. From this project it was not possible to cluster together all arrangements identified into distinct and narrowly defined models of care, however broadly speaking we identified 5 common, and somewhat loosely grouped, models of care for people with MND:

- **Model 1 – MND Care Centres:** These are largely funded by the MND Association and are MND specialist centres which run multidisciplinary clinics for people with MND. These are based in neurology/neuroscience departments of district general hospitals and offer a holistic package of care. Many of these centres are able to perform specialist procedures such as inserting gastrostomies and setting up non-invasive ventilation, and many are also research centres. All MND Care Centres have a Care Centre Coordinator who acts as the single point of contact and who in many cases offers home visits. An example is provided in the Oxford case study.
- **Model 2 – MND Care Networks:** These are similar to the MND Care Centres but not all are fixed in a set location. They generally cover larger, rural areas and utilise clinics and outpatient services across the area. Much of the care is offered in the community. An example is provided in the Peninsula case study.
- **Model 3 – Non-MND Association specialist clinics:** These are MND clinics outside of an MND Care Centre. In some cases they may be outreach clinics and may have input from an MND specialist nurse or neurologist from an MND Care Centre, but in other cases they are completely independent of an MND Care Centre. They offer the same multidisciplinary approach as MND Care Centres whereby people with MND can attend and can be seen by multiple professionals, however they are not involved in research and usually cannot perform specialist procedures. These clinics may take place in district hospitals, community hospitals/centres, and hospices. They are generally led by a consultant, either in neurology or palliative care, and have MDT meetings in conjunction with the clinics. An example is provided in the West Suffolk case study.
- **Model 4 – Community-based teams with a specialist care coordinator:** These are primarily based in the community and are led by specialist nurses and therapists. They link in with local hospices and district hospitals, as well as nearby MND Care Centres. The key feature of this model is the presence of a care coordinator, who is usually a clinical nurse specialist or has a background in nursing. Importantly, the care coordinator is not just a key point of contact, but plays an active role in coordinating care. These are similar to the MND Care Centre/Network Coordinators as they have experience in MND, but they do not focus solely on MND. In many cases they cover other rare and rapidly progressing neurological conditions. These models often have a MDT, sometimes for rare and

rapidly progressing neurological conditions and in some cases specifically for MND. An example is provided in the Milton Keynes case study.

- **Model 5 – Mixed teams *without* a coordinator role:** These have been loosely grouped together and may vary considerably, with varying input from hospitals, hospices, and community teams. Generally speaking they have less MND specialism than the previous models, however most still have a MDT for MND or rare and rapidly progressing neurological conditions. They may also have some form of an MND clinic, although this is not multidisciplinary. Most are based primarily in the community, similar to Model 4, and may have a key point of contact or multiple points of contact across different teams. However, the key distinction with Model 4 is the absence of a specific care coordinator and, as such, they may face issues with care coordination. Examples are provided in the Bromley and North Wales case studies.

What makes an effective model of care for MND?

This research identified a number of aspects and factors that contribute to an effective model of care for MND, and which many participants thought should be best-practice and replicated elsewhere. The most commonly reported, and important, are outlined below.

The call for evidence, interviews, and case studies outlined the many benefits of having **MND multidisciplinary teams**. They keep professionals up-to-date, inform them of newly diagnosed people, and identify issues that need to be addressed. By doing this, they contribute to care coordination and ensure care and care planning is patient-centred and multidisciplinary. In addition to this, they facilitate joint working between different teams and services, and relationships between professionals.

Both patients and professionals alike highlighted the benefits of having **MND-specific clinics**, primarily as they offer a one stop shop for people with MND. There is no rule as to where these clinics should be held, whether in a district hospital, community hospital, or hospice, as each has its own advantages. The importance lies on who attends the clinics, and the variety of services and professionals on hand. Accessibility for people with MND must be considered. This research has also highlighted some virtual clinics, and the benefits these may bring to people with MND as well as health and social care professionals.

The research identified the importance of having **local community services** that can provide sufficient care at home: Despite the benefits of attending a Care Centre or MND clinic, the reality is that many people with MND require care in their own home, and others may simply prefer not to attend a Care Centre or clinic. Being able to access high quality services in the community, from a range of disciplines, is paramount. Many Care Centres are able to offer home visits, and people with MND and professionals highlighted the importance of providing specialist MND services at

home, either by an MND specialist nurse or a broader neurological nurse, such as for rare and rapidly progressing neurological conditions. The Oxford MND Care Centre and Milton Keynes case studies show how Care Centres and local services can interact and allow people with MND to attend a Care Centre whilst also being sufficiently cared for at home. People with MND should have the choice to be cared for in both settings.

Lastly, this research found that **care coordination** for people with MND varies greatly. The Bromley case study, in particular, highlights poorly coordinated care and the difficulties navigating the system. MND is a condition that requires input from multiple disciplines, and as such it is crucial that care is properly coordinated for people with MND. Care coordination is required to proactively manage people with MND, anticipate problems early on, and avoid unwanted crises. However, it is not simply enough to provide people a list of contact details. MDTs contribute greatly to care coordination, as do MND clinics, but in many cases it is necessary to have a key point of contact who can liaise between services. Many patients and professionals have highlighted the need for a care coordinator, and those who have come across an MND Care Centre/Network Coordinator or the Neurological Conditions Clinical Specialist in Milton Keynes have outlined the benefits of this. These roles impact greatly on people with MND as they are a source of information and advice, which is hugely important for a newly diagnosed person. They also provide ongoing emotional support, organise care, reduce stress, identify issues and needs, and importantly provide a continuous point of contact for people with MND and their families. It also impacts on professionals by similarly providing a point of contact and advice, improving communication and links between different services as well as understanding of others' roles, facilitating coordination of care, and reducing some of the workload of other professionals. Many professionals have highlighted that MND specialism and experience is essential for this role, but the Neurological Conditions Clinical Specialist in Milton Keynes is a good example to show that this role does not need to be solely confined to people with MND. The Coordinator for Rare and Rapidly Progressing Neurological Conditions in Hertfordshire and Clinical Nurse Specialist for Rare Neurological Conditions in West Berkshire further demonstrate the impacts on quality of care, satisfaction, and the cost-effectiveness and cost-savings through, for example, reduced avoidable hospital admissions.

Appendix 1 – Interview participants

Role	
Regional Care Development Advisor	East Anglia
Regional Care Development Advisor	Hertfordshire and Essex
Regional Care Development Advisor	North and West London
Regional Care Development Advisor	South London
Regional Care Development Advisor	North Wales
MND Association Regional Manager	South England
Care Network Coordinator	MND Association Care Network
Care Centre Coordinator	MND Association Care Centre
Care Centre Coordinator	MND Association Care Centre
Care Centre Coordinator	MND Association Care Centre
MND Specialist Nurse	MND Association Care Centre
Neurological Conditions Clinical Specialist	Community Neuro Team
Clinical Lead Nurse	Community Neuro Team
Palliative Care Specialist Nurse	Hospice
Palliative Care Consultant	Hospice
Palliative Care Consultant	Hospice
Palliative Care Consultant	Community Palliative Care Team
Neurologist	Altnagelvin Area Hospital
Team Leader	Community Neuro Rehabilitation
Occupational Therapist	Community Rehabilitation

Appendix 2 – Case study activities

Case study	Activities undertaken
Bromley	<p>1 x focus group with professionals: 5 attendees</p> <p>1 x telephone interview (professional)</p> <p>2 x telephone interviews (carers)</p>
North Wales	<p>2 x telephone interviews (professionals)</p> <p>3 x telephone interviews (people with MND)</p> <p>Email survey of 2 people with MND</p> <p>Targeted online survey (professionals): 8 respondents</p>
Oxford MND Care and Research Centre	<p>1 x focus groups with professionals: 11 attendees</p> <p>2 x telephone interviews (professionals)</p> <p>1 x face-to-face interview (people with MND)</p> <p>Email survey of 2 people with MND</p>
Milton Keynes	<p>2 x telephone interviews (professionals)</p> <p>2 x telephone interviews (people with MND)</p>
Peninsula MND Care Network	<p>8 x telephone interviews (professionals)</p>
West Suffolk	<p>1 x focus group with professionals: 5 attendees</p> <p>4 x face-to-face interviews (people with MND and carers)</p>

Appendix 3 – Findings from the evaluation of models of care in Scotland

NHS Ayrshire & Arran provides a comprehensive service for patients with motor neurone disease. The review panel noted a detailed motor neurone disease patient pathway is in place within the region which covers all aspects of the illness including links to specialist palliative care and respiratory medicine, gastrostomy services and social services. However, we could not find additional information and specifics of this patient pathway.

- Patients diagnosed with MND in Ayrshire are seen at a multi-disciplinary clinic at the Douglas Grant Rehabilitation Centre, Ayrshire Central Hospital. This service provides access to a Consultant, MND Regional Care Specialist as well as input from Speech and Language Therapy, Dietetics, Physiotherapy, Occupational Therapy and Psychology
- Patients attending the MND clinic have a medical assessment and are reviewed by appropriate members of the team. These can include a neurophysiotherapist, occupational therapist, speech and language therapist, dietitian and the regional MND Scotland Nurse. At the end of each clinic the team discusses the needs of the patients and the appropriate treatment. The timing of each appointment is determined by the patients' clinical needs – patients whose condition is changing quickly are reviewed sooner and patients whose situation is stable are reviewed routinely. Clinic appointments are no more than four months apart. However most patients are reviewed more frequently than this
- The review panel noted the high quality multidisciplinary care provided to patients with motor neurone disease within the NHS board area.
- The review panel also noted that the NHS board has a clear commitment to continuing development of the service and ensuring that the needs of patients with motor neurone disease and their families are met.

NHS Dumfries and Galloway care pathway exists for patients with motor neurone disease, and this pathway was revised following feedback from staff and patients in July 2011.

- The members of the motor neurone disease subgroup developed the pathway, which included representation from specialist palliative care, respiratory medicine, gastrostomy services and social services. This facilitates close working and strong links between the relevant services. NHS Dumfries and Galloway has strong links with the Glasgow based West of Scotland clinical nurse specialist for people with motor neurone disease as well as a McMillan Nurse / Specialist Palliative Care Nurse
- The review panel also noted dedicated GP input to pathway development. The pathway is available in the local palliative care guidelines and the medical

handbook, and is also to be published on the neurological services section of the NHS board's website. However, to date, it has not been made available on the website

NHS Forth Valley has a comprehensive care pathway covering all aspects of motor neurone disease; however we could not find this online. There is, though, a highly detailed PEG/RIG pathway available on their website

- The care pathway was developed within the multidisciplinary motor neurone disease clinic, which runs every 8 weeks. The clinic has active input from medical and nursing staff, representatives from the community rehabilitation team, dietitians, home ventilation and palliative care. Patients referred to the clinic are reviewed by each discipline. Occasionally, a patient may prefer not to be seen at the clinic. In such cases, the specialist nurse refers the patient to other disciplines, taking advantage of the close working relationships developed through the clinic.
- The review panel encouraged that the service include prioritised timelines on the pathway.

NHS Grampian, at the time of the review panel, had well-established and clear arrangements for referral and management of patients with motor neurone disease, however had not yet clearly documented these arrangements in agreed pathways.

- Currently a draft pathway to refer people with this condition to the specialist motor neurone disease clinic following initial diagnosis. The panel also noted that this pathway did not include links to respiratory medicine, gastrostomy services, social services and specialist palliative care. However, it is clear that access to these services is in place across the NHS board area and there is strong evidence of multidisciplinary team working.
- Once the diagnosis is established early referral is made to the MND clinical Care Specialist and MND team for ongoing care, support and information. Follow up is offered in the multidisciplinary MND clinic
- When a patient attends a motor neurone disease clinic for a full review, there is input from neurology, clinical specialist, physiotherapy, occupational therapy, dietetics, palliative care medicine, and social work service. Further referral to other specialist services is arranged if necessary.
- 3-year plan highlights the need for the development of care pathways and the panel looked forward to continued progress in this area.

NHS Orkney reported very low numbers of patients diagnosed with motor neurone disease on the islands, and providing a specialist service is not viable. NHS Grampian provides the specialist motor neurone disease services through the clinical care specialist and consultant neurologist

- Assessment, guidance and advice can be delivered locally by visits, email, telemedicine, telephone or letter. NHS Grampian also provides the specialist respiratory medicine service.
- A draft motor neurone disease pathway developed by the clinical care specialists in NHS Grampian is awaiting approval, which will be adapted by NHS Orkney to suit local needs.
- The local multidisciplinary team consists of GPs, allied health professionals, nurses and the palliative care team. Strong links are in place with social services who attend the neurology subgroup and focus group meetings.

Appendix 4 – MND Care Centre/Network call for evidence respondents

MND Care Centre/Network
Belfast x 2
Bristol
Cambridge
Leeds
London - Bart's
London - King's
London - National Hospital for Neurology and Neurosurgery
Liverpool
Middlesbrough
Newcastle
Oxford⁸
Preston
Sheffield
South Wales MND Care Network x 2
Southampton

⁸ Two respondents from the Oxford MND Care Centre responded to the general call for evidence

Appendix 5 – Overview of the MND Care Centres/Networks

Care Centre/ Network	Number pwMND seen/ on caseload	Type and frequency of clinics	Source
Bart's	91 new patients, 319 follow up	7 clinics a month in multiple locations	Call for evidence
Birmingham	150 home visits per year, 368 patients seen in clinic (2008/09)	Monthly MND clinic Seven clinics per month for newly diagnosed patients 5 nurse led clinics per month for patients newly established on Riluzole Monthly therapist led clinic for newly diagnosed patients/ crisis intervention.	Grant application/ progress report
Bristol	78 (2013/14)	2 MND clinics a month Monthly joint NIV/MND clinic	Call for evidence
Cambridge	42 new patients, caseload 181 (2011/12)	Weekly MND clinic at the Care Centre Weekly clinic by respiratory unit at Papworth Hospital	Call for evidence, grant application/ progress report
King's	212	Weekly MND clinic	Call for evidence
Leeds	68 (2013)	Monthly MDT clinic Monthly nurse-led clinic	Call for evidence
Liverpool	198	Weekly MND clinic	Call for evidence

Manchester	-	Monthly newly diagnosed clinic Weekly follow-up clinics	Grant application/ progress report
Middlesbrough	168	Weekly MND clinics Twice weekly general neurology clinics for suspected MND	Call for evidence
National Hospital	180	Weekly clinic Bi-monthly advance planning clinic	Call for evidence
Newcastle	-	Weekly MND Clinic Daily Nurse telephone clinics	Call for evidence
Nottingham	40+ new referrals, 300 follow up	Weekly MND clinic Monthly nurse-led clinic	Grant application/ progress report
Northern Ireland	~115-150 (call for evidence)	3 MND clinics per month General neurology clinics every day	Call for evidence
Oxford	133 new referrals, 318 attendances	Weekly clinics Safari visits Virtual clinics	Grant application/ progress report
Peninsula	85 new referrals, 130 total attendances	Bimonthly MDTs throughout the Peninsula	Grant application/ progress report
Preston	189	3 monthly nurse-led clinics in each of the 6 hospices	Call for evidence
Sheffield	57 new referrals, 505 follow up attendances	Weekly MND clinic	Call for evidence, Grant application/ progress report
Southampton	-	Monthly MND clinic in Southampton/ Portsmouth/ Basingstoke	

South Wales

144

4 clinics a month

Call for evidence