



**Coordination of care and access to community
therapies for people with non-DMT progressive MS**

Prepared for the MS Society by ICF

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Acronyms and terminology

- **EDSS:** Expanded Disability Status Scale
- **MS:** Multiple Sclerosis
- **Neuro:** Neurological
- **Non-DMT progressive MS:** Patients who do not respond to disease modifying therapies (DMTs) and have progressive MS (i.e. their condition is progressing without improvements in symptoms)
- **OT:** Occupational therapy / Occupational therapist
- **Physio:** Physiotherapy / Physiotherapist
- **Rehab:** Rehabilitation
- **SLT:** Speech and language therapy / Speech and language therapist

Executive summary

- The desk research identified several key features of best practice in care for people with MS: MDT involvement, care coordination, community support, support for self-management, service accessibility and the need for specific care pathways for MS patients.
- The basic principles of patient pathways for both DMT and non-DMT patients with MS were similar, and in four of five case study areas the level of care offered to DMT and non-DMT patients was the same.
- However, non-DMT patients can require more support due to their level of disability and the deterioration of their health over time. They are more likely to disengage with services and would benefit from local, community based support that minimises the need to travel. No evidence was found to suggest specific or alternative approaches to care were taken for non-DMT patients.
- The case studies evidenced geographic disparities that exist in care for people with non-DMT progressive MS, including variation in the frequency of follow up appointments, the breadth of health professionals involved in core care teams for people with MS and the types of clinics and wider support available.
- Elements of best practice were reflected across the case studies: all areas had MDTs in place and offered at least some form of self-management support, and there were NHS community services for people with MS available in most areas. However, formal care coordination and use of care plans was relatively uncommon.
- Some evidence indicated that non-DMT patients were discussed less frequently in MDT meetings, as the focus was often on patients being considered for DMTs and those already receiving DMTs. Despite this, there were examples of MDT clinics where patients could access support from all relevant staff members in a single day – this is particularly valuable for non-DMT patient as reduces their need to travel to the hospital for separate appointments.
- The quality of self-management support appeared to be fairly inconsistent across case study areas, due to the differences in the health care professionals involved in MS care. Similarly, there was a need for more joined up care provision between hospital and community services.
- Care coordination was only in place in one case study area. In other areas, there were some informal arrangements but the level of patient support (both DMT and non-DMT) was more limited. However, there are many benefits of care coordination for non-DMT patients and this was evidenced in the interview with the Advanced MS Champion.

→ Background & methodology

Background and study objectives

There are different types of MS, with a variety of symptoms. For people with [progressive MS](#) specifically, symptoms of the condition get progressively worse, with few or no relapses (unlike [relapsing remitting MS](#), which involves periods of worsening symptoms that improve again). Progressive MS can be either primary or secondary: in [primary progressive MS](#) the disease is progressive from the first (primary symptoms), whereas [secondary progressive MS](#) is a stage of MS which often follows relapsing remitting MS.

A number of medications (known as [disease modifying therapies - DMTs](#)) are used to treat people with MS; DMTs can reduce the frequency and seriousness of relapses, and slow down the build up of damage caused. Most people with progressive MS are unable to benefit from DMTs and so the term '[non-DMT progressive MS](#)' refers to those with progressive MS and not on a DMT.

People with non-DMT progressive MS will need care and to be supported in other ways to manage their condition. Specifically, access to [health, social and community services](#) is important in supporting their health and wellbeing.

There is evidence to suggest that services for people with MS focus more heavily on DMTs, which results in people with non-DMT progressive MS disconnecting from such services and not receiving the necessary support they need. With this in mind, the research aimed to:

- a) identify the current approaches to coordinating care for people with non-DMT progressive MS both pre- and post-Covid, by looking at five case study areas;
- b) assess how these approaches compare with the optimum clinical pathway and other guidance on health and social care for people with MS;
- c) inform recommendations on how to improve care coordination and access to community therapies for people with progressive MS that are unable to benefit from DMTs.

Methodology

To complete the aims of this project, [desk research](#) and [interviews](#) have been completed.



Desk research

To establish the characteristics of best practice in service delivery for people with progressive MS and draw out wider contextual insights, [we reviewed 10 sources](#):

- [The optimum clinical pathway for MS](#) (The Neurological Alliance, 2019)
- [Recommendations of the GIRFT report on neurology](#) (GIRFT, 2021)
- [Progressive Neurological Conditions Toolkit](#) (NHS RightCare, 2019)
- [Neurology now](#) (MS Society, 2021)
- [Forgotten Many](#) (Thomas, Thomas and Mehta, 2020)
- [Neuro Patience – National Neurology Patient Experience Survey 18/19](#) (The Neurological Alliance, 2019)
- [Together for the 1 in 6: UK Findings from My Neuro Survey](#) (Neurological Alliance, 2022)
- [NHS Reset and Reform](#) (Thomas, Giovanni & Lawton, 2021)
- [Multiple sclerosis in adults: management](#) (NICE, 2022)
- [Multiple sclerosis Quality Standard](#) (NICE, 2016)



Case study interviews

A total of six interviews were completed:

- Five in selected case study areas in England and Scotland to provide a qualitative assessment of the extent to which best practice was reflected in the care of people with non-DMT progressive MS.
- One interview was completed with an [Advanced MS Champion](#) to consider the successes and challenges of the role, considering how it connects with models of best practice service delivery (with a specific focus on support for people with non-DMT progressive MS).

The participants interviewed for this study had different roles within their services, and so the information provided varied depending on their position. Therefore, the case studies are illustrative of the services from the perspective of interviewees.

Case studies should not be published externally without prior agreement from interviewees.

Best practice in care for people with non-
→ DMT progressive MS

An overview of best practice in care for people with progressive MS

People with MS can have varying and complex needs, so it is important for their care to be individualised to assist with the symptoms that the patient is experiencing.

The desk research analysis identified the following as best practice when caring for people with MS:

- The involvement of a multidisciplinary team (MDT)
- Care coordination and case management
- Community support
- Support for self management

The following slides discuss these features in more detail.

Other elements of care that are considered important when caring for people with MS include:

- [Accessibility to neurological services](#) at all sites that admit patients with acute neurological disorders; this is especially important given that progressive MS can decrease mobility, which makes accessing sites more challenging.
- [A specific care pathway for people with MS](#). The National Neuro Advisory Group (NNAG) is currently developing a template integrated care pathway for people with MS which will illustrate what good treatment, care and support involves, and may help services to provide patients with an idea of what support they may receive.

To facilitate best practice, it is important that the following take place:

- Both healthcare professionals and case managers/care coordinators should complete training on the different types of MS and their treatment to ensure they understand the options available for people with progressive MS who do not respond to DMTs.
- There should be an appropriate level of administration support and sufficient workforce capacity to free up specialist time and ensure that support can be accessible and tailored to the individual's needs.

Of the 9 resources reviewed that provided recommendations and guidance on care for people with neurological conditions, only one referred specifically to care for people who cannot benefit from DMTs. This highlighted that patients who do not respond to DMTs are often left without the necessary support to manage their condition.



Multidisciplinary teams (MDTs)

- People with MS should have access to a formalised multidisciplinary team (MDT) that includes [professionals across specialist teams](#).
- The MDT should provide a [holistic, coordinated approach](#) to an MS patient's care to get the most out of specialist resources.
- Support provided for people with MS should include a mix of [DMTs \(where feasible\)](#), [symptom management](#) and [neurorehabilitation](#). With different providers delivering these services, it is important that members of MDTs have [formal ways of interacting](#) to coordinate the care for a patient.
- Core members of an MDT for patients with non-DMT MS (according to NICE) include: [physiotherapist](#), [occupational therapist](#), [wheelchair clinic](#), [speech and language therapists](#), [continence advisor](#), [pain clinician](#), [podiatrist](#), [optometrist](#), [psychologist](#), [tissue viability practitioner](#), [respiratory practitioner](#) and [palliative care/ end of life practitioner](#).

People with non-DMT progressive MS have varying care needs. MDTs encourage specialists to collaborate and collectively consider the specific needs of each patient in order to ensure their care is tailored accordingly.

Benefits of an MDT for people with MS:

- MDT staff can share knowledge and work together to decide upon the best treatment options for a patient.
- Multiple problems experienced by the patient can be addressed in a way that is more coordinated (instead of disjointed care where individual clinicians do not know what others are delivering for a single patient)

Care coordination and case management

- People with MS should have a clear **care plan** and a single point of contact for their care – a **care coordinator** (also known as a **case manager**).
- The care plan describes **how an individual's condition is going to be managed**. The role of the care coordinator is to **identify and coordinate** the services that an individual needs, and **oversee the delivery** of the care plan.
- Care coordinators need a good level of **knowledge of MS** services. They might be non-clinical administrative staff or health professionals with specific case management responsibilities.
- Care coordinators **organise the care provided by the multidisciplinary MS clinical team** as well as assisting patients in accessing **other types of support** such as community services.

People with progressive MS often have complex needs. As well as coordinating the health care they receive, case managers/care coordinators can liaise with other agencies providing services used by people with MS. This might include social care, third sector providers and local authorities.

Benefits of care coordination and well-designed care plans for people with MS:

- Receiving interventions tailored to their specific needs, at the right time.
- Reassurance that there is a point of contact who has full oversight of their condition and care.
- Better access to other support services outside of clinical settings which impact health and wellbeing.

Community support

- Access to **local support** (including home-based care) should be **integrated into care pathways for people with MS**
- **Neuro rehabilitation, holistic and specialist support services** should be commissioned to support those with MS to manage their symptoms within the community, outside of hospital settings.
- People with MS may also require access to wider community services including **peer support groups, social care and housing**.
- A **local directory** of services and support would enable the signposting and/or referral of people with MS to the most appropriate support.

Local and home-based care is particularly valuable for those with higher levels of disability, which makes it more difficult to leave home or travel to hospital to receive the care they need.

Benefits of community support for people with MS:

- Care can be received locally or even within a patient's home, making it more easily accessible.
- Home visits allow health care professionals to assess the suitability of the patients' environment and make equipment recommendations or arrange adjustments to improve their quality of life.

Support for self-management

- Patients should be provided with advice and guidance on how to manage their condition.
- Self-management information should be provided at the time of diagnosis and during care planning. It should be **personalised and tailored** to the symptoms and needs of the individual. Guidance may include information about **symptom management** and **treatment options**.
- The NHS should also support providers to produce tools that make this information easily accessible.
- Support should encompass **maintaining physical activity** to address issues with mobility or fatigue. Professionals specialising in supporting those with MS (such as physiotherapists or MS Champions) may discuss suitable physical activities, including aerobic, resistive and balance exercises and moderate progressive resistance activity.

Self-management techniques can help people with progressive MS to minimise the deterioration of their condition and provide relief without the individual needing to rely solely on services for support.

Benefits of self-management support for people with MS:

- Patients are equipped with the ability to manage their condition, minimising the inputs needed from clinicians and therefore reducing the volume of interactions needed with health care services.
- Self-management can help people have an improved understanding and more control over their condition.

Approaches to care for people with non-DMT
→ progressive MS

Overview of current approaches to care for people with non-DMT progressive MS (1)

- The basic principles of the patient pathways for people with both DMT and non-DMT MS were similar across the five case studies: following a referral, patients are assessed to identify their clinical needs before being seen by the appropriate staff member(s) that can help address these needs, and/or referred on to other relevant symptom management and support services. They will also receive a follow up appointment with their consultant/nurse within a specified period.
- However, the case studies illustrate the [geographic disparities](#) that exist in care for people with MS, and particularly care for people with non-DMT progressive MS. The types of services patients could access, the frequency with which they could access them, and the extent to which these services incorporated best practice, varied considerably. For example:
 - Follow up appointments for people with non-DMT progressive MS ranged from as frequently as once every 6 months, up to once every 2 years
 - Core MS teams differed in the type of health care professionals available. Some were restricted to nurses, consultants and physios, while others also incorporated OTs, orthoptists, neuropsychologists and/or care coordinators.
 - The types of clinics and wider support available also varied. In one area, symptom management clinics were restricted to one funded session per week of physio and OT. Notably, fatigue management was unfunded so had to be carried out as part of the physio offering. In another area though, there a range of clinics were available including fatigue management, vestibular rehabilitation and emotional/psychological support.

Overview of current approaches to care for people with non-DMT progressive MS (2)

- A similarity across most the case studies was the [lack of formalised links with community services](#), regardless of how those services were funded. One interviewee reported that they had tried to undertake a mapping exercise to identify all the community services (e.g. neuro rehab teams) available to their patients within the geographic scope of their Trust but it had proved “impossible” to find them or establish how they were commissioned – some services they approached did not know themselves who had commissioned them. As a result, there can be duplication and wasted resources in care provision, and a disjointed experience for patients who are receiving support from both a core hospital-based MS team and a community service.
- Although there was no clearly named pathway in place there is a series of processes specifically instigated to support this patient group and evidence found to suggest specific approaches were taken in caring for people with non-DMT progressive MS. Even where the *same* level of care was provided to both DMT and non-DMT patients, one interviewee noted that [some non-DMT patients need even more support](#) than those on DMTs, as they often had higher levels of disability which was getting progressively worse. A common theme was the increased likelihood of non-DMT patients [disengaging from services](#): they can feel there is no treatment available to them if they do not respond to DMTs, or lack awareness about the support they could access.
- In two instances, interviewees highlighted the ever-increasing number of both the [DMTs available](#) as well as [the number of people being diagnosed with MS](#). This can impact staff capacity for caring for people with non-DMT MS - in one example, the necessity of regularly following up with people on DMTs (due to DMTs being toxic drugs) had resulted in non-DMT patients being followed up less frequently (every 2 years, as opposed to annual follow ups for those on DMTs).

Extent to which current approaches reflect best practice (1)

- Case study areas generally tried to provide an equal level of care for people with non-DMT progressive MS as that offered to DMT patients:
 - There were general pathways for people with MS in all of the case study areas, encompassing both DMT and non-DMT patients. In some instances formalised approaches to treatment and care for non DMT patients have been established
 - Four interviewees explicitly noted that they ensured they offered the same level of care to both DMT and non-DMT patients. Those based in neuro rehab teams stated that their teams were focused on addressing specific patient symptom management needs which meant both non-DMT and DMT patients received the same care offer (a specific intervention to address the issue(s) they were having). Those in hospital teams offered the same frequency of follow up appointments to both DMT and non-DMT patients.
 - However, the remaining interviewee recognised that non-DMT patients were treated differently in their Trust. Those on DMTs required regular follow up due to the need to monitor the effect of the drugs, but this had led to reduced staff capacity for non-DMT patients. As such, non-DMT patients only had appointments every 2 years whereas DMT patients were seen every 6 months.
- MDTs for people with MS were in place in all of the case study areas, but the way the MDT operated and the professionals involved was variable and there was often a focus on DMT patients:
 - In some cases MDTs met as frequently as once a week, while in other cases meetings were once every quarter. Professionals involved often included a mixture of MS specialists as well as general neurology staff members. As described on the previous slide 14, some case study areas had a greater breadth of professionals involved than others participating in the MDT than others.
 - MDT meetings tended to revolve around specific patients and decisions on their care. In at least two cases, discussions focused on patients being considered for DMTs and those already on DMTs. Non-DMT patients were discussed less frequently and generally only when they had multiple, complex needs.
 - However, there were two cases where patients (both DMT and non-DMT) could access support through MDT clinics. All the MDT professionals were available during these clinics, allowing patients to see all the relevant staff members on the same day. This is an example of best practice as it means patients do not need to travel to hospital across multiple different days to see different staff members.

Extent to which current approaches reflects best practice (2)

- **Care coordination was uncommon for both DMT and non-DMT patients:**
 - Only one case study area had a designated care coordinators. They acted as a point of contact for patients, responding to their general queries, booking appointments, making referrals (including to third parties, such as adult social care) and providing other types of support to both patients and staff. Their value was noted by the interviewee, who stated that the list of tasks they carried out was “endless” and she didn’t know “what we would do” without them.
 - In other case study areas, any informal arrangements for coordinating care were generally between MDT staff members and/or staff providing them with administrative support. One area the interviewee described how the MS MDT would coordinate their approach to address a particular need that a patient might have. In another area, an administrative MDT would answer patient calls and pass on relevant information. In at least three areas, MS nurses were the main point of contact for patients. However, one interviewee acknowledged that their MS nurse advice line was “very oversubscribed”. Sometimes MS nurses were involved in referring patients to relevant services and monitoring their progress, whereas sometimes their coordination activities were more limited to signposting.
- **However, the benefits of effective care coordination for people with non-DMT progressive MS were illustrated through the Advanced MS Champion programme:**
 - The Champion interviewed felt that non-DMT patients needed more support – particularly with chest management and loneliness. Some of the patients she had worked with had only ever received support from their GP. By identifying symptom management issues, making referrals into appropriate services and monitoring their progress, Champions helped to address patients’ needs. In turn, the deterioration of their health was slowed and their ability to self-manage their condition improved, providing better quality of life.
- **Use of formal care plans was also uncommon, though there were examples of informal care plan arrangements:**
 - Formalised care plans only existed in one of the case study areas, and only for patients with highly progressed disease. Delivery on these plans was a collaborative activity between the relevant professionals involved with their care. For other patients, plans were less formal – they were written into their clinical letters and updated every 6 months. This was considered sufficient for their needs. Similarly in another case study area, the clinical letters of newly diagnosed patients’ clinical letters would include information about their diagnosis and available treatments.

Extent to which current approaches reflects best practice (3)

- All of the case study areas offered at least some form of self-management support, but it is likely the quality of this support varies:
 - Both DMT and non-DMT patients received advice and information about their condition when they were first diagnosed. This could include information about their diagnosis, treatments and support available, lifestyle advice (e.g. diet, smoking, exercise), signposting (e.g. to websites, community services/groups). However, this was not always standardised. One interviewee stated that they included such information in their clinical letters to patients confirming their diagnosis but they were unsure whether others in their Trust did the same and, if so, what information they tended to include.
 - Ongoing, practical self-management support (e.g. exercises to support mobility and speech, managing continence and fatigue etc) tended to be provided by the relevant therapists involved in the different case study areas. However, there were differences in the types of therapists and the specific support they provided in across the case study areas and it is therefore likely that the quality of the self-management support also varied. For example, in only one case study area did the interviewees state that patients had access to SLT and dietetics support, even though dietary advice was highlighted as particularly important for self-management by the Advanced MS Champion as it affected patients' cognition, bladder and bowels, fatigue and weight (which in turn affects mobility).
- There were NHS community services available for people with MS in all but one of the case study areas, but links between Trusts/hospitals and these community services were often inefficient and disjointed:
 - There was often overlap in the services offered by community and hospital services – whether funded by the NHS, local authorities or charities – and a lack of knowledge from both sides about what service was actually being provided. In some cases, hospitals were unaware of the community services that were actually available within the geographic scope of their Trust. Data was also not routinely shared. It is therefore likely that patients have disjointed experiences of care. Further, health care staff may be unable to signpost patients towards appropriate community services in the first instance as they are unaware of them.
 - The interviewee in the case study area that did not have a specific community service explicitly highlighted their importance for people with progressive MS, as they faced barriers accessing care in the hospital setting as a result of their level of disability. As such, she wanted to see the introduction of a community based MS nursing service in the area that could carry out home visits.

→ Case studies

University Hospitals Coventry and Warwickshire NHS Trust

Interviewee: Consultant Neurologist who coordinates the MS and neuroinflammatory service

Overview

- Care for people with non-DMT progressive MS and patients on DMTs differs: **those on DMTs receive more regular contact** with the service due to treatment monitoring. Non-DMT progressive MS patients can be “lost” to follow up due to the more irregular nature of their interactions with the service.
- The MS MDT (MS consultants and nurses, physios and OTs) meet every 3 months. The consultants and nurses also meet more regularly. **The focus of these meetings tends to be on patients on DMTs** (e.g. escalating treatments, more complex cases etc).
- Self-management support is not a specific element of care, but it is **offered in the form of patient education** when they are newly diagnosed – increasing awareness of brain health & lifestyle (smoking, diet), support available and how to access it.
- **No formalised care coordination is available.** There is a nurse helpline for patients to call if they have questions or issues but it is very oversubscribed. There is also an MS MDT coordinator/secretary who operates in an administrative capacity (e.g. ensuring the information is passed on if patients call). Patients do not have dedicated care plans.
- There was **no linked community-based service**, which is a **barrier to optimising care for people with progressive MS**. A community nursing team could better respond to the needs of more disabled patients by visiting them in their homes - hospital nurses are too busy with DMT patients. However, the service do have some links with non-NHS community services (e.g. [Mercia MS Therapy Centre](#) in Coventry, MS Society patient support groups).

Patient pathway

People with suspected MS are referred by their GPs to a neurologist for an MRI. If MRI shows MS lesions, they will see an MS consultant for a diagnosis and allocated to the consultant’s regular list. MS patients will also have an appointment with an MS nurse. A decision is then made on whether or not the patient can receive DMTs. This might be discussed in an MDT meeting.

Clinics for patients with MS include the newly diagnosed clinic, a relapse clinic, a progressive MS clinic, a clinic for people on DMTs, an infusion clinic for administering DMTs and symptom management clinics. Patients are offered or referred to this support as deemed appropriate by their clinicians and the MS MDT.

Patients on DMTs will receive follow up appointments every 6 months, alongside regular blood tests and an annual MRI. They also have monthly infusions which provide an additional point of review. DMT patients are generally the focus of MDT meetings.

Non-DMT patients will receive follow up appointments every 2 years unless they contact the service requesting support, or someone contacts the service on their behalf (e.g. GPs, other clinicians treating them for comorbidities).

Regular follow up with DMT patients is a necessity as DMTs are toxic drugs and when providing a treatment, side effects need to be monitored. The number of patients on DMTs have increased over time, which has reduced capacity to follow up with people who have non-DMT progressive MS. Although MS patients are never discharged, those with progressive MS are more likely to disengage: an estimated 20-30% of the service’s progressive patients had not seen a neurologist in 5 years.

The service has taken steps to use patient feedback and evidence to inform future development. They have MS patient days where they present the services and gather feedback on them. They also are hoping to get a group of patients together to provide ongoing feedback. The service has also undertaken ad-hoc analyses of their data and tried to take action accordingly (e.g. looking at many people hadn’t received a follow up and bringing their appointments forward). However, they are limited by capacity in how frequently such activities can be carried out.

Patient population

- Around 3,000 patients with MS, of which:
 - 1,500 have progressive MS
 - 900 are on DMTs*
- Patients come from a diverse range of socio-economic, ethnic and cultural backgrounds

Summary of best practice features

- ✓ Multidisciplinary team (MDT)
- ✗ Care coordination / case management offering
- ✓ Self-management support
- ✗ Specific treatment pathway for people with non-DMT progressive MS
- ✗ NHS community service(s)

Staff supporting people with MS

- Core MS MDT service is 2.8 FTE MS consultants and 3.6 FTE MS nurses (hospital-based)
- One funded session a week for symptom management clinics:
 - MS therapy services which includes physiotherapy and occupational therapy
 - Contingence management
 - Fatigue management is unfunded, but carried out as part of physiotherapy
- External to the MS MDT there is the possibility to make referrals to neuropsychology, neurorehabilitation and palliative care.



✓ Incorporated in the service

✗ Not incorporated in the service

*exact number of patients with non-DMT progressive MS was unknown

Greater Glasgow and Clyde Health Board

Interviewee: Neuro Rehabilitation Consultant within the neurological rehabilitation service

Overview

- Patients with MS are cared for by the neurology MS service. **Although there is no formal care coordination arrangement**, patients have an allocated MS nurse who assesses their needs. If appropriate, the nurse will refer them into the other services (such as the neuro rehabilitation team) and monitor their care.
- The interview focused on the role of the neuro rehab team and touched on how it fit into the wider services available for people with MS. The neuro rehab is designed to address **specific patient symptom management needs** arising from their neurological condition and receives referrals from wider neurology services.
- Most MS patients referred to the service are not on DMTs. This is because those with non-DMT progressive MS generally require a more intensive level of symptom management. Nevertheless, because the focus is on a patient need, there were **no identified differences in the care provided for DMT and non-DMT patients**.
- Support provided by the service is generally focused on management of physical symptoms (e.g. spasticity, neuropathic pain and dizziness) through an inpatient service. **Self-management is encouraged** through provision of advice and signposting patients to relevant support (e.g. useful websites).
- There is a **community rehab team** which the neuro rehab team has some informal links with.

Patient population

- For the neuro rehab service specifically, in the last 6 months, around 26% of patients have had MS.
- Of the MS patients reviewed by the consultant in the past 6 months:
 - 91% have progressive MS and 87% have non-DMT progressive MS (as 13% are receiving DMTs)

Summary of best practice features

- ✓ Multidisciplinary team (MDT)
- ✗ Care coordination / case management offering
- ✓ Self-management support
- ✗ Specific treatment pathway for people with non-DMT progressive MS
- ✓ NHS community service(s)

Staff supporting people with MS

- The **wider neurology MS service** within the Greater Glasgow and Clyde Health Board includes the following*:
 - at least 3-4 MS consultants
 - 3-4 specialist nurses
 - 2 MS physiotherapists
- Wider support services available for people with MS include:
 - neuro rehab (where the interviewee sits)
 - community rehab team
 - ophthalmology
 - urology

**the consultant interviewed does not work in this department and so these are guesses*

Patient pathway

This pathway is focused on the neuro rehab pathway as this was the interviewee's primary area of expertise.

Patients are usually referred by the MS specialist nurse who sits within the wider neurology service. Some referrals come from GPs, other neurology services and health professionals (such as physiotherapists).

A member of the neuro rehab team will go through the patient's MS history and ask questions to gauge how the condition is impacting them. Then a clinical examination is completed. A decision on the best intervention(s) for the patient will be established on this basis. Some patients (particularly those with more physical symptoms) may be seen by a consultant and physiotherapist concurrently in order to formulate the best possible intervention(s).

Patients are seen by the appropriate team members and will be referred to other services if necessary (including Revive MS – see box below).

After interventions are complete, the patient's case load will typically remain open so the service can monitor their condition, unless they experience a long period of stability or are no longer benefiting from the service.

From the perspective of the consultant interviewed, the patient experience of services provided by the Greater Glasgow and Clyde Health Board varies significantly, so there is no clearly established patient pathway. The service ensures all patients are either referred into or are aware of the local **Revive MS** charity within Glasgow. This provides people with MS opportunities for peer support, alongside access to an in-house physiotherapist, continence advisors and a hyperbaric oxygen chamber.

NHS Frimley Health Foundation Trust

Interviewee: Lead MS Nurse Specialist and Advanced Clinical Practitioner

Overview

- The Trust has both an MS MDT and a neurology MDT. Services available for MS patients including OT, neuropsychology, physio, botox therapy, SLT, dietetics, support for spasticity, neuro rehab, mental health support (through Talking Therapies) and palliative care. Referrals to services within the Trust (such as neuro psychology and neuro rehab) could be made through the weekly neurology MDT meetings.
- The service emphasised that they provided the same level of care for DMT and non-DMT patients with MS by focusing on level of clinical and social need. However, when patients are no longer responding to DMTs they can feel as if the service will no longer help them and may disengage, even though they often need more support.
- The service had two care coordinators acting as a single point of contact for patients: assisting with any queries, booking appointments with MS consultants and nurses, providing help with prescription management and pharmacovigilance, and completing referrals (including those to external services, such as adult social care). Formal care plans were used for those with multiple complex care needs. For those with less complex care needs, clinical needs would be addressed in clinic and a plan for care would be written through patients' clinical letters and updated every 6 months.
- Community services include neuropsychology and neuro rehab, and community nurses. Self management is supported across a breadth of interventions across a range of services and providers; medication management and advice provision (e.g. surrounding exercise, diet etc).

Patient population

- Around 1600 - 1700 patients have MS*, of which around 25% do not respond to DMTs*
- There appear to be more MS patients at their Frimley Park site, which may be because the service has been established longer.

Summary of best practice features

- ✓ Multidisciplinary team (MDT)
- ✓ Care coordination / case management offering
- ✓ Self-management support

The NET (neurology extended team) Clinics- a "one stop" for patients with progressive neurological conditions are seen by a range of HCP (e.g. a neurologist, MS nurse, physiotherapist/psychologist) at the same time, allowing specialists to communicate about a patient's care, while improving the accessibility of appointments for patients.

- ✓ NHS community service(s)
- ✓ Spasticity and botox clinics offered.

✓ Incorporated in the service

Staff supporting people with MS

- Across the Trust, MS patients are supported by:
 - 4 MS-specific consultants
 - 4 neuro physiotherapists
 - 2 neuro psychologists
 - 2 neuro OTs
 - 2 MS coordinators
 - 7.2 FTE MS nurses (including community nurses)
 - 1 MS therapies nurse
 - 1 WTE Therapies Nurse Assistant
 - 0.2 Clinical Commissioning Pharmacist
- An MDT of MS specialists is used to discuss patients being considered for DMTs, in addition to some patients with MS that have multiple, complex needs.
- There is also a wider neurology weekly MDT (which includes an occupational therapist, a neuro physiotherapist, care coordinators, MS nurses, OT, Parkinson's disease nurses, motor neurone disease practitioner and a psychologist) to collectively consider the best care to provide for complex patients.

Patient pathway

Patients with MS are referred into the service by a GP or another consultant from a different centre or through a Ward referral.

Patient is reviewed by a consultant neurologist to confirm diagnosis. The initial assessment involves a neurological examination, establishing the patient's EDSS (Expanded Disability Status Scale), alongside gauging the individual's clinical and social history. Additional investigations may be arranged at this time

The case will then be given to an MS nurse. Depending on the level of disability the patient has, they will be offered home visits, clinical appointments or telephone consultations.

The individual's needs are assessed through referrals into the areas of support they need (either internally or externally), and the team will signpost the patient to other services that may benefit them.

People with MS are offered 2 appointments every year and dependent on clinical need this could be f2f/home visit/telephone, if additional appointments are required this is facilitated.
The service offers extended consultant reviews every 2 years for patients that are clinically stable, while the nurse follows them up in the mean time. If there is a need to see a consultant, this is possible.

- Services at Frimley Foundation Trust (Frimley Park, Heatherwood and Wexham sites) are developed in response to the needs of patients and considering the good practice of colleagues in other Trusts. The Trust offers the same services on each of their sites to ensure equally accessible care across the area that they cover.
- The Trust has recently set up NET (neurology extended team) Clinics, in which those with complex neurological conditions can be seen by a selection of people in the team (for example, a neurologist, MS nurse, physiotherapist and urologist) at the same time, allowing specialists to communicate about a patient's care, while improving the accessibility of appointments for patients.

United Lincolnshire Hospitals NHS Trust

Interviewee: Neuro Physiotherapist in the community neuro-rehabilitation outreach team (CNOT)

Overview

- The service is itself a community MDT supporting patients with neurological conditions with **symptom management**. Patients are usually referred to them at the point their condition is becoming more progressive. Care is provided both as **outpatients and in the patient's home**.
- Care is **tailored to addressing a specific patient need** and therefore DMT and non-DMT patients are not treated differently. When the need has been addressed they are discharged from the service. However, the interviewee had the impression that in hospital settings non-DMT patients did not receive the same level of attention as those on DMTs.
- The service **supports patient self-management** through provision of advice (e.g. on exercise, equipment) and developing key skills for managing their condition.
- There is **no formal patient care coordination** and they **do not routinely produce care plans**. However, the team aim to coordinate their approach to assist with a particular need, e.g. physiotherapy for mobility, ordering equipment, prevention of symptom deterioration and assistance with other medical needs. They will also **signpost and refer** patients on to other services when necessary. This includes referrals to other community services (e.g. adult social care, district nurses, hospices).

Patient population

- Of all patients that have neurological conditions, 50% of these have MS. Of these, less than 50% are on DMTs*.
- Because people with progressive MS fall under the Rehabilitation Medicine Consultants (as does the Community Neuro Outreach Team), a high proportion of their MS patients have progressive MS.

Summary of best practice features

- ✓ Multidisciplinary team (MDT)
- ✗ Care coordination / case management offering
- ✓ Self-management support
- ✗ Specific treatment pathway for people with non-DMT progressive MS
- ✓ NHS community service(s)

✓ Incorporated in the service ✗ Not incorporated in the service

*exact number of patients with non-DMT progressive MS was unknown as patients come in and out of contact with the service depending on their needs

Staff supporting people with MS

- The Community Neuro Outreach Team are a MDT. Most patients are supported by more than one team member.
 - 1.0 - Therapy Team Lead
 - 1.0 – Clinical Nurse Specialist and Nursing Lead
 - 1.0 – Occupational Therapy Clinical Specialist
 - 3.23 – Specialist Physiotherapists
 - 4.06 – Specialist Occupational Therapists
 - 0.8 – Clinical Nurse Specialist
 - 1.0 – Home Enteral Feeding Specialist Dietitian
 - 1.0 – Occupational Therapy Apprentice
 - 2.04 – Rehabilitation Assistants
 - 1.27 – Physiotherapy Assistants
 - 1.58 – Occupational Therapy Assistants

Patient pathway

This pathway is focused on the neuro rehab pathway as this was the interviewee's primary area of expertise.

Often, neurologists will refer patients for symptom management when an individual's condition becomes more progressive. It is at this point they are usually referred into the CNOT. GPs and other services (such as some community therapy teams) can also refer into them.

The MS patient will be triaged with the information provided through the referral to determine who on the team is most appropriate to visit the individual in their home (and whether multiple specialists should attend the visit).

A telephone consultation may be completed to gather further information. Then, a home visit would be arranged and attended by the most necessary members of staff. A physical assessment is normally completed at this stage to gauge the individual's abilities and needs.

The specific patient needs are identified, and appropriate support provided (either through the team or through referring to other organisations). Once appropriate interventions are complete, the patient is discharged from the service.

Previously, there was an MS-specific exercise class in Lincoln through the NHS, but this changed due to funding availability. MS-specific exercise offering currently under discussion with MSS. Capacity issues persist as the service continues to work through the backlog that accumulated during the pandemic (as members of staff were redeployed during Covid-19 times). Each area in Lincolnshire has different members of staff (in accordance with the size of the area), staff work across teams to improve equality of access across the county. Staff are based at Lincoln, Louth, Boston and Grantham hospitals.

Advanced MS Champion

The Advanced MS Champion programme:

The role of the Advanced MS Champion is to coordinate care through assessing the patient's needs and ensuring that they are receiving report from all relevant services. Therefore, the Advanced MS Champion Programme is an example of good practice in terms of care coordination and case management.

- Initiated and funded by the MS Trust since 2018 the Advanced MS Champion (AMSC) role is a specialist health professional, either a nurse or a therapist, who works as part of the MS Team. Their role has been developed by the MS Trust to provide much needed support to those living with advanced MS through accessing and coordinating existing services to deliver a coordinated care plan. They also provide specialist and individual care for people living with a complex set of symptoms.
- The Advanced MS Champion Pilot Programme is a three-year programme, aiming to **reconnect people with advanced MS to specialist services**. Six Advanced MS Champions (all of whom are health care professionals working as part of an MS Team) across the UK are funded through the programme.
- The Advanced MS Champion role involves **coordinating the care** for people with advanced MS through providing **direct support** and **referring patients to health and social care services**. While the Advanced MS Champion responds to the patient's present struggles, they also help to prevent the condition from progressing where possible.
- The Advanced MS Champion interviewed was in the role for around three years, supporting around 90 people (all with non-DMT MS). Before the Covid-19 lockdowns (when they were active in the role), the position involved assessing people with MS to establish their care needs in order to form a care plan, referring the patient into necessary services and educating those involved in a person's care about how to best manage the condition.

Support for people with non-DMT progressive MS:

- Support included symptom management as well as advice and education surrounding the condition (e.g. on diet, exercise, preventing spasticity and lifestyle choices). Champions could make referrals to other services, including community rehab teams, palliative care teams, bladder and bowel teams, SLTs, urologists and respiratory physicians (though access to these varied depending on the patient's geographical area).
- The Champion wrote care plans in collaboration with patients and their families: this would list patient needs, a solution and who could provide it. This would be sent to both the patient and their GP. The plan encouraged self-management by including 'jobs' that patients themselves needed to undertake. It was revisited every 3 months to assess patients' progress towards their goals.
- The main clinical needs of patients related to their chest, bladder and having falls. Social needs were primarily depression and loneliness. The Champion felt non-DMT patients did need more support – particularly with chest management (e.g. chest physio) and loneliness. The extent to which they were accessing health care services varied – some had only received support via a GP, whereas others had carers and district nurses visiting them at home.
- One particular group of patients in need of support are those who were diagnosed with MS 20+ years ago, before there were treatments in place. They can be in a "really terrible condition" by the time the interviewee was in contact with them, which meant the Champion could only provide comfort and support "rather than meaningful intervention that reverses where they are".
- Contact with patients was usually face-to-face, with some telephone follow-ups. Frequency of contact between Champions and patients varied: sometimes it was weekly or every fortnight, sometimes she would just make the referrals and then follow up with the patient after 3 months.

Patient pathway

People with MS are referred to the Advanced MS Champion by members of the MS team (i.e. MS consultants and nurses), GPs and occasionally through self-referrals.

The Advanced MS Champion visits the patient at home to conduct an initial assessment in which the patient's goals, needs and solutions are established. This informs a care plan constructed and disseminated by the Advanced MS Champion which illustrates who will be assisting with the patient's care.

Depending on the patient's care needs, the Champion may visit the individual again to provide further support. They will also refer the individual on to necessary services for further support.

After interventions set out in the care plan have been completed, the Champion will follow up with the patient (in person or by telephone) to establish whether the individual's initial goals have been achieved. If goals are not achieved, further support will be provided/requested by the Advanced MS Champion and the care plan will be renewed accordingly.

After the Advanced MS Champion has supported the individual to achieve their goals, the patient will be passed back over to be cared for by the MS nurse. Patients can be referred back to the Advanced MS Champion if further complex symptom management is required.

Benefits for people with non-DMT progressive MS:

- Improved ability to manage symptoms
- Improved understanding and awareness of MS
- Improved mental health
- Slows condition progression

"A lady in her 70s had been in a hospital bed in the lounge for 12 years and moved through hoist transfers. She has aphasia (impacting her speech). We helped to get a specialised chair with a battery pack so she could be sat out of the bed and her husband could take her outside. She also reviewed her medication - a typical situation is that the individual will be taking a lot of medication, and sometimes getting rid of these means the patient feels better (as they may be more alert). As a result, the lady was much more alert and able to communicate."



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