



RightCare Progressive Neurological Conditions Toolkit

People with progressive neurological conditions are experiencing delays in diagnosis and treatment, fragmented and uncoordinated services, limited availability of neurospecialist rehab and reablement and a lack of psycho-social support.

This toolkit will provide you with expert practical advice and guidance on how to address the key challenges when commissioning services and treating people with progressive neurological conditions.

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Multiple System
Atrophy Trust

PARKINSON'S^{UK}
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PSPFA



Informed by relevant NICE recommendations

NICE National Institute for
Health and Care Excellence

Progressive Neuro System Improvement Priorities

Joint Consensus Statements:

Shared Decision Making

Referral & Diagnosis

MDT & Coordination of Care

Symptom Management

Mental Health Support

Conditions:

Motor Neurone Disease

Parkinson's

MSA, PSP & CBD

Multiple Sclerosis

NICE Quality Standards

Guidance & Best Practice

Additional Tools:

RightCare neurology resources

Shared Decision Making

Elective Care handbook

RightCare Toolkit: Progressive Neurological Conditions

This RightCare system toolkit will support systems to understand the priorities in care for people living with various progressive neurological conditions. This toolkit covers the following neurological conditions; multiple sclerosis (MS), motor neurone disease (MND), Parkinson's and the atypical Parkinsonism's of multiple system atrophy (MSA), progressive supranuclear palsy (PSP) and corticobasal degeneration (CBD). It provides the opportunity to assess and benchmark current systems to find opportunities for improvement. **In this RightCare toolkit each priority has supporting slides that contain 'key areas of focus' and 'actions to take'**. It is produced with reference to an expert group of stakeholders and wider consultation has taken place with patient representatives, clinicians, professional bodies and other [key stakeholders](#).

The National Challenges:

- **Delays in primary and secondary care leading to delayed diagnosis and treatment**
- **Fragmented or uncoordinated multidisciplinary working**
- **Limited availability of neurospecialist rehabilitation and reablement**
- **Lack of availability of appropriate psycho-social support**

The National RightCare Opportunity for Improvement:

- Around **£10m** could be saved on emergency admissions for MS, Parkinson's and Motor Neurone Disease combined, if CCGs achieved the rate of their best 5 peers
- **2,500 fewer emergency admissions** for MS, Parkinson's and Motor Neurone Disease combined, if CCGs achieved the rate of their best 5 peers

Additional resources:

RightCare has a dedicated [neurology workstream](#) which includes the following resources:

- RightCare Neurological Conditions Focus Pack: This provides each CCG in England with the most relevant neurological data, compared to their most similar ten CCGs. To access please contact your [local Delivery Partner](#).
- [Parkinson's scenario](#) – Using a fictional patient, Sarah along with her husband, this scenario examines a Parkinson's pathway from the initial first symptoms and diagnosis through to end of life care. It compares a sub-optimal but typical scenario against an ideal pathway. At each stage we have modelled the costs of care, both financial to the commissioner but also the impact on Sarah and her family's outcomes and experience.

Elective Care Transformation Programme: [Transforming elective care services handbook: Neurology](#)

RightCare Progressive Neurology Toolkit: Shared System Improvement Priorities

Joint Consensus Statements on Shared System Improvement Priorities

Shared Decision Making

Referral and diagnosis

Multidisciplinary Teams and Coordination of Care

Symptom Management

Mental Health Support

Condition Specific System Improvement Priorities

Motor Neurone Disease

Implementation of NICE Quality Statements

Increasing knowledge and awareness of the signs and symptoms of MND

Consistent access to multidisciplinary community based care

Timely access to specialist and personalised equipment and support

Parkinson's

Increased use of specialist staff across the pathway

Ongoing quality patient centered care

Better use of data and technology across different healthcare settings

Anticipatory and advance care planning

MSA, PSP & CBD

Quicker and accurate diagnosis

Use of Multi Disciplinary Team Working

Access to specialist equipment and support

Multiple Sclerosis

Formalised MDTs across specialist teams

Comprehensive access to holistic support (particularly for advanced MS)

Better use of data and technology

Improved DMD Administration

Joint Consensus Statement: Shared Decision Making (SDM)

Aim: Ensure a system where shared decision making (SDM) is integral to all decisions made about the health and social care needs of patients affected by any of these conditions.

Rationale: SDM is a collaborative process through which a clinician supports a patient to reach a decision about their treatment. The conversation brings together:

- The clinician's expertise: such as treatment options, evidence, risks and benefits, and conversations about anticipatory care and advance care planning/ decision making;
- What the patient knows best: their preferences, personal circumstances, goals, values and beliefs.

When talking to patients it is important that discussions are conducted in a style and manner that allows patients to express their personal needs and preferences. Patients should have the opportunity to discuss their diagnosis, prognosis and investigations. This further involves avoiding medical jargon, managing expectations about the aims of treatment, and ensuring that patients have time to ask questions. It is important that further consultations are arranged if patients require further discussion about their condition and care, and that systems use patient decision making aids and decision support tools such as coaching, if required.

In individuals with MND, MSA, PSP and CBD it is important to recognise that disease progression can be rapid, and that preparation and pre-planning for this eventuality is important. For patients with MS, recognising it is a fluctuating condition is important, and there should be availability for patients who are experiencing a crisis or relapse to be able to discuss their changing needs. It is also important that when required, discussions around end of life care take place, which should be done sensitively and clinicians involved in this should be adequately trained. When discussions take place there also needs to be an awareness of possible cognitive change / loss of mental capacity and therefore extra support and time may be required for someone with cognitive changes or communication/language issues.

Key messages:

For Patients:

- You, and your support network, should be involved in making decisions about all aspects of your care.
- Health and social care staff should explain all aspects of your care in a way you fully understand.
- You should be given all the information you require about your condition and care to make informed choices about your care from the point of diagnosis.

For Commissioners:

- Ensure services have adequate time to embed shared decision making.
- Ensure staff are trained in the delivery of shared decision making principles.
- Information or signposting to information should be available for all patients to enable informed decisions from diagnosis.

Guidance & best practice

NICE Quality Statements

Joint Consensus Statement: Referral and Diagnosis

Aim: To ensure that patients who are suspected of one of the specified neurological conditions have a referral from primary to secondary care services to ensure a rapid diagnosis of their condition to enable appropriate options for treatment to be discussed.

Rationale: When patients start to exhibit signs and symptoms that may relate to the onset of one of the neurological conditions of Parkinson's/ Parkinsonisms (MSA, CBD or PSA), Multiple Sclerosis (MS) or Motor Neurone Disease (MND) it is important that these patients are referred as soon as possible to secondary or specialist services (incl. movement disorder specialists) in order that a diagnosis can be made.

Currently in the UK it is thought that MND affects up to 5,000 people, MS around 120,000 people, Parkinson's 145,000 people and MSA, PSP and CBD around 10,000 people combined. Due to the rarity of some of these conditions, general practitioners may never or only come across 1 or 2 presentations of early onset symptoms their professional working life and patients may therefore experience delays in being referred into neurology or specialist services for diagnosis. For all patients, early diagnosis is important in order to enable options for appropriate treatment to be discussed; however it is particularly important with suspected MND, MSA, PSP and CBD due to the rapid deterioration and poor prognosis of these conditions.

It is recognised that there can be lengthy waiting times to get an appointment to see either a neurologist (in the case of MS and MND) or in the case of Parkinson's, a movement disorder specialist to get a definitive diagnosis. Waiting times around the country can vary due to differences in referral processes and management and crucially staffing and appointment capacity. A fast track referral system should be available for people with suspected MND.

Key messages:

For Patients:

- Early diagnosis is important for these conditions, if you experience any symptoms of these conditions you should seek referral to a specialist from your GP as first contact.

For Commissioners:

- Review system capacity for accepting new referrals into local neurology and Parkinson's appropriate movement disorder services.
- Are there opportunities for new service models in primary care to speed up referrals to specialists e.g. utilising specialist nurses to triage referrals that may be able to reduce waiting times for first and follow up appointments, electronic referral systems, or an advice line for GPs to get advice from a specialist consultant to support management of patients with suspected neurological condition.
- Ensure patients are aware of the need for early diagnosis of these conditions
- Ensure primary care services, especially GPs, are aware of existing resources to support their knowledge of, and confidence dealing with, these conditions, including the relevant NICE guidelines.

Guidance & best practice

NICE Quality Statements

Joint Consensus Statement: Multidisciplinary Teams and Coordination of Care

Aim: Patients with any of the specified neurological conditions should receive co-ordinated multidisciplinary (MDT) care and timely review in a setting that is suited to the patient. This should be from health care practitioners best suited to the patient's needs, with associated seamless and timely MDT communication and care planning, including provision of information about voluntary organisations that can offer support for the specific neurological condition.

Rationale:

Effective coordination and care planning is essential for people with these neurological conditions in accessing health and social care. It is recognised that multidisciplinary teams (MDT) should include healthcare and social care practitioners who have specialist expertise in the condition. Patients when first encountering these services should be informed about who is responsible for their clinical care and the roles and responsibilities of the MDT. The individual's preferences about involvement of family and carers in decision making need to be clarified at first contact.

Accessibility and coordination of services in a clinic setting is important, but also service delivery in the patients' home should be available if required. Continuity of care is important too. Patients should be provided with a single point of contact/ care coordinator for their care who they can contact for advice in between appointments.

Assessments should be tailored to individuals and patients' needs to have early assessments if required. These can be triggered by the patient, their family/carers or healthcare professionals if they identify a need for this, especially in the case of MND, MSA, PSP and CBD as disease progression can be rapid. It is important for this to be anticipated so care and any equipment or adaptations can be accessed.

Clear and timely exchange of information, along with shared decisions about care should occur between all practitioners in both health and social care. Mechanisms should be in place to allow communication with the patient and (if appropriate) their family or carers to take place suited to the individual's needs. Tailored written and verbal information about the condition and management should be provided in formats that are suited to the individual's needs.

Key messages:

For Patients:

- You should be seen by healthcare professionals who have expertise in your condition
- You should be able to access services suited to your individual needs.
- With your permission, all decisions about your care will be shared with the MDT who are responsible for your care.
- Any information you receive should be available in a format that is suited to your individual preferences.

For Commissioners:

- Ensure that systems of care and protocols to support this are in place and happen in your area.
- Ensure that MDTs contain all the specialist health and social care practitioners required for the needs of patients with these conditions.
- Ensure patients have access to services that are suited to the individuals need.

Guidance & best practice	NICE Quality Statements

Joint Consensus Statement: Symptom Management

Aim: People who have any of these neurological conditions should have access to optimal symptom management strategies for any symptoms they encounter.

Rationale:

Numerous symptoms can develop in people affected by these diseases. Symptoms are specific to an individual and any symptom management should be tailored to the individual's needs. NICE guidance specifies numerous strategies that are specific for MS, MND and Parkinson's, however there is no NICE guidance associated with MSA, PSP or CBD. Management strategies offered by neuro therapists are vital for all these conditions to optimise mobility, daily living, swallow and communication.

It is important that symptoms are assessed routinely on an on-going basis by an expert MDT and changes monitored closely. Easy and timely access to core MDT practitioners such as physiotherapists, occupational therapists, dieticians, psychologists, speech and language therapists and social workers are critical to continuity of care so that symptom management is responsive to disease progression.

Patients and their families and carers also require clear reliable and accessible information about their condition and management strategies in whichever format suits their needs. Also, information about what specialist services are able to offer to enable symptom control should be available for patients and their families/carers including national organisations / helplines and local support groups. It is also important to have links into social care as patients will require ongoing support as their condition progresses.

Key messages:

For Patients:

- You should get help to manage any symptoms you encounter from the team responsible for your care.
- You should receive information about what services are available to help with symptom management and also how you can best manage any symptoms you have.

For Commissioners:

- Map the local/regional pathway of support for each of the symptoms caused by any of these diseases.
- Services should be equipped with the appropriate skills to identify, assess, and facilitate management of all symptoms caused by these conditions.
- If the core MDT responsible for the patients care cannot support management of certain symptoms, then pathways (e.g. bladder and bowel services, pain management, palliative care etc) should exist to services that can provide this management.

Guidance & best practice

NICE Quality Statements

Joint Consensus Statement: Mental Health Support

Aim: Ensure that discussion of emotional, psychological and cognitive needs takes place with individuals with any of these conditions. Mental health and cognitive status should be reviewed regularly. Patients should have the options of mental health support available made clear to them, and support from specialist neuropsychiatry or neuropsychology services should be available if required.

Rationale: The diagnosis and living with any of these neurological conditions can create significant pressure on the mental health of patients and their families or carers. It is therefore extremely important that the mental health needs of individuals and their families/carers are met.

It's important that people with all of these progressive neurological conditions have the opportunity to discuss their psychological, emotional and cognitive well-being, and shared decision making principles should be instigated to enable these discussions to take place. Patients and their support networks should be helped to have a clear understanding of what help is available to support their mental health wellbeing. Many areas of an individual's life can be affected by these conditions and adjustments in life that have to occur can have an impact on emotional and psychological wellbeing, this also applies to families and carers. These needs should be assessed and reviewed routinely by the team of health and social care professionals responsible for their care. If the input of other non-core multidisciplinary team services such as specialist neuropsychiatry is required, patients should be referred appropriately and seamless communication of the individual's diagnosis and care should occur.

Key messages:

For Patients:

- The team responsible for your care will offer you, and your support network, opportunities to discuss and review your emotional and psychological status regularly.
- You should be supported to access information and services to support your mental health and cognition when you need it. Support may include counselling, cognitive behavioural therapy, written advice, or a neuro-psychological specialist if required.

For Commissioners:

- Ensure local pathways include assessment and on-going support of patients' mental and psychological wellbeing and cognitive status.
- Ensure health and social care practitioners have on-going training to understand the emotional, cognitive and psychological needs of patients.
- Ensure that established pathways exist between neurological, psychological and specialist neuropsychiatric services.
- Collect data on prevalence, demand and effectiveness of mental health services for patients with these disorders.
- Ensure that information is readily available for patients, families and carers to help with management of mental health, cognitive, psychological and emotional wellbeing.

Guidance & best practice

NICE Quality Statements

RightCare Toolkit: Motor Neurone Disease (MND)

This RightCare system toolkit will support systems to understand the priorities in care for those people who are living with motor neurone disease. It provides the opportunity to assess and benchmark current systems to find opportunities for improvement. **In this RightCare toolkit each priority has supporting slides that contain 'key areas of focus' and 'actions to take'**. It is produced with reference to an expert group of stakeholders and is supported by NICE. Wider consultation has taken place with patient representatives, clinicians, social care organisations, professional bodies and other [key stakeholders](#).

The National Challenge for MND

- Increasing knowledge and awareness of the signs and symptoms of MND.
- Commissioned services need to be **coordinated** flexible and responsive to the rapidly changing needs of the patient.
- Improving choice in end of life care, including ensuring that more people are able to achieve their preferred place of care and death.

System Enablers

Commission services based on:

Nationally agreed service specifications:

[NHS England Service Specification for Neurosciences Specialised Neurology \(adult\)](#)

Shared decision making, care planning, and multidisciplinary working:

- [Joint consensus statement on shared decision making](#)
- [Resources for shared decision making](#)
- [Joint consensus statement on multidisciplinary team working](#)
- [Resources for MDT working](#)
- NICE - [Shared Decision Making, Making Every Contact Count \(MECC\) STP Resource](#)
- NICE - [Patient experience in adult NHS services: Improving the experience of care for people using adult NHS services](#), Recommendation 1.5.20
- Public Health England - [Making Every Contact Count \(MECC\): practical resources](#)

NICE Guidance

[MND NICE pathway](#)

[NG42 Motor neurone disease: assessment and management](#)

[QS126 Motor neurone disease](#)

Motor Neurone Disease (MND) System Improvement Priorities



Implementation of the NICE 5 quality statements



Timely access to specialist and personalised equipment and support



Increasing knowledge and awareness of the signs and symptoms of MND



Anticipatory and advance care planning through specialist care coordinators



Consistent access to multidisciplinary community based care

System Improvement Priority: Implementation of the NICE 5 Quality Statements

MND can affect adults of any age, but mainly affects people aged 55 to 79. The cause is unknown, although about 5–10% of people with MND have a family history of the disease, and there is no cure available. Therefore, care focuses on maintaining functional ability and enabling people with MND and their family members to live as full a life as possible.

The quality standards are expected to contribute to improvements in the following outcomes:

- quality of life
- functional ability
- patient-reported outcome: symptoms
- patient- and carer-reported outcome: satisfaction with care and support provided
- survival from onset of symptoms.

Key areas for focus:

Quality statement 1: Information and support at diagnosis

Adults diagnosed with motor neurone disease (MND) are given information about the diagnosis, prognosis and management of MND by a consultant neurologist with expertise in treating people with MND.

Quality statement 2: Respiratory assessment and non-invasive ventilation

Adults with motor neurone disease (MND) who have respiratory impairment are offered non-invasive ventilation (NIV) based on regular assessments of respiratory function and symptoms.

Quality statement 3: Provision of equipment and adaptations based on multidisciplinary team assessment

Adults with motor neurone disease (MND) receive tailored equipment and adaptations without delay, based on regular multidisciplinary team assessments.

Quality statement 4: Continuity of care

Adults with motor neurone disease (MND) receive personal care and support from a consistent team of workers who are familiar with their needs.

Quality statement 5: Planning for end of life care

Adults with motor neurone disease (MND) are given opportunities to discuss their preferences and concerns about end of life care at diagnosis and key stages of disease progression.

Guidance & Best Practice

System Improvement Priority: Increasing knowledge and awareness of the signs and symptoms of MND

MND is a rare condition affecting approximately 5,000 people at any one time, as such general practitioners and health professionals may only come across 1 or 2 presentations of early onset symptoms in their professional working life and patients may therefore experience delays in being referred into neurology or specialist services for diagnosis.

Key areas for focus:

Fast track symptom pathway for suspected MND

Early diagnosis is important in order to enable options for appropriate treatment to be discussed; however it is particularly important with unexplained neurological symptoms or signs for suspected MND due to the rapid deterioration and prognosis of this condition.

Appointment within 4 weeks of referral to a neurologist

Ensuring patients with suspected MND are seen within 4 weeks of referral is imperative because a confirmed diagnosis of MND will require immediate support and assessment of current symptoms and needs.

Follow up appointment within 4 weeks after diagnosis

Receiving a diagnosis of MND is distressing for a person, and they (and their family members or carers) are likely to have a variety of questions that they may not have been able to ask when they received their diagnosis.

MND services to take part in audit and quality improvement programmes

Participating in clinical quality and audit programmes will provide a benchmark of the quality of services that patients with MND are receiving in your area.

Guidance & best practice

Actions to Take

System Improvement Priority: Increasing knowledge and awareness of the signs and symptoms of MND

Key area for focus	Actions to take
Fast track symptom pathway for suspected MND	<ul style="list-style-type: none">Ensure that training and/or education sessions on the signs and symptoms of MND is available for all healthcare professionalsHave a local protocol in place to ensure rapid referral to secondary care services if MND is suspected.
Appointment within 4 weeks of referral to a neurologist	<ul style="list-style-type: none">Where a patient is suspected to have MND ensure that this is clearly and explicitly stated on the referral letter to secondary care.Have a process in place to ensure that suspected MND patients are seen within 4 weeks of referral.
Follow up appointment within 4 weeks after diagnosis	<ul style="list-style-type: none">Have a prioritisation process in place to ensure that people who are diagnosed with MND are seen within 4 weeks of their diagnosis.
MND services to take part in audit and quality improvement programmes.	<ul style="list-style-type: none">Employ the use of tools such as the NICE baseline assessment tool or the Transforming MND Care audit tool at a local levelAct upon the outcomes of the audit tools to address any gaps in service quality or provision, in line with NICE guidelines.

System Improvement Priority: Consistent access to multidisciplinary community based care

A consistent team of multidisciplinary and personal care workers can ensure familiarity with the person with MND and their specific needs. It provides consistency of care and enables close monitoring of rapidly-changing needs. This avoids care needs having to be repeatedly explained to new workers. Such explanations can be difficult for people with MND, who may have reduced communication abilities and need a family member or carer to be present to help them. Providing care closer to home in community clinics will allow patients whose mobility has deteriorated to avoid travelling long distances.

Key areas for focus:

Ongoing coordinated care provided in community based settings from an MDT with access to specialist MND expertise.

Care for people with MND is complex and requires a variety of professionals to support the person and their family as their condition changes.

Guidance & best practice

MDT to undertake regular reviews (every 2-3 months) of patients symptoms and needs in line with NICE recommendations (1.5.2)

Regular review of a persons symptoms and needs should be undertaken to ensure that any changing needs are supported and that quality of life is maintained for as long as possible.

Guidance & best practice

3 month SALT review for all MND patients

SALT has been specifically highlighted in this toolkit as the outcome of the initial assessment will determine whether the person can be managed by the local service or require more complex support

Guidance & best practice

Regular review of saliva control using clinical saliva score tool

Regular review and management of saliva control is important to ensure that the person does not suffer from choking when eating, drinking or swallowing particularly as muscle function deteriorates and coughing may no longer be possible to clear any blockages.

Guidance & best practice

Medication to treat saliva problems in line with NICE guidance

All medication prescribed to treat saliva problems should be based on NICE guidelines.

Guidance & best practice

Actions to Take

Actions to Take

System Improvement Priority: Consistent access to multidisciplinary community based care

Key area for focus	Actions to take
Ongoing coordinated care provided in community based settings from an MDT with access to specialist MND expertise.	<ul style="list-style-type: none"> • Ensure all patients with MND are under the care of an MDT. • Understand numbers of people living with MND in the local population and match MDT team capacity to this demand. • MDT to be comprised of healthcare professionals and social care practitioners with expertise in MND and staff who will see people in their home.
MDT to undertake regular reviews of patients symptoms and needs in line with NICE recommendations	<ul style="list-style-type: none"> • Ensure that there is a robust processes in place to assess the following on a regular basis: <ul style="list-style-type: none"> • Weight, diet, nutritional intake and fluid intake, feeding and swallowing • Muscle problems, such as weakness, stiffness and cramps • Physical function, including mobility and activities of daily • Saliva problems, such as drooling of saliva (sialorrhoea) and thick, tenacious saliva • Speech and communication • Cough effectiveness • Respiratory function, respiratory symptoms and non-invasive ventilation • Pain and other symptoms, such as constipation. • Cognition and behaviour • Psychological support needs • Social care needs • End of life care needs
3 month SALT review	<ul style="list-style-type: none"> • Ensure that MND patients have regular appointments scheduled with SALT teams. • If the person's needs are too extensive to be managed by a local SALT team, ensure there is a robust referral process in place to be seen by a specialist team

Progressive Neuro Summary

Progressive Neuro System Improvement Priorities

Motor Neurone Disease (MND)

MND System Improvement Priorities:

NICE 5 Quality Statements

Knowledge and awareness of the signs and symptoms of MND

Multidisciplinary community based care

Specialist and personalised equipment and support

Anticipatory and advanced care planning

Other conditions:

Parkinson's

MSA, PSP & CBD

Multiple Sclerosis

NICE Quality Standards

Guidance & Best Practice

Additional Tools:

RightCare neurology resources

Shared Decision Making

Elective Care handbook

System Improvement Priority: Consistent access to multidisciplinary community based care

Key area for focus	Actions to take
Regular review of saliva control using clinical saliva score tool	<ul style="list-style-type: none">Employ use of a saliva tool such as CSS-MND to assess saliva control
Medication to treat saliva problems in line with NICE guidance	<ul style="list-style-type: none">Have local protocols to be in place to ensure that prescribing is in line with NICE guidance for saliva medication

Guidance and best practice examples

System Improvement Priority: Timely access to specialist and personalised equipment and support

People with MND can have multiple functional problems and may therefore have complex equipment needs that will change as MND progresses. Regular assessment by the MND multidisciplinary team can ensure the provision of equipment and adaptations is responsive to a person's changing needs. Providing equipment and adaptations without delay maximises the impact on the person's quality of life, allowing them to continue with usual activities and reduce the likelihood of harm from adverse events such as falls.

Key areas for focus:

Commissioners to adopt the NHS model service specification for wheelchair services

Wheelchair services should aim to provide an efficient, cost effective service that is person-centred and supports individuals, their families and carers to achieve improved quality of life and independence through timely provision of the right wheelchair and associated equipment at the right time.

Guidance & best practice

Advanced wheelchair prescribing of a chair that can be adapted as the person's needs change, with regular review and adaption as needed.

Equipment, adaptations, daily living aids, and assistive technology should be provided and be suitable to meet the changing needs of the patient. All equipment should be able to be integrated e.g. AAC devices with wheelchairs.

Guidance & best practice

Cognitive ability and capacity should be assessed by a qualified assessor for all decision making, with referral as appropriate to clinical neuropsychology for treatment and care.

Although cognitive assessment doesn't need to be undertaken by a neuropsychologist, there should be access to one through referral if the outcome of the screen requires it.

Guidance & best practice

Actions to Take

System Improvement Priority: **Timely access to specialist and personalised equipment and support**

Key area for focus	Actions to take
Commissioners to adopt the NHS model service specification for wheelchair services.	<ul style="list-style-type: none">Commission a wheelchair service based against the NHS Model Service Specification.Ensure submission of your wheelchair service data to the quarterly collection.
Advanced wheelchair prescribing of a chair that can be adapted as the person's needs change, with regular review and adaption as needed.	<ul style="list-style-type: none">Ensure that all wheelchairs prescribed for MND patients are based on individual needs and are not generic wheelchairs.Ensure that the wheelchair, plus any required modifications, is provided in an acceptable timescale to the Service User.Re-assess the Service User within agreed timescale to ensure the wheelchair and seating continue to meet their individual needs .Ensure there is a protocol or referral process in place if a person needs to change/upgrade their wheelchair due to changing needs.
Cognitive ability and capacity should be assessed by a qualified assessor for all decision making, with referral as appropriate to clinical neuropsychology for treatment and care.	<ul style="list-style-type: none">Assessments for cognitive ability should be undertaken by a qualified assessor.Have local protocols in place to refer to a clinical neuropsychologist where appropriate.

System Improvement Priority: Anticipatory and advanced care planning through specialist care coordinators

MND can present in different ways and the prognosis may be variable, but the majority of people with MND die within 2–3 years of diagnosis. Discussions about end of life are difficult, but sensitive discussions can address concerns and result in increased support, control and choice for the person and their families and carers. Such discussions can take place at any time, but there are particular times when people should be given the chance to discuss the topics. These times include at diagnosis, if there is a significant change in respiratory function, or if interventions such as gastrostomy or non-invasive ventilation are needed.

Key areas for focus:

Patients, carers & families given information and advice on legal rights and support services.

Ensure people are provided with information about MND and support at diagnosis or when they ask for it to support them as their condition deteriorates.

Guidance & best practice

Anticipatory medication to be prescribed for at home

Suitable anticipatory medicines and routes should be prescribed as early as possible so that the person has them available to manage symptoms likely to occur during their last days of life.

Guidance & best practice

Early identification of respiratory impairment and preference for NIV

It is important to undertake regular assessment of respiratory function and to know the person's wishes for NIV as respiratory function may decrease rapidly.

Guidance & best practice

Advance care plans to be in place, which may include ADRT, LPA, preferred place of care, DNACPR.

Early planning for care at the end of life ensures that families and professionals can be made aware of a person's wishes for end of life care before communication or cognitive changes make this difficult or impossible.

Guidance & best practice

Actions to Take

Progressive Neuro Summary

Progressive Neuro System Improvement Priorities

Motor Neurone Disease (MND)

MND System Improvement Priorities:

NICE 5 Quality Statements

Knowledge and awareness of the signs and symptoms of MND

Multidisciplinary community based care

Specialist and personalised equipment and support

Anticipatory and advanced care planning

Other conditions:

Parkinson's

MSA, PSP & CBD

Multiple Sclerosis

NICE Quality Standards

Guidance & Best Practice

Additional Tools:

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System Improvement Priority: Anticipatory and advanced care planning through specialist care coordinators

Key area for focus	Actions to take
Patients, carers & families given information and advice on legal rights and support services.	<ul style="list-style-type: none">Have a local directory of services and support available which enables ease of signposting or referral for people with MND to the services they may find useful, including the MND Association / helpline.
Anticipatory medication to be prescribed for at home	<ul style="list-style-type: none">Have a process in place to ensure that suitable anticipatory medicines and routes are prescribed as early as possible.Review these medicines as the person's needs change.
Early identification of respiratory impairment and preference for NIV	<ul style="list-style-type: none">Have a protocol in place to assess regularly and monitor respiratory function.Ensure the persons wishes and preference for NIV is recorded.
Advance care plans to be in place, which may include ADRT, LPA, preferred place of care, DNACPR.	<ul style="list-style-type: none">Ensure that advance care plans are recorded in a timely manner and ensure this is known to the family and carers as well as held by all agencies the person engages with.Staff working with people with MND are confident to recognise that a person is approaching the end of their life and act on this understanding.Staff working with people with MND are confident in recognising that a person is approaching the end of their life and feel equipped to engage effectively with patients/carers to discuss end of life care.If not are quality improvement plans in place to address this?

Guidance and best practice examples

Parkinson's

Parkinson's System Improvement Priorities:

Increased use of specialist staff

Quality patient centred care

Data and technology

Anticipatory and advanced care planning

Other conditions:

Motor Neurone Disease

MSA, PSP & CBD

Multiple Sclerosis

NICE Quality Standards

Guidance & Best Practice

Additional Tools:

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Elective Care handbook

RightCare Toolkit: Parkinson's

This RightCare system toolkit will support systems to understand the priorities in care for those people who are living with Parkinson's. It provides the opportunity to assess and benchmark current systems to find opportunities for improvement. **In this RightCare toolkit each priority has supporting slides that contain 'key areas of focus' and 'actions to take'.** It is produced with reference to an expert group of stakeholders and is supported by NICE. Wider consultation has taken place with patient representatives, clinicians, social care organisations, professional bodies and other [key stakeholders](#).

The National Challenge for Parkinson's

- Increase knowledge of signs and symptoms for Parkinson's
- Reducing hospital admissions
- Widespread implementation of integrated services

System Enablers

Commission services based on:

Nationally agreed service specifications:

[NHS England Service Specification for Neurosciences Specialised Neurology \(adult\)](#)

Shared decision making, care planning, and multidisciplinary working:

- [Joint consensus statement on shared decision making](#)
- [Resources for shared decision making](#)
- [Joint consensus statement on multidisciplinary team working](#)
- [Resources for MDT working](#)
- NICE - [Shared Decision Making, Making Every Contact Count \(MECC\) STP Resource](#)
- NICE - [Patient experience in adult NHS services: Improving the experience of care for people using adult NHS services](#), Recommendation 1.5.20
- Public Health England - [Making Every Contact Count \(MECC\): practical resources](#)

NICE Guidance

[Parkinson's NICE pathway](#)

[NG71 Parkinson's disease in adults](#)

[QS164 Parkinson's disease](#)

Parkinson's System Improvement Priorities



Increased use of specialist staff
across the pathway



Better use of data and technology
across different healthcare settings



Ongoing quality patient centred care
in both acute and community
settings



Anticipatory and advance care
planning

Parkinson's

Parkinson's System Improvement Priorities:

Increased use of specialist staff

Quality patient centred care

Data and technology

Anticipatory and advanced care planning

Other conditions:

Motor Neurone Disease

MSA, PSP & CBD

Multiple Sclerosis

NICE Quality Standards

Guidance & Best Practice

Additional Tools:

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System Improvement Priority: Increased Use of Specialist Staff Across the Pathway

Increasing the use of specialist staff, including therapists, across the pathway would ensure that people with Parkinson's get the highest level of care in a safe and effective environment. Nurse specialists play a key role in supporting people with Parkinson's, but they could be ably supported in their role by increasing the use of the wider specialist workforce such as community pharmacists.

Key areas for focus:

Core MDT to include Consultant with a special interest in Movement Disorders, PDNS (Prescriber), Therapists – Physio, SLT, OT (Neuro therapists with an interest in Parkinson's) who need to meet regularly and work together

A core MDT will ensure that the best outcomes are achieved from specialist resources by ensuring that the right members of the multidisciplinary team are involved at the optimal time for patient care.

Guidance & best practice

Enhanced/ Integrated MDT to include a psychologist and pharmacist with a special interest in Parkinson's

Including wider specialist of psychologists and pharmacists into the MDT will be better placed to treat more complex patients and improve patient outcomes.

Guidance & best practice

Clinical pharmacists to undertake enhances Structured Medication Reviews

The appropriate use of medicines is crucial to the management of Parkinson's, however effective management can be time consuming and complex and may present challenges to achieve this in primary care. Pharmacists are expert on all aspects of medication management including prescription screening, interactions, side effects, adherence and establishing pathways and protocols for prescribing and dispensing drugs and are therefore well placed to support medication review for people with Parkinson's.

Guidance & best practice

Actions to Take

Parkinson's

Parkinson's System Improvement Priorities:

Increased use of specialist staff

Quality patient centred care

Data and technology

Anticipatory and advanced care planning

Other conditions:

Motor Neurone Disease

MSA, PSP & CBD

Multiple Sclerosis

NICE Quality Standards

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Additional Tools:

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System Improvement Priority: Increased Use of Specialist Staff Across the Pathway

Key area for focus	Actions to take
Core MDT to include Consultant with a special interest in Movement Disorders, PDNS (Prescriber), Therapists –Physio, SLT, OT (Neuro therapists with an interest in Parkinson's)	<ul style="list-style-type: none"> Understand numbers of people living with Parkinson's in the local population and match MDT team skills to this demand Ensure that there is a core MDT in place for people with Parkinson's that comprises of specialists in Parkinson's as well as therapeutic services Ensure Parkinson's nurse specialists, therapists and health and care staff have the skills and knowledge as outlined in the learning pathways and the Parkinson's nurse competency framework
Enhanced/ Integrated MDT to include a psychologist and pharmacist with a special interest in Parkinson's	<ul style="list-style-type: none"> Utilise wider specialist input into MDTs to provide input into complex cases If wider specialist input is not available within the MDT, ensure that there are processes in place to access specialist input as required.
Clinical pharmacists to undertake enhanced Structured Medication Reviews	<ul style="list-style-type: none"> Clinical pharmacists within Primary Care Networks (PCNs) to undertake enhanced Structured Medication reviews in line with the The Community Pharmacy Contractual Framework for 2019/20 to 2023/24: supporting delivery for the NHS Long Term Plan Use the Parkinson's UK learning foundation modules for pharmacists

Parkinson's

Parkinson's System Improvement Priorities:

Increased use of specialist staff

Quality patient centred care

Data and technology

Anticipatory and advanced care planning

Other conditions:

Motor Neurone Disease

MSA, PSP & CBD

Multiple Sclerosis

NICE Quality Standards

Guidance & Best Practice

Additional Tools:

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System Improvement Priority: Ongoing quality patient centred care in both acute and community settings

Parkinson's is a complex and chronic condition and it is accepted that people with Parkinson's receive the best care within specialist Parkinson's or movement disorder clinics. Within the specialist clinic setting, this is further supported by an integrated whole systems approach to be provided by a multidisciplinary team. This ensures the best quality of life for the person with Parkinson's and their families

Key areas for focus:

Medicine optimisation, including time adherence for Levodopa

Serious complications can develop if levodopa is not taken on time. These include acute akinesia and, if delays are significant, neuroleptic malignant syndrome. These complications can lead to increased care needs and increased length of stay in hospital or a care home.

Signposting to Parkinson's UK local advisers and patient support services

Having Parkinson's can feel overwhelming if people are not provided with the right information and support when they need it.

Care coordination to reduce duplication of tests and appointments and to improve referral pathways

Every patient should have a care coordinator assigned to them to ensure that their relevant information is available at appointments and to reduce the duplication of tests

All Parkinson's services to take part in audit programme and in Quality Improvement Programme based on the outcomes of the Parkinson's Clinical Audit.

Guidance & best practice

Actions to Take

Parkinson's

Parkinson's System Improvement Priorities:

Increased use of specialist staff

Quality patient centred care

Data and technology

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Other conditions:

Motor Neurone Disease

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Multiple Sclerosis

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System Improvement Priority: Ongoing quality patient centred care in both acute and community settings

Key area for focus	Actions to take
Medicine optimisation, including time adherence for Levodopa	<ul style="list-style-type: none">Have local protocols in place around the use and administration of medication to treat Parkinson'sHave self-administration of medication policies, protocols, information resources and equipment in place and ensure staff are aware of how to implement the policyEnsure local protocols are in line with NICE guidance
Signposting to local Parkinson's advisors and local patient support services	<ul style="list-style-type: none">Have a local directory of services and support available which enables ease of signposting or referral for people with Parkinson's to the services they may find useful.Utilise the national Parkinson's UK website for access to resources
Care coordination to reduce duplication of tests and appointments and to improve referral pathways	<ul style="list-style-type: none">Have a network of care coordinators/ facilitators/ equivalent role to support patient journeys through the system
All services to take part in audit programme and to take part in Quality Improvement Programme based on the outcomes of the Parkinson's Clinical Audit.	<ul style="list-style-type: none">Providers of Parkinson's service should take part in the Parkinson's Clinical AuditLocal areas should look at their Excellence Network Data Dashboards to understand their current secondary care and prescribing use locally and to identify areas of improvement.

Parkinson's

Parkinson's System Improvement Priorities:

Increased use of specialist staff

Quality patient centred care

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System Improvement Priority: Better use of data and technology across different healthcare settings

Improving access to data and technology will improve patient care as information will be real time and also will not require the person to have to continually repeat their information which takes up valuable clinic time.

Key areas for focus:

Consistent use of evidence based standardised assessment and outcomes frameworks across settings

Use of standardised assessments across all care settings will facilitate better patient care and ensure that disease progression can be monitored effectively

Use of virtual clinics for routine follow up appointments

Virtual clinics allow patients whose mobility has deteriorated to avoid travelling, instead having consultations on the phone or via video conferencing. It also increases efficiency of a specialist service as it means patients are less likely to miss appointments due to travel difficulties.

Use of technology to share information about medications and care between settings

To improve and streamline patient care, the ability to share information between specialist and community settings is important and is currently undertaken by email or fax because access to patient information systems is not shared between providers or settings.

Guidance & best practice

Actions to Take

Progressive Neuro Summary

Progressive Neuro System Improvement Priorities

Parkinson's

Parkinson's System Improvement Priorities:

Increased use of specialist staff

Quality patient centred care

Data and technology

Anticipatory and advanced care planning

Other conditions:

Motor Neurone Disease

MSA, PSP & CBD

Multiple Sclerosis

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System Improvement Priority: **Better use of data and technology across different healthcare settings**

Key area for focus	Actions to take
Consistent use of evidence based standardised assessment and outcomes frameworks across settings	<ul style="list-style-type: none">Utilise standard assessment monitoring/ forms across all settings
Use of virtual clinics for routine follow up appointments	<ul style="list-style-type: none">Where appropriate for the patient implement virtual clinics e.g. use of skype or telemedicine for routine appointments
Use of technology to share information about medications between settings	<ul style="list-style-type: none">Work at a local level to improve sharing of information between primary, secondary and social care settings

Guidance and best practice examples

Parkinson's

Parkinson's System Improvement Priorities:

Increased use of specialist staff

Quality patient centred care

Data and technology

Anticipatory and advanced care planning

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System Improvement Priority: Anticipatory and advance care planning

Sensitive discussions about end of life are difficult, but these discussions can address concerns and result in increased support, control and choice for the person and their families and carers. Such discussions can take place at any time, but there are particular times when people should be given the chance to discuss the topics. These times include at diagnosis, if there is a significant change in symptoms such as respiratory function, if interventions such as gastrostomy or non-invasive ventilation are needed or there are repeated infections or hospital admissions. These discussions should always be recorded to ensure other professionals know the individual's needs and wishes.

Key areas for focus:

6-12mth reviews with specialist/ consultant to identify changing needs early.

It is important to recognise the changing needs of the person and what support they will need in light of these changes.

Ongoing reviews to include discussion and agreement of advance care plans.

Early planning for care at the end of life ensures that families and professionals can be made aware of a person's wishes for end of life care before communication or cognitive changes make this difficult or impossible.

Actions to take:

6-12 month reviews with specialist/ consultant to identify changing needs early.

- Have a process in place to ensure that all patients are reviewed at least annually to identify any changing needs.
- Ensure that discussions about end of life are conducted at any time that is required.

Ongoing reviews to include discussion and agreement of advanced care plans.

- Ensure that advanced care plans are recorded in a timely manner and ensure this is known to the family and carers as well as held by all agencies the person engages with.
- Staff working with people with Parkinson's are confident to recognise that a person is approaching the end of their life and act on this understanding
- Staff working with people with Parkinson's are confident to recognise that a person is approaching the end of their life and feel equipped to engage effectively with patients/carers to discuss end of life care.
- If not are quality improvement plans in place to address this?

Guidance & best practice

MSA, PSP & CBD

MSA, PSP & CBD System Improvement Priorities:

Quicker and accurate diagnosis

Multidisciplinary team working

Specialist and personalised equipment and support

Anticipatory and advanced care planning

Other conditions:

Motor Neurone Disease

Parkinson's

Multiple Sclerosis

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Additional Tools:

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RightCare Toolkit: **Multiple System Atrophy (MSA), Progressive Supranuclear Palsy (PSP) and Corticobasal Degeneration (CBD)**

This RightCare system toolkit will support systems to understand the priorities in care for those people who are living with MSA, PSP or CBD. It provides the opportunity to assess and benchmark current systems to find opportunities for improvement. **In this RightCare toolkit each priority has supporting slides that contain 'key areas of focus' and 'actions to take'.**

The National Challenge for MSA, PSP and CBD

- Increasing knowledge of signs and symptoms for MSA, PSP and CBD
- Reducing hospital admissions
- Widespread implementation of integrated services

System Enablers

Commission services based on:

Nationally agreed service specifications:

[NHS England Service Specification for Neurosciences Specialised Neurology \(adult\)](#)

Shared decision making, care planning, and multidisciplinary working:

- [Joint consensus statement on shared decision making](#)
- [Resources for shared decision making](#)
- [Joint consensus statement on multidisciplinary team working](#)
- [Resources for MDT working](#)
- NICE - [Shared Decision Making, Making Every Contact Count \(MECC\) STP Resource](#)
- NICE - [Patient experience in adult NHS services: Improving the experience of care for people using adult NHS services](#), Recommendation 1.5.20
- Public Health England - [Making Every Contact Count \(MECC\): practical resources](#)

Multiple System Atrophy (MSA), Progressive Supranuclear Palsy (PSP) and Corticobasal Degeneration (CBD) System Improvement Priorities



Quicker and accurate diagnosis



Timely access to specialist and personalised equipment and support



Use of Multi Disciplinary Team Working



Anticipatory and advance care planning

MSA, PSP & CBD

MSA, PSP & CBD System Improvement Priorities:

Quicker and accurate diagnosis

Multidisciplinary team working

Specialist and personalised equipment and support

Anticipatory and advanced care planning

Other conditions:

Motor Neurone Disease

Parkinson's

Multiple Sclerosis

NICE Quality Standards

Guidance & Best Practice

Additional Tools:

RightCare neurology resources

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System Improvement Priority: **Quicker and accurate diagnosis**

MSA is a condition with a similar prevalence to MND (c4,000 patients at any one time), and along with PSP and CBD, the symptoms and signs may be complex and can be similar to a range of other neurological conditions. This can mean that patients are misdiagnosed in the first instance and a diagnosis may only be made after exclusion of other diseases and over time. There is little in the evidence base about best practice to treat MSA, PSP and CBD and there are also no associated NICE guidance or quality standards available for these conditions. However commissioners should be aware of them as the issues and optimal system components facing the group of people with these life limiting conditions is similar to that of both MND and Parkinson's.

Key areas for focus:

Supporting professionals to recognise the early signs of MSA, PSP and CBD.

The symptoms of MSA, PSP and CBD are similar to Parkinson's and so patients may have a delayed diagnosis whilst these other conditions are ruled out.

Recognition of symptoms should trigger early referral to movement disorder specialist/neurologist to clarify diagnosis.

Ensuring an accurate diagnosis by a movement disorder specialist or a neurologist will ensure that patients can start to be supported with their symptom management as soon as possible.

Regular assessment of symptoms - especially for postural hypotension / incontinence/ constipation/ stridor / pain.

All symptoms should be regularly assessed so that the patient is supported, e.g. by a key worker, as their condition changes or deteriorates.

Ensure correct diagnosis coding recorded in all patient records and that diagnosis included on death certificates.

Improving recorded coding on all patient records will ensure that patients are managed appropriately for their condition in all healthcare settings. Ensuring that the correct coding is used on death certificates will improve the understanding of the prevalence of the condition.

Guidance & best practice

Actions to Take

Progressive Neuro Summary

Progressive Neuro System Improvement Priorities

MSA, PSP & CBD

MSA, PSP & CBD System Improvement Priorities:

Quicker and accurate diagnosis

Multidisciplinary team working

Specialist and personalised equipment and support

Anticipatory and advanced care planning

Other conditions:

Motor Neurone Disease

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System Improvement Priority: **Quicker and accurate diagnosis**

Key area for focus	Actions to take
Supporting professionals to recognise the early signs of MSA, PSP or CBD.	<ul style="list-style-type: none">Ensure that training and/or education sessions on the signs and symptoms of MSA, PSP and CBD is available for healthcare professionals.
Recognition of symptoms should trigger early referral to movement disorder specialist/neurologist to clarify diagnosis.	<ul style="list-style-type: none">Ensure referral to a movement disorder specialist or neurologist to make the diagnosis of MSA, PSP or CBD once symptoms have been recognised.
Regular assessment of symptoms - especially for postural hypotension / incontinence/ constipation/ stridor / pain	<ul style="list-style-type: none">Undertake regular neurological appointments and assessments to assess changing symptomsHave a robust protocol in place to systematically review and record symptomsHave a system in place to refer onto other specialities e.g. respiratory, urology if indicated or assessment is required.
Ensure correct diagnosis coding recorded in all patient records and that diagnosis included on death certificates	<ul style="list-style-type: none">ICD10 codes for MSA, PSP and CBD should be consistently recorded on patient records: (G90.3 for MSA, G23.1 for PSP, G31.8 for CBD).Work with clinical coders to ensure that the correct coding is used on all patient records.

Guidance and best practice examples

MSA, PSP & CBD

MSA, PSP & CBD System Improvement Priorities:

Quicker and accurate diagnosis

Multidisciplinary team working

Specialist and personalised equipment and support

Anticipatory and advanced care planning

Other conditions:

Motor Neurone Disease

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System Improvement Priority: Use of Multi Disciplinary Team Working

A consistent team of multidisciplinary and personal care workers can ensure familiarity with the person with MSA, PSP or CBD and their specific needs. This avoids care needs having to be repeatedly explained to new workers. Such explanations can be difficult for people with MSA, PSP or CBD who may have reduced communication abilities and need a family member or carer to be present to help them. Providing care closer to home, where appropriate, in community clinics will allow patients whose mobility has deteriorated to avoid travelling long distances.

Key areas for focus:

Regular consultations with specialists.

Due to the rapid deterioration in these conditions it is important that people are seen on a regular basis by specialists (for example biannually with a neurologist and biannually with a nurse specialist e.g. patient is seen every 3 months). Consultations may need to be more often if there is quicker deterioration or the development of new symptoms. Consider need for extended appointments to enable shared decision making as people may have impaired communication and processing ability.

Effective and responsive medicines and care plans provided with associated co-ordinated MDT services.

An MDT that consists of a range of services will ensure more holistic and joined up care for the patient.

Effective data sharing between all professionals involved in care and support.

Shared care records and data will ensure that the patient does not need to keep repeating themselves particularly, when communication skills deteriorate.

Optimise medication regime with 3 monthly review.

Ensuring medication is reviewed every 3 months, or on deterioration of condition, to take into account any changes in symptoms.

Care-coordinators to assist people with referrals and interventions in a timely manner.

A care coordinator will ensure that people with MSA, PSP, CBD and their families/carers are supported in how to access, in a timely way, different parts of the system.

Guidance & best practice

Actions to Take

Progressive Neuro Summary

Progressive Neuro System Improvement Priorities

MSA, PSP & CBD

MSA, PSP & CBD System Improvement Priorities:

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System Improvement Priority: Use of Multi Disciplinary Team Working

Key area for focus	Actions to take
Regular consultations with specialists.	<ul style="list-style-type: none">Have six monthly appointments with the neurologist and 6 monthly appointments with a nurse specialist e.g. seen every 3 monthsConsider need for extended appointments to enable shared decision making as people may have impaired communication and processing ability.
Effective and responsive medicines and care plans provided with associated co-ordinated MDT services.	<ul style="list-style-type: none">Ensure that the MDT consists of: community neurotherapy team, neuropsychology, pharmacist, neuro-urologist, speech and language therapist, dietitian and specialist palliative care team.
Effective data sharing between all professionals involved in care and support.	<ul style="list-style-type: none">Ensure that patient records are able to be shared across the professionals looking after the patient to avoid unnecessary repetition and duplication
Optimise medication regime with 3 monthly review.	<ul style="list-style-type: none">Ensure there is a protocol in place to review medications on a 3 monthly basisClinical pharmacists within Primary Care Networks (PCNs) to undertake enhanced Structured Medication reviews in line with the The Community Pharmacy Contractual Framework for 2019/20 to 2023/24: supporting delivery for the NHS Long Term Plan
Care-coordinators to assist people with referrals and interventions in a timely manner.	<ul style="list-style-type: none">Have a network of care coordinators/ facilitators/ equivalent role to support patient journeys through the systemEnsure that all patients are provided with a named care coordinatorEnsure that the care coordinator is part of the MDT team

Guidance and best practice examples

MSA, PSP & CBD

MSA, PSP & CBD System Improvement Priorities:

Quicker and accurate diagnosis

Multidisciplinary team working

Specialist and personalised equipment and support

Anticipatory and advanced care planning

Other conditions:

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System Improvement Priority: **Timely access to specialist and personalised equipment and support**

People with MSA can have multiple functional problems and may therefore have complex equipment needs that will change as MSA progresses. Regular assessment by the MSA multidisciplinary team can ensure the provision of equipment and adaptations is responsive to a person's changing needs. Providing equipment and adaptations without delay maximises the impact on the person's quality of life, allowing them to continue with usual activities and reduce the likelihood of harm from adverse events such as falls.

Key areas for focus:

Commissioners to adopt the NHS model service specification for wheelchair services

Wheelchair services should aim to provide an efficient, cost effective service that is person-centred. This should support individuals, their families and carers to achieve improved quality of life and independence through timely provision of the right wheelchair, which can be adapted for future deterioration and needs, and associated equipment at the right time.

Anticipatory prescribing of appropriate equipment and adaptations to maximise independence including wheelchair prescribing with regular review for bespoke wheelchair modifications, particularly for posture, skin integrity, circulation and blood pressure management

It is important to have proactive planning and provision for specialist equipment, adaptations and wheelchairs in place as the person's needs can be unpredictable and provision is important for falls prevention and quality of life.

Open ended therapy support, including cognitive testing, to be in place due to rapidly progressing needs

It is important that patients are kept in a service and not discharged back out as their rapidly changing needs may mean that they need to be seen quickly.

Guidance & best practice

Actions to Take

MSA, PSP & CBD

MSA, PSP & CBD System Improvement Priorities:

Quicker and accurate diagnosis

Multidisciplinary team working

Specialist and personalised equipment and support

Anticipatory and advanced care planning

Other conditions:

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System Improvement Priority: **Timely access to specialist and personalised equipment and support**

Key area for focus	Actions to take
Commissioners to adopt the NHS model service specification for wheelchair services	<ul style="list-style-type: none"> Commission a wheelchair service based against the NHS Model Service Specification Ensure submission of your wheelchair service data to the quarterly collection Ensure wheelchair and other aids that are provided can be adapted to cope with future needs and can be used with other aids, such as AAC
Anticipatory prescribing of appropriate equipment and adaptations to maximise independence including wheelchair prescribing with regular review for bespoke wheelchair modifications, particularly for posture, skin integrity, circulation and blood pressure management	<ul style="list-style-type: none"> Ensure that all wheelchairs prescribed for MSA, PSP and CBD patients are based on individual needs and are not generic wheelchairs Ensure that the wheelchair, plus any required modifications, is provided in an acceptable timescale to the Service User Re-assess the Service User within agreed timescale to ensure the wheelchair and seating continue to meet their individual needs Ensure there is a protocol or referral process in place if a person needs to change/upgrade their wheelchair due to changing needs.
Open ended therapy support, including cognitive testing, to be in place due to rapidly progressing needs	<ul style="list-style-type: none"> Patients should be kept within a service rather than be discharged and have to be referred back in for an appointment Assessments for cognitive ability should be undertaken by a qualified assessor

Guidance and best practice examples

MSA, PSP & CBD

MSA, PSP & CBD System Improvement Priorities:

Quicker and accurate diagnosis

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System Improvement Priority: **Anticipatory and advance care planning**

MSA, PSP and CBD can present in different ways, and the prognosis for people with these conditions is hugely variable and unpredictable; but many will have a short prognosis. During the course of their disease it is important that people are supported not only in terms of their physical and cognitive symptoms but also in respect of their wishes for the end of their life and with a focus on quality of life. Discussions about end of life are difficult, but sensitive discussions can address concerns and result in increased support, control and choice for the person and their families and carers. Such discussions can take place at any time, but there are particular times when people should be given the chance to discuss the topics.

Key areas for focus:

Patients, families and carers should be provided with details on how to access medical care, information and support between outpatient appointments including signposting to local support services.

In between outpatient appointments the persons condition may deteriorate, families and carers should be aware of who and how to contact for medical advice or care where appropriate.

Guidance & best practice

Advice and training for patients/carers to recognise signs of infection and to take action to reduce hospitalisation.

Supporting families and carers to recognise the signs of infection that could be treated earlier, at home or through primary care will help to minimise unnecessary or distressing admissions to hospital.

Guidance & best practice

Providing guidance and support with eligible benefits, including Continuing Healthcare, referral to housing adaptations and grants advice in timely manner.

People with long-term complex health needs may qualify for free care arranged and funded solely by the NHS, however often patients and their families are often unaware of what support they may be entitled to.

Guidance & best practice

Actions to Take

MSA, PSP & CBD

MSA, PSP & CBD System Improvement Priorities:

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System Improvement Priority: Anticipatory and advance care planning (continued)

Key areas for focus:

Discussion on advance care planning to be started as early as possible due to rapidly changing communication ability and unpredictable prognosis.

Guidance & best practice

Access to specialist palliative support from diagnosis and specialist palliative care when required

People with MSA, PSP and CBD have a limited life expectancy after diagnosis and access to palliative care teams from the outset will ensure that the patient is supported throughout the progression of their disease.

Guidance & best practice

Anticipatory prescribing of medication for symptom control to minimise hospital admissions.

Suitable anticipatory medicines and routes should be prescribed as early as possible so that the person has them available to manage symptoms likely to occur which will minimise hospital admissions.

Guidance & best practice

People being supported to die in their chosen place whenever possible.

Early planning for care at the end of life ensures that families and professionals can be made aware of a person's wishes for end of life care before communication or cognitive changes make this difficult or impossible. Extra health and social care support may be needed at the end of life to support people at home. Discussion on advance care planning to be started as early as possible due to rapidly changing communication ability and unpredictable prognosis.

Guidance & best practice

Actions to Take

MSA, PSP & CBD

MSA, PSP & CBD System Improvement Priorities:

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Specialist and personalised equipment and support

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Other conditions:

Motor Neurone Disease

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System Improvement Priority: Anticipatory and advance care planning

Key area for focus	Actions to take
Patients, families and carers should be provided with details on how to access medical care, information and support between outpatient appointments including signposting to local support services.	<ul style="list-style-type: none"> Have a local directory of services available to support people with MSA, PSP and CBD including voluntary and charity support organisations from diagnosis and throughout the time a person is living with these conditions. Provide contact details for local support teams to provide advice when symptoms deteriorate.
Advice and training for patients/carers to recognise signs of infection and to take action to reduce hospitalisation.	<ul style="list-style-type: none"> Ensure families/ carers know who to contact when they identify possible signs of infection for advice on what to do.
Providing guidance and support with eligible benefits, including Continuing Healthcare, referral to housing adaptations and grants advice in timely manner.	<ul style="list-style-type: none"> Provide patients with details of benefits that they may be entitled to. Provide patients with details of local support groups who can provide support in making benefits claims
Discussion on advance care planning to be started as early as possible due to rapidly changing communication ability and unpredictable prognosis	<ul style="list-style-type: none"> Ensure that advance care plans are recorded in a timely manner and ensure this is known to the family and carers as well as held by all agencies the person engages with.
Access to palliative support from diagnosis and specialist palliative care when required	<ul style="list-style-type: none"> Engage with local palliative support teams to work with the patient and their family/carers when needed
Anticipatory prescribing of medication for symptom control to minimise hospital admissions.	<ul style="list-style-type: none"> Have a process in place to ensure that suitable anticipatory medicines and routes are prescribed as early as possible. Review these medicines as the person's needs change.
People being supported to die in their chosen place whenever possible	<ul style="list-style-type: none"> Staff working with people with MSA, PSP and CBD are confident in recognising that a person is approaching the end of their life and feel equipped to engage effectively with patients/carers to discuss end of life care and where they wish to die. Provide additional care and support to the individual and family to prepare to die at home.

Multiple Sclerosis (MS)

MS System Improvement Priorities:

Formalised MDTs across specialist teams

Data and technology

Improved DMD administration

Comprehensive access to holistic support

Other conditions:

Motor Neurone Disease

Parkinson's

MSA, PSP & CBD

NICE Quality Standards

Guidance & Best Practice

Additional Tools:

RightCare neurology resources

Shared Decision Making

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RightCare Toolkit: **Multiple Sclerosis (MS)**

This RightCare system toolkit will support systems to understand the priorities in care for those people who are living with multiple sclerosis. It provides the opportunity to assess and benchmark current systems to find opportunities for improvement. **In this RightCare toolkit each priority has supporting slides that contain 'key areas of focus' and 'actions to take'.**

The National Challenge for Multiple Sclerosis

- Increasing specialist nurse and neurologist capacity and getting the best value from MS services.
- Ensuring that high quality care is joined up and coordinated across the whole pathway for all MS patients.
- Improving care and coordination for advanced MS patients.
- Reducing the burden of the DMD pathway on MS services.

System Enablers

Commission services based on:

Nationally agreed service specifications:

[NHS England Service Specification for Neurosciences Specialised Neurology \(adult\)](#)

Shared decision making, care planning, and multidisciplinary working:

- [Joint consensus statement on shared decision making](#)
- [Resources for shared decision making](#)
- [Joint consensus statement on multidisciplinary team working](#)
- [Resources for MDT working](#)
- NICE - [Shared Decision Making](#), [Making Every Contact Count \(MECC\) STP Resource](#)
- NICE - [Patient experience in adult NHS services: Improving the experience of care for people using adult NHS services](#), Recommendation 1.5.20
- Public Health England - [Making Every Contact Count \(MECC\): practical resources](#)

NICE Guidance

[Multiple sclerosis NICE pathway](#)

[CG186 Multiple sclerosis in adults: management](#)

[QS108 Multiple sclerosis](#)

Multiple Sclerosis System Improvement Priorities



Formalised MDTs across specialist teams



Improved DMD administration



Better use of data and technology



Comprehensive access to holistic support (particularly for advanced MS patients)

Multiple Sclerosis (MS)

MS System Improvement Priorities:

Formalised MDTs across specialist teams

Data and technology

Improved DMD administration

Comprehensive access to holistic support

Other conditions:

Motor Neurone Disease

Parkinson's

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System Improvement Priority: Formalised MDTs across specialised teams

Increasing formal multidisciplinary working would help to get the best out of specialist resources by ensuring that the right members of the multidisciplinary team are involved at the optimal time for patient care.

Holistic MS care relies on a mix of disease modification, symptom management and neurorehabilitation. These services are currently delivered across multiple specialities and providers, which can present a barrier to multidisciplinary working. To deliver a seamless experience, services should endeavour to break down these barriers and establish formal ways of different professionals and different teams interacting, especially if they are not co-located. It is widely recognised that whilst the majority of MS services have good networks with other service providers in their locality, these networks are largely informal and often rely on goodwill between individual healthcare professionals rather than more robust, formalised care pathways and protocols.

Key areas for focus:

Ensure there is an appropriate level of administration support available to support specialists

Sufficient administrative support is an essential enabler to maximise an MS team's productivity and effectiveness, while making the most appropriate use of specialist's time. It is not cost effective or a good use of MS nurse expertise, for instance, for them to be undertaking all tasks along the DMD pathway. (See the [MS Trust Report](#) (p.13) for their recommendations on amount of administration support required)

Administrative support enables MS nurses to focus on clinical tasks requiring their specialist expertise, allowing them to deliver more effective services and therefore reduce the workload of other health professionals, particularly neurologists. A DMD coordinator, for example, can schedule and track DMD monitoring, liaise with homecare companies, resolve non clinical queries and maintain records.

Formal shared care MDT arrangements across a range of disciplines (including pharmacy and neuro-rehabilitation)

Formal multidisciplinary working helps get the best out of specialist resources by ensuring that the right members of the multidisciplinary team are involved at the optimal time.

Robust, formalised care pathways and protocols within MDTs, including joint meetings, help ensure sustainable delivery of holistic MS care, rather than informal networks that rely on goodwill between individual healthcare professionals.

Guidance & best practice

Actions to Take

System Improvement Priority: Formalised MDTs across specialised teams

Key areas for focus:

Named care coordinator for each patient

A single point of entry and contact for health and care needs characterises successful approaches to care coordination and is what people with MS want. It means that they know where to go when things change and are less likely to contact acute services unnecessarily. The care coordinator does not necessarily require a clinical background, but is part of the patient's MDT.

Guidance & best practice

Actions to take:

Ensure there is an appropriate level of administration support available to support specialists

- Review current administration support
- Ensure that nurse specialists have dedicated administration support available to them

Formal shared care MDT arrangements across a range of disciplines

- Formalise MDT networks across different healthcare settings

Named care coordinator for each patient

- Have a network of care coordinators/ facilitators/ equivalent role to support patient journeys through the system
- Ensure that all patients are provided with a named care coordinator
- Ensure that the care coordinator is part of the MDT team

Multiple Sclerosis (MS)

MS System Improvement Priorities:

Formalised MDTs across specialist teams

Data and technology

Improved DMD administration

Comprehensive access to holistic support

Other conditions:

Motor Neurone Disease

Parkinson's

MSA, PSP & CBD

NICE Quality Standards

Guidance & Best Practice

Additional Tools:

RightCare neurology resources

Shared Decision Making

Elective Care handbook

System Improvement Priority: Better use of data and technology

Improving access to data and technology will improve patient care as information will be real time and also will not require the person to have to continually repeat their information which takes up valuable clinic time.

Key areas for focus:

Shared protocols on information sharing across MS teams and providers

Where care is shared between more than one MS team, for example with a neuroscience centre prescribing DMDs and monitoring undertaken by MS nurses in the community, communication of test results is frequently done by email or even fax because access to patient information and pathology systems is not shared between providers.

Similarly, whilst some GPs are happy to take on responsibility for phlebotomy for blood monitoring within their surgeries, many MS centres are unable to view the results if the surgery is outside their local area and uses a different laboratory. MS teams at prescribing centres therefore spend a huge amount of time chasing up results from other teams and professionals, with increased clinical risk that monitoring will be missed. In many cases, the informatics-related barriers to phlebotomy being available locally are so insurmountable that people with MS have to travel many miles to a neuroscience centre simply to have blood taken

Robust DMT monitoring systems in place

It is essential that the DMD coordinator has access to a system for tracking everyone on the caseload taking a DMD, enabling them to see who is due for monitoring and who has had this. Systems do not necessarily need to be high-tech and a good Excel database can be a very effective tool. Examples include:

- Many hospital information systems which now allow for scheduling of planned monitoring and flag anomalies.
- MS Specific database systems, such as iMed and DAWN

Guidance & best practice

Actions to Take

Multiple Sclerosis (MS)

MS System Improvement Priorities:

Formalised MDTs across specialist teams

Data and technology

Improved DMD administration

Comprehensive access to holistic support

Other conditions:

Motor Neurone Disease

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NICE Quality Standards

Guidance & Best Practice

Additional Tools:

RightCare neurology resources

Shared Decision Making

Elective Care handbook

System Improvement Priority: Better use of data and technology (continued)

Key areas for focus:

Use of digital tools to support people with MS to self-manage their condition where appropriate

If someone with MS is able to manage their condition and symptoms effectively they are more likely to maintain a high quality of life and less likely to need health services. Technology has great potential to help people with MS do this, from use of apps to online patient networks. Clinicians need to be aware of a patient's level of activation, health literacy and understanding, targeting information accordingly when giving patients advice on how to manage their MS and using digital tools to do so.

(This recommendation is based on a recent Nuffield Trust Report (July 2018) commissioned by the MS Society - [Improving care for people with MS: the potential of data and technology](#) (Chapter 2) and is not included in the 2014 NICE guidance)

Digital care planning employed where appropriate

Effective care planning empowers patients to manage their condition and should ensure services are well coordinated around their needs.

Digital technology provides the opportunity for all patients to be able to easily access their care plan which they can share with their entire health care team as well as carers and relatives. The Professional Record Standards Body in conjunction with NHS Digital has developed a template integrated care plan setting out the core components.

This would be further enhanced if there was seamless record sharing across the NHS so that professionals could see the agreed care plan as well as treatment records. Electronic links would also give professionals an easy way to refer to each other, maximising the chances that people with MS will receive all of the treatments and services that could help them. The key components of care planning can be built into existing practice (e.g. primary care referral letters) and record sharing systems.

(This recommendation is based on a recent Nuffield Trust Report (July 2018) commissioned by the MS Society - [Improving care for people with MS: the potential of data and technology](#) (Chapter 2) and is not included in the 2014 NICE guidance)

Guidance & best practice

Guidance & best practice

Actions to Take

Multiple Sclerosis (MS)

MS System Improvement Priorities:

Formalised MDTs across specialist teams

Data and technology

Improved DMD administration

Comprehensive access to holistic support

Other conditions:

Motor Neurone Disease

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NICE Quality Standards

Guidance & Best Practice

Additional Tools:

RightCare neurology resources

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Elective Care handbook

System Improvement Priority: **Better use of data and technology (continued)**

Key areas for focus:

Improved data analysis around MRI planning and avoidable hospital admissions

Imaging data can be used to reduce waiting times for MRIs and improve patient experience.

Locally collected diagnostic imaging datasets can help you understand whether your area experiences particularly long waiting times for MRIs compared to similar areas or the national average, and if so whether anything can be done to address the wait. This would mean people with MS (or suspected MS) wouldn't have to wait so long for an MRI scan, enabling them to more rapidly access preventative care and assistance to prevent deterioration.

Planners and commissioners should use such information routinely and systematically in order to develop and design effective services for people with MS.

Guidance & best practice

Actions to Take

Multiple Sclerosis (MS)

MS System Improvement Priorities:

Formalised MDTs across specialist teams

Data and technology

Improved DMD administration

Comprehensive access to holistic support

Other conditions:

Motor Neurone Disease

Parkinson's

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NICE Quality Standards

Guidance & Best Practice

Additional Tools:

RightCare neurology resources

Shared Decision Making

Elective Care handbook

System Improvement Priority: **Better use of data and technology**

Key area for focus	Actions to take
Shared protocols on information sharing across MS teams and providers	<ul style="list-style-type: none"> Develop shared protocols on information sharing between settings.
Robust DMT monitoring systems in place	<ul style="list-style-type: none"> Locally implement the use of MS Specific database systems, such as iMed and DAWN. If technology does not allow the use systems such as iMed and DAWN develop an excel database incorporating monitoring review dates.
Use of digital tools to support people with MS to self-manage their condition where appropriate	<ul style="list-style-type: none"> Discuss with patients how they can best manage their condition at home. Assess the individual's ability to use digital tools and apps to self manage their condition. Signpost patients to available tools and apps.
Digital care planning employed where appropriate	<ul style="list-style-type: none"> Where appropriate and available, provide patients with access to an electronic written care plan. If information systems allow, ensure this care plan is accessible to all those health and care professionals involved in a patient's care in accordance with patient consent. Ensure patients are offered opportunities across the care pathway to co-produce a care plan with a health and care professional and to review that plan when circumstances/their condition changes.
Improved data analysis around MRI planning and avoidable hospital admissions	<ul style="list-style-type: none"> Routinely analyse diagnostic imaging datasets to understand how long people are waiting for MRIs. Use the diagnostics data to design and implement effective services to reduce waiting times for MRIs.

Guidance and best practice examples

System Improvement Priority: Improved DMD administration

DMDs vary significantly in terms of their benefit-risk profiles but all carry risks and need to be prescribed and monitored (for both safety and efficacy) by an MS specialist team including an MS neurologist and MS specialist nurse. As a result MS teams have become increasingly overwhelmed by the workload associated with DMD provision and MS specialist nurses in particular are struggling with the monitoring requirements, therefore having improved administration for DMDs will free up valuable clinical specialist time.

Key areas for focus

Increased use of pharmacists, where appropriate, for monitoring DMDs

Neurospecialist pharmacists and pharmacy technicians could be playing a greater role within the DMD pathway. Pharmacists are expert on all aspects of medication management including prescription screening, interactions, side effects, adherence and establishing pathways and protocols for prescribing and dispensing drugs. Aside from this expertise, other benefits of using pharmacists and pharmacy technicians to deliver elements of the DMD pathway are that they typically have cross-cover arrangements within their departments to allow for absences, which small MS teams may not, and they can spread learning and innovation from other specialties. 91% of pharmacists responding to an MS Trust survey agreed that 'pharmacists are well placed to play a greater role in the management of DMDs in MS than they do now.

(This recommendation is based on the evidence contained within the MS Trust report "[Improving the efficiency of disease modifying drug provision](#)" published in November 2016, and is not included in the 2014 NICE guidance).

Workforce training and development for MS nurse specialists to request repeat prescribing and MRIs

There is scope for more widespread nurse prescribing to improve the efficiency of the DMD management process. Patients with MS can benefit from smoother pathways with reduced delays obtaining treatment and the ability to discuss side effects and regimens at the time of prescribing (which has the potential to increase adherence). Around one third of MS nurse prescribers currently prescribe repeat DMDs according to an MS Trust Survey. The survey also found that 70% of MS specialist neurologists 'agreed' or 'strongly agreed' with the statement that MS nurses, with appropriate training, could undertake repeat DMD prescribing. DMD monitoring could also be made more efficient if MS nurses were empowered to order MRI scans in advance of neurology reviews, making more efficient use of neurologist time.

(This recommendation is based on the evidence contained within the MS Trust report "[Improving the efficiency of disease modifying drug provision](#)" published in November 2016, and is not included in the 2014 NICE guidance).

Guidance & best practice

Guidance & best practice

Actions to Take

Multiple Sclerosis (MS)

MS System Improvement Priorities:

Formalised MDTs across specialist teams

Data and technology

Improved DMD administration

Comprehensive access to holistic support

Other conditions:

Motor Neurone Disease

Parkinson's

MSA, PSP & CBD

NICE Quality Standards

Guidance & Best Practice

Additional Tools:

RightCare neurology resources

Shared Decision Making

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System Improvement Priority: Improved DMD administration (continued)

Key areas for focus:

Use of virtual clinics and telemedicine, where appropriate, to communicate blood test results with patients

Virtual clinics allow patients whose mobility has deteriorated to avoid travelling, instead having consultations on the phone or via video conferencing. It also increases efficiency of a specialist service as it means patients are less likely to miss appointments due to travel difficulties.

(This recommendation is based on the evidence contained within the Nuffield Trust report (2018) commissioned by the MS Society - [Improving care for people with MS: the potential of data and technology](#) and is therefore not included in the 2014 NICE guidance)

Ability to schedule blood tests without MS nurse or neurology appointments first

MS Trust analysis has shown that there may be scope to cut down on routine face-to-face appointments with people on DMDs without compromising safety. This would help to create additional clinic time that could be used to see other patients not on DMDs and help to reduce waiting lists or to respond more quickly to those patients who are in crisis or relapsing. The MS nurse survey showed that only 32 out of 148 (22%) prescribing and monitoring centres reported that they were able to schedule blood tests without the need for an MS specialist nurse or neurologist appointment (with the results available at a later date).

(This recommendation is based on the evidence contained within the Nuffield Trust report (2018) commissioned by the MS Society - [Improving care for people with MS: the potential of data and technology](#) and is therefore not included in the 2014 NICE guidance)

Guidance & best practice

Actions to Take

Multiple Sclerosis (MS)

MS System Improvement Priorities:

Formalised MDTs across specialist teams

Data and technology

Improved DMD administration

Comprehensive access to holistic support

Other conditions:

Motor Neurone Disease

Parkinson's

MSA, PSP & CBD

NICE Quality Standards

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Additional Tools:

RightCare neurology resources

Shared Decision Making

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System Improvement Priority: Improved DMD administration

Key area for focus	Actions to take
Increased use of pharmacists, where appropriate, for monitoring DMDs	<ul style="list-style-type: none">Commission community pharmacist to undertake DMD monitoringEnsure formal MDT arrangements are in place between pharmacists and specialist prescribers
Workforce training and development for MS nurse specialists to request repeat prescribing and MRIs	<ul style="list-style-type: none">Undertake workforce training with nurse specialists to become nurse prescribersDevelop protocols for nurse specialists to be able to order MRIs
Increased use of virtual clinics and increased use of telemedicine to get blood test results	<ul style="list-style-type: none">Implement virtual clinics e.g. use of skype or telemedicine for routine appointments or to receive test results
Ability to schedule blood tests without MS nurse or neurology appointments first	<ul style="list-style-type: none">Investigate the current patient pathway to identify the possibilities associated with scheduling blood tests without the need for an MS specialist nurse or neurologist appointment first

Multiple Sclerosis (MS)

MS System Improvement Priorities:

Formalised MDTs across specialist teams

Data and technology

Improved DMD administration

Comprehensive access to holistic support

Other conditions:

Motor Neurone Disease

Parkinson's

MSA, PSP & CBD

NICE Quality Standards

Guidance & Best Practice

Additional Tools:

RightCare neurology resources

Shared Decision Making

Elective Care handbook

System Improvement Priority: Comprehensive access to holistic support (particularly for advanced MS patients)

A holistic flexible MS service with strong referral routes into community support and specialist therapies will significantly improve care and outcomes for people with MS leading to improved quality of life.

Key areas for focus:

Access and referral to local and community based, and other specialist, services including; fatigue management, emotional support, peer support, neuro rehab, vocational rehab, palliative care, neuropsychology services

People with MS may need input from a wide range of specialists and community services during the course of their disease. Primary care and MS specialist teams need clear referral pathways to be able to refer people with MS to services to manage their symptoms and promote their emotional and physical wellbeing. Self-referral should be available where appropriate to enable more timely access to these services for patients with MS.

A lack of specialist services, specifically, to help people maintain physical and cognitive function and confidence can impact on the individual's ability to maintain employment and social activities, which are key drivers of overall well-being.

Patients with progressive MS offered an annual review with an appropriate member of the MS MDT

People with progressive MS are particularly vulnerable to becoming disconnected from MS services. An annual review, which is both best practice and a NICE Quality Standard, is an opportunity to reconnect, review the patient's care plan, goals and needs and refer them where necessary to support services. A review does not necessarily need to be carried out by a neurologist, depending on the needs and condition of the patient.

Guidance & best practice

Actions to Take

Multiple Sclerosis (MS)

MS System Improvement Priorities:

Formalised MDTs across specialist teams

Data and technology

Improved DMD administration

Comprehensive access to holistic support

Other conditions:

Motor Neurone Disease

Parkinson's

MSA, PSP & CBD

NICE Quality Standards

Guidance & Best Practice

Additional Tools:

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System Improvement Priority: Comprehensive access to holistic support (particularly for advanced MS patients)

Key areas for focus:

Named professional lead for advanced MS in every MS team

Every MS team should have a named professional lead for advanced MS. People with advanced MS and those who care for them have a particular need for coordinated care from a wide range of services. For some, this includes timely access to palliative care. The lead for advanced MS should be responsible for involving the wider network of services, developing care pathways and making sure people with advanced MS know what services are available to them.

Guidance & best practice

Actions to take:

Access and referral to local and community based, and other specialist, services including; fatigue management, emotional support, peer support, neuro rehab, vocational rehab, palliative care, neuropsychology services

- Have a local directory of services and support available which enables ease of signposting or referral for people with MS to the services they may find useful, this should include national organisations and helplines.
- Commission a range of holistic community and specialist support services to meet the needs of the local population with neurological conditions like MS and develop quick and easy referral pathways into such services.

Patients with progressive MS offered an annual review with an appropriate member of the MS MDT

- Have a process in place to ensure that all patients are reviewed at least annually to identify any changing needs

Named professional lead for advanced MS in every MS team

- Have a network of professional leads that can be assigned to each MS patient

NICE Quality Standards

This section contains all the NICE quality statements relevant to the joint consensus statements within this RightCare toolkit.

Joint Consensus Statements	Motor Neurone Disease	Parkinsons	Multiple Sclerosis
Shared Decision Making	Quality Standard 126 (2016) QS 2 – Non-invasive ventilation QS 5 – End of Life Care	Quality Standard 164 (2018) QS 1 – Point of contact QS 2 – Information about impulse control	Quality Standard 108 (2016) QS 1 – Support at diagnosis QS 2 – Follow-up after diagnosis
Referral and diagnosis	Quality Standard 126 (2016) QS 1 – Information and support at time of diagnosis	NG71 (2017) Recommendation 1.2 – Diagnosing Parkinson's Disease	Quality Standard 108 (2016) QS 1 – Support at diagnosis
Symptom Management	Quality Standard 126 (2016) QS 2 – Non-invasive ventilation	Quality Standard 164 (2018) QS 3 – Referral to physio, OT, SALT	Quality Standard 108 (2016) QS 4 , Physical activity
Multidisciplinary Teams	Quality Standard 126 (2016) QS 2 – Non-invasive ventilation QS 4 – Continuity of care	Quality Standard 164 (2018) QS 1 – Point of contact QS 2 – Information about impulse control QS 3 – Referral to physio, OT, SALT	Quality Standard 108 (2016) QS 2 – Follow-up after diagnosis QS 3 – Coordinated care QS 5 – Managing relapses QS 6 – Comprehensive review
Mental Health Support	Quality Standard 126 (2016) QS 1 – Information and support at time of diagnosis	NG71 (2017) Recommendation 1.5.11 - Depression	Quality Standard 108 (2016) QS 2 – Follow-up after diagnosis

Progressive Neuro Summary

Progressive Neuro System Improvement Priorities

Joint Consensus Statements:

Shared Decision Making

Referral & Diagnosis

MDT & Coordination of Care

Symptom Management

Mental Health Support

Conditions:

Motor Neurone Disease

Parkinson's

MSA, PSP & CBD

Multiple Sclerosis

NICE Quality Standards

Guidance & Best Practice

Additional Tools:

RightCare neurology resources

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Guidance and best practice

This section contains all the relevant guidance, evidence and case studies aligned to each of this toolkit's system improvement priority and key areas for focus. It supports development of improvement actions when system priorities have been identified.

Overarching NICE Guidelines:

[Motor Neurone Disease : Assessment and Management \(NG42\)](#)

[Multiple Sclerosis in Adults: Management \(CG186\)](#)

[Parkinson's Disease in Adult's \(NG71\)](#)

[Suspected Neurological Conditions \(NG127\)](#)

Progressive Neuro System Improvement Priorities

Joint Consensus Statements:

Shared Decision Making

Referral & Diagnosis

MDT & Coordination of Care

Symptom Management

Mental Health Support

Conditions:

Motor Neurone Disease

Parkinson's

MSA, PSP & CBD

Multiple Sclerosis

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Additional Tools:

RightCare neurology resources

Shared Decision Making

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Condition

Where to Look/ Guidance

Implementation & Practical Examples

Joint Consensus Statement on: Shared Decision Making

MND

NICE evidence services: [What is shared decision making?](#)
[Shared decision making](#) – NHS England web page
[MAGIC: shared decision making](#) – The Health Foundation shared decision making programme
 Public Health England - Shared decision making [Making Every Contact Count \(MECC\): practical resources](#)

[Development of patient decision support tools for motor neuron disease using stakeholder consultation: a study protocol](#) - Hogden A, Greenfield D, Caga J, et al

Multiple Sclerosis
(Additional resources as above under Motor Neurone Disease)

NICE CG186 – [Patient-centred care](#): Treatment and care should take into account individual needs and preferences. Patients should have the opportunity to make informed decisions about their care and treatment, in partnership with their healthcare professionals.

[Digital integrated care plan standard, case study examples](#) - Professional Record Standards Body

[‘Okay to Stay’ Plan using SystemOne](#) - Sheffield Teaching Hospitals NHS Trust

[Developing a database for audit and evaluation to improve MS care](#) - Audit, evaluation and development - Salford MS team, Salford Royal NHS Foundation Trust - scroll down to last item on webpage

Parkinson's
(Additional resources as above under Motor Neurone Disease)

NICE NG71 – [Recommendations](#) 1.9.1

[Involving Patients in Weighting Benefits and Harms of Treatment in Parkinson's Disease](#) - Weernink, Marieke G. M. et al.

Condition	Where to Look/ Guidance	Implementation & Practical Examples
Joint Consensus Statement on: Referral and Diagnosis		
MND	<p>NICE NG42 – Recommendation 1.1.4: If you suspect MND, refer the person without delay</p> <p>NICE NG127 Recommendations: 1.7.5: Slowly progressive limb or neck weakness. 1.13.2: Progressive slurred or disrupted speech</p>	<p>MND Association Red Flag Diagnosis Tool for GPs</p> <p>Sue Ryder: The Case for Proactive Care This report uses a case study approach to assess the health and social care costs and values of different care pathways for people with MND, HD, and ABI in the UK.</p>
Multiple Sclerosis	<p>NICE CG186 – Recommendations 1.1.6: Refer people suspected of having MS to a consultant neurologist 1.1.7: Only a consultant neurologist should make the diagnosis of MS on the basis of established up-to-date criteria</p> <p>NICE CG186 – Diagnosis</p>	<p>A responsive and effective service in a centre of excellence for MS – Effective multidisciplinary working - Royal Stoke MS centre of excellence, Royal Stoke University Hospital, Section 2, Effective Multidisciplinary Working, Example 5</p> <p>Walton Centre Consultant Advice Line Case Study</p>
Parkinson's	<p>NICE NG71 – Recommendations: 1.2.2: If Parkinson's disease is suspected, refer people quickly and untreated to a specialist 1.2.5: Review of diagnosis</p> <p>NICE NG127 Recommendations: 1.15.2: Tremor suggesting Parkinson's disease</p>	<p>Vale of York CCG – Referral Support Service, Parkinson's Disease</p>

Progressive Neuro Summary

Progressive Neuro System Improvement Priorities

Joint Consensus Statements:

Shared Decision Making

Referral & Diagnosis

MDT & Coordination of Care

Symptom Management

Mental Health Support

Conditions:

Motor Neurone Disease

Parkinson's

MSA, PSP & CBD

Multiple Sclerosis

NICE Quality Standards

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Additional Tools:

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Condition

Where to Look/ Guidance

Implementation & Practical Examples

Joint Consensus Statement on: **Symptom Management**

MND

NICE NG42 -
[Recommendations](#) 1.8.1-
1.8.15: Managing symptoms

[NICE Quality Standard126 -
Motor Neurone Disease](#)

- [Respiratory Care Pathway, NIV – Dorset June 2018](#), Multi disciplinary Pan Dorset MND Group
- [Care pathway for people living with MND in Dorset](#) Multi Disciplinary Pan Dorset MND Group
- [Care pathway for patients with motor neurone disease](#) -Middlesbrough MND Care Centre
- [Overview of Riluzole supply \(51 kb\)](#). Leicestershire and Rutland MND Supportive and Palliative Care Group
- [Pathway for people with suspected motor neurone disease \(167 kb\)](#) Leicestershire and Rutland MND Supportive and Palliative Care Group
- [Nutrition care pathway for people living with MND in Dorset](#) Dorset MND MDT Working Group
- [Leeds Motor Neurone Disease PEG Pathway](#) - Leeds Centre for Neurosciences
- [Assessment for gastrostomy tube placement in MND patients](#) - Middlesbrough MND Care Centre
- [Gastrostomy placement risk assessment for patients with potential respiratory muscle weakness](#) - Oxford Care and Research Centre
- [Oral Feeding Difficulties and Dilemmas](#) (with specific mention of MND) A Working Party Report. Royal College of Physicians in association with the British Society of Gastroenterology
- [MND Respiratory Pathway](#) - MND Association
- [Pathway and guidelines for withdrawing non-invasive ventilation \(NIV\) in patients with](#) Leicestershire and Rutland MND Supportive and Palliative Care Group
- [AAC Pathway for MND: full guidance](#) - MND Association

Condition	Where to Look/ Guidance	Implementation & Practical Examples
Joint Consensus Statement on: Symptom Management		
Multiple Sclerosis	NICE CG186 – Recommendations 1.5: MS symptom management and rehabilitation.	Improving care for people with MS: the potential of data and technology - MS Society and the Nuffield Trust, July 2018, Chapter One, pp. 22-32.
	NICE Multiple Sclerosis Quality Standards (QS108): QS4 - Adults with MS who have problems with mobility or fatigue are offered support to remain physically active	Walton Centre Specialist Nurse Advice Line Case Study
Parkinson's	NICE NG71 Recommendations : 1.3 Pharmacological management of motor symptoms 1.4 Managing and monitoring impulse control disorders as an adverse effect of dopaminergic therapy 1.5 Pharmacological management of non-motor symptoms 1.6 Pharmacological neuroprotective therapy 1.7 Non-pharmacological management of motor and non-motor symptoms 1.8 Deep brain stimulation and levodopa-carbidopa intestinal gel	Lambeth CCG (2018) - Management of motor symptoms in people with Parkinson's with motor complications – opicapone place in therapy

Condition	Where to Look/ Guidance	Implementation & Practical Examples
Joint Consensus Statement on: Multidisciplinary Teams and Coordination of Care		
MND	NICE NG42 – Recommendations 1.5.1 – 1.5.8: Organisation of Care Recommendations 1.6.1, 1.6.3: Psychological and social care support NICE QS126 Motor Neurone Disease	Coordination of care - Royal College of Nursing – Motor Neurone Disease. Caring for a person with motor neurone disease: a guide for care workers - MND Association
Multiple Sclerosis	NICE CG186 – Recommendation 1.3.1: Care for people with MS using a coordinated multidisciplinary approach	Community neuro-rehabilitation service - CSH Surrey: Multidisciplinary team of the year (QuDoS in MS 2016 winner) Effective Multidisciplinary Working, Example 2 Efficient multi-disciplinary working in a large MS specialist team - Cardiff MS nurse team, University Hospital of Wales - Effective Multidisciplinary Working, Example 4
Parkinson's	NICE NG71 – Recommendation 1.7: Non-pharmacological management on motor and non-motor symptoms	Parkinson's Advanced Symptoms Unit - South Tees Hospitals NHS Foundation Trust - Innovating for Improvement

Sue Ryder (2019)

[Time to get it right: A report on the provision of health and social care services for people with neurological conditions in England](#)

Condition	Where to Look/ Guidance	Implementation & Practical Examples
Joint Consensus Statement on: Mental Health Support		
MND	NICE NG42 – Recommendations 1.6.2, 1.6.3: Psychological and social support	<p>Living with Motor Neurone Disease, Section 4: Emotional Impact - MND Association</p> <p>Information sheet 9C – Managing emotions www.mndassociation.org/wp-content/uploads/2015/07/09c-managing-emotions.pdf</p> <p>Making the most of life with motor neurone disease (MND) www.mndassociation.org/wp-content/uploads/Making-the-most-of-life-with-MND.pdf</p>
Multiple Sclerosis	<p>MS Trust - MS Forward View</p> <p>NICE CG186 - Recommendation 1.6.3: Tailoring the comprehensive review to the needs of the person with MS</p>	<p>MS Society - Causes of mental health problems</p> <p>MS Society - MS and your emotions: understanding and dealing with your feelings</p>
Parkinson's	<p>Parkinson's UK policy statement: Mental health - Parkinson's UK</p> <p>Patricia de la Riva, Kara Smith, Sharon X. Xie, Daniel Weintraub. Neurology Aug 2014. Course of psychiatric symptoms and global cognition in early Parkinson disease</p>	<p>Improving mental health services for people with Parkinson's who experience anxiety and depression - All-Party Parliamentary Group (APPG) on Parkinson's (May 2018)</p>

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MND System Improvement Priority: **Implement the 5 NICE Quality Statements**

NICE QS1 - [Information and support at diagnosis](#)
 NICE QS2 - [Respiratory assessment and non-invasive ventilation](#)
 NICE QS3 - [Provision of equipment and adaptations based on multidisciplinary team assessment](#)
 NICE QS4 - [Continuity of care](#)
 NICE QS5 - [Planning for end of life care](#)

MND System Improvement Priority: **Knowledge awareness of the signs and symptoms of MND**

Fast track symptom pathway for suspected MND

NICE NG42 – [Recommendation](#) 1.1.1: If you suspect MND, refer the person without delay and specify the possible diagnosis in the referral letter.
 NICE NG127 Recommendations:
[1.7.5](#): Slowly progressive limb or neck weakness.
[1.13.2](#): Progressive slurred or disrupted speech

[Painless, progressive weakness – Could this be Motor Neurone Disease?](#) - MND Association Red Flag Diagnosis Tool

Follow up appointment within 4 weeks after diagnosis

NICE NG42: [Recommendation](#) 1.2.5: Offer the person with MND a face-to-face, follow-up appointment with a healthcare professional from the multidisciplinary team, to take place within 4 weeks of diagnosis.

MND services to take part in audit and quality improvement programmes

Motor Neurone Disease Association - [Transforming MND Audit Tool](#)
 NICE - [Baseline Assessment Tool](#)

[Audit of Motor Neurone Disease \(MND\) multidisciplinary team clinic services against NICE guidelines in a University Health Board](#) - Aneurin Bevan University Health Board (2017)

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MND System Improvement Priority: **Consistent access to multidisciplinary community based care**

Ongoing care provided in community based setting with nurse specialists

MND Association Resources: [Caring for a person with MND Management of MND](#), [MND resource website](#) – a guide for registered nurses, student nurses, health care assistants(HCA) or assistant practitioners working in any health care setting or specialism – Royal College of Nurses & MND Assoc

Wolverhampton(January 2019) [Long Term Case Management of patients with Motor Neurone Disease within a Community Neurological Rehabilitation Team: A review of quality care within Wolverhampton](#)

MDT to undertake regular reviews (every 2-3 months) of patients symptoms and needs in line with NICE recommendations (1.5.2)

NICE NG42 – [Recommendation](#) 1.5.2: Regular assessments (usually every 2–3 months) to assess people's symptoms and needs

Prospect Hospice (October 2018) [Audit proposal to address cough augmentation for people with Motor Neurone Disease \(MND\) - a shared resource tool](#)

3 month SALT review for all MND patients

NICE NG42 – [Recommendations 1.11](#) – Communication [Recommendation](#) 1.5.2: Regular assessments (usually every 2–3 months) to assess people's symptoms and needs

Middlesbrough MND Care Centre - [SALT assessment pathway](#)
[Augmentative and Alternative Communication \(AAC\) Pathway for MND](#)

Regular review of saliva control using clinical saliva score tool

NICE NG42 – [Recommendations:](#) 1.5.3: Assess, manage and review saliva problems
1.8.10-1.8.15: Saliva problems

MND Association – [Managing saliva problems in motor neurone disease](#)

Middlesbrough MND Care Centre - [Guidelines for provision of portable suction units for patients with MND who are cared for within community settings](#)

Medication to treat saliva problems in line with NICE guidance

NICE NG42 – [Recommendations](#)1.8: Saliva problems, 1.8.12 -1.8.14

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MND System Improvement Priority: Timely access to specialist and personalised equipment and support

Commissioners to adopt the NHS model service specification for wheelchair services

NHS England – [Model Service Specification for wheelchair and posture services](#)

NHS England and Local Government Association [Integrated personal commissioning emerging framework](#)

NHS England [Wheelchair services dataset](#)

Advanced wheelchair prescribing of a chair that can be adapted as the person's needs change, with regular review and adaption as needed

NICE NG42 – [Recommendations](#) 1.9: Equipment and adaptations to aid activities of daily living and mobility; 1.9.4, 1.9.5

MND Association - [National MND Wheelchair Pathway](#)

[Rolfe, J. Planning wheelchair service provision in motor neurone disease: implications for service delivery and commissioning.](#) - British Journal of Occupational Therapy, Vol 5, Number 5, pp217-222

NICE QS3 - [Provision of equipment and adaptations based on multidisciplinary team assessment](#)

Cognitive ability and capacity should be assessed by a qualified assessor for all decision making, with referral as appropriate to clinical neuropsychology for treatment and care

NICE NG42 – [Recommendations](#) 1.3: Cognitive assessments

MND Association Resources:

[Cognitive change, frontotemporal dementia and MND](#)
Information sheet 9A – [Will the way I think be affected?](#)

Information sheet 9B – [How do I support someone if the way they think is affected?](#)

Information sheet 9C – [Managing emotions](#)

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MND System Improvement Priority: **Anticipatory and advanced care planning through specialist care coordinators**

Patients, carers & families given information and advice on legal rights and support services

NICE NG42 – [Recommendations](#) 1.2: Information and support at diagnosis; 1.2.3

NICE QS1 - [Information and support at diagnosis](#)

NICE NG127: [Recommendations 1.16](#): Information and support

Anticipatory medication to be prescribed for at home

NICE NG42 – [Recommendations](#) 1.7: Planning for End of Life; 1.7.3, 1.7.7

NICE NG31: Care of Adults in the last days of life – [Recommendation](#) 1.6: Anticipatory Prescribing

Early identification of respiratory impairment and preference for NIV

NICE NG42 – [Recommendation](#) 1.14: Non-invasive ventilation, 1.14.7: Identification and assessment of respiratory impairment

NICE QS2 - [Respiratory assessment and non-invasive ventilation](#)

[MND Respiratory Pathway](#)

Royal Free London NHS Foundation Trust (2018) [Development of a multidisciplinary respiratory assessment tool to facilitate early identification of respiratory impairment in clients with motor neurone disease](#) -

Dorset (June 2018) - [Respiratory Care Pathway, NIV](#)

Multi Disciplinary Pan Dorset MND Group
Information sheet 8C – [Withdrawal of ventilation with MND](#)

Advance care plans to be in place, which may include ADRT, LPA, preferred place of care, DNACPR

NICE NG42 – [Recommendations](#) 1.7: Planning for End of Life; 1.7.2, 1.7.3, 1.7.5

MND Association - [Advance care planning and advance decisions](#)

MND Association - [Advance Decision to Refuse Treatment \(ADRT\) and advance care planning](#) -

MND Association - [End of life: a guide for people with motor neurone disease](#)

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Parkinson's System Improvement Priority: **Increased use of specialist staff across the pathway**

Core MDT to include Consultant with a special interest in Movement Disorders, PDNS (Prescriber), Therapists –Physio, SLT, OT (Neuro therapists with an interest in Parkinson's)

UK Parkinson's Excellence Network. - [2017 UK Parkinson's Audit Reference report](#): Model of service provision

[National survey of speech and language therapy provision for people with Parkinson's disease in the United Kingdom: therapists' practices](#) – research report from the International Journal of Language and Communication Disorders - abstract only

[Occupational therapy for people with Parkinson's](#) – best practice guidelines

[European Physiotherapy Guideline for Parkinson's Disease](#) – Guide developed with 20 European professional associations

[Addressing Unmet needs: A multidisciplinary group clinic for people with Parkinson's Disease and their carers](#) - Kings College Hospital (2009)

[Standard Multidisciplinary Parkinson's Disease Care](#) - Derby Hospitals NHS Foundation Trust

[The role and structure of the multidisciplinary team in the management of advanced Parkinson's disease with a focus on the use of levodopa-carbidopa intestinal gel](#) – Article published in Dove Press Journal – contains examples of best practice

Kings College Hospital (Sept 2009)

[Addressing Unmet needs: A multidisciplinary group clinic for people with Parkinson's Disease and their carers](#)

Enhanced/ Integrated MDT to include a neuro psychologist and pharmacists

[Integrated multidisciplinary care in Parkinson's disease: a non-randomised, controlled trial](#) - journal entry – abstract only

[Innovating for Improvement - Parkinson's Advanced Symptoms Unit](#) - South Tees Hospital NHS Trust

[The Multidisciplinary Parkinson's Disease Clinic](#) – Derby Hospitals NHS Trust

Clinical pharmacists to undertake enhanced Structured Medication Reviews

DHSC, NHSE&I, PNSC: [The Community Pharmacy Contractual Framework for 2019/20 to 2023/24: supporting delivery for the NHS Long Term Plan](#)

NICE NG5 - [Medicines optimisation: the safe and effective use of medicines to enable the best possible outcomes](#)

NICE CG76 - [Medicines adherence: involving patients in decisions about prescribed medicines and supporting adherence](#)

NICE QS120 - [Medicines optimisation](#)
Quality statement 6 - [Structured medication review](#)

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Parkinson's System Improvement Priority: **Ongoing quality patient centred care in both acute and community settings**

Medicine optimisation, including time adherence for Levodopa

NICE NG71 - [Recommendations 1.3](#):
Pharmacological management of motor symptoms
NICE QS164 - QS4: [Levodopa in hospital or a care home](#)

Parkinson's UK - [Information and support on drug treatments](#)

Signposting to local Parkinson's advisors and local patient support services

NICE NG71 – [Recommendations 1.1.4, 1.1.5 & 1.1.7](#)
NICE NG127: [Recommendations 1.16](#): Information and support

Parkinson's UK - [Information and Support](#)
Hereford PCT (Sept 2008) [Singing as a form of voice therapy for people with Parkinson's \(update 2008\)](#)

Care coordination to reduce duplication of tests and appointments and to improve referral pathways

NICE NG71 - [Recommendation 1.1.6](#)

All services to take part in audit programme and to take part in Quality Improvement Programme based on the outcomes of the Parkinson's Clinical Audit

UK Parkinson's Excellence Network. – [UK Parkinson's Audit](#)

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Parkinson's System Improvement Priority: **Better use of data and technology across different healthcare settings**

Consistent use of evidence based standardised assessment and outcomes frameworks across settings

[Role of the Personal KinetiGraph in the routine clinical assessment of Parkinson's disease: Recommendations from an Expert Panel](#) – Researchgate journal – abstract only

Use of virtual clinics for routine follow up appointments

[National randomized controlled trial of virtual house calls for Parkinson disease](#) - Christopher A. Beck, Denise B. Beran et al
Neurology Sep 2017 pp1152-1161

[The promise of telemedicine for chronic neurological disorders: the example of Parkinson's disease](#) – Lancet journal entry – abstract only

Use of technology to share information about medications between settings

[Shared Care Guideline for the treatment of Parkinson's Disease](#) - Barnsley CCG, S.W Yorkshire Partnership & Barnsley Hospital

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Parkinson's System Improvement Priority: **Anticipatory and advanced care planning**

6-12mth reviews with specialist/ consultant to identify changing needs early.

NICE Clinical Knowledge Summary – [Parkinson's disease](#): When to suspect end-stage Parkinson's disease

NICE NG71 – [Recommendation](#) 1.2.5: Review of diagnosis.

Ongoing reviews to include discussion and agreement of advance care plans.

NICE Clinical Knowledge Summary - [Parkinson's disease](#): Managing end-stage Parkinson's disease

UK Parkinson's Excellence Network. - [2017 UK Parkinson's Audit Reference report](#): Advance care planning

[Palliative care for Parkinson's disease: A summary of the evidence and future directions](#) – Sage journal entry – abstract only

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MSA, PSP & CBD System Improvement Priority: **Quicker and accurate diagnosis**

Supporting professionals to recognise the early signs of MSA, PSP and CBD

MSA Symptoms - www.nhs.uk/conditions/multiple-system-atrophy/

www.msatrust.org.uk/what-is-msa/symptoms/

PSP Symptoms - www.nhs.uk/conditions/progressive-supranuclear-palsy-ppsp/

<https://pspassociation.org.uk/information-and-support/what-is-ppsp/signs-symptoms-ppsp/>

CBD Symptoms -

<https://www.nhs.uk/conditions/corticobasal-degeneration/>

MSA Trust – [Support for Healthcare Professionals](#)

PSP Association - [Resources for professionals](#)

Recognition of symptoms should trigger early referral to movement disorder specialist/neurologist to clarify diagnosis.

NICE [NG127](#):

Recommendation 1.4.3 [Gradually progressive unsteady gait](#)

Recommendation 1.15 [Tremor in adults](#)

Regular assessment of symptoms - especially for postural hypotension / incontinence/ constipation/ stridor / pain

NICE [NG42](#) – [Recommendation](#) 1.5.2: Regular assessments (usually every 2–3 months) to assess people's symptoms and needs

NICE [QS3](#) - [Provision of equipment and adaptations based on multidisciplinary team assessment](#)

Ensure correct diagnosis coding recorded in all patient records and that diagnosis included on death certificates

ICD10 codes for MSA, PSP and CBD should be consistently recorded on patient records:

(G90.3 for MSA, G23.1 for PSP, G31.8 for CBD)

www.who.int/classifications/icd/icdonlineversions/en/

www.who.int/classifications/icd/icdonlineversions/en/

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MSA, PSP & CBD System Improvement Priority: **Use of multi disciplinary team working**

Regular consultations with specialists.

PSP Association - [PSPA CBD Guide](#)

PSP Association - <https://pspassociation.org.uk/app/uploads/2018/06/PT009-13-6-Pathway-Guide-web-2013.pdf>

Implementation & Practice Examples

Calver M, Pall H, Hoppitt T, Eaton B, Savill E, Sackley C. Health-related quality of life and supportive care in patients with rare neurological conditions. Qual Life Res 2013; 22: 1231-1238

Peters M, Fitzpatrick R, Doll H, Palyford ED, Jenkinson C. Patients experience of health and social care in long-term neurological conditions in England: a cross sectional survey. J Health Serv Res Policy 2013 28-33

Clerici I, Ferrazzoli D, Maestri R, Bossio F, Ziviv I, Canesi M et al. Rehabilitation in Progressive Supranuclear Palsy: Effectiveness of two multidisciplinary treatments. PLoS ONE 2017; 12: e0170927

Effective and responsive medicines and care plans provided with associated co-ordinated MDT services.

PSP Association - [OT Guide](#)

PSP Association - [A Guide to PSP CBD for GPs and the Primary Healthcare Team](#)

PSP Association - [Cognition Guide](#)

Oliver DJ, Borasio GD, Caraceni A, de Visser M, Grisold W, Lorenzi S, Veronese S, Voltz R. A consensus review on the development of palliative care for patients with chronic and progressive neurological disease. Eur J Neurol 2016;23: 30-38. doi:10.1111/ene.12889

Effective data sharing between all professionals involved in care and support.

NHSE - [Personalised Health and Care 2020 Using Data and Technology to Transform Outcomes for Patients and Citizens A Framework for Action](#), p. 6

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MSA, PSP & CBD System Improvement Priority: **Use of multi disciplinary team working**

Commissioners to adopt the NHS model service specification for wheelchair services

NHS England – [Model Service Specification for wheelchair and posture services](#)

[Integrated personal commissioning emerging framework](#)- NHS England and Local Government Association
[Wheelchair services dataset](#) - NHS England

Anticipatory prescribing of appropriate equipment and adaptations to maximise independence including wheelchair prescribing with regular review for bespoke wheelchair modifications, particularly for posture, skin integrity, circulation and blood pressure management

[See MND Guidance slide 66](#)

Norfolk Community Health and Care (Feb 2016)
[Supporting people with multiple sclerosis, who have limited mobility or are full-time wheelchair users, to remain physically active with the use of Oswestry standing frames](#)

Open ended therapy support, including cognitive testing, to be in place due to rapidly progressing needs

[See MND Guidance slide 66](#)

MSA, PSP & CBD System Improvement Priority: **Anticipatory and advanced care planning**

Patients, families and carers should be provided with details on how to access medical care, information and support between outpatient appointments including signposting to local support services.

MSA Trust - www.msatrust.org.uk/what-is-msa/symptoms/

PSA Association - <https://pspassociation.org.uk/>

Advice and training for patients/carers to recognise signs of infection and to take action to reduce hospitalisation.

[Ambulatory emergency care guide: same day emergency care — clinical definition, patient selection and metrics](#) (NHS Improvement),
NICE NG74 - [Referral into intermediate care, recommendation 1.4.6](#)
NICE NG74 – [Crisis Response, recommendations 1.5.4 – 1.5.6](#)

CSP Innovations Database:
[Educating staff to identify frailty](#)
[Early identification of non-medical patients in ED](#)
[Triaging community referrals](#)

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MSA, PSP & CBD System Improvement Priority: **Anticipatory and advanced care planning (continued)**

Providing guidance and support with eligible benefits, including Continuing Healthcare, referral to housing adaptations and grants advice in timely manner.

[NHS continuing healthcare information](#)

GOV.UK -

- [Carers and Disabilities benefits](#)
- [Disabled Facilities Grants](#)

Discussion on advance care planning to be started as early as possible due to rapidly changing communication ability and unpredictable prognosis

NICE Quality Standards (QS13) End of Life Care for Adults - [Quality statement 2: Communication and information](#)
[Quality statement 3: Assessment, care planning and review](#)

Access to palliative support from diagnosis and specialist palliative care when required

NICE Quality Standards (QS13) End of Life Care for Adults - [Quality statement 10: Specialist palliative care](#)

Anticipatory prescribing of medication for symptom control to minimise hospital admissions.

NICE NG31: Care of Adults in the last days of life – [Recommendation 1.6: Anticipatory Prescribing](#)

People being supported to die in their chosen place whenever possible.

NHS – [End of Life Care](#)

[Introduction of the North Manchester Macmillan Palliative Care Specialist Service \(NNMPCSS\)](#)

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MS System Improvement Priority: **formalised MDTs across specialised teams**

Ensure there is an appropriate level of administration support available to support specialists

[MS Specialist Nursing in the UK 2016: Report on Progress Towards Equitable Provision](#) - MS Trust pp 8-10

[Improving the efficiency of disease modifying drug provision, November 2016](#) - MS Trust

Formal shared care MDT arrangements across a range of disciplines (including pharmacy and neuro-rehabilitation)

NICE CG186 – [Recommendation 1.3.1](#): Care for people with MS using a coordinated multidisciplinary approach. Involve professionals who can best meet the needs of the person with MS and who have expertise in managing MS

MS Trust - [Improving the efficiency of disease modifying drug provision, November 2016](#)

[DMD coordinator](#) - Leeds MS Service - (p.14)
[Mid Essex GEMSS Team](#) (p.54)

[Effective multidisciplinary working](#)

- Community neuro-rehabilitation service, CSH Surrey
- Cardiff MS nurse team, University Hospital of Wales
- [Improving the efficiency of a DMD service](#) - City Hospitals Sunderland MS Team and 'CHOICE Ltd' outpatient pharmacy: Dispensing DMDs through hospital pharmacy as an alternative to homecare
[Walton Centre Consultant Advice Line Case Study](#)

Royal Bolton Hospital NHS Foundation Trust (Sept 2014) [Separating Diagnostic Neurology from Management of Long-Term Neurological Conditions: A new concept of service delivery](#)

Named care coordinator for each patient

NICE CG186 – [Recommendation 1.3.2](#): Offer the person with MS an appropriate single point of contact to coordinate care and help them access services.

NICE CG186 - [Recommendation 1.2.6](#): Ensure people with MS and their family members or carers have a management plan that includes who to contact if their symptoms change significantly.

[Improving the accessibility of MS services](#) - MS Clinical Specialists Community Team, Neurological Clinical Specialist Team, Milton Keynes Community Health Services: Two community MS specialist each dedicated to different areas of care.

[Walton Centre Specialist Nurse Advice Line Case Study](#)

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MS System Improvement Priority: **Better use of data and technology**

Shared protocols on information sharing across MS teams and providers

[Personalised Health and Care 2020 Using Data and Technology to Transform Outcomes for Patients and Citizens A Framework for Action](#) - NHSE, p. 6

[Datawell, Manchester](#)

[Digital integrated care plan standard, case study examples](#), Professional Record Standards Body

[Walton Centre Specialist Nurse Advice Line Case Study](#)

Robust DMT monitoring systems in place

[Improving the efficiency of disease modifying drug provision](#) - MS Trust . An information system for tracking monitoring across the caseload (p.18)

[Disease Modifying Therapy Care Pathway for Multiple Sclerosis Service](#) - County Durham and Darlington NHS Foundation Trust
[Alemtuzumab for relapsing-remitting multiple sclerosis](#) - Cambridgeshire & Peterborough CCG Shared Care Guideline

[Audit of safe monitoring of MS patients on natalizumab](#) - Sheffield Teaching Hospitals NHS Trust

[Improving the efficiency of a DMD service](#) - St George's, South west London and North Surrey: Keeping track of monitoring and reducing MS specialist nurse time on DMDs

Use of digital tools to support people with MS to self-manage their condition where appropriate

[MS and me: a self-management guide to living with MS](#) - MS Trust, 2015
[Improving care for people with MS: the potential of data and technology](#) - MS Society and the Nuffield Trust, July 2018, Ch 1
[NHS Digital apps library](#)

[Improving care for people with MS: the potential of data and technology](#) - MS Society and the Nuffield Trust, July 2018, Ch 1, pp. 22-32.

Guidance

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MS System Improvement Priority: **Better use of data and technology (cont.)**

Digital care planning employed where appropriate

[Digital integrated care plan standard](#) - Professional Record Standards Body, March 2018

[Digital integrated care plan standard, case study examples](#), Professional Record Standards Body

[Improving care for people with MS: the potential of data and technology](#) - Nuffield Trust/MS Society, July 2018, Chapter Two

[Okay to Stay' Plan using SystemOne](#) - Sheffield Teaching Hospitals NHS Trust - [Audit, evaluation and development](#) - Salford MS team, Salford Royal NHS Foundation Trust: Developing a database for audit and evaluation to improve MS care

Improved data analysis around MRI planning and avoidable hospital admissions

[Improving care for people with MS: the potential of data and technology](#) - Nuffield Trust/MS Society, July 2018

[Audit, evaluation and development](#) - Salford MS team, Salford Royal NHS Foundation Trust: Developing a database for audit and evaluation to improve MS care

MS System Improvement Priority: **Improved DMD administration**

Increased use of pharmacists for monitoring DMDs

[Improving the Efficiency of DMD Provision](#) - MS Trust section 6.1.3 (p.14) – The role of pharmacists. Discussion point 10 (p.17)- Should pharmacists undertake DMD-related consultations with people with people with MS and non-medical prescribing

[Improving the efficiency of a DMD service](#) - City Hospitals Sunderland MS Team and 'CHoICE Ltd' outpatient pharmacy: Dispensing DMDs through hospital pharmacy as an alternative to homecare

Progressive Neuro Summary

Progressive Neuro System Improvement Priorities

Joint Consensus Statements:

Shared Decision Making

Referral & Diagnosis

MDT & Coordination of Care

Symptom Management

Mental Health Support

Conditions:

Motor Neurone Disease

Parkinson's

MSA, PSP & CBD

Multiple Sclerosis

NICE Quality Standards

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RightCare neurology resources

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MS System Improvement Priority: **Improved DMD administration**

Workforce training and development for MS nurse specialists to request repeat prescribing and MRIs

[Improving the Efficiency of DMD Provision](#) - MS Trust section 6.1.3 (p.14) – The role of pharmacists.
Discussion point 10 (p.17)- Should pharmacists undertake DMD-related consultations with people with people with MS and non-medical prescribing

[Improving the efficiency of a DMD service](#) - City Hospitals Sunderland MS Team and 'CHOICE Ltd' outpatient pharmacy: Dispensing DMDs through hospital pharmacy as an alternative to homecare

[Improving the efficiency of a DMD service](#) - MS service at Sunderland City Hospitals: MS nurse prescribing for repeat DMD prescriptions and symptomatic therapies

Use of virtual clinics and telemedicine, where appropriate, to communicate blood test results with patients

[MS Five Year Forward View](#) - MS Trust

[Datawell, Manchester](#)

[Improving the efficiency of disease modifying drug provision, November 2016](#) - MS Trust

[Rehabilitation engineering unit \(REU\) at Morriston Hospital, South Wales](#) – virtual clinic

[MS Five Year Forward View](#) - MS Trust ,
Figure 12: Case study - DMD monitoring without face to face consultation

Ability to schedule blood tests without MS nurse or neurology appointments first

[MS Five Year Forward View](#) - MS Trust , p.21
[Improving the Efficiency of DMD Provision](#) - MS Trust , section 6.3.1 (p.19) Phlebotomy-related appointments.

[Improving the Efficiency of DMD Provision](#) - MS Trust – Case Study – DMD monitoring clinics at St George's Hospital, p.20

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MS System Improvement Priority: **Comprehensive access to holistic support (particularly for advanced MS patients)**

Access and referral to local and community based, and other specialist, services

NICE CG186 – [Recommendation](#) 1.5.14: Help the person with MS continue to exercise, for example by referring them to exercise referral schemes.

NICE CG186 – [Recommendations](#) 1.5.32 - 1.5.33

NICE CG186 – [Recommendation](#) 1.5.14: Help the person with MS continue to exercise, for example by referring them to exercise referral schemes.

NICE CG186 – [Recommendations](#) 1.5.32 - 1.5.33

[Supporting people with MS in self-management](#) - Hertfordshire Neurological Service: Self-management programme for people with neurological conditions

[Walton Centre Specialist Nurse Advice Line Case Study](#)

[Walton Centre Consultant Advice Line Case Study](#)

PhysioFunction Ltd (Sept 2011) [Educating Healthcare Professionals about Functional Electrical Stimulation to improve patient care](#)

Patients with progressive MS offered an annual review with an appropriate member of the MS MDT

NICE CG186 – [Recommendation](#) 1.6.1

NCE QS108 – [Quality statement 6: Comprehensive review](#)

[Maintaining regular contact with people with MS](#)

- NHS Greater Glasgow and Clyde Chronic Disease Management team, Glasgow City Health and Social Care Partnership - Ensuring annual contact with people with MS: MS support workers
- Ayrshire MS team, Douglas Grant Rehabilitation Centre - Annual reviews of people with progressive MS and benign disease
- Northumbria Healthcare Community MS Specialist Nurse team - Reinstating contact with people with MS lost to follow up

Named professional lead for advanced MS in every MS team

MS Trust - [MS Five Year Forward View](#)

[MS Clinical Specialists Community Team, Neurological Clinical Specialist Team, Milton Keynes Community Health Services](#)

Case Study: Walton Centre Specialist Nurse Advice Line (Liverpool)

Overview

The Nurse Advice Line (NAL) provides anyone with a diagnosis of MS in the Walton Centre catchment area with specialist advice and management in-between their hospital appointments via the phone with their specialist neurology nurse.

Background

The Walton Centre MS team is made up of five MS-specialist neurologists, three MS-Specialist Nurses (MSSNs), two MS-specialist physiotherapists (1 WTE), two MS-specialist occupational therapists (1 WTE) and an MS-specialist orthoptist (0.2 WTE), all working closely together in a single department with a shared office and regular team/service development meetings. This allows for shared clinical working, including a weekly multidisciplinary relapse clinic at which people with MS (pwMS) with suspected relapses can be jointly assessed and advised, self-management groups run jointly by MSSNs and AHPs and the development of joint treatment plans for pwMS involving medical, nursing and therapy input to address problems.

The Walton Centre has a very large caseload, with an establishment of 2.6 WTE MSSNs for over 3900 pwMS under the care of the neurologists at the Centre. Nurses are frequently out of the office at 'spoke' clinics, and so getting hold of one on the telephone was previously very difficult for pwMS.

About the Service

During 2014, the team worked with the IT department to develop and trial a new Nurse Advice Line (NAL), open 9am – 4.30pm Monday to Friday. Rather than going to an answering machine, all calls to the service are now answered by a trained call handler who takes the details of the caller and filters out and deals with any administrative enquiries. If the caller wishes to speak to an MS Nurse then they are booked into a designated telephone clinic and given a two hour window on a date that suits them to receive a call back. The NAL system allows nurses to look ahead, see who is booked in (with the reason for the call) and triage and bring forward urgent calls if possible. They aim for all calls to be responded to within two working days. Messages from pwMS can also be sent via email.

Nurses calling back have access to case notes and all calls are fully documented. The system allows for data to be recorded on the ID of each caller, date of call, reason for call, outcome and date completed and response times are monitored monthly as part of a report on Key Process indicators. The MS Specialist Nurses staffing the telephone clinics now have 44 slots a week. The service has since been expanded to include other nurse specialists including epilepsy, Parkinson's, and MND and also integrated neurology nurses as part of the Vanguard programme.

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Case Study: Walton Centre Specialist Nurse Advice Line (Liverpool) cont.

Outcomes and benefits

- During 2016/17 the MS Specialist NAL handled over 2,000 calls.
- An audit carried out during April – September 2014 showed that, of 1,057 calls to the line:
 - only 70% of callers needed to speak to an MS nurse, illustrating the value of the call handler in filtering out administrative issues.
 - 34% of those who needed a call back received one the same or next working day.
 - 92% of those calling with suspected relapses received a call back within 2 working days.
- Evaluation of the service for all neurological conditions as part of the Neuro Network Vanguard, a partnership led by The Walton Centre, found that, between April 2016 and December 2017:
 - 56% (1,451) of the total NAL appointments (2,595) received advice and guidance only, thereby potentially avoiding an out-patient follow-up attendance.
 - This equates to a saving of £265,533 across the 9 Vanguard CCGs assuming an out-patient follow-up attendance cost of £183.00.
 - During this time period, a further 73 patients received a follow-up NAL appointment, thereby avoiding an out-patient follow-up attendance and a further saving for CCGs.

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Case Study: Walton Centre Consultant Advice Line (Liverpool)

Overview

The Consultant Advice Line (CAL) provides GPs with specialist neurology consultant advice and guidance by phone to support management of their patients with neurological symptoms/conditions within primary care.

Background

The Walton Centre is unique as they are the only specialist hospital trust in the UK dedicated to providing comprehensive neurology, neurosurgery, spinal and pain management services. The CAL is part of the neurological services provided by the Walton Neuroscience Centre.

About the Service

The advice line is accessible week-days to all GPs in the Cheshire and Merseyside area.

Outcomes and benefits

- Patients are seen by the right services first time and treated quicker.
- Patients avoid unnecessary appointments, meaning less time off work for patients and less travelling.
- Reduced number of patients being referred to hospital outpatients inappropriately
- Evaluation of the service for all neurological conditions as part of the Neuro Network Vanguard, a partnership led by The Walton Centre, found that, between April and December 2017:
 - Between April to December 2017, 43% (189) of total calls (443) to the CAL received advice and guidance only, thereby potentially avoiding an outpatient's or specialist's appointment
 - This equates to a saving of £37,303 across the 9 CCGs in the Walton Centre catchment.
 - Where GPs asked for and subsequently received specialist advice and guidance, only 33% of patients went on to be referred to secondary care.

Acknowledgements

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- Motor Neurone Disease Association
- Multiple Sclerosis Society
- Multiple Sclerosis Trust
- Multiple System Atrophy Trust
- National Institute for Health and Care Excellence
- NHS England Patient Experience Team
- Parkinson's UK
- PSP Association
- Sue Ryder

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Or visit the RightCare website:

www.england.nhs.uk/rightcare



Multiple System
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Informed by relevant NICE recommendations

NICE National Institute for
Health and Care Excellence