




Optimal clinical pathway for adults: Movement Disorders

National Neurosciences Advisory Group (NNAG)

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Overview: About the optimal pathway

This pathway is part of a suite of optimal neuroscience clinical pathways that have been developed by the neurological community, with the support of NHS England and the National Neurosciences Advisory Group (NNAG).

The development of this pathway was overseen by NNAG, with input from professional bodies and patient organisations. A 6 week public consultation was held to gather input, views and experience from people affected by neurological conditions and wider stakeholders.

The pathways set out what good treatment, care and support looks like. This includes treatment and support for people who may be experiencing the first symptoms of a neurological condition, right through to people who have lived with a condition for a long time. They set out the aspirations for good care, support improvement of services and enable commissioning of quality services, locally and nationally.

Optimal Clinical Neuroscience Pathways



NEUROSCIENCE

SUBARACHNOID/INTRACRANIAL HAEMMORHAGE

PITUITARY TUMOUR

BRAIN TUMOURS

MULTIPLE SCLEROSIS (MS)

EPILEPSY

AUTOIMMUNE

HEADACHE & FACIAL PAIN

NEUROMUSCULAR CONDITIONS

MOVEMENT DISORDERS

MOTOR NEURONE DISEASE (MND)

FUNCTIONAL NEUROLOGICAL DISORDER (FND)

TRAUMATIC BRAIN INJURY (TBI)



CROSS-CUTTING

TRANSITION FROM CHILDREN TO ADULT SERVICES

NEUROGENETICS

MENTAL HEALTH

REHABILITATION

FIND OUT MORE

Optimal clinical pathways and resources (NHS England and NHS Improvement. NHS log in required): www.future.nhs.uk/about

Optimal clinical pathways and resources (NNAG): www.nnag.org.uk/optimum-clinical-pathways

Neurological patient organisation websites & resources (Neurological Alliance): www.neural.org.uk/membership/our-members



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Executive summary

Movement disorders (MD) encompass a wide range of different disorders such as Parkinson's disease (PD), atypical parkinsonian disorders such as Multiple system atrophy (MSA) or Progressive supranuclear palsy (PSP), Huntington's disease (HD), Ataxia, Dystonia and Tourette's syndrome (TS). MD can occur at all ages, and frequently result in complex motor and non-motor symptoms. Non-motor symptoms are often under-recognized and may have a more severe effect on quality of life than motor symptoms.

Current care for people with MD is often fragmented and may only address some of their symptoms. Challenges include poor quality or absent explanation of the diagnosis by neurologists or other health care providers without a clear treatment plan after initial appointment, lack of a clear pathway to access such specialist services (e.g. physiotherapy, mental health), lack of availability of specialist services, lack of specialised MD expertise within these treatment services and lack of coordination between mental and physical health services in assessment and treatment.

The pathway steering group emphasised the fundamental importance of people with MD receiving a timely, correct and well-explained diagnosis. The quality of on-going symptom management and specialist MDT care will depend on sufficient staffing (in particular, specialist nurses and neurologists), access to AHPs (in particular, physiotherapists) with expertise in MD, and appropriate support from occupational therapists to ensure that MD patients can maintain their independence for as long as possible and

have the best possible quality of life. PD and all other neurodegenerative MD conditions are relentlessly progressive. Optimal MD clinical pathways therefore need to acknowledge that many MD patients will have changing needs.

A fully integrated system wide care pathway, integrated across primary, secondary and tertiary care and the different disciplines will be crucial to achieve optimal care addressing each patient's individual needs. Novel ways of working (e.g. remote appointments, digital monitoring, virtual MDTs) should be actively explored and embraced but need to take the individual needs and abilities (e.g. digital literacy) of each patient and their families into account.

Access to research must be a mandatory, integrated part of MD patient care.

This pathway requires a significant investment in consultant and therapist time to provide specialist MD services within each regional neuroscience centre and to bolster community services. However, the pathway is expected to create efficiency savings while improving clinical outcomes for people with MD by, for example, providing early diagnosis, reducing unnecessary investigations, reducing unnecessary treatments, and ensuring that patients are referred in a timely fashion to the most suitable treatment service, depending on their individual needs. Wherever possible, patients should be empowered and actively involved in treatment decisions.

Pathway: Referral to diagnosis

Guiding principle:

People with movement disorders should have an accurate and timely diagnosis, in order to access appropriate therapies efficiently

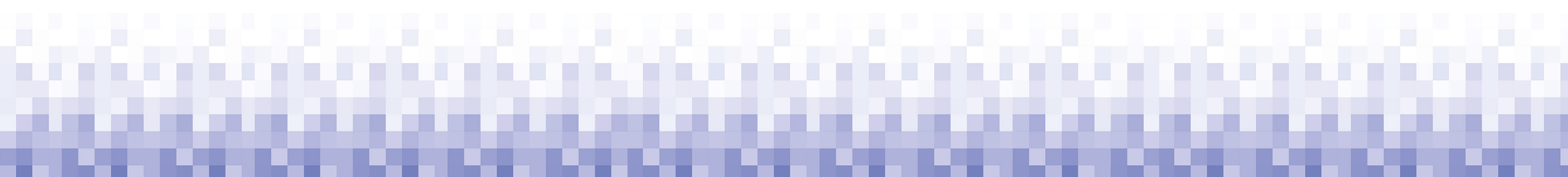
People with movement disorders should be referred to an appropriate specialist movement disorders service if on-going care required or diagnosis uncertain

Barriers

Number and capacity of specialist neurologists
Availability of diagnostic services (MRI, DATscan)

Enablers

Sufficient capacity in specialist movement disorders services across the country, addressing on-going “post-code lottery” issues



Pathway: Diagnosis to specialist MD service assessment

Guiding Principles:

- All people with movement disorders who require ongoing input from specialist services should have a single point of contact for access
 - PD and related disorders: A decision should be reached early as to the most appropriate specialist (eg Care of the Elderly or Neurology), based on individual patient factors such as frailty, co-morbidities and dementia and the respective local service arrangements
 - Dystonia: A decision should be reached early as to the most appropriate specialist (e.g. Neurology or Ophthalmology), based on individual patient factors such as the presentation of symptoms
 - All patients with neurodegenerative movement disorders should be able to access a specialist nurse
- All people with movement disorders should have a care/management plan agreed through shared decision making
- At each stage of the disease, patients should have access to education and opportunities for self-management with appropriate support, including information about peer/charity support
- All people with neurodegenerative movement disorders should have an annual review by an (ideally named) consultant with expertise in MD [NICE].
- All patients with movement disorders should have access to Neuropsychiatry and Neuropsychology when indicated
- Services should ensure rapid access for assessment of acute changes in a patient's condition (e.g. psychosis)

- Patients (and, where appropriate, their carers) should be informed of route for rapid access which will vary and depend on local service provision arrangements

Services should be research active and provide access to a broad range of research participation opportunities

Barriers:

- “Postcode Lottery” of available services (i.e. specialist nurses)
- No nation-wide information portal on available services
- Lack of formal integration of community-based services with hospital-based services
- Lack of clear distinction between required local service (such as PD nurse support) vs regional services (such as habit reversal therapy for TS)
- Postcode lottery for care co-ordination community matron service, and for acceptance of palliative care referrals

Enablers:

- MD services might be delivered by a network of professionals linked virtually, connecting hospital-based and community-based services
- MD services should be supported by an administrator
- Technology might allow patients to be more involved in their care and support care delivery

Pathway: Symptomatic treatment

Guiding Principles

- All patients with MD should be appropriately and rapidly assessed for symptomatic therapy options
- All treatment options need to be considered (motor vs non-motor, pharmacological vs non-pharmacological), including lifestyle and peer support information
- Secure transparent access to additional specialties where required (e.g. Urology, Gastroenterology, Palliative Care, Genetics, Ophthalmology, Respiratory Specialists, Bladder and Bowel team, Neuropsychology and Neuropsychiatry)
- All patients, from diagnosis on, should be assessed for required psychological support and eligibility from mental health services

Barriers:

- Lack of nurse prescribers
- Lack of staff to support non-pharmacological intervention,

especially staff with relevant expertise in movement disorders (e.g. physiotherapist with expertise in PD or dystonia)

- Lack of integration/agreed care pathway between Neurology and associated specialties, in particular Mental Health Services
- Lack of access to typically community-based allied health services (e.g. SLT, OT) and resulting poor integration
- Inconsistent expertise of SLT, OT etc with movement disorders
- Lack of access to care co-ordination and community matrons

Enablers

- Treatment can be delivered by a network of specialists linked virtually, operating in the community with access to hospital services where required
- Routine prescribing and monitoring does not need to be by consultant neurologist, but could be by Nurse or Pharmacist with necessary experience and knowledge
- Improved access to allied health services

Pathway: Specialist components of care

- “Specialist services” are those which require technology and expertise only available in regional neuroscience centres
- Examples include: Deep brain stimulation (DBS), Duodopa, Botulinum toxin (Botox)

Barriers

Commissioning barriers to local access to treatments
Lack of knowledge about indication and availability of services
Lack of specialised neuropsychiatry services in neuroscience centres

Enablers

Clear designation of regional centres with regular regional virtual MDTs to discuss suitability of individual patient for specialised intervention (e.g. DBS) prior to referral

Pathway: Treatment

Symptom management and specialist MDT care

- People with MD should be offered MDT input where appropriate with clear care plan
- Patients should be assessed for ability to self-manage and self-refer

Barriers

- Insufficient PD/MD nurses to provide safe and high-quality service for patients in their caseload
- Lack of consistency in service specification (e.g. whether PD nurses should also be responsible for patients with atypical Parkinsonism or those with parkinsonism after the onset of dementia, and whether ophthalmologists should also be responsible for patients with blepharospasm (eye dystonia))
- Lack of specialist AHPs, especially those with rehabilitation expertise

Enablers

- Tailored Support to enable self-management
- Digital technology, e.g. remote monitoring
- Virtual clinics
- Using local optometry services, e.g. to manage dry eyes in blepharospasm (eye dystonia)

Pathway: Treatment of advanced MD

Holistic care for people with MD and increased care needs

- Care of people with advanced, MD needs to include a suitable community-based MDT (e.g. physiotherapists, OT, SLT, social workers)
- Attention should be given to advance care planning and carers' support
- Input of palliative care teams should be sought where appropriate

Barriers

- Lack of integrated working between primary and secondary care teams
- Lack of skills, lack of funding, insufficient time, and unsuitable environment for advanced care planning discussions during specialist MD out-patient appointments
- Discussion of advanced care plans is a sensitive matter and optimal timing can be difficult (between too early and too late)
- Lack of capacity for specialist palliative care team to take on MD

Enablers

- Integrated primary and secondary care with MDT forum as platform for communication and decision-making
- Disease-specific specialist skill set with knowledge of both MD and advanced care planning within the team
- Adequate infrastructure and funding
- On-going ability to access hospital-based or community-based specialist services and remote advice (with appropriate remuneration) irrespective of ability to attend clinic (see guiding principles)
- System wide integration to include primary, secondary and tertiary care as well as the third sector, social care amongst others.
- Communication between MD team and specialist palliative care team

Recommendations & key changes: Technology

- Services should take advantage of local technology and clinical management systems
- Improved data sharing between professionals, sharing access to systems and data
- Promotion of patient portals to access clinic letters, test results, care plans and facilitate PROMS
- National portal with reliable, routinely updated information on locally available services
- Appropriate infrastructure for data management, including digital (e.g. sensors, apps, web portals)
- Appropriately skilled work force for data management
- Appropriate training, time and remuneration of clinical work force to deliver digitally enabled care

PROMS Patient reported outcome measures,

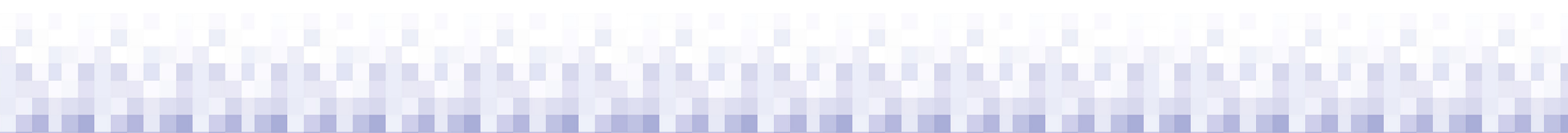


Recommendations & key changes: MD quality standards and associated metrics

Quality Standard	Clinical metric	Patient self-reported metric
All patients diagnosed with a MD who require ongoing input must be referred to a MD specialist team within 4 weeks.	Percentage of new referrals to MD specialist teams that were referred within 4 weeks of diagnosis of MD.	Were you referred to a specialist MD team within 4 weeks of being diagnosed with a MD?
A care plan must be agreed within 3 months of receipt to a specialist MD team	Percentage of people who have agreed care plan within 3 months of receipt of referral to specialist MD team	Did you have the opportunity to discuss the management of your MD with a specialist MD team within 3 months of being referred?
All patients must be given information about their condition tailored to their individual needs and local/regional services at first appointment with specialist MD team	Percentage of people with confirmed diagnosis of MD who have received appropriate written information about condition and locally/regionally available services at first appointment with specialist MD team.	Were you given appropriate information about your condition and available services at the first appointment with the specialist MD team?
All patients with confirmed diagnosis of MD should be referred to the appropriate specialist nurses (e.g. all patients with PD to be referred to PDNS) within 3 months	Percentage of people with a confirmed diagnosis of MD referred to the appropriate specialist nurses within 3 months of first appointment with specialist MD team	Were you contacted by an appropriate specialist nurse within 6 months of first appointment with specialist MD team?
All services should have a process to identify patients who are eligible for device-assisted therapies (e.g. DBS, enteral levodopa infusion, apomorphine pump)	Percentage of patients referred for device-assisted therapies	N/A
Care plans and follow up arrangements should depend on clinical need and patient preference	Percentage of people with MD with an agreed personalized care plan	Have you agreed a care plan with your specialist team? Were you offered a range of follow-up options for review (e.g. in-person clinic review, telephone/video review)?

Recommendations & key changes: MD quality standards and associated metrics (continued)

Quality Standard	Clinical metric	Patient self-reported metric
People with MD who require ongoing input from specialist MD services should have a defined point of contact	Percentage of people with MD who have a defined point of contact within the MD service	Do you know who to contact within the MD team if you have any questions or concerns?
Responses to unscheduled patient contact should prompt and prioritised according to clinical urgency	Median number of days taken to respond	Have you ever contacted your MD specialist team about an urgent issue? If so, how many days did they take to respond?
MD patients should be provided with appropriate information about their illness throughout their disease course (rather than just at the point of diagnosis)	Percentage of patients seen at follow up appointments in the last year who were offered written information about their condition	Have you been provided with information tailored to your needs throughout your disease or signposted to suitable resources?
Every MD service should maintain a current database of patients with people with MD	Percentage of new referrals and follow up patients seen in the MD service over last year who were added to database.	To your knowledge, are you signed up to a patient register through your specialist?
Every patient with a MD should be offered opportunities to take part in clinical research	Percentage of people with whom research participation has been discussed	Have opportunities to participate in research been discussed with you?



Recommendations & key changes: Research and clinical trials

Barriers to research and clinical trials

- Research not considered as part of core clinical care both at individual and organizational level
- Insufficient funded time to embed research into routine care activity for clinicians, specialist nurses and AHPs
- Clinician gate-keeping
- Inadequate tariff for providers to support research activity as part of routine clinical care
- Insufficient research delivery work force
- Excess treatment costs hinder intervention studies

Suggestions

- Training in research competencies to become compulsory part of medical/clinical/nursing education
- Embed research into routine clinical care by including research time in job plans
- Implement NICE guidance
- Include research delivery metrics as a key criterium to assess an MD service for its quality of clinical care
- Tariffs for care to include provision for access to research opportunity
- Novel solutions to increase and empower future research work force (e.g. NAHPs)



Movement Disorders Health Care Pathway



Person with movement disorder (MD)

FIRST NEUROLOGICAL SYMPTOMS SUGGESTIVE OF MOVEMENT DISORDER

CO-MORBIDITIES GENERAL WELL-BEING SYMPTOM MANAGEMENT

PROGRESSION OF DISABILITY SYMPTOM MANAGEMENT

PALLIATIVE CARE

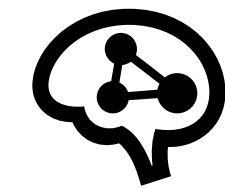
END OF LIFE CARE



GP & community team

GP
• Assessment
• Referral to most appropriate local service

GP-PRIMARY CARE
• All routine screening
• Co-morbidity care and appropriate referral
• General well-being
• Medication + review
• MD symptom and complication recognition requiring re-referral e.g. hallucinations



Local Neurology Service

DIAGNOSIS
Timely and accurate

ASSESSMENT FOR SYMPTOMATIC TREATMENT
• Timely and appropriate
• Both pharmacological and non-pharmacological treatment options to be considered

SYMPTOM MANAGEMENT AND DIAGNOSTIC REVIEW
• MD nurse led
• Supported by regular consultant review Responsive and appropriate to patient needs
• Ensure patients/care partners are appropriately supported to self-manage
• Integrated care plan with community-based services
• Apomorphine treatment
• Botulinum toxin treatment



Regional Centre

SPECIALIST INTERVENTIONS
• DBS
• Duodopa
• Habit reversal therapy
• Specialist Trial interventions



Supra-regional service

SUPRA-SPECIALIST INTERVENTIONS
• FUS
• Select future disease-modifying therapy (e.g. stem cell transplantation)

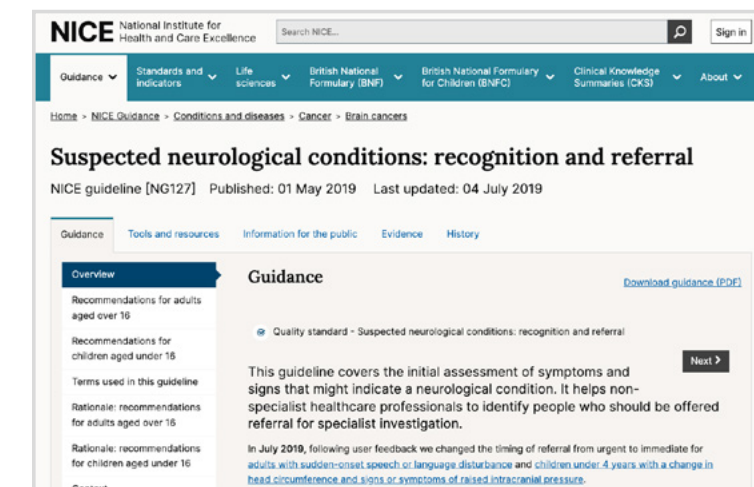
INFORMATION, EDUCATION, ADVICE, SUPPORTED SELF-MANAGEMENT, SHARED DECISION MAKING, ACCESS TO RESEARCH OPPORTUNITIES

Clinical guidance to be considered alongside the pathway

We refer to the available NICE guidelines for detailed clinical guidance:

Suspected neurological conditions: recognition and referral (NG127)

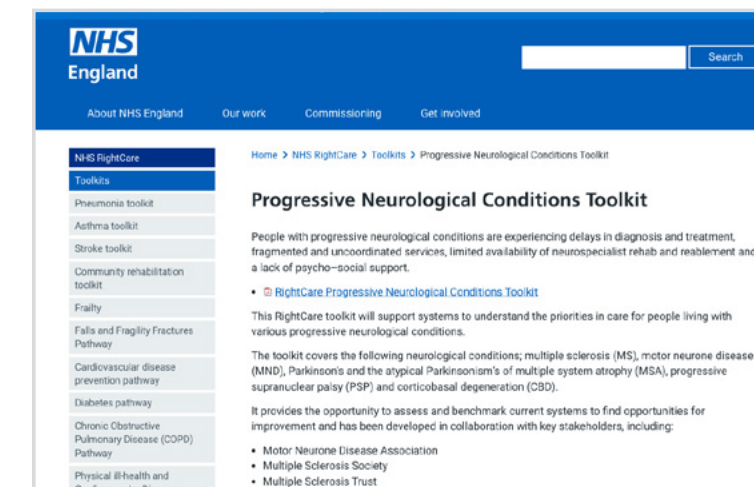
[VISIT THE NICE WEBSITE](#)



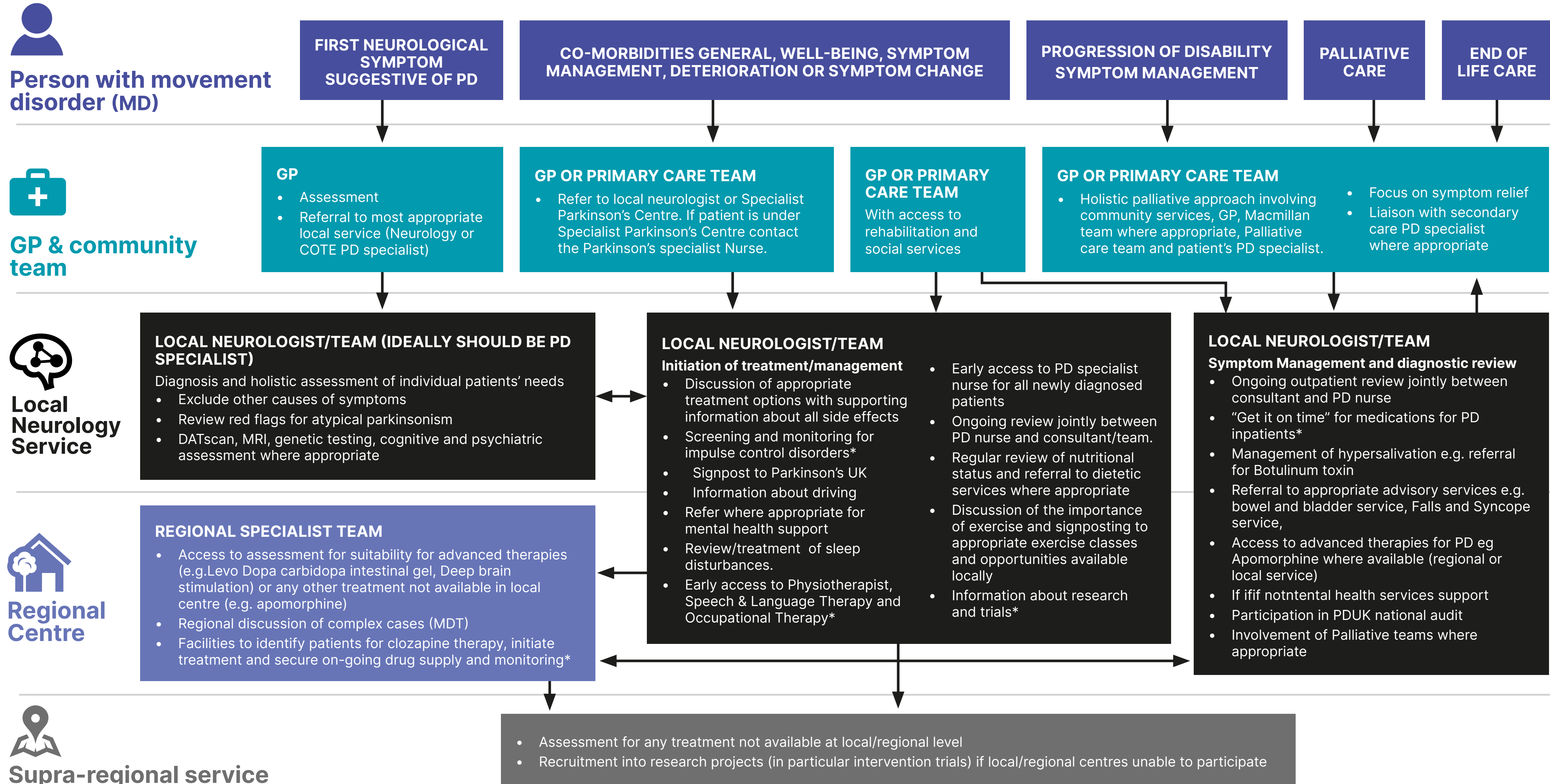
Useful Resources:

NHS RightCare Progressive Neurological Condition Toolkit

[VISIT NHS WEBSITE](#)



Appendices: Parkinson's Disease Health Care Pathway*



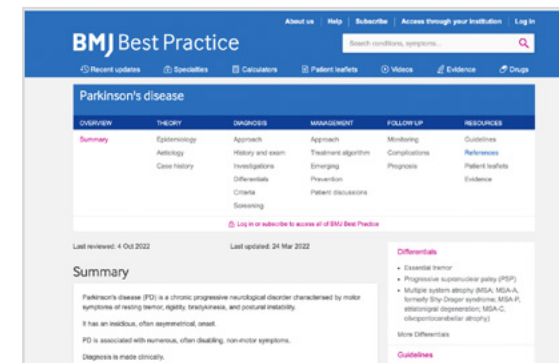
Information, education, advice, supported self-management, shared decision making, access to research opportunities

DBS Deep Brain Stimulation, COTE Care of the Elderly, MDT multi-disciplinary team, PD Parkinson's Disease * Refers to QS – NICE quality standard NB: Specialist Parkinson's Centres may sit within neurology or CoTE

Guidance and support to be considered alongside the Parkinson's appendices

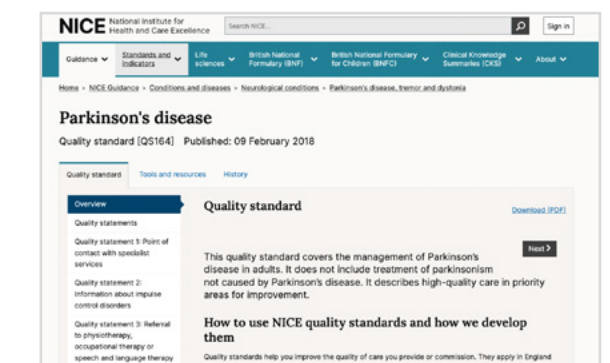
BMJ Best practice Parkinson's disease

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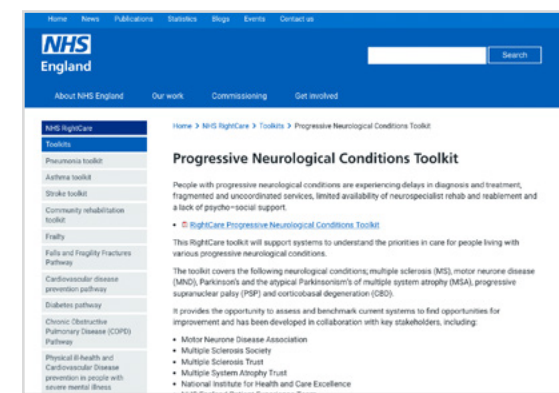
Parkinson's NICE Quality Standards [QS164] 2018

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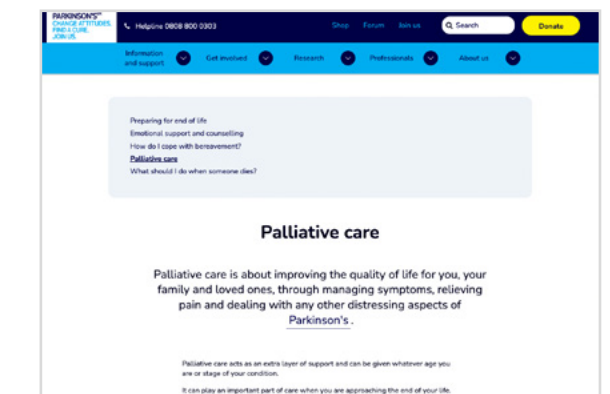
NHS Rightcare Progressive Neurological Conditions Toolkit

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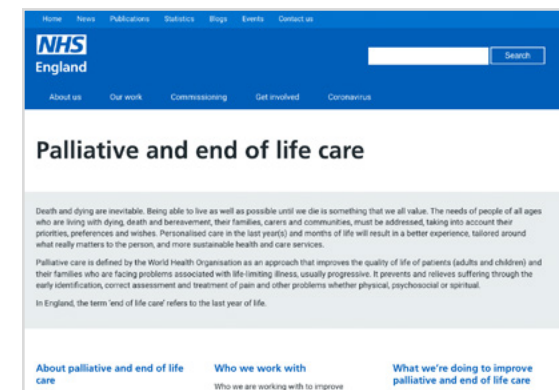
Parkinson's UK information on palliative care

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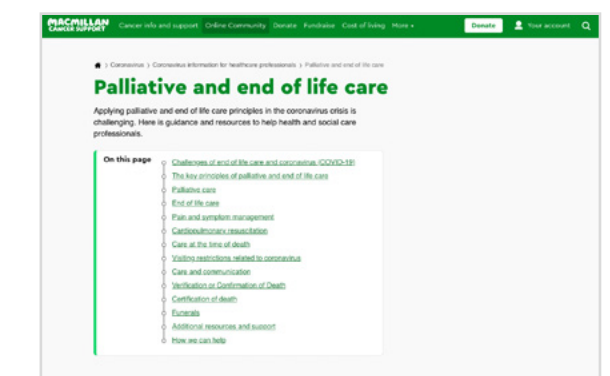
NHS England information on palliative and end of life care

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Macmillan information on palliative and end of life care

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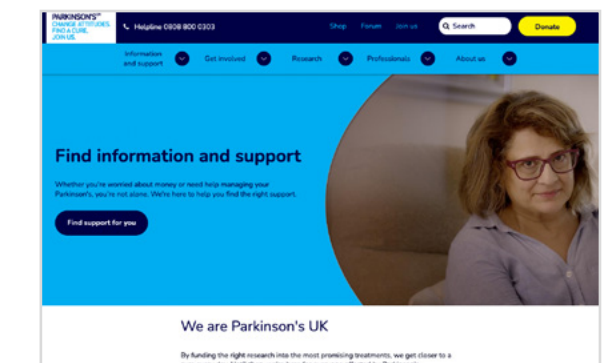
Parkinson's disease in adults [NG71] 2017

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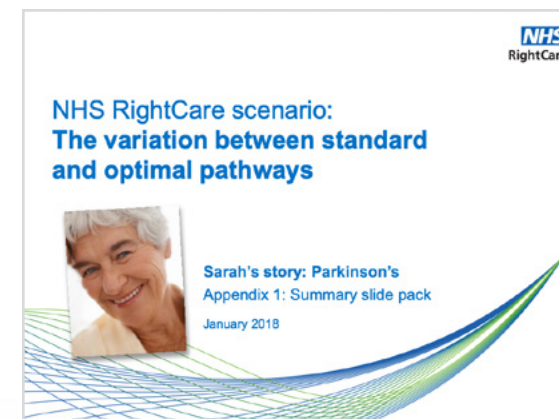
Parkinson's UK www.parkinsons.org.uk

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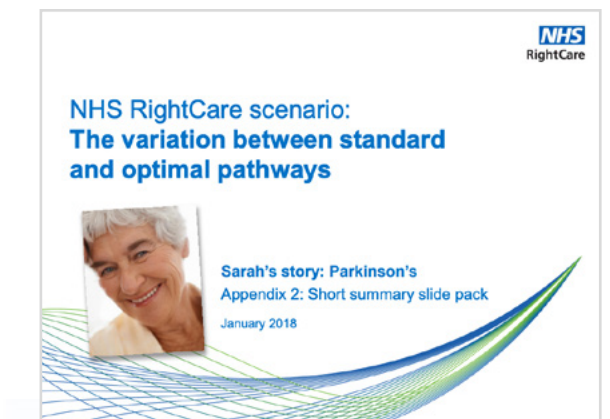
NHS RightCare scenario: The variation between standard and optimal pathways Sarah's story: Parkinson's Appendix 1: Summary slide pack

[OPEN PDF ONLINE](#)



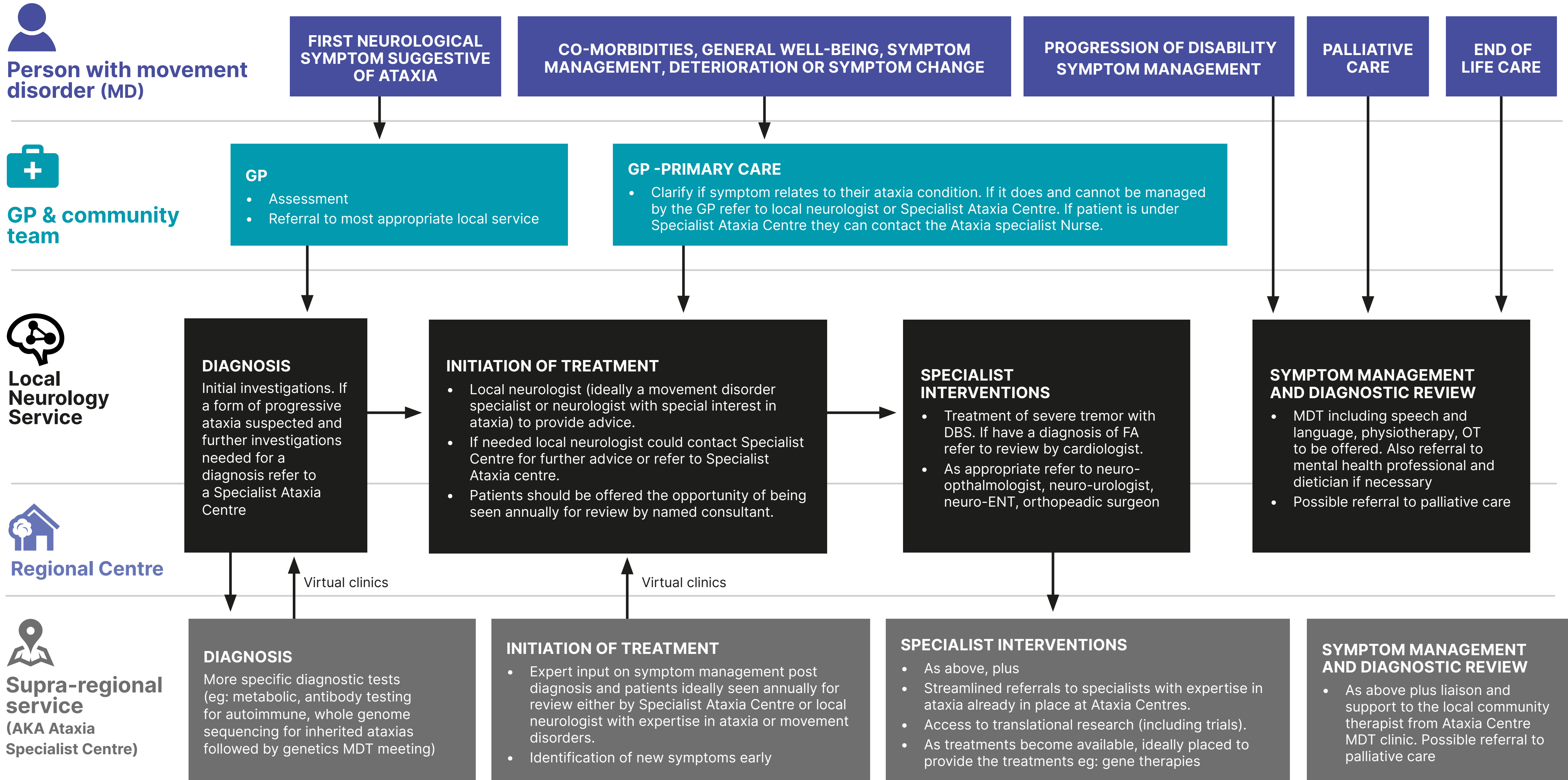
The variation between standard and optimal pathways Sarah's story: Parkinson's Appendix 2: Short summary slide pack

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Ataxia Health Care Pathway

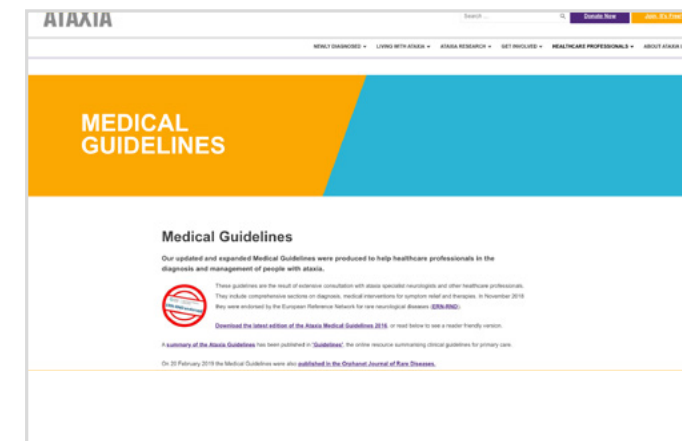
This Appendix is for people with progressive ataxia that can be caused by many different conditions (eg: Friedreich's ataxia, inherited cerebellar ataxia, auto-immune ataxia, idiopathic cerebellar ataxia). It does not cover people with ataxia as a result of stroke, MS, tumours etc.



Guidance and support to be considered alongside the Ataxia appendices

Ataxia UK, Management of the ataxias:
Towards best clinical management. Third Edition

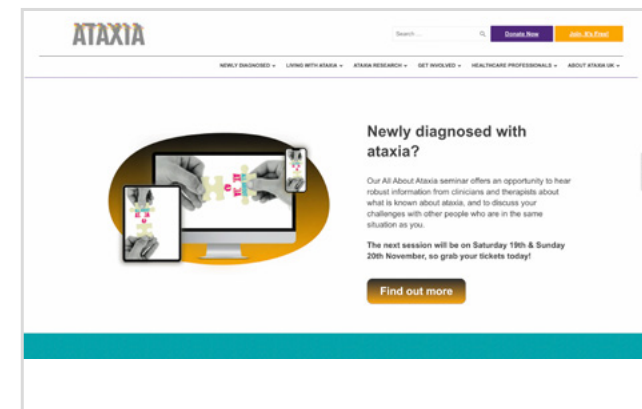
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Ataxia Specialist Centres and other ataxia experts

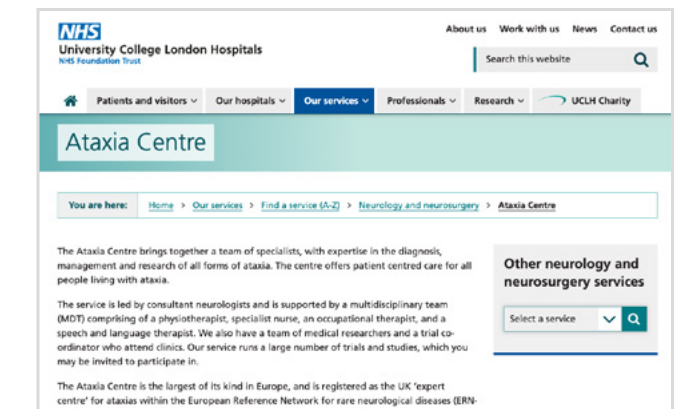
Ataxia UK www.ataxia.org.uk

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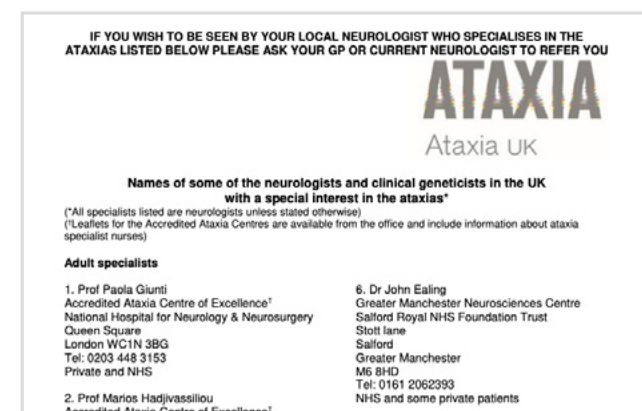
UCLH, About the London Ataxia Centre

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Ataxia UK, Neurologists with
a special interest in Ataxia

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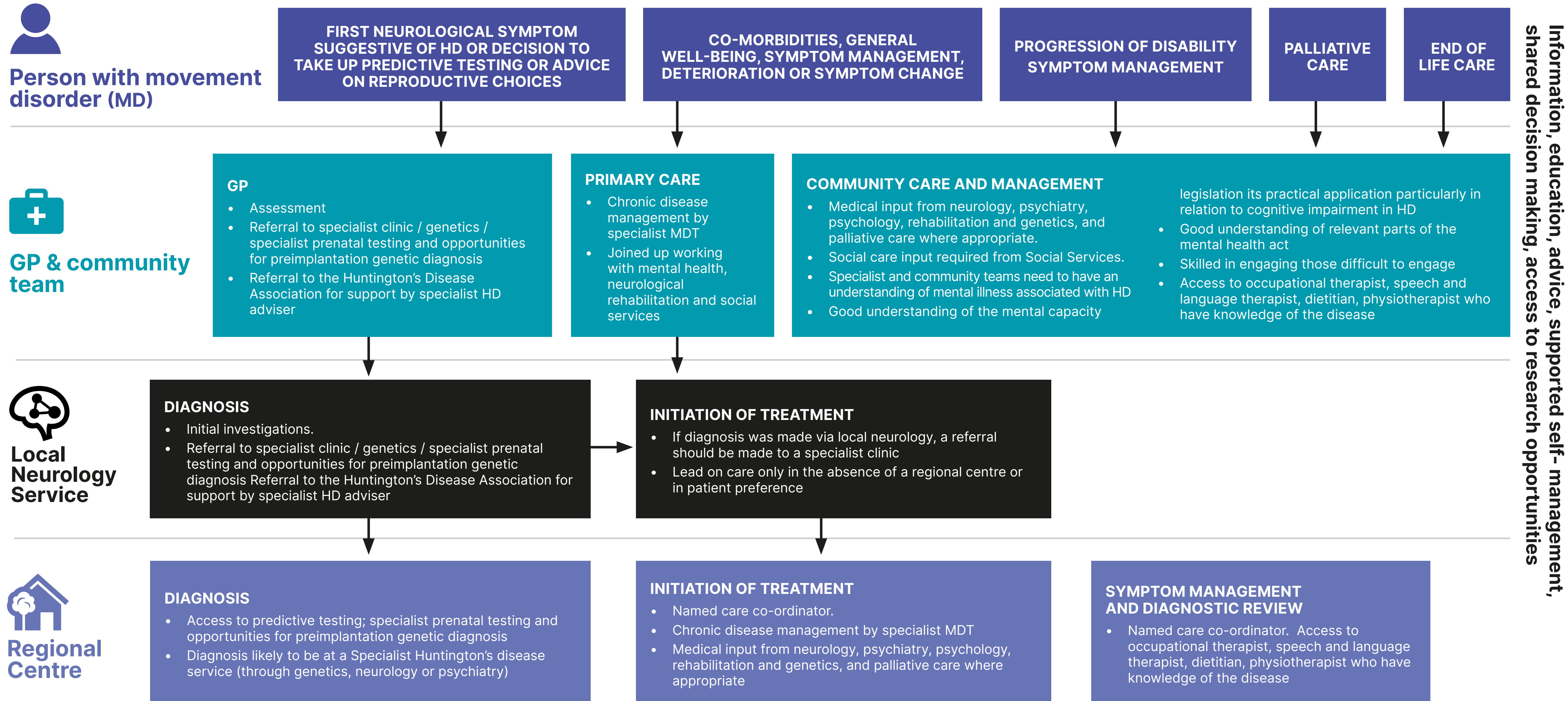


Sheffield Teaching Hospitals, About
the Sheffield Ataxia Centre

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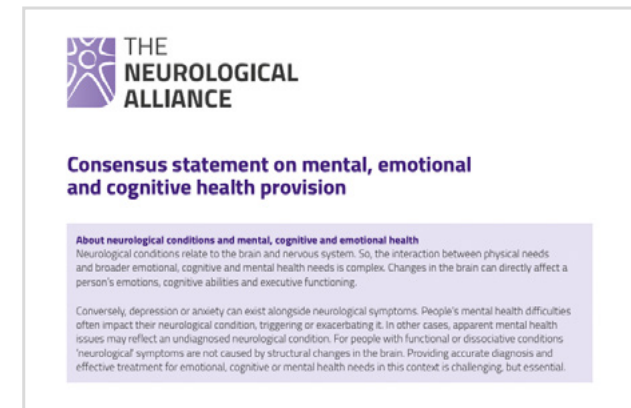
Huntington's Disease Health Care Pathway



Guidance and support to be considered alongside the Huntington's disease appendices

The Neurological Alliance Consensus statement on mental, emotional and cognitive health provision

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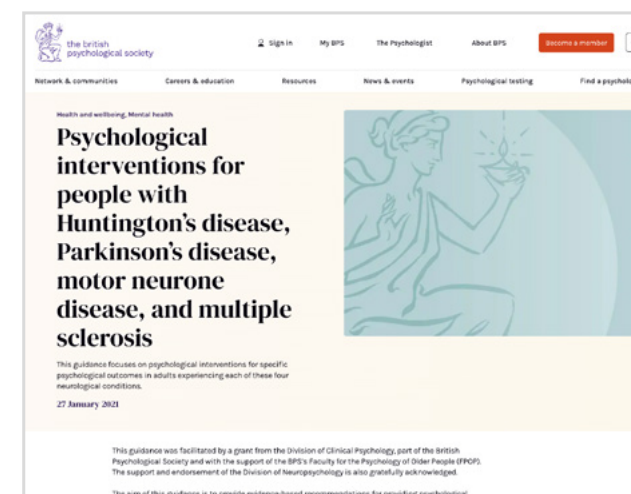
European Huntington's Disease Network (2009) Physiotherapy Guidance Document

VISIT WEBSITE



The British Psychological Society, Psychological interventions for people with Huntington's disease, Parkinson's disease, motor neurone disease, and multiple sclerosis

VISIT WEBSITE



Veenhuizen, R.B., Kootstra, B., Vink, W. et al. Coordinated multidisciplinary care for ambulatory Huntington's disease patients. Evaluation of 18 months of implementation.

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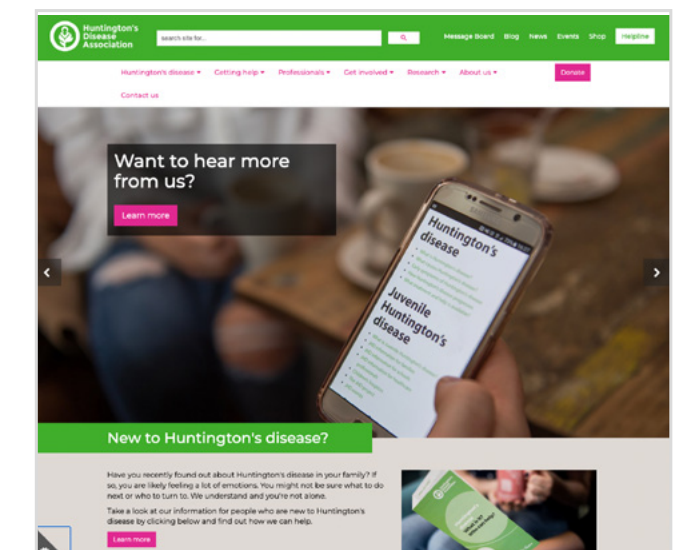
Simpson S A, Rae D A (2012) A standard of care for Huntington's disease: who, what and why, Neurodegenerative Disease Management, 2(1) Foreword

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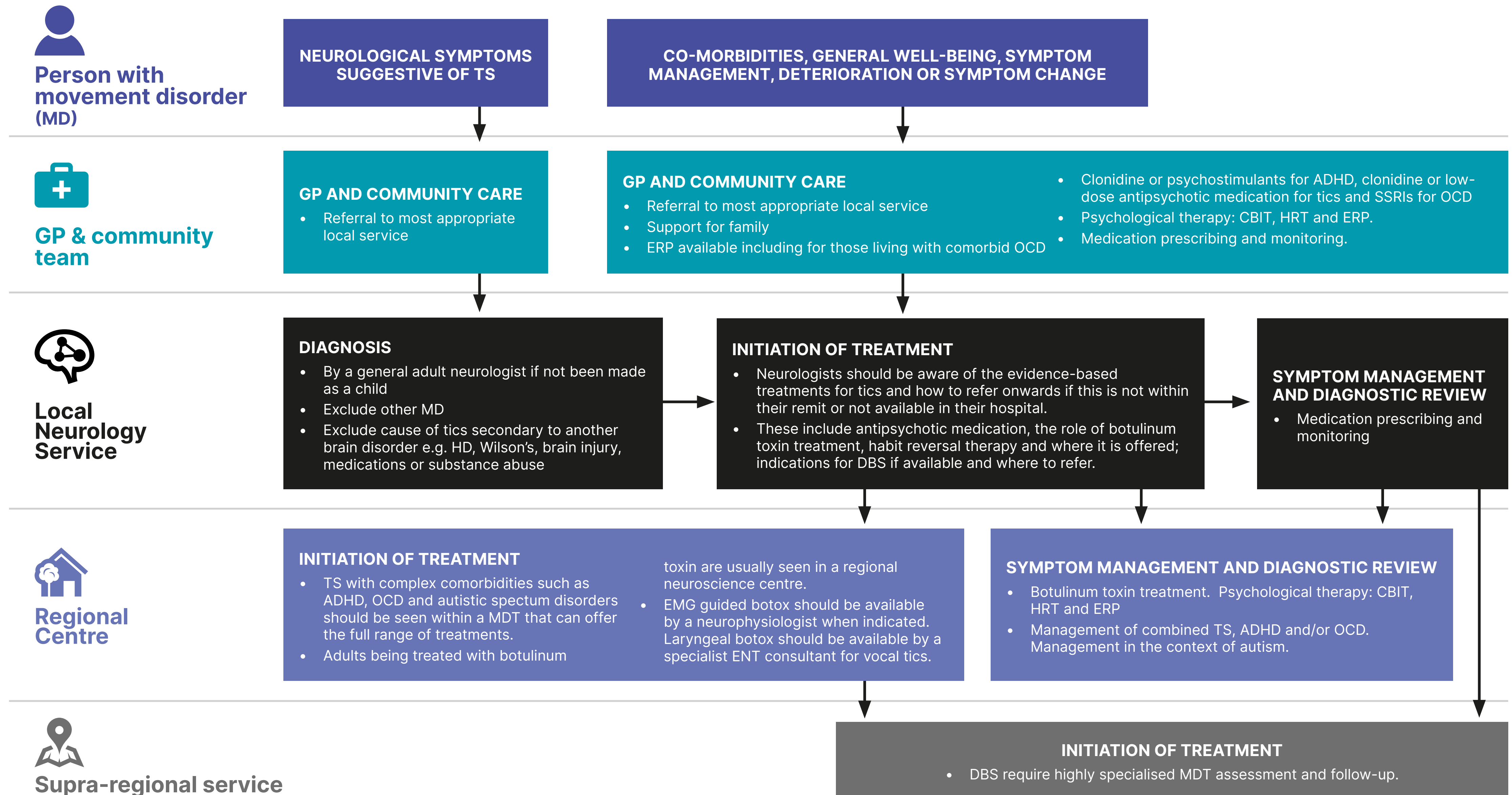


Huntington's Disease Association

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Tourette Syndrome Health Care Pathway

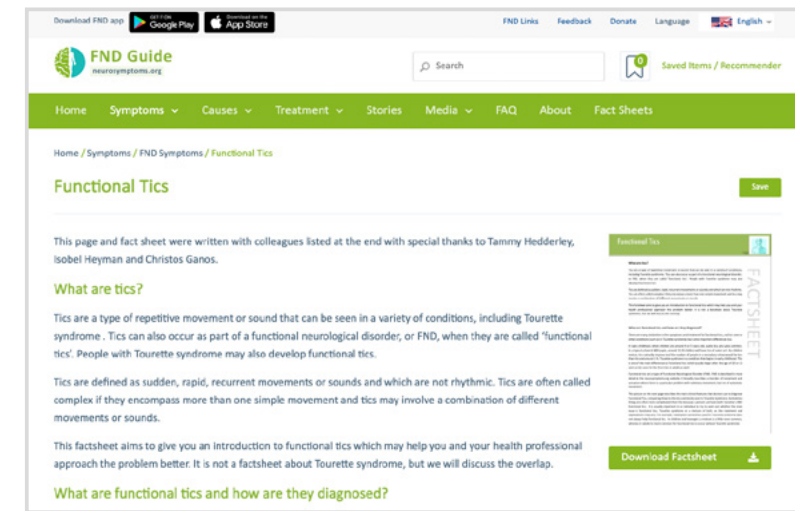


Information, education, advice, supported self-management, shared decision making, access to research opportunities

Guidance and support to be considered alongside the Tourettes Syndrome appendices

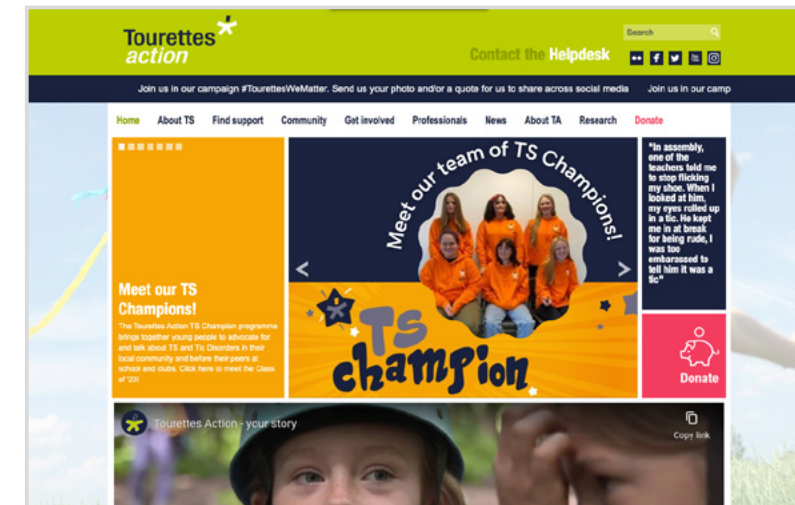
FND Guide information on Functional Tics

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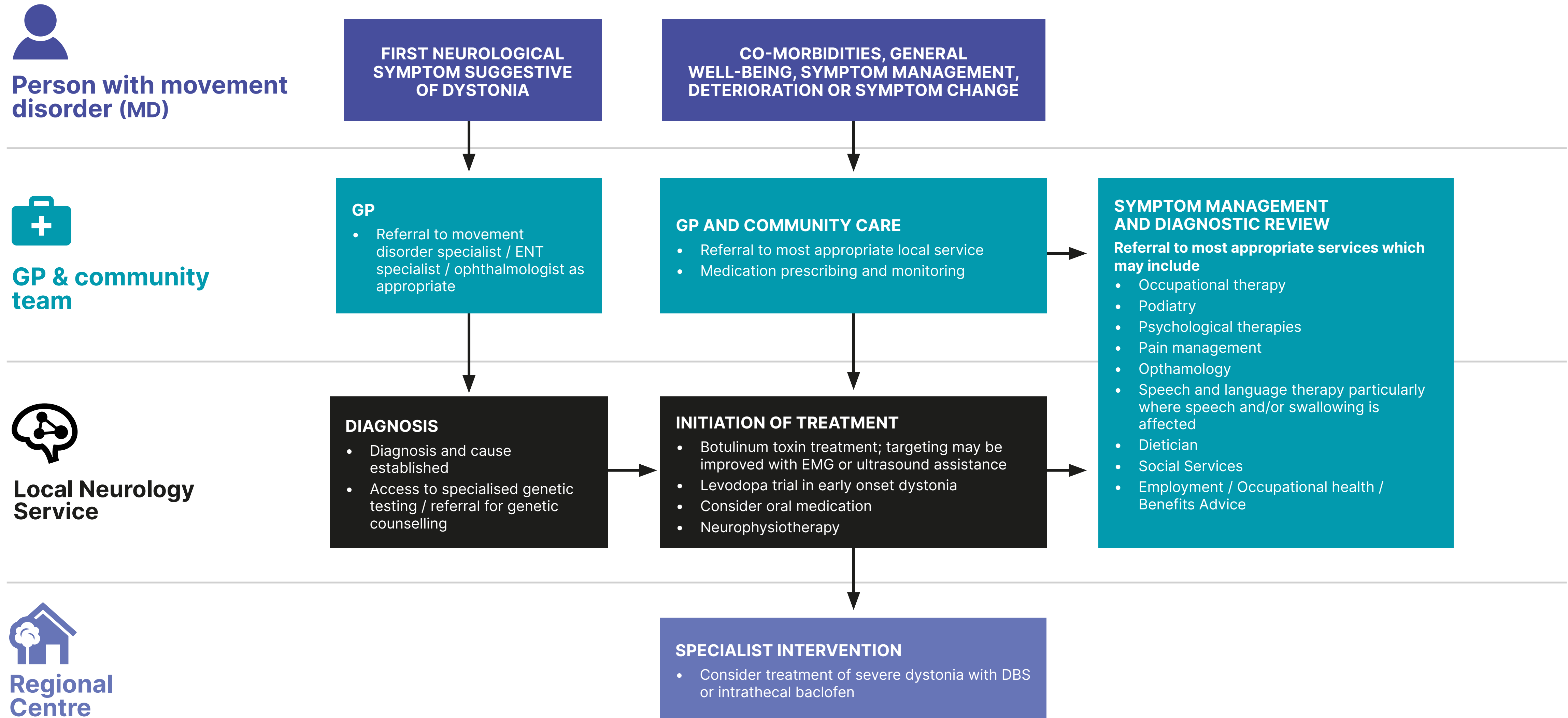


Tourettes Action www.tourettesaction.org.uk

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Dystonia Health Care Pathway

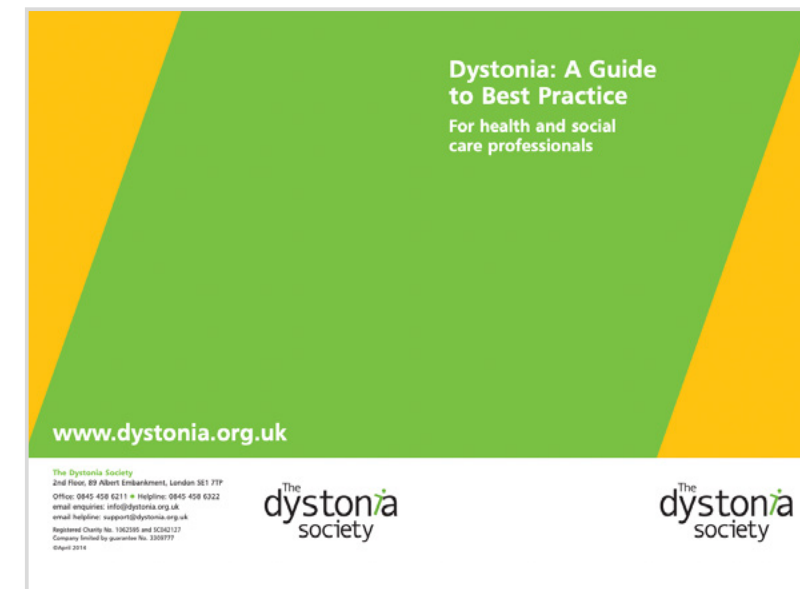


Information, education, advice, supported self- management, shared decision making, access to research opportunities

Guidance and support to be considered alongside the dystonia appendices

Dystonia UK: A Guide to Best Practice for health and social care professionals.

[VIEW PDF ONLINE](#)



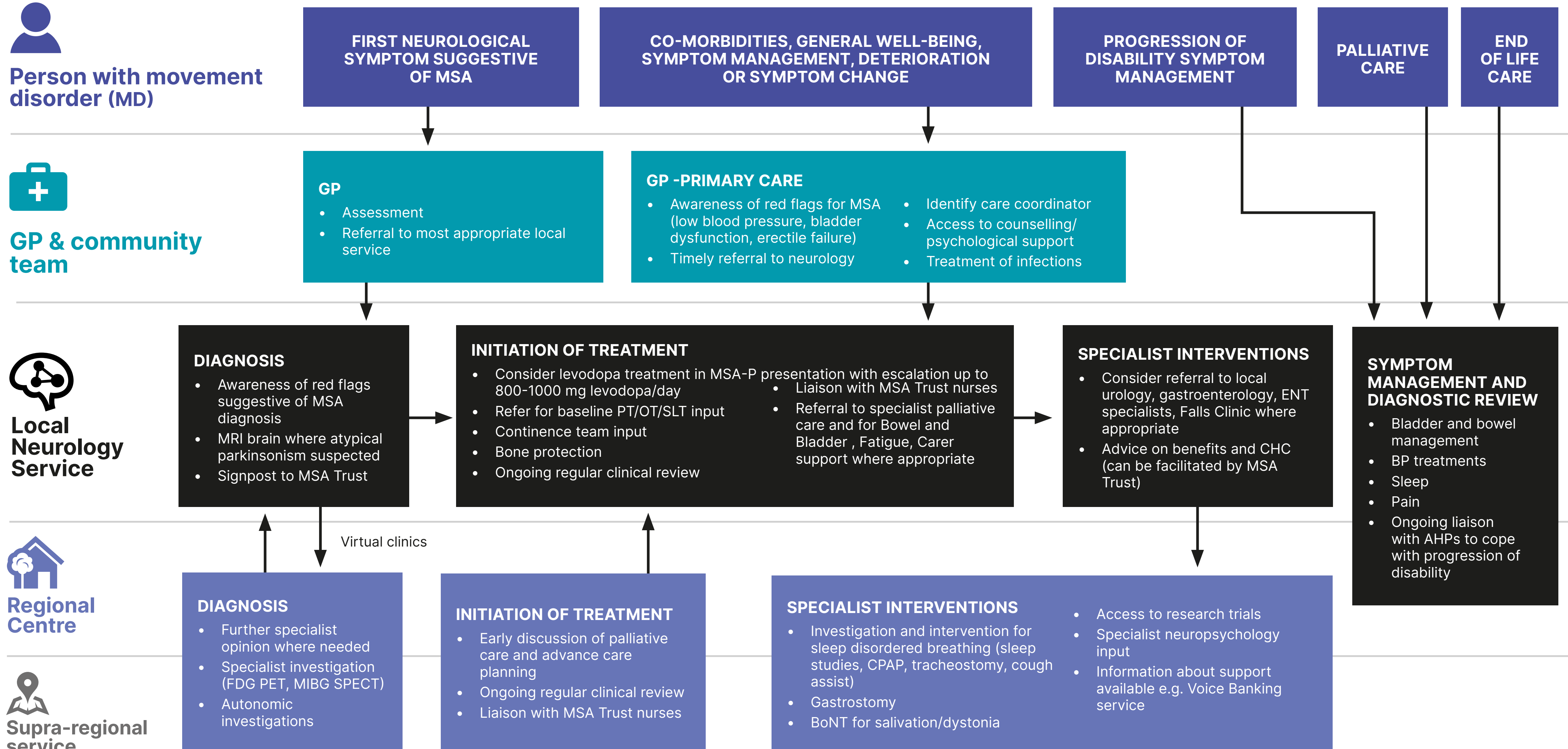
Suspected neurological conditions: recognition and referral [QS198] 2021
Quality statement 3: Suspected dystonia in adults

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Multiple System Atrophy (MSA) health care pathway

The MSA Trust recommends that all people with MSA should be reviewed at least 6 monthly by their specialist or local centre and that many people with MSA may require more frequent review.



Information, education, advice, supported self-management, shared decision making, access to research opportunities

Guidance and support to be considered alongside the MSA appendices

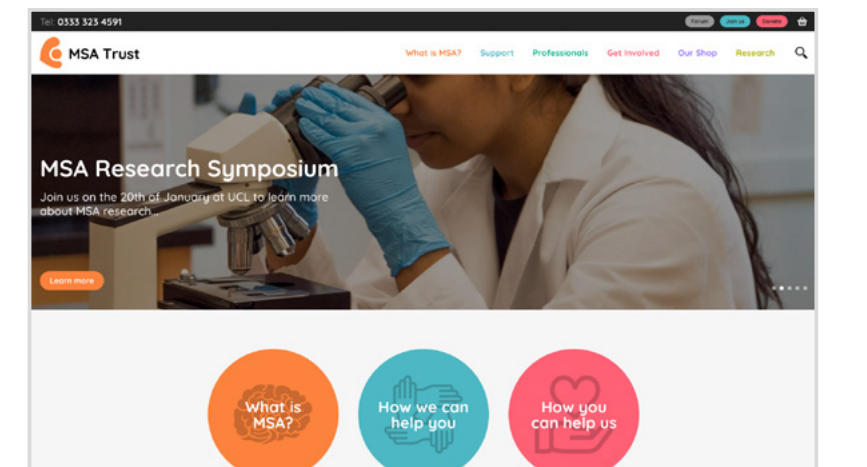
The Movement Disorder Society Criteria for the Diagnosis of Multiple System Atrophy 2022

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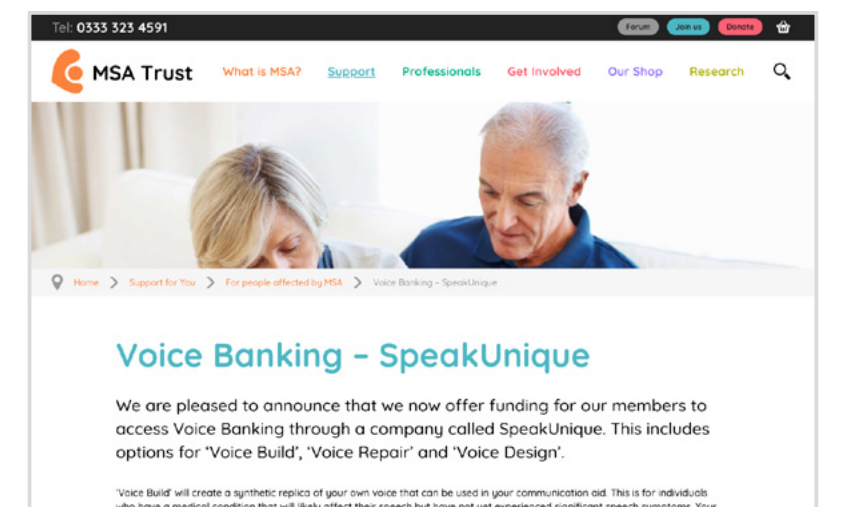
The MSA Trust : www.msatrust.org.uk

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Voice Banking: <https://www.msatrust.org.uk/support-for-you/for-people-affected-by-msa/speakunique/>

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Movement Disorders pathway clinical working group membership

Name	Profession	Organisation
Professor Oliver Bandmann (Pathway lead)	<ul style="list-style-type: none"> ■ Professor of Movement Disorders & Honorary Consultant Neurologist 	<ul style="list-style-type: none"> ■ University of Sheffield/Sheffield Teaching Hospitals Foundation Trust
Professor Camille Carroll	<ul style="list-style-type: none"> ■ Professor of Clinical Neuroscience and Honorary Consultant Neurologist 	<ul style="list-style-type: none"> ■ University Hospitals Plymouth NHS Trust
Professor Donald Grosset	<ul style="list-style-type: none"> ■ Senior Research Fellow and Honorary Professor 	<ul style="list-style-type: none"> ■ University of Glasgow
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Patient organisations



National Neurosciences Advisory Group c/o The Neurological Alliance (England)
www.nnag.org.uk

The Neurological Alliance is a coalition working together to improve treatment, care and support for people affected by neurological conditions. Together we campaign to ensure people affected by neurological conditions can access high quality, joined up care and support to meet their individual needs, at every stage of their life.

www.neural.org.uk

Email: info@neural.org.uk

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