

RCN Neuroscience Forum Conference 2026

Beyond Diagnosis: Neuroscience Nursing Across
Complex and Long-term Conditions



Wednesday 24 June 2026
Royal College of Nursing
20 Cavendish Square, London W1G 0RN

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Welcome

Dear Colleague,

On behalf of the Royal College of Nursing (RCN), welcome to the RCN Neuroscience Forum Conference 2026 - Beyond Diagnosis: Neuroscience Nursing Across Complex and Long-term Conditions.

We trust that you will find the event stimulating and informative and that you'll have an opportunity to network with colleagues during the event. We hope you will go away feeling inspired, invigorated and armed with information to share with colleagues in your workplace.

The RCN believes in life-long learning and actively promotes the continuing professional development of nurses. For this reason, certificates of attendance are provided. You are encouraged to contribute attendance at RCN events towards your framework for reflection which can be included in your portfolio.

At the end of the event, you will receive an email with a link to the online conference evaluation. We'd be grateful if you would complete this as soon as possible and within seven days of the conference. Your comments and feedback are invaluable in helping us plan future RCN conferences.

RCN staff and committee members are on hand to answer any queries you may have regarding your membership. Or if you're a non-member, they can inform you of the many benefits of joining the RCN. As a member, you can join any number of the RCN Forums. Forums have active Facebook groups that provide you with the opportunity to connect with colleagues and keep up to date on current practice related issues.

The RCN has professional forums across the diverse nursing arena and RCN members can join as many of these forums as they wish. Forums are a huge area of influence and direction for the RCN and are a valuable opportunity to network with colleagues around the UK and be involved in consultation responses, conferences, events and workshops, and forum-led publications. Find out more at: <https://www.rcn.org.uk/Get-Involved/Forums-and-networks>

We'd like to thank you for supporting this conference and look forward to welcoming you back to future RCN events. A full list of future events can be found on page 22 of this conference brochure.

With best wishes,

Siobhan Jones
Chair, RCN Neuroscience Forum

Programme at a glance

	Registration, networking and refreshments
9.50	<p>Chair's opening remarks Siobhan Jones, Headache Nurse Consultant, North Cumbria Integrated Care NHS Foundation Trust Chair, RCN Neuroscience Forum</p>
10.00	<p>Delivering a clinical neuroscience workforce fit for the future Sue Thomas, Healthcare Consultant, Kings College London</p>
10.30	<p>Listening to lived experience – what we would like nurses to know Frances Quinn, British Polio Fellowship Trustee and polio survivor Will Howell, MS Warrior and Passionate Believer that Life is for Living (via MS Teams) Aaron Hume, Disability Rights Campaigner, Researcher and Educator (via MS Teams) Chair: Siobhan Jones and Emma Edwards, RCN Neuroscience Forum</p>
11.00	Refreshments and networking
11.30	<p>Living well with neurological conditions: partnership, policy and patient voice Georgina Carr, Chief Executive, The Neurological Alliance Kripen Dhrona, Chief Executive, British Polio Fellowship</p>
12.00	<p>Supporting transition into adult services for young people with Cerebral Palsy and complex health needs Melissa Clarke, Neurodisability Clinical Nurse Specialist, Tulip - Paediatric Neurodisability Nursing Team, Croydon Health Services</p>
12.30	Lunch and networking
13.30	<p>Introducing the Nursing Competency and Education Framework for the Management of Headache Disorders Christine Callender, Head of Nursing Practice, RCN Siobhan Jones, Headache Nurse Consultant, North Cumbria Integrated Care NHS Foundation Trust, Chair, RCN Neuroscience Forum Susie Lagrata, Advanced Headache Nurse Practitioner and Lead Nurse in Headache & Neuromodulation, The National Hospital for Neurology and Neurosurgery, UCLH NHS Foundation Trust and Secretary to the British Association for the Study of Headache</p>
14.00	<p>The work of the Royal Hospital for Neuro-disability: describing neuro-disability nursing practice and the academic nursing work on post qualification training Sandy Gill, Lead Nurse, Royal Hospital for Neuro-disability (RHN) Academy</p>
14.30	Refreshments and networking
14.50	<p>The Hidden MDT in Parkinson's Care Emma Edwards, Parkinson's Specialist Nurse, Livewell Southwest</p>

15.15	Multiple Sclerosis: a changing story of care, treatment and opportunity Ruth Stross, Director of Services, MS Trust
15.40	The development of an MND care centre Rachael Marsden, Consultant Nurse MND, Oxford MND Care Centre
16.05	Chair's closing remarks Siobhan Jones, Headache Nurse Consultant, North Cumbria Integrated Care NHS Foundation Trust Chair, RCN Neuroscience Forum
16.15	Conference close

General information

Conference enquiries

Please ask staff on the registration desk if you have any specific requirements regarding access, dietary requirements, lost property or have queries regarding your membership.

Badges

For security purposes, participants must wear their badges at all times. Participants will not be admitted to the conference sessions without the appropriate badge.

Programme

Please refer to the programme for details of the times and locations of all conference sessions. Staff will be on hand to guide you as necessary.

Q&A

Roving microphones will be available during question times for the audience to use. Any person chosen to ask a question should announce their name and workplace before asking their question. Following a response, they may be invited to comment on that response.

Event evaluation

We aim to produce high quality events for all our delegates. An event evaluation will be emailed to all delegates. Please spare 5 minutes to complete this, your feedback helps us plan future events.

Receipts

If you require a receipt or have any queries relating to your registration or payment for this event, please contact staff on the registration desk at the event. Alternatively, receipts are also available by contacting RCN Event Registrations direct on 029 2054 6460 between 9.00am and 4.30pm Monday to Friday.

Electronic devices

Out of courtesy to others, delegates are requested to switch off or set to silent all electronic devices during conference sessions.

Smoking

20 Cavendish Square operates a no-smoking policy (this includes electronic cigarettes). This means that smoking is prohibited in any part of the building including the restaurant patio area and the access areas to the building; for example the main steps and ramp to 20 Cavendish Square and by the goods entrance at 1a Henrietta Place.

Toilets

Toilets are located on all floors, and toilets for all on the ground floor.

Fire Evacuation Procedure

In the event of an evacuation:

- If the alarm sounds, please make your way to the nearest fire exit. The meeting point is Cavendish Square Gardens.
- Use the stairs – do not use the lifts.
- Anybody who would need help to evacuate the building should let reception or the organiser know when they enter the building so the venue is aware in the case of a fire alarm.
- If anyone is trapped or in need of assistance, please inform Reception or a Fire Marshal.

Assembly Point

- Cavendish Square Gardens is the assembly point.
- Cross the road using the zebra crossing or traffic lights, it is dangerous to cross the road at any other place.
- Please remain in Cavendish Square Gardens until a Fire Marshall instructs you otherwise.

Liability

The RCN will not accept any liability for loss or damage to personal effects which may arise as a result of attendance at this event.

Continuing Professional Development

The RCN believes in lifelong learning and actively promotes the continuing professional development of all nurses. Authorised RCN certificates of attendance will be issued to all participants online. This event is also subject to the RCN Events quality assurance framework. You should log what you have learnt at this event using the Framework for Reflection guidelines and keep this document in your personal professional portfolio.

Free information at your fingertips

The RCN offers several FREE online resources with all the latest information and guidance on nursing practice issues such as clinical guidelines, patient safety and eHealth - see <http://www.rcn.org.uk/development/practice>.

National conference partner

LV= General Insurance, one of the UK's largest personal lines insurers, pride themselves in putting customers at the heart of all they do. RCN members can benefit from exclusive* discounts and savings on a range of LV= insurance products, including Car and Home insurance, for a quote and more information visit LV.com/RCN.

*Exclusive RCN member discount vs general public prices on lv.com and through the call centre



Speaker information

Conference chair:

**Siobhan Jones, Headache Nurse Consultant, North Cumbria Integrated Care
NHS Foundation Trust
Chair, RCN Neuroscience Forum**

Biography

Siobhan Jones is the UK's first Headache Nurse Consultant, a pioneering role through which she leads the advancement of headache care and services across Cumbria. Since qualifying as a registered nurse in 2004, she has built an extensive clinical background in neurosciences and neurology, underpinned by a strong academic foundation and a passion for improving patient outcomes.

In 2015, Siobhan completed her Non-Medical Prescribing (NMP) qualification, followed by an MSc in the Clinical Management of Pain and Headache from the University of Edinburgh in 2019. Her research from this programme was published in the *British Journal of Neuroscience Nursing*, reflecting her commitment to evidence-based practice.

Siobhan currently plays a central role in Clinical Governance for the headache service in Cumbria and is working to replicate this model across neighbouring regions. In addition to her clinical leadership, she contributes nationally through her role as Chair of the Royal College of Nursing's Neuroscience Forum and was a former Honorary Advisor for the British Association for the Study of Headache (BASH). She is also involved in the Neurology Academy supporting education and training for healthcare professionals in headache and migraine care.

She is highly driven in pushing forwards many other exciting initiatives for headache management in the future.

Furthering her dedication to the field, Siobhan is also a PhD Clinical Researcher at Newcastle University's Translational Clinical Research Institute, where her research focuses on migraine and the future of headache care.

Delivering a clinical neuroscience workforce fit for the future

Sue Thomas, Healthcare Consultant, Kings College London

Summary

Neurology nursing is a critical component of modern neuroscience nursing as Integrated Care Systems (ICSs) and Health Boards across the UK work to deliver specialist neurological care closer to home. A recent report from the Association of British Neurologists which included a review of neurology specialist nursing, highlighted that "no UK region is meeting the recommended minimum of neurologists per 100,000 population" and that there are "significant gaps in specialist nursing provision". The numbers of nurses currently working in neurology is unknown. This presentation synthesises national guidance,

published neurology nursing models and the ABN workforce report to explore the expanding role of neuroscience nurses. It argues that specialist nursing is central to the viability of neurology models of care and that investment in the nursing workforce is essential to deliver equitable, person centred neurological care.

Learning outcomes

1. Be aware of current neurology workforce numbers and UK neurology workforce policy plans
2. Identify the value neurology nurses provide to patients
3. Understand how neurology nurses can be involved in plans for a national workforce census

Recommended reading list / references

1. ABN (2026) The State of the UK Neurology Workforce: Needs for a Population of 100,000. Association of British Neurologists.
2. NHS England (2025) Commissioning community neurology: guidance for integrated care boards. Draft version. NHS Futures

Biography

Sue Thomas is a former district nurse from Sheffield and worked for 17 years as RCN policy and practice adviser in Long Term Conditions during which time she established the neuroscience forum. She moved from the RCN to set up a unique neurology commissioning support service for a group of neurology charities to bring the patient voice central to commissioning NHS services. She is currently a member of the NHS England Neurology and Neurosurgery Clinical Reference Groups, a nurse member of the Association of British Neurologists Services Committee and is joint author of the ABN report on neurology workforce. She is currently working with Kings College London.

Listening to lived experience – what we would like nurses to know

Frances Quinn, British Polio Fellowship Trustee and polio survivor

Will Howell, MS Warrior and Passionate Believer that Life is for Living (via MS Teams)

Aaron Hume, Disability Rights Campaigner, Researcher and Educator (via MS Teams)

Summary

Sharing experiences of accessing healthcare and key messages for nurses to take away.

Learning outcomes

1. Gain deeper insight into patient experience of receiving healthcare and understand from their perspective what works for them, and what doesn't
2. Understand greater what living with a long term neurological condition, such as cerebral palsy or long polio syndrome is like.

Recommended reading lists / references

Biography:

Frances Quinn, British Polio Fellowship Trustee and polio survivor

Frances Quinn contracted polio in 1957 at 11 months and spent 2 years as an infant in hospital. She relearned how to walk with two callipers, and still uses leg supports and walking aids.

She spent 30 years as a physicist in a national research facility - a physically active and challenging role. In her late 30s and 40s, she experienced additional deterioration. It took 15 years to get diagnosed with post polio syndrome, only possible due to the help of the British Polio Fellowship. This led to her becoming a volunteer researcher with them, helping to produce guidelines and factsheets and becoming a Trustee.

Will Howell, MS Warrior and Passionate Believer that Life is for Living

Will Howell is a 55 year old from Harrogate living with Primary Progressive Multiple Sclerosis (PPMS), diagnosed in 2021 after symptoms began in 2018. As his condition rapidly progressed, he transitioned from walking unaided to requiring full-time wheelchair use and 24 hour care. Despite this, he has become known for his honesty, humour, positivity, resilience and sharing the lived reality of PPMS. Will raises awareness through public speaking and fundraising, including completing the York 10K in an adapted wheelchair. His story offers clinicians a powerful, human perspective on progressive neurological disease and the importance of compassionate, person-centred care.

Aaron Hume, Disability Rights Campaigner, Researcher and Educator

Aaron Hume is a researcher, student, and disability rights campaigner from West Lothian, Scotland. He lives with cerebral palsy, autism, and a moderate learning disability. Aaron is currently studying for an HNC in Social Services at West Lothian College. His research involvement includes collaborations with universities across the UK and Europe, and he works closely with several third sector organisations. Aaron is really passionate about using his lived experience and the power of humour to break down the stereotypes and barriers in order to educate future healthcare professionals helping them truly understand the meaning behind the social model of disability.

Living well with neurological conditions: partnership, policy and patient voice

Georgina Carr, Chief Executive, The Neurological Alliance

Kripen Dhrona, Chief Executive, British Polio Fellowship

Summary

Neurological conditions affect at least one in six people and are the leading cause of disability globally, placing sustained demand on health and care services. Yet many people continue to experience fragmented pathways, long waits for specialist care and limited coordination between services.

This session will explore how stronger partnerships between NHS Commissioners, clinical services, voluntary sector organisations and people with lived experience can support people to live well with neurological conditions. Drawing on national policy developments and system transformation work, the session will highlight the importance of lived experience voice, community-based support and cross-sector collaboration in improving outcomes.

Georgina Carr will outline the current policy context for neurological services and the role of the voluntary sector in supporting system improvement and amplifying lived experience. Kripen Dhrona will provide further practical examples, including the development of the optimal clinical pathway for polio survivors, which sets out principles for coordinated, multidisciplinary care including specialist assessment, personalised care planning, and locally delivered ongoing support.

Together, the speakers will reflect on how collaboration between clinicians, charities and people with lived experience can strengthen neurological care pathways and support more holistic, person-centred care.

Learning outcomes

At the end of this session, participants will be able to:

Describe the current policy and service context for neurological care and its implications for clinical practice.

Explain the role of voluntary sector organisations and lived experience in shaping neurological services and care pathways.

Identify practical examples of collaborative approaches, including the optimal clinical pathway for polio survivors, that support coordinated multidisciplinary care.

Recommended reading list / references

British Polio Fellowship. Optimal clinical pathway for polio survivors (including the late effects of polio and post-polio syndrome)

<https://britishpolio.org.uk/professionals/optimal-clinical-pathway/>. The Neurological Alliance. My Neuro Survey reports and patient experience data. (<https://www.neural.org.uk/>) NHS England. Neuroscience Transformation Programme. <https://future.nhs.uk/> (NHS login required)

Biography

Georgina Carr is the Chief Executive of The Neurological Alliance, where she leads the organisation's strategic direction and works with members, partners and people with lived experience to influence national policy and improve outcomes for the 1 in 6 people in England living with a neurological condition. She has worked in neurological policy and advocacy for more than a decade, previously serving as Head of Campaigns and External Affairs at the MS Society. She currently sits on a wide range of governmental advisory groups, including the NHS England Adult Neurology Clinical Reference Group, the National Neuroscience Transformation Programme Board and the UK Neuro Forum. Georgina's commitment to this work is both professional and personal, shaped by family experiences of MS and acquired brain injury. Alongside her

role at the Alliance, she is a trustee of NCVO and Canine Partners, supporting leadership, equity and disability inclusion across the charity sector.

Kripen Dhrona, Chief Executive, British Polio Fellowship

Building on many years in the banking, events and hospitality industry, since 2014 Kripen has been working at the BPF in different roles and has a real understanding of all aspects of running a charity. He was appointed to Senior Management in 2018 and took on the role of CEO in 2022. Kripen is also a Trustee at the Neurological Alliance (NA) and since August 2023 has been elected to the role of Treasurer at the NA.

Supporting transition into adult services for young people with Cerebral Palsy and complex health needs

Melissa Clarke, Neurodisability Clinical Nurse Specialist, Tulip - Paediatric Neurodisability Nursing Team, Croydon Health Services

Summary

This presentation will explore best practice approaches to supporting the transition of young people with Cerebral Palsy (CP) and complex health needs from paediatric to adult services. With increasing numbers of young people with CP living into adulthood, effective transition planning is essential to ensure continuity of care, reduce health inequalities, and continue holistic management of their needs.

Transition is a multifaceted process that extends beyond transfer of care at age 18, requiring early planning, coordinated multidisciplinary input, and a person-centred approach. However, evidence highlights ongoing challenges including fragmented services, differences between paediatric and adult care models, and insufficient preparation for young people and families.

This session will examine the unique clinical, psychosocial, and communication needs of this population, alongside the critical role of nurses in facilitating safe and effective transition into adult services.

Practical strategies will be presented, including early engagement, use of transition pathways, development of health passports, and the role of a named coordinator.

The session aims to provide healthcare professionals with actionable insights to improve transition experiences and outcomes for young people with CP and complex needs.

Learning outcomes

By the end of this session, participants will be able to:

1. Describe at least three common challenges experienced by young people with cerebral palsy and complex health needs during and/or after transition to adult services.
2. Explain the key components of an effective, person-centred transition

process, including the role of multidisciplinary working and early planning.
3. Identify practical nursing interventions that support safe, coordinated transition, including the use of transition tools such as health passports and named care coordinators.

Recommended reading list / references

1. Together for Short Lives (2023). Transition to Adult Services Pathway. Available at: <https://www.togetherforshortlives.org.uk/resource/transition-adult-services-pathway/>
2. National Institute for Health and Care Excellence (NICE) (2017). Cerebral palsy in under 25s: assessment and management (NG62). Available at: <https://www.nice.org.uk/guidance/ng62>
3. National Institute for Health and Care Excellence (NICE) (2016). Transition from children's to adults' services for young people using health or social care services (NG43).

Biography

Melissa qualified as a Children's Nurse in 2012 and worked at Great Ormond Street Hospital for the first 3 years of her career. Since 2015 she has worked with Children and Young People (CYP) with Disabilities in Croydon providing clinical and holistic care for CYP with highly complex medical needs. Melissa's current role as Neurodisability Clinical Nurse Specialist provides case management and holistic care for CYP with disabilities and complex health needs aged 0-25 years. Melissa is passionate about improving coordinated care for children and young people with life limiting conditions and has developed a complex care pathway working in partnership with children and their families to manage their fluctuating needs. Melissa has a specialist interest in children and young people with Cerebral Palsy and complex health needs, particularly supporting them as they transition into adult services and palliative care.

Introducing the Nursing Competency and Education Framework for the Management of Headache Disorders

Christine Callender, Head of Nursing Practice, RCN

Siobhan Jones, Headache Nurse Consultant, North Cumbria Integrated Care NHS Foundation Trust, Chair, RCN Neuroscience Forum

Susie Lagrata, Advanced Headache Nurse Practitioner and Lead Nurse in Headache & Neuromodulation, The National Hospital for Neurology and Neurosurgery, UCLH NHS Foundation Trust and Secretary to the British Association for the Study of Headache

Summary

This presentation introduces the RCN Headache Nursing Competency Framework, designed to strengthen the role of nurses in delivering high-quality, consistent migraine and headache care across the UK.

Headache disorders are among the leading causes of disability worldwide, yet access to specialist care remains variable, and many patients experience delays, misdiagnosis, or suboptimal management. Nurses are uniquely

positioned to address these challenges through advanced clinical assessment, prescribing, patient education, and continuity of care.

The framework provides a structured approach to competency development across different levels of practice, supporting nurses from foundational knowledge through to advanced and consultant roles. It aligns with national priorities to improve access, reduce variation, and deliver care closer to home.

A key message is that investment in nurse education and competency directly improves patient outcomes, service efficiency, and workforce sustainability.

By standardising skills and expectations, the framework enables:

Safer, more effective clinical decision-making
Greater confidence among non-specialist clinicians
Enhanced career pathways within headache care

Ultimately, this work supports the transformation of headache services and ensures patients receive timely, expert, and stigma-free care, regardless of where they live.

Learning outcomes

1. Describe the key components and structure of the Royal College of Nursing Headache Nursing Competency Framework, including how competencies are mapped across different levels of nursing practice.
2. Explain how the framework can be applied within their own clinical setting to improve consistency of care, support clinical decision-making, and enhance patient outcomes in headache and migraine management.
3. Identify at least two practical actions they can take to support implementation of the framework within their service, including opportunities for workforce development, education, or pathway redesign.

Recommended reading list / references

National Institute for Health and Care Excellence (2021, updated). Headaches in over 12s: diagnosis and management (CG150). International Headache Society (2018). The International Classification of Headache Disorders, 3rd edition (ICHD-3). Cephalalgia, 38(1), 1–211. Global Burden of Disease Study (2019). Global, regional, and national burden of migraine and tension-type headache. The Lancet Neurology. The Migraine Trust (2023). State of the Nation: Migraine Care in the UK. British Association for the Study of Headache (2019, updated 2023). Guidelines for All Healthcare Professionals in the Diagnosis and Management of Migraine and Tension-Type Headache.

Biography

Susie Lagrata is an Advanced Headache Nurse Practitioner and Lead Nurse at UCLH NHS Foundation Trust. She has undergone numerous post-graduate courses including the Master of Headache Disorders and a registered independent non-medical prescriber.

She won the 2022 RCN Awards in view of the pioneering nurse-led services she established in the UK. She was committee member in the NICE guidelines (2015 CG150 review). She is Education Committee member of International Headache Society, Board Member of International Forum for Headache Nurses and secretary of the British Association for the Study of Headache (BASH). Susie has presented at national and international meetings. She has authored and co-authored several scientific papers in the past 17 years. She is a guest lecturer at the London Southbank University.

The work of the Royal Hospital for Neuro-disability: describing neuro-disability nursing practice and the academic nursing work on post qualification training

Sandy Gill, Lead Nurse, Royal Hospital for Neuro-disability (RHN) Academy

Summary

Neuro-disability represents a significant and growing area of healthcare need, affecting millions of people and requiring highly specialised, long-term support. This presentation will highlight that neuro-disability is more than a diagnosis, it encompasses complex, lifelong physical, cognitive, emotional, and social challenges that demand coordinated, person-centred care.

Specialist neuro-disability nursing plays a central role in meeting these needs, combining advanced clinical expertise with advocacy, rehabilitation, and a strong focus on quality of life. However, despite its importance, the field remains under-recognised, with notable gaps in education, structured career pathways, and workforce capacity.

The development of the RHN Academy represents a strategic response to these challenges, aiming to strengthen the workforce through education, leadership, and national collaboration. Neuro-disability nursing is a distinct and essential speciality that must be recognised, invested in, and developed to meet future healthcare demands and improve outcomes for people living with complex neurological conditions.

Learning outcomes

1. Describe the complexity and impact of Neuro-disability, including its definition, prevalence, and the multifaceted needs of individuals living with these conditions.
2. Explain the role and value of specialist Neuro-disability nursing, including its contribution to holistic care, long-term support, and improving quality of life.
3. Discuss current workforce challenges and future developments, including the need for enhanced education, recognition of the speciality, and the role of initiatives such as the RHN Academy in shaping the future workforce.

Recommended reading list / references

1. Brain Research UK (2026). Neurological Conditions Statistics.
2. National Institute for Health and Care Excellence (NICE) (2014, updated). Rehabilitation after traumatic brain injury (NG211) and related guidance.

3. Royal College of Nursing (RCN) (2023). Advanced Level Nursing Practice Competencies

Biography

Sandy Gill is a senior nursing leader specialising in neuro-rehabilitation, complex care, and workforce development. She holds a Master's degree in Nursing and has completed the Professional Nurse Advocate programme, alongside multiple leadership and specialist neuro-rehabilitation qualifications. Sandy has extensive experience in clinical, operational, and strategic leadership and has contributed to organisational achievements including Pathway to Excellence® accreditation and Safeguarding excellence at the Royal Hospital for Neuro-disability (RHN). She has served as Deputy to the Chief Nurse, strengthening her expertise in governance, service redesign, patient safety, and education. She is now the Lead Nurse for the RHN Academy, driving innovative educational pathways that advance specialist neurorehabilitation and neuro-disability nursing nationally.

The Hidden MDT in Parkinson's Care

Emma Edwards, Parkinson's Specialist Nurse, Livewell Southwest

Summary

Parkinson's is a progressive neurological condition affecting over 160,000 people in the UK. While motor symptoms such as tremor, rigidity and slowness of movement are commonly recognised, many people also experience non-motor symptoms including anxiety, sleep disturbance, pain, bladder and bowel dysfunction, fatigue and cognitive changes. These symptoms can significantly affect quality of life for both the individual and their family.

This session will explore Parkinson's care beyond the traditional medical model, highlighting the role of the wider multidisciplinary team (MDT) in supporting people to live well with the condition. Alongside specialist nurses, neurologists and allied health professionals, many individuals also rely on charities, peer support groups, carers, exercise providers and social prescribing services. These networks can provide education, emotional support, opportunities for self-management and reduced social isolation alongside statutory healthcare services.

The presentation will discuss how collaborative and community-based approaches may strengthen person-centred care and support nurses working within increasingly pressured healthcare systems.

Learning outcomes

1) Describe the motor and non-motor features of Parkinson's disease that commonly affect quality of life and care needs.

2) Identify the roles of the wider multidisciplinary team, including community and voluntary sector organisations, in supporting people living with Parkinson's and their families.

3) Explain how partnership working and community-based support can contribute to more holistic, person-centred Parkinson's care within nursing practice.

Recommended reading list / references

Thomas S, Edwards E, Kobylecki C. Parkinson's Nurses Are Crucial for the Management of Parkinson's Disease: 2007–2024. *Journal of Parkinson's Disease*. 2024;14(S1):S209–S217. doi:10.3233/JPD-230224 Bloem BR, Henderson EJ, Dorsey ER, et al. Integrated and patient-centred management of Parkinson's disease: a network model for reshaping chronic neurological care. *The Lancet Neurology*. 2020;19(7):623–634. (This one fits your "hidden MDT/network care" theme beautifully.) When Your Neurons Dance. Acheson J. *When Your Neurons Dance: A Story of a Doctor with Parkinson's Disease*. CRC Press; 2025.

Biography

Emma works currently as a Parkinson's Specialist Nurse in the Southwest and has done for the last 16 years. She qualified as a mental health nurse in 1997. Emma also volunteers as the Deputy CEO of SpotlightYOPD, a charity that supports younger people with Parkinson's, as well as Deputy Chair for the RCN Neuroscience Nursing Forum. Her special interests are Suicide prevention and mental health in Parkinson's and speaks on this across the county and on the Neurology Academy Advanced Masterclass.

Multiple Sclerosis: a changing story of care, treatment and opportunity

Ruth Stross, Director of Services, MS Trust

Summary

This session provides an accessible introduction to multiple sclerosis (MS), charting the journey from historical understanding and limited treatment options to the transformative advances shaping care today. It will explore how rapidly evolving disease-modifying therapies and emerging innovations are changing outcomes, expectations, and opportunities for people living with MS.

Crucially, the session highlights the central and ever-expanding role of neurology nurses in delivering high-quality, person-centred MS care. Attendees will gain insight into how nursing practice has evolved alongside scientific progress, and how neurology nurses now act as educators, coordinators, advocates, and clinical leaders throughout the MS pathway.

Designed for all neurology nurses, this presentation aims to demystify MS, build confidence, and spark interest in neurology nursing as a dynamic and rewarding career choice. The key takeaway is clear: MS is no longer a static condition with limited options, but a rapidly changing field where skilled, compassionate nurses are essential to translating innovation into real-world impact for patients, and where the future neurology workforce can truly make a difference.

Learning outcomes

1. Describe the key features of multiple sclerosis, including its basic pathophysiology and how understanding of the condition has evolved from past to present.
2. Identify major advances in MS treatments and explain how these developments are transforming outcomes and expectations for people living with MS.
3. Explain the current and future role of neurology nurses in MS care, including how nursing practice contributes to effective, person-centred management across the MS pathway.

Recommended reading list / references

NICE (2022, updated 2026). Multiple sclerosis in adults: management (NG220). National Institute for Health and Care Excellence. This guideline outlines best practice for diagnosis, treatment, and long-term management of MS, including disease-modifying therapies, relapse management, symptom control, and coordinated care. It provides the national evidence base underpinning MS services and neurology nursing practice in England and is essential reading for anyone new to MS care. Available at: <https://www.nice.org.uk/guidance/ng220>

1 National Neurosciences Advisory Group (NNAG) (2024). Optimal Clinical Care Pathway for Adults with Multiple Sclerosis. This pathway sets out what “good looks like” across the MS journey – from referral and diagnosis through treatment, long-term management, and advanced care. It highlights multidisciplinary working, service standards, and the critical role of MS and neurology nurses in delivering timely, person-centred care. Available at: <https://www.mssociety.org.uk/sites/default/files/2024-12/NNAG%20MS%20optimal%20pathway%202024.pdf>

2 MS Trust. National guidelines for multiple sclerosis care and services. An accessible overview of UK MS guidance, including NICE recommendations, multidisciplinary team roles, and practical implications for everyday nursing practice. This resource is particularly helpful for nurses exploring or entering neurology and MS services. Available at: <https://mstrust.org.uk/a-z/national-guidelines-multiple-sclerosis-care-and-services>

Biography

Ruth trained at the Royal Free Hospital, London, working in neurology in her first year as a student nurse in 1988. Ruth has worked as a specialist nurse since 1998 in Multiple Sclerosis, Motor Neurone disease, Parkinson’s and Movement Disorders (MD). During her career Ruth has set up a few specialist neurology nurse services in the UK and helped set up a multi-disciplinary clinic for patients with Motor Neurone Disease (MND) in Australia.

Ruth won the Neurology Academy Intermediate MasterClass project in 2019 and Advanced MasterClass project in 2022 with a joint venture mapping pathways for people with MS across Surrey, she also completed the MS Leaders Academy inaugural course, from which her home urine test kit which was developed during lockdown has now been launched, published nationally and shortlisted for the QuDoS awards 2023; in 2019 Ruth was invited to work with NHS Right Care to develop NHS RightCare Progressive Neurological Conditions Toolkit.

In 2022/2023 Ruth was part of a consensus group who published the 'Management of Bladder dysfunction in Multiple Sclerosis' document and Bladder Management Pathway and more recently has published A simple and successful solution to issues relating to urinary tract infections in people with MS) and MS care: integrating advanced therapies and holistic management. Ruth is lead faculty for MS, Uro-neurology, and Palliative Care Academies and a trustee for MS Together charity.

Ruth remains dedicated to improving care for people diagnosed with a long-term neurological condition and supporting neurology nurses in her role as head of nursing with Neurology Academy and as a neurology specialist nurse in the NHS.

The development of an MND care centre

Rachael Marsden, Consultant Nurse MND, Oxford MND Care Centre

Summary

Motor Neurone Disease (MND) presents complex clinical and emotional challenges for patients, families, and healthcare professionals. Establishing a dedicated MND Care Centre in Oxford has been a multidisciplinary effort aimed at improving access to specialist care, coordination, and research opportunities. This talk will outline the journey from initial planning to the ongoing development of the Centre, highlighting the essential elements required to build an integrated service within an NHS framework.

Key themes include engaging stakeholders, securing sustainable funding, embedding evidence-based care pathways, and fostering collaboration between neurology, palliative care, therapy services, and community teams. The presentation will also explore the role of specialist nurses in leadership, service design, and patient advocacy, as well as the challenges of managing growth and maintaining quality within a regional model of care.

Reflections from the Oxford experience will illustrate how a coordinated, patient-centred approach can enhance outcomes, promote research participation, and support innovation in MND care delivery. Attendees will gain practical insights relevant to developing or strengthening similar services, with emphasis on collaboration, adaptability, and compassion as core principles of successful implementation.

Learning outcomes

Reflect on the opportunities and challenges in developing an MND Care Centre
Recognise the importance of collaboration across acute, community, and palliative care services

Consider how specialist nurses can influence system-level change and patient experience

Identify transferable lessons to support development of similar services in other regions

Explore how compassionate, patient-centred approaches underpin high-quality MND care

Recommended reading list / references

Core MND clinical guidance National Institute for Health and Care Excellence – Motor neurone disease: assessment and management (NG42) The key UK guideline – covers diagnosis, symptom management, and multidisciplinary care. Motor Neurone Disease Association – MND Care Guidelines / Professional resources Very practical, especially around care coordination and patient-centred support.

Biography

Rachael started her career working in a Young Disabled Unit where she gained a great deal of experience in the care and management of young people with highly complex disabilities. Rachael learned just how important sex and relationships are to all adults, regardless of disability or impairment. This gave her the perfect background to become the Motor Neurone Disease Care Centre Coordinator for the Oxford Care Centre in 2002. The Centre has developed in so many ways over the past 20 years, it is now one of the larger MND care and research centres in the UK. Having completed a Degree and Masters in Rehabilitation she is now an Independent Practitioner & Consultant Nurse coordinating the care of people living with MND.

When not working, Rachael is normally cycling. She currently holds the World Record for being the fastest Women to Circumnavigate the globe on a tandem (tandemwow)

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