

Developing plans for neurological patients

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Medway Neurological Network



Medway Neurological Network

- **We are an umbrella Community Support Group for the neurological charities/ support groups active in the Medway area.**
 - **Launched in November 2015**
- **Aim to be the voice of those affected by neurological conditions in Medway & District**
 - **A single point of access**
- **Applying to Charity Commission for CIO (Associate) status**

Medway Neurological Network - Mission

To defend and improve the quality of health and social care services available to those with neurological conditions

To campaign for improved disability services and facilities

To provide/ promote support services/ therapies/ research to improve health & wellbeing, e.g. Skylarks/ Neuro-cafes

To raise awareness of neurological conditions, including rare conditions, in Medway & District and the support services that are available, Neuro-Fairs/ Neuro-Arts Festivals

To be inclusive and links with BAME groups

Medway Neurological Network - Members

Alzheimer's UK

Medway Dementia Action Alliance

Ataxia UK

Dystonia Society

FND Action (Functional Neurological Disorder)

Foetal Alcohol Spectrum Disorder Awareness

Headway Medway

Kent Brain Injury Forum

Hereditary Spastic Paraplegia UK

Huntington Disease Association

Motor Neurone Disease Association

Multiple Sclerosis Society

Multiple System Atrophy Trust Parkinson's UK

Progressive Supranuclear Palsy Association

Transverse Myelitis Society.

M N N Collaboration

Anna Chaplaincy, Rochester Cathedral (NVDi)

Carers First Medway

Disability Medway Network

Medway Adult Education

Medway Community Healthcare

Medway Council

Medway Foundation Trust

Medway Healthwatch

Medway Voluntary Action

Medway & Swale Health & Care Partnership

Music4Wellbeing

Canterbury Cantata Trust

University of Greenwich

University of Kent

MNN Achievements

Medway Skylarks holds hybrid (Face-to-face/ Zoom) weekly sessions throughout the year at the University of Greenwich, Medway Campus. Now under Music4Wellbeing CIC

MNN was represented at the Neurological Alliance Parliamentary Reception held at the House of Commons on 16 January 2025, in furtherance of the '1 in 6' Campaign. Phil Bungay represented the MNN, accompanied by Rochester and Strood MP, Lauren Edwards.

MNN Achievements

Rare Diseases Day: Celebrated at the Jasper's Rare Conditions Neuro-café

Medway Non-Visible Disability Initiative, under MNN governance.

Developed two online non-visible disability awareness short-courses.

Medway Neuro-Tech 25 – study day 2025

Neuro-cafe services - monthly

Parkinson's Centre for Integrated Therapy – collaboration

Plans for event in 2027

Plan

- **Neurological developments**
 - **Internationally**
 - **Nationally**
 - **Locally**
- **Issues in Medway**
- **Possible solutions**
- **Future plan**

The problem – world wide

- **Deaths**
 - **11.1 million deaths per year worldwide**
 - **Second cause of global deaths**
- **Disability**
 - **First in Disability-adjusted life years -443 million DALYs**
 - **By 2034 50% increase**
- **3.40 billion people – 43% of the World population – have condition affecting nervous system**

Winter et al 2024; GBD 2021 Nervous System Collaborators 2024

World Health Organisation- International

- **Intersectoral Global Action Plan on Epilepsy and other Neurological Disorders**
 - **To reduce stigma and burden of neurological disorders**
 - **To improve quality of life of people, carers and families**
- **2022-2030**
 - **2024 IGAP Toolkit for all countries to complete**
- **Internationally important**

WHO IGAP

- **Raise policy prioritisation and strengthen governance**
- **Provide effective, timely and responsive diagnosis, treatment, care**
- **Implement policies for promotion and prevention**
- **Foster research and innovation, strengthen information systems**
- **Strengthen public health approach to epilepsy**

Europe -EFNA Survey

- **Across Europe – 560 people**
 - **82% healthcare professionals did not believe the extent/severity of symptoms**
 - **78% felt that they did not receive appropriate treatment as doctor did not take them seriously enough**
 - **50% had difficulty describing symptoms**
 - **65% initially misdiagnosed**

Neurology - National

- **GIRFT**
 - **Use of remote consultation**
 - **Clinically triggered follow-up for results**
 - **Patient initiated follow ups**
 - **Timed follow up for unstable disease / disease modifying treatment**
 - **eg Parkinson's disease at least every 12 months**
 - **Triage referral to allow investigations**
 - **Senior clinical time defined for advice / triage**
 - **Nurse specialists and MDT**

Neurology - national

- **Neighbourhood Health**
- **Moving services to the community**
 - **Outpatient services into community by 2035**
 - **Strengthen proactive care**
 - **Reduce hospital attendances**
- **Ensure neurologists are included in this**
 - **Time and contracts to allow this**
 - **Wider MDT involvement**

Neurology - national

- **Specialised Neurology Services (Adults) – Service Specification 2025**
 - **Provide timely access to treatments**
 - **Improve patient and carer experience by providing person-centred care that maximises quality of life**
 - **Support integrated and responsive care through collaboration between hospital and community providers**
 - **Ensure referral for appropriate psychiatric or psychological input to manage cognitive, behavioural, and emotional needs associated with neurological conditions**
 - **Work collaboratively with other providers of neurology services to ensure access to all specialised neurology services for their entire catchment population**

Neurology - national

- **UK NeuroForum**
- **Aim: To unite and empower people affected by neurological conditions and our member organisations to influence health and care policy in England, so it reflects real-life experiences, ensuring that everyone affected by a neurological condition can access the support they need.**
- **We do this by:**
 - **Providing a leading collective, national voice to improve health.**
 - **Developing a strong community**
 - **Developing compelling evidence**

Neurology - National

- **National Neurology Transformation Meeting 2026**
 - **Neurology is a priority- affects 1 in 6**
 - **Data – National Neurology Data Dashboard**
 - **National specifications**
 - **Workforce**
 - **1.6 neurologists / 100,000**
 - **Voluntary sector involvement**
 - **Mental health integration**
 - **Neuropsychiatry and neuropsychology**
 - **Strategy into Action**

The case for a Modern Service Framework

- **Neurological Alliance**
 - **Right people – MDT workforce**
 - **Right care – integrated care**
 - **Right time – early / rapid access**
 - **Right place – community**
 - **Right systems – data, accountability**

Marmot Place

- **Medway as a Marmot Place**
 - **Community committed to reducing health inequalities**
 - **Enabling people to maximise their capability and have control over their lives**
 - **Strengthen ill health prevention**

Neurology - national

Neurological Alliance - My Neuro Survey 2024/25

20% waited over 5 years to obtain diagnosis

Often not given helpful information

Problems getting support

Neuropsychiatry Pain Mental health

Only 33% care met their needs

20% felt they had no support

50% felt involved in decision making

Neurology - local

Neurological Alliance - My Neuro Survey 2024/25

| | Kent and Medway | National |
|----------------------------------|-----------------|----------|
| Time at appointment | 36.9% | 39% |
| I know my contact | 36.2% | 40% |
| Care met my needs | 29.5% | 31% |
| Able to have follow up | 19.2% | 24% |
| Consistent professionals | 29.2% | 32% |
| Mental health services met needs | 6.2% | 10% |

Medway neurological diseases (pop 292,000)

| | |
|--------|--------------------------------|
| 838 | Parkinson's disease |
| 550 | Multiple sclerosis |
| 58 | Muscular dystrophy |
| 18 | Huntington's disease |
| 20 | Motor neurone disease |
| 15 | Multiple systems atrophy |
| 21 | Progressive Supranuclear Palsy |
| 24 | Cerebellar ataxia |
| 5 | Hereditary spastic paraplegia |
| 27 | Dystonias |
| 27 | Frontotemporal dementia |
| 1862 | Epilepsy |
| 40,000 | Migraine |
| 4200 | Dementia |

Issues

- **Diagnosis**
 - **Delays**
- **Monitoring and follow up**
 - **Restricted**
 - **Local availability**
 - **London clinics**
 - **Transport**
 - **Time**
 - **Local clinics**
 - **Not available**
 - **Not multidisciplinary**

Issues

- **Neurological plan**
 - **Inclusion with NHS plan for Medway**
- **Clinical pathways**
 - **For all neurological conditions**
- **Neuroscience workforce**
 - **Neurologists**
 - **Specialist nurses**
 - **Allied Health Professionals**
 - **GPs with a special interest – in practices**

Issues

- **Multidisciplinary teams**
 - **NICE Cost effective for MND**
 - **Suitable for all progressive neurological diseases**
- **Local clinics**
 - **Neurohubs**
 - **Disease related in health centres**
 - **Fuller multidisciplinary team involvement**
 - **Easier for patients / families**
 - **Allows professionals to see more people in coordinated way**

Issues

- **Neurology**
 - **Increase neurologist numbers (6)**
 - **Allow time for MDT / hub clinics**
 - **Collaboration with other services**
- **Professionals to provide ongoing support**
 - **Not discharging and patient able to contact for further advice**
- **Mental health support**
 - **Neuropsychiatry**
 - **Neuropsychology**

Issues

- **Palliative care**
 - **Ensure neurological disease included within remit / contracts of Wisdom hospice and palliative care services**
 - **Enable end of life plans / advance care planning**
 - **Training of professionals**
 - **Time for completion**
 - **Coordinated recording**
 - **Available in hospital and community, including ambulance**

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Issues

- **Equipment**
 - **Delays**
 - **Appropriate equipment needed**
 - **To cope with change**
- **Disabled facilities grants**
 - **Fast Track for certain diseases**
 - **Means testing for adaptations**
 - **Increase cap – not changed since 2008**

Future

- **Develop a Medway Plan for neurology**
- **Develop community services**
 - **NeuroHub**
 - **Community team**
- **Coordinate / accessible care**
 - **Hospital and community**
- **Include patients/ families/ charities**
 - **Medway Neurological Network and the charities involved in the Network**

Thank you