



Neuroscience

North Bristol 
NHS Trust

Bristol MND care centre Southmead Hospital Bristol

Helen Madden
MND care coordinator
29th April 2015

Bristol MND care centre



Exceptional healthcare, personally delivered



Neuroscience

Bristol MND care centre

- Dr Andria Merrison, Consultant Neurologist & Director of MND care centre, North Bristol NHS Trust
- Helen Madden, MND care coordinator, North Bristol NHS Trust



Referrals

- Referral through Consultant or GP to Dr Merrison
- Welcome new referrals or appointments for second opinions
- Clinics held on Tuesday afternoons
- Follow-up appointments can be offered on a regular basis, usually every 2 to 6 months depending on need
- Follow-up appointments will either be with Dr Merrison or Neurology Specialist Registrar

What we offer

- Opportunity for the person with MND and their family to meet MND specialists
- Answer any questions you may have
- Discuss management options available
- Specialist Dietitian in attendance at clinic
- Palliative care available in clinic
- MND Association Visitors in attendance in waiting area to signpost people, offer advice, information and support
- MND Association information leaflets available
- Onward referral to health and social care professionals who can provide help and support as well as voluntary organisations



MND care coordinator

- Main point of contact for people with MND known to care centre as well as their families/carers
 - Provide support and information
 - Review people within 2 weeks of diagnosis (if known to care centre)
 - Try to ensure people are receiving the care they need at the right time by liaising with health and social care teams and voluntary organisations
 - Attend MND MDTs across region i.e. Bristol, South Gloucs, North Somerset, Somerset, BaNES
 - In attendance at MND clinic
-



MND care coordinator

- Will review if an inpatient at Southmead
- Can offer home visits if needed for those who struggle to attend clinic or who require further support
- Point of contact for other professionals involved in your care who might not have experience of seeing people with MND before e.g. GPs, social care, community nurses/matrons etc.
- Work closely with MND Association
- Can be contacted through phone or e-mail



Joint monthly MND/respiratory clinic

- People with MND respiratory systems are monitored closely – lung function and overnight oximetry & monitoring of type II respiratory signs and symptoms
- Dr Merrison and Helen Madden attends the monthly MND and respiratory medicine clinic
- Held at sleep unit, Bristol Royal Infirmary, UHB
- Provision of equipment which may support breathing when indicated i.e. non-invasive ventilation and cough assist



Our future development plans

- More MND clinics
- Opportunity to be involved in research projects
- Continue to raise awareness of Bristol MND care centre
- Questionnaire to ask feedback from people with MND and their carers accessing our service
- Continue to try and improve the care and support for people with MND across our region in partnership with MND Association

Patient information leaflet



North Bristol **NHS**
NHS Trust

Bristol Motor Neurone Disease (MND) care centre

Information for patients and carers



Exceptional healthcare, personally delivered

- Recently published
- Information same as on our webpages on NBT website
- Includes info on MND clinic as well as MND Association
- Our contact details

MND Association



- National charity for people with MND and their carers
- At Bristol MND care centre we mention MNDA to everyone diagnosed with MND
- Free for person with MND and their carer/spouse/partner to be a member
- People can choose the level of involvement they wish to be known by the charity

MND Association – for people with MND and carers

- **Website** full of information and advice
- Well researched and “safe” **information leaflets** on a variety of topics i.e. living with MND pack, wheelchairs, PEGs, CHC, benefits etc
- **Regional Care Development Advisors** for geographical areas – Neil Drinkwater (Bristol & West)
- **Local branches and support groups** for people with MND and carers

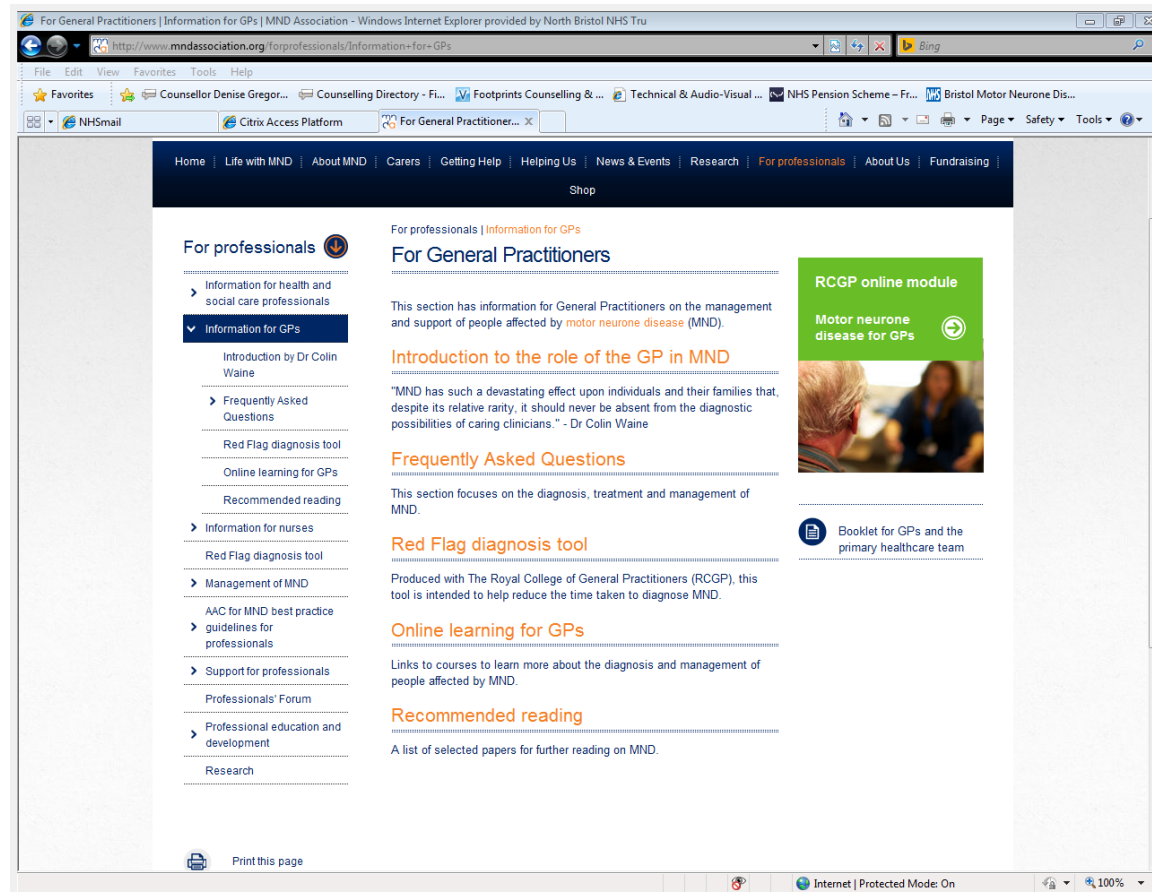


MND Association – for people with MND and carers

- **Association Visitors** (subject to availability) who can visit and support people with MND and their families on a 1:1 basis
- **Support grants** - equipment, quality of life e.g. holidays
- not financially means tested
- **MND Connect** – an advice line for people with MND and their carers, as well as health and social care professionals



MND Association professional section



The screenshot shows a web browser window displaying the MND Association's professional section. The browser's address bar shows the URL: <http://www.mndassociation.org/forprofessionals/Information+for+GPs>. The page features a dark blue navigation bar with links for Home, Life with MND, About MND, Carers, Getting Help, Helping Us, News & Events, Research, For professionals (highlighted), About Us, and Fundraising. Below the navigation bar is a 'Shop' button. The main content area is titled 'For professionals' and includes a sidebar with a tree view of navigation options. The 'Information for GPs' section is expanded, showing links to an introduction by Dr Colin Waine, frequently asked questions, a red flag diagnosis tool, online learning for GPs, and recommended reading. The main content area also features sections for 'For General Practitioners', 'RCGP online module', 'Introduction to the role of the GP in MND', 'Frequently Asked Questions', 'Red Flag diagnosis tool', 'Online learning for GPs', and 'Recommended reading'. A 'Print this page' button is located at the bottom left of the page.

For General Practitioners | Information for GPs

Home | Life with MND | About MND | Carers | Getting Help | Helping Us | News & Events | Research | **For professionals** | About Us | Fundraising

Shop

For professionals

- Information for health and social care professionals
- Information for GPs**
 - Introduction by Dr Colin Waine
 - Frequently Asked Questions
 - Red Flag diagnosis tool
 - Online learning for GPs
 - Recommended reading
- Information for nurses
 - Red Flag diagnosis tool
- Management of MND
 - AAC for MND best practice
 - guidelines for professionals
- Support for professionals
 - Professionals' Forum
- Professional education and development
 - Research

For General Practitioners

This section has information for General Practitioners on the management and support of people affected by **motor neurone disease (MND)**.

Introduction to the role of the GP in MND

"MND has such a devastating effect upon individuals and their families that, despite its relative rarity, it should never be absent from the diagnostic possibilities of caring clinicians." - Dr Colin Waine

Frequently Asked Questions

This section focuses on the diagnosis, treatment and management of MND.

Red Flag diagnosis tool

Produced with The Royal College of General Practitioners (RCGP), this tool is intended to help reduce the time taken to diagnose MND.

Online learning for GPs

Links to courses to learn more about the diagnosis and management of people affected by MND.

Recommended reading

A list of selected papers for further reading on MND.

RCGP online module

Motor neurone disease for GPs

Booklet for GPs and the primary healthcare team

Print this page

MND Association – Red flags



Painless, progressive weakness – Could this be Motor Neurone Disease?

1. Does the patient have one or more of these symptoms?

Bulbar features

- Dysarthria
- Slurred or quiet speech often when tired
- Dysphagia
- Liquids and/or solids
- Excessive saliva
- Choking sensation especially when lying flat
- Tongue fasciculations

Limb features

- Focal weakness
- Falls/trips – from foot drop
- Loss of dexterity
- Muscle wasting
- Muscle twitching/ fasciculations
- Cramps
- No sensory features

Respiratory features

- Hard to explain respiratory symptoms
- Shortness of breath on exertion
- Excessive daytime sleepiness
- Fatigue
- Early morning headache
- Orthopnoea

Cognitive features (rare)

- Behavioural change
- Emotional lability (not related to dementia)
- Fronto-temporal dementia

2. Is there progression?

Supporting factors

- Asymmetrical features
- Age – MND can present at any age
- Positive family history of MND or other neurodegenerative disease

Factors NOT supportive of MND diagnosis

- Bladder / bowel involvement
- Prominent sensory symptoms
- Double vision / Ptosis
- Improving symptoms

If yes to 1 and 2 query MND and refer to Neurology

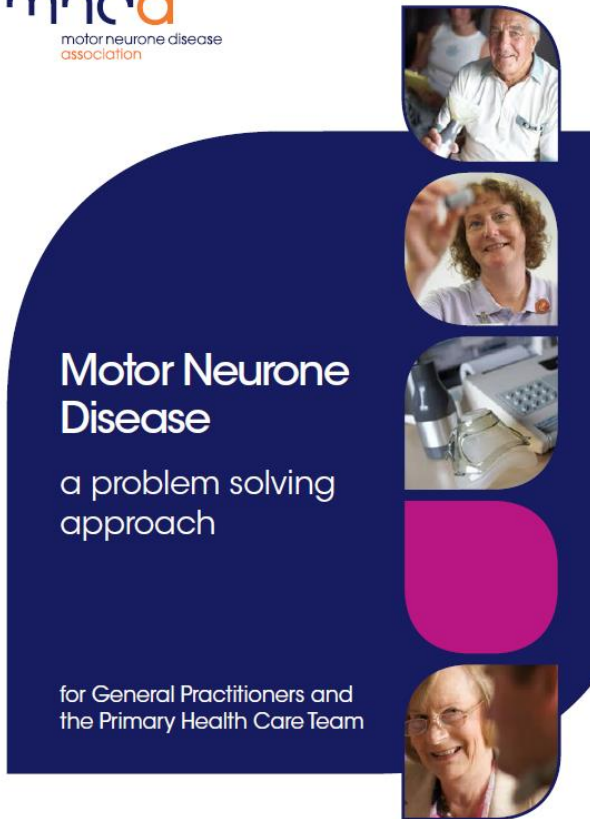
If you think it might be MND please state explicitly in the referral letter.
Common causes of delay are initial referral to ENT or Orthopaedic services.

Additional resources
MND Association



- MND Association & Royal College of General Practitioners worked together on red flag tool

MND Association publication for GPs



- Overview of MND and its management for GPs
- Revised version due for publication shortly
- We send this to GPs routinely after someone is diagnosed with MND at care centre



MND study day at Bristol MND care centre

Tuesday 22nd September at Southmead Hospital

Overview of MND including diagnosis, role of therapies, respiratory surveillance including NIV and cough assist, palliative care, role of MND Association

For health and social care professionals across the region

Due to be advertised May/June

Cost TBC but likely to be £20-25 to include lunch and refreshments

Contact details

Helen Madden
MND care coordinator
Bristol MND care centre
North Bristol NHS Trust

Tel: 0117 414 0803 (answerphone available)

E-mail: Helen.Madden@nbt.nhs.uk

Website: <http://www.nbt.nhs.uk/bristolmnd>

