ANTIBIOTIC GUARDIAN

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NHS Vale of York Clinical Commissioning Group

Referral Support Service

Neurology

NE04
Multiple Sclerosis (MS)

Definition

MS is an autoimmune condition that affects the central nervous system which gives rise to a range of symptoms and disabilities with an often unpredictable course. MS is a very individual condition in which no two people are affected in the same way. There are many different symptoms which can vary from one day (or even hour) to the next.
Common symptoms: fatigue, sensory problems, visual problems, pain, loss of muscle strength and dexterity, problems with walking, balance and coordination, muscle stiffness and spasms, difficulties with speech and swallowing, bladder and bowel problems, cognitive problems.

More than 100,000 people in the UK have MS. This equates to approximately 600 people with MS in the Vale of York area and approximately 10 new diagnoses each year.

There are three main types of MS:

- **Relapsing remitting MS** – where people have relapses of symptoms that occur for a period of time (days, weeks or months) and then improve. Approximately 85% of people with MS are diagnosed with this type.
- **Primary progressive MS** – people don't have any distinct attacks or remissions but begin with subtle problems that slowly get worse over time. Approximately 10 – 15% of people with **MS have primary progressive MS.**
- **Secondary progressive MS** – many people with relapsing remitting MS go on to have secondary progressive MS. If someone's symptoms have become progressively worse over a period of at least six months independent of any relapses, they are likely to have moved on to secondary progressive MS. Approximately 65% of people with relapsing remitting MS will have developed secondary progressive MS 15 years after being diagnosed.

Most commonly diagnosed between 20 and 40 years with three times as many women as men. Most require access to symptomatic treatments, including medicines and expert multidisciplinary care; many of those diagnosed with relapsing remitting MS also require access to Disease Modifying Therapies (DMTs).

Key Presenting Symptoms

MS can present with a range of symptoms and will be different in every person. Symptoms can develop over days or weeks and can include:

- Loss or reduction of vision in one eye with painful eye movement (optic neuritis).
- Dissemination in space (involvement of more than one region of the nervous system) and time (episodes/events occurring at different times).
- Double vision (diplopia).
- Sensory or motor abnormalities, including ascending sensory disturbance and/or weakness, with or without bladder and bowel involvement (myelitis).
- Problem with balance, unsteadiness or clumsiness.

- Altered sensation travelling down the back and sometimes into the limbs when bending the neck forwards (Lhermitte's symptom).

Be aware that people with MS can present with neurological symptoms as above and:

- Are often under 50.
- May have a history of previous neurological symptoms.
- Have symptoms that have evolved over more than 24 hours.
- Have symptoms that may persist over several days or weeks and then improve.

You should not routinely suspect MS if a person's main symptoms are fatigue, depression or dizziness unless they have a history or evidence of focal neurological symptoms or signs.

There is a wide list of differential diagnoses for the above neurological symptoms summarised by NICE CKS - click here.

Management

After diagnosis MS is usually managed by the MS team including neurologist and specialist nurse. However it is useful to be aware of common symptoms associated with MS:

- Fatigue – an overwhelming feeling of lassitude or lack of physical or mental energy that interferes with activities:
  - For MS exclude underactive thyroid, sleep disturbance, anaemia, nocturia, vitamin B12 or D deficiency, depression, medication induced (anticonvulsant, muscle relaxant etc).
  - Made worse by depression, poor sleep, drug side effects.
  - Consider OT/physio – personalised fatigue management programme.
  - Consider **amantadine** (consultant prescribed only).
  - Please note - **modafanil is NOT commissioned** for the treatment of fatigue in patients with Multiple Sclerosis following NICE CG 186.
- Bladder symptoms including urgency, frequency, urge incontinence and incomplete emptying:
  - Review diet, hydration, lifestyle, decrease fluid intake (1500ml), reduce caffeine, artificial sweeteners and alcohol intake, avoid excessive drinks after dinner, planned urination (2 hourly), pelvic floor exercises.
  - Prescribing option, after excluding incomplete emptying, anti-cholinergics e.g. **tolterodine.**
  - Prescribing option for nocturia is **desmopressin** (amber specialist recommendation).
  - Risk of Urinary Tract Infections (UTIs) which can present like a relapse.
  - Intermittent self-catheterisation.
  - Refer to local continence team.
- Depression, anxiety, mood, memory and cognitive symptoms:
  - Associated with lesion site/load, disability, reaction to life events and side effects of medication.
  - Respond to usual treatment – anti depressants, clinical psychology/psychotherapy.
  - Increased suicide rate compared to general population.
  - Socially isolated patients can have a higher risk of drug and alcohol abuse.
- Spasticity including stiffness and spasms:

  - Can be made worse by pain, bladder infection, constipation and poor posture/seating.
  - Physical treatments first – active and passive posture and positioning.
  - Treat exacerbating factors.
  - Drug treatments if necessary (e.g. **baclofen, tizandine, diazepam**).
- Bowel dysfunction, constipation, faecal urgency and faecal incontinence:
  - Review diet hydration and lifestyle.
  - Exclude other causes.
  - Consider current medications including anti-depressants, opioids, anti-convulsants etc.
  - Refer to local constipation or faecal incontinence pathway.
- Pain:
  - Neuropathic and paraesthesia – pain killers, anti-convulsants, anti-depressants, opioids.
  - Musculoskeletal – pain killers, physiotherapy.
  - Painful spasms – treat spasticity.
- Mobility:
  - Consider relapse, infection, pharmacological management and consider referring to physiotherapist or MS nurse for advice.
- Smoking
  - Advise smokers to quit smoking as smoking may adversely affect the disease course.

Information is available on all MS symptoms and treatment at: https://www.mstrust.org.uk/understanding-ms/ms-symptoms-and-treatments/treating-ms-symptoms and https://www.mssociety.org.uk/ms-resources/key-publications (see MS Essentials in key publications).

Outcome

MS is a long term condition that can be treated with Disease Modifying Therapies (DMTs) in the relapsing remitting phase and will require some symptom management for all types but increasingly for the progressive types. DMT treatment should occur as quickly as possible to reduce the likelihood of relapses and disease progression. DMTs can only be prescribed by a neurologist or consultant nurse.

MS is a life changing condition and many people with the condition can experience increased disability, including loss of mobility, cognitive issues including memory, recall, concentration, attention and mental speed over time. People with MS are also more likely to experience mental health issues including depression, stress and anxiety.

Referral Information

Information to include in referral letter

- History of current neurological problems.
- Any previous neurological problems (might that ‘trapped nerve’ actually have been a previous relapse of MS?)

- Neurological examination findings

Investigations may be considered including:

- Full blood count.
- Inflammatory markers eg. CRP
- Liver, renal, thyroid function tests.
- Coeliac screen.
- ANCA and ANA.
- Glucose, Vitamin B12, Vitamin D and Calcium.
- HIV serology.

Referral Criteria

- Refer anyone suspected of having MS to a consultant neurologist. Only a consultant neurologist should make the diagnosis on the basis of up to date criteria.
- Speak to the consultant if you think someone needs to be seen urgently.
- Note MS is never diagnosed on the basis of an MRI alone.
- If a person has an episode of isolated optic neuritis, confirmed by an ophthalmologist, refer them to a consultant neurologist for further assessment.

Patient information leaflets/ PDAs

Range of materials available from www.mssociety.org.uk for general information and https://www.mssociety.org.uk/ms-resources/key-publications for free publications (download and hard copy) and www.mstrust.org.uk

References:

NICE CKS: https://cks.nice.org.uk/multiple-sclerosis#!diagnosis