



Multiple Sclerosis Society



North Durham Group

(serving Durham, Chester-le-Street,
Derwentside & surrounding areas)

Chairman Alistair Crisp

Group Info line 0191 386 0006

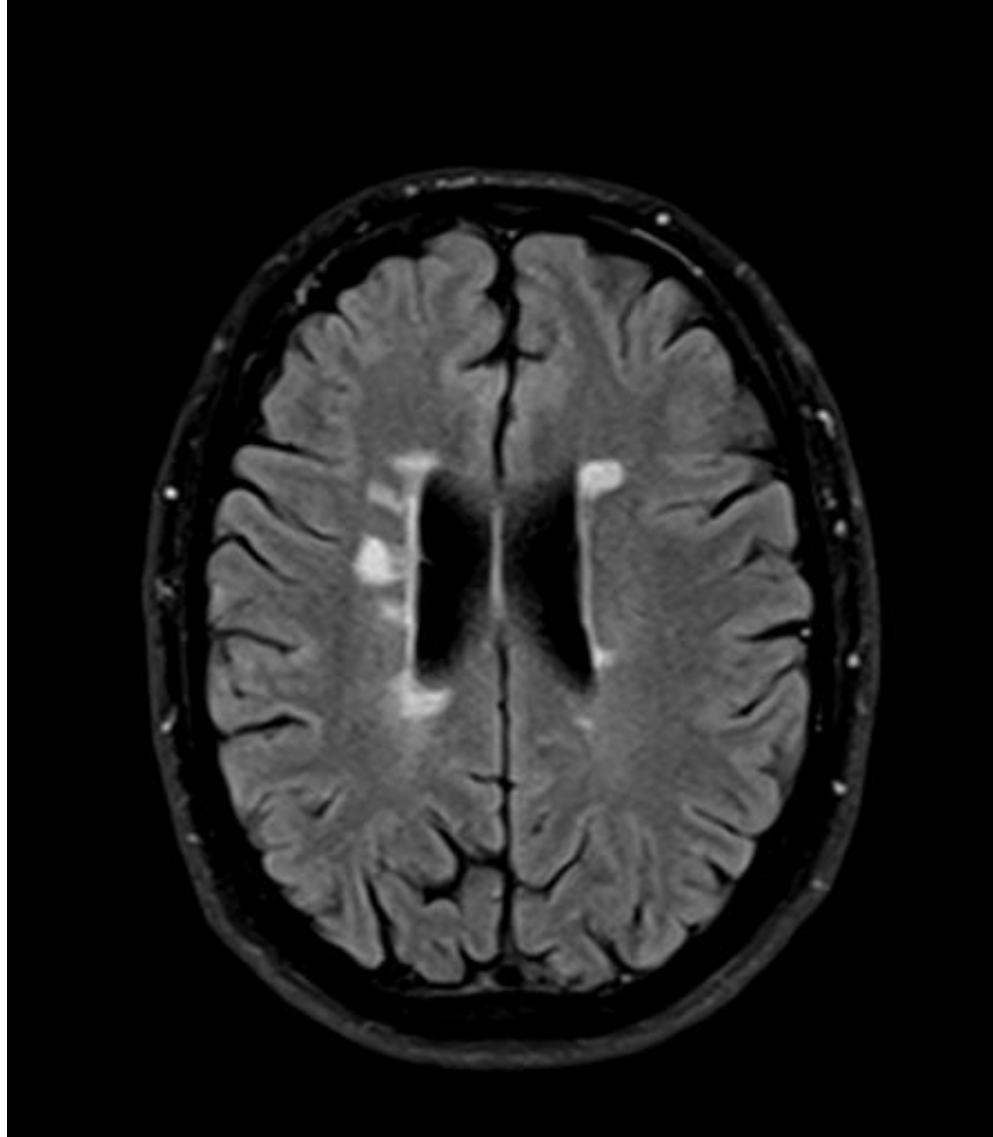
National Free Helpline 0808 800 8000

- In excess of 103,000 people in UK have MS
- At least 103,000 family carers affected by MS
- North Durham Group as 140 paid up members
- RVI estimate that there are at least 500 known cases of MS in old Durham PCT area



Multiple Sclerosis Society

What is Multiple Sclerosis (MS)?



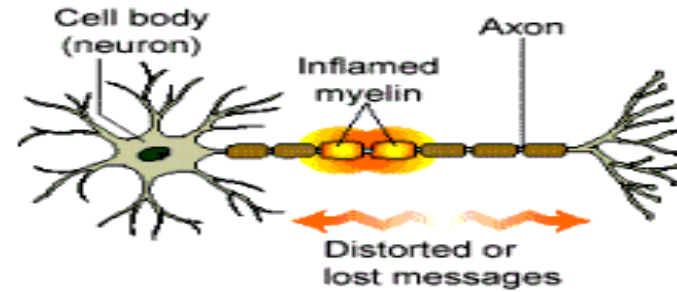
- Multiple Sclerosis (MS) is an illness of the central nervous system (CNS).
- Autoimmune disease that scars and destroys sheath around CNS nerves

- Once diagnosed, MS stays with you for life; there is no cure
- Some treatments and specialists can help you to manage many symptoms.

- It is the most common disabling neurological disease among young adults but can strike anyone at any time
- Cause is not known and a cure to be identified, research continues into all aspects of the condition.

A nerve affected by MS

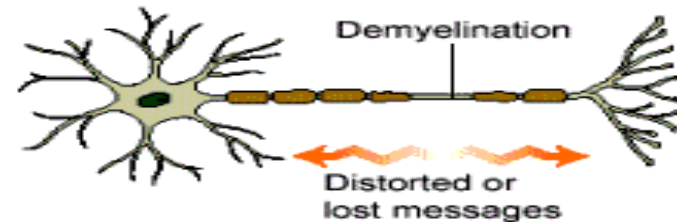
1. Axon with inflamed myelin



2. Axon with damaged myelin



3. Axon that is largely demyelinated



4. Demyelinated axon that is broken



Relapsing & Remitting MS

Primary/Secondary Progressive MS

Range of symptoms

- Muscle Problems: Spasticity, spasms and contractures at joints; Ataxia and tremor; paralysis
- Pain (sensory, muscle, nerve)
- Fatigue (out of all proportion to activity/inactivity)
- Cognitive losses (memory, thinking, concentration)
- Depression; Anxiety; Emotionalism especially when disease first diagnosed or changes
- Bladder control reduced (incontinence) and UTI
- Bowel control (incontinence, constipation, diarrhoea)
- Visual problems (temporary or permanent loss of sight)
- Sexual dysfunction (male & female)
- Swallowing difficulties (choking); Speech difficulties

NICE in its MS protocol recognises

- High-dose steroids for relapses
- disease modifying therapies for relapses
- symptomatic treatment all conditions
- In all cases **DISEASE MANAGEMENT**

multidisciplinary team

Palliative care

- Specialized care for people with serious illnesses.
- Focuses on providing patients with relief from the symptoms and stress of a serious illness.
- The goal is to improve quality of life for both the patient and the family.

- specially-trained team of doctors, nurses and other specialists delivering day to day care
- **who work together?**
 - Postcode Lottery

North Durham CCG area

Who	Where
Specialist MS Neurologists,	RVI (UHND), Sunderland, James Cook
MS Specialist Nurses	RVI, Sunderland, James Cook
Community MS Nurse	????
Occupational therapists	Cddft Community Hospital
Physiotherapists	Cddft Community Hospital
Speech therapists	UHND
Continence advisers	Cddft Community Peripatetic
Counselling	Walkergate Hospital (GP?)
Emotional/practical/financial help	MS Society North Durham 0191 386 0006 or 0808 800 8000

RVI	MS Consultant Neurologist	Annually
RVI	MS Specialist Nurse	Annually
Chester Hospital	Occupational therapist	Self referral
Chester Hospital	Physiotherapist	Self referral
Various hospitals	Continence Advisors	Via GP
UHND???	Ms Nurse	??

- 1. MS Neurologists – RVI, Sunderland, James Cook
Middlesbrough (RVI 30 mile round trip from Durham)**
- 2. Patient transport service to RVI dependent on tick box
exercise. Often refused necessitating appeal**
- 3. Service Location and availability depends on location of GP**
- 4. Unplanned Hospital Admissions £200 per day**
- 5. Mortality through complications**
- 6. Incorrect self-injection technique – lapsing use**
- 7. High drop out rate from system**



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CDDFT Specialist Nurses ??

- CFS/ME
- COPE
- Dermatology
- Diabetes
- Enteral Feeding
- Epilepsy
- Falls & Osteoporosis
- Heart Disease
- Lymphoedema
- Offender Health
- Older People's Urgent Care
- Pain Management
- Palliative Care
- Respiratory Services
- Stroke Services
- Vasectomy
- Wound Management
- **MS Nurse???**



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MS Specialist Nurse

- See Handout: compare MS Community Nurse description with specialist epilepsy nurse role
- Interchangeable

- Met chair of CCG Dr Bidwell 2012
- Attended numerous CCG forums * Patient congresses 2012-2015
- Report to Prof Keane Chair cddft 2016
- Meeting Head of long term conditions cddft
- Spoke at PRG 2017?

What can the PRG do?

- Cddft state they want to have a county-wide MS Nurse service Dependent on CCG Commissioning
- Go back to your respective practices and highlight problem faced by PwMS
 - GP's lobby North Durham CCG to commission an MS Nurse service

“Question Time???”

