The Motor Neurone Disease Association

Insights into MND

Annemieke Fox

Regional Care Development Adviser

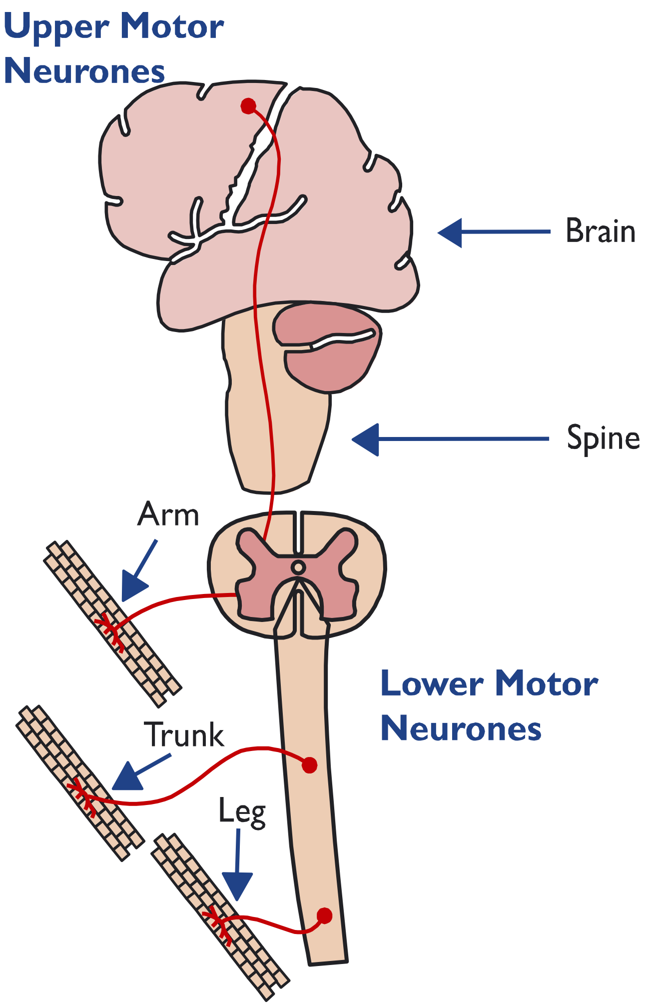
Hampshire, Dorset, Isle of Wight and Channel Islands

Introduction

- What is motor neurone disease?
- Symptoms of MND
- Supporting a person with MND
- What is it like to have MND?

mnda
motor neurone disease association

Function of the motor neurones



- Upper motor neurones originate in the motor cortex of the brain
- Lower motor neurones originate in the spinal cord

mnda
motor neurone disease association

Motor Neurone Disease (MND)

- Terminal Disease
- Rare Illness
- Incidence: 2 per 100,000
- Prevalence: 5-6 per 100,000
- Hampshire population = 1.7 million
- Number of pwMND approx 85-102
- MND Ass aware of 117

Motor Neurone Disease

- Onset and progression is variable – Can progress swiftly
- 90-95% of people have the sporadic form
- Adult illness – most people are above 50

Diagnosis

- No specific diagnostic test
- Clinical picture & elimination of other causes
- Mean delay in diagnosis of 1 year
- This has significant psychological consequences for the person with MND

Causes of Motor Neurone Disease

Primary gene abnormalities

Excess glutamate

Abnormal structural proteins

Excess oxidation

Viral infection

Deficient neuronal blood supply

Ageing mitochondria

mnda
motor neurone disease association

Motor Neurone Disease types

- Amyotrophic Lateral Sclerosis (ALS)

  Most common 65%

- Progressive Bulbar Palsy (PBP)

  Affects 25%

- Progressive Muscular Atrophy (PMA)

  Affects 10%

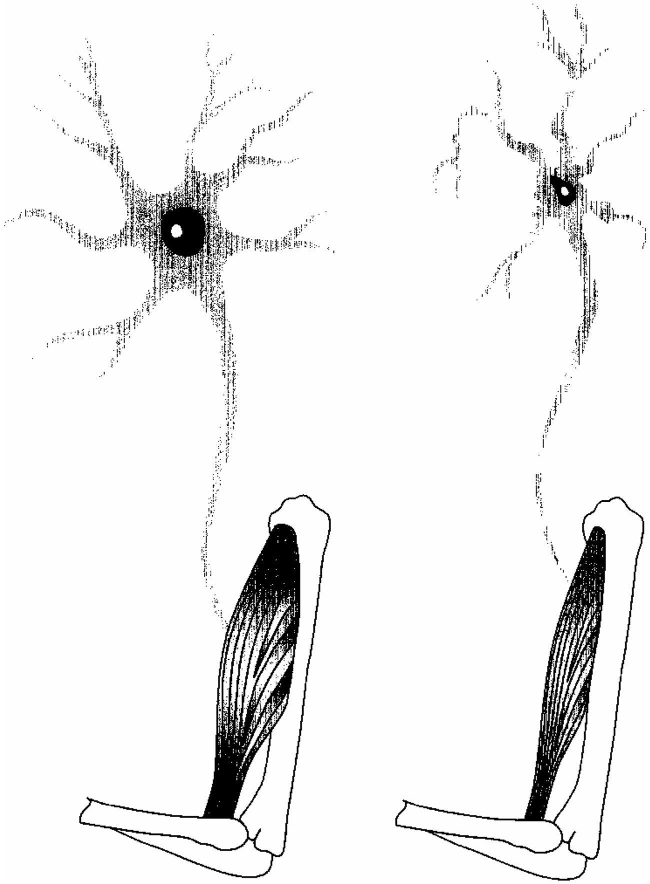
- Primary lateral sclerosis (PLS)

  Affects 2-5%

mnda
motor neurone disease
association

Symptoms of MND

- Muscle wasting and weakness causing difficulties with mobility and self care
- Fasciculations (twitching)
- Cramps
- Fatigue
- Respiratory problems
- Difficulties swallowing
- Weight loss
- Secretions
- Pain



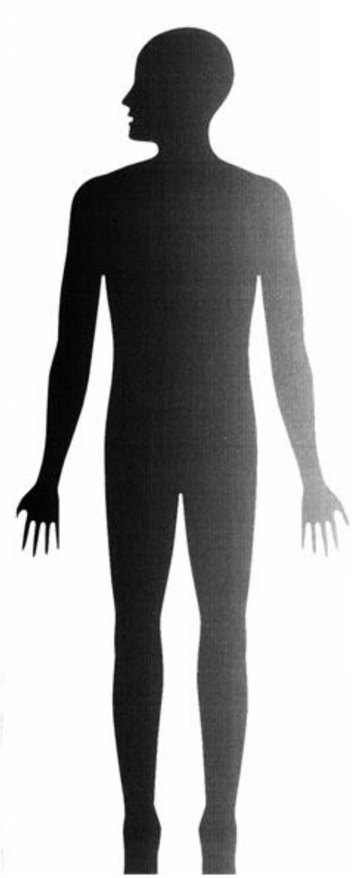
mnda
motor neurone disease association

Symptoms of MND

- Emotional lability
- Cognitive changes

Rarely Affected

- Senses: touch, taste, sight, smell and hearing
- Bowel and Bladder Function
- Sexual function
- Eye muscles



motor neurone disease association

Supporting a person with MND

PEOPLE LIVING with MND

Gastroenterologist

District Nurse

Dietitian

Specialist Nurses

Care Workers

Speech & Language Therapist

Counsellor

Palliative Care Team

Voluntary Services

General Practitioner

Physiotherapist

Social Worker/ Care manager

Neurologist

Respiratory Physician

Occupational Therapist

mnda
motor neurone disease association

Supporting a person with MND

- Seek advice from experts (palliative care teams, neuro teams, MND Association)
- Communication
- Communication
- Communication

Services provided by the MND Association

- MND Connect
- Equipment loan
- Financial support
- Care information
  www.mndassociation.org
- Local branch network
- Regional Care Development Advisers

mnda
motor neurone disease
association

Volunteers and local branches

- Local support
- Point of contact
- Open meetings
- Raising awareness
- Fundraising
- Helping to influence service provision

What is it like to have MND?

- During coffee, or later in the day, imagine you are a person with MND.

  You are unable to speak, or move any part of your body apart from to blink your eyes.

  - how will you cope with every day life?

  - what help will you need?

  - what emotions do you think you will feel?

mnda
motor neurone disease association

Thank you for listening

annemieke.fox@mndassociation.org

0845 3751831

MND Connect:08457 626262

www.mndassociation.org