East Riding
Social
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Academy

Multiple Sclerosis

Multiple Sclerosis fact sheet for Adults Social Care and Health

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EAST RIDING
OF YORKSHIRE COUNCIL

Multiple Sclerosis

…for Adults Social Care and Health

Overview:	This fact sheet will explain what Multiple Sclerosis is and describe the different types of MS. It will clarify the signs and symptoms of MS and detail the different treatments and support available for people living with the condition.
Content:	1. Introduction to Multiple Sclerosis (MS) 2. Types of MS 3. Signs and Symptoms 4. Treatment and Support 5. Caring for someone with MS

1 Introduction

Multiple sclerosis (MS) is a condition that affects nerves within the central nervous system - the brain and spinal cord. In MS, the protective coating around the nerves, called myelin, becomes damaged. Once diagnosed, MS stays with someone for life, but treatments and support from specialists can help to manage the condition and its symptoms.

More than 150,000 people in the UK have MS.

In the central nervous system, a fatty substance called myelin protects the nerve fibres. Myelin also helps messages travel quickly and smoothly along the nerves in the brain, spinal cord, and optic nerve, which connects the eye to the brain.

MS develops when the immune system doesn't work properly and mistakenly attacks the myelin in the central nervous system.

2 Types of MS

There are three main types of MS – relapsing remitting, primary progressive and secondary progressive.

Relapsing remitting MS (RRMS)

People with RRMS experience attacks of new or returning symptoms, these episodes are called relapses. Around 85% of people with multiple sclerosis are diagnosed with RRMS. Taking a disease modifying therapy (DMT) could mean fewer relapses which could slow down MS.

Secondary progressive MS (SPMS)
SPMS is a stage of MS that comes after relapsing remitting MS for many people. With this type of MS, symptoms or disability steadily progress, meaning they gradually get worse. People with SPMS are less likely to have relapses, where symptoms get worse for a time and then improve.

Primary progressive MS (PPMS)
Primary progressive MS is called this because, from the very first, or **primary** signs of MS, a person's symptoms begin to **progress**. This means they slowly but steadily get worse. Early symptoms are often subtle, like problems with walking, which develop over time. There will usually be few or no relapses with PPMS. Instead, disability and symptoms will gradually increase over a long time.

What is advanced MS?
When we talk about **advanced MS**, we mean MS which severely affects some people, usually after many years. Advanced MS can limit how much someone is able to move around, and people are likely to experience many symptoms at the same time. MS might also affect them in a similarly severe way after a very bad relapse.

3 Signs and Symptoms

There are many different MS symptoms, but not everyone will experience all of them. Some of them are visible and some of them are invisible.

MS symptoms can come and go and change over time. They can be mild, or more severe.

Invisible

Fatigue
Bowel/Bladder problems
Eyes and sight
Pain
Swallowing
Memory/thinking
Hearing problems
Mental Health

Visible

Balance
Walking problems
Dizziness
Tremors
Spasms and Stiffness
Speech problems

4 Treatment and Support

Diagnosing multiple sclerosis isn't easy. It's a complex condition with many different symptoms. Tests for MS could include blood tests and magnetic resonance imaging (MRI). If you think someone might have MS, the first thing to do is talk to the GP.

When someone is diagnosed with MS, they will then be referred to a specialist such as a neurologist. An MS nurse can discuss treatments in general for MS, but only an MS specialist can advise and prescribe many of the specific treatments. Patients should meet with their MS specialist at least once a year.

Some of the main treatments for multiple sclerosis are:

- Physiotherapy - to help improve strength and mobility.
- Disease modifying therapies (DMTs): treatments that can change how MS develops over time.
- HSCT (haematopoietic stem cell transplantation) – chemotherapy treatment.
- Actively managing health: diet, exercise, and giving up smoking.
- Medicines can be used to treat fatigue, pain, muscle spasms/stiffness, and bladder problems.
- Alternative lawful treatments, such as Cannabis, Sativex, and CBD oil.
- Pilates or Mindfulness sessions.
- Acupuncture.
- Aromatherapy.
- Reflexology.
- CBT (Cognitive Behaviour Therapy) for stress and mental health.
- Other alternatives such as massage, osteopathy, meditation, and Reiki.

MS and Mental Health

The emotional effects of MS often go undiagnosed. This doesn't mean there aren't ways to manage them. It's not unusual for someone to experience depression, stress and anxiety when they have MS. Medication, talking therapies and self-help techniques can all make it easier to cope with mental health issues.

Up to half of people with MS might experience depression at some point. It is often misunderstood, and it can be hard to get a diagnosis. For example, fatigue can be related to depression, or may be a direct result of MS, or a combination of the two.

Stress can make people feel anxious or worried, irritable, depressed or low in mood, or overwhelmed and pessimistic. Long-term stress can also lead to physical problems, including impaired memory, headaches, and high blood pressure.

Stress is a normal part of life for everyone, but in addition to facing normal everyday stresses, people with MS must deal with the unpredictability and pressures the condition itself causes. MS can affect many areas of life, such as the ability to work, cognitive functioning, friendships and relationships, housework and parenting. If all these areas of functioning are being affected by MS, it is likely people will experience more stress.

5 Caring for someone with MS

Caring for someone with Multiple Sclerosis requires an understanding of the changing symptoms they may experience, these should be monitored closely and addressed through a personalised approach.

A person's care and support plan and their risk assessment should clearly outline how MS affects them individually. This includes the symptoms they experience, the support required, any risks identified, and the personal goals they wish to work towards. Key areas to consider and what support should be included are:

Mobility, Balance and Involuntary Movements

MS often affects movement, including tremors, slow movement, and balance difficulties.

- Close monitoring of mobility changes and any difficulties with daily tasks.
- Referrals to Occupational Therapy and Physiotherapy for assessment, physical therapy, and specialist equipment.
- Clear documentation in the care plan if there is a risk of falls.
- Referral to the Falls Team where appropriate, following the Post-Falls Protocol.
- Referrals to Speech and Language Therapy for support at mealtimes, including mealtime equipment to aid independence when struggling with tremors or movement e.g. spouted beakers, easy grip cutlery and dignity plates.

Incontinence

Bladder or bowel changes are common in MS.

- Maintaining the person's dignity at all times.
- Discussing available support options, such as referral to the Bowel and Bladder Team for assessment and continence aids if needed.
- Being responsive to the person's routines and individual needs/goals
- Seeking GP advice where appropriate, which may include a review of medication.

Memory, Speech and Pain

Memory changes, difficulties speaking, and pain can affect overall Mental Health and increase the potential for someone to have depression.

- Having an understanding that the person with MS will likely be frustrated when finding it difficult to complete daily tasks they could do previously, always showing patience and encouragement.
- Providing access to meaningful activities that promote both physical and mental health.
- Encouraging social engagement and cognitive stimulation.
- Assessing someone's communication needs and offering any support including any tools they may need to communicate effectively and ensuring this is documented within a communication passport.
- Supporting healthy eating to ensure adequate nutrients that support muscle and neurological health.
- Monitoring changes in mood and referring to the GP or mental health teams if needed.

Some useful support tools

- Decision tool for DMTs - https://www.mssociety.org.uk/living-with-ms/treatments-and-therapies/disease-modifying-therapies/disease-modifying-treatment-dmt-decision-tool
- Fact sheets/publications for MS - https://www.mssociety.org.uk/living-with-ms/resources-and-publications/publications-search
- MS Society Hull, Beverley and Holderness Group - 07512 292 744/hull@mssociety.org.uk
- Samaritans emotional support - 116 123/jo@samaritans.org
- Call GP direct or NHS 111 for support with medical conditions
- MS helpline - 0808 800 8000
- MS befriending service (12 weeks) - https://www.mssociety.org.uk/support-and-community/ms-helpline-support-services/befriending-service
- MS Society - https://www.mssociety.org.uk/
- Support for family, friends and carers - https://www.mssociety.org.uk/supporting-someone-with-ms/supporting-family-friends-and-carers
- NHS - https://www.nhs.uk/conditions/multiple-sclerosis/