

Programme: Msc In Public Health and Social
Care In Practice

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Module: Community Care Management Of Long
Term Conditions

Module Code: LCHS7003

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Assignment Title: Component1 Information
Booklet Of Long Term Condition Management:
Multiple Sclerosis

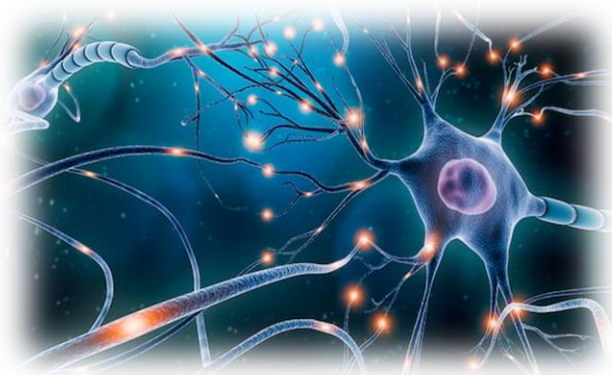


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Introduction

The booklet is going to work as an information resource for the health and care professionals dealing with **multiple sclerosis (MS)** in the UK. The booklet will cover the definition, burden, and risk factors associated with MS. A critical evaluation of the long-term disease, including its impact on physical, social, and psychological aspects of individuals, as well as its wider implications for families, will also be discussed. Identifying and investigating the frameworks used to improve patient outcomes affected by long-term conditions. The booklet can act as a guide for the healthcare workers, community health workers and nurses providing MS related treatment services in the UK.

Definition of multiple sclerosis (MS)

Multiple sclerosis is a long-term condition. The condition occurs when the immune system attacks the brain and the spinal cord. MS affects the cognitive, visual, sensory, motor, and emotional functions and occurs because of the immune system attacking the central nervous

system (CNS) (World Health Organisation, 2023). Multiple sclerosis (MS) is an autoimmune condition where own immune system attacks CNS and considers it as a foreign body (Cleveland Clinic, 2024). As a result, in MS causes, demyelination of CNS where the protective cover around the nerve cell (myelin) gets damaged causing numbness, vision changes and memory issues (Cleveland Clinic, 2024). Symptoms of MS for example fatigue, numbness, vision problems, muscle stiffness etc, vary from person to person and depend on the severity and location of nerve fibre damage. The symptoms may include vision problems, trouble walking, keeping balance and tiredness while feeling weakness or numbness in the legs and arms (WHO, 2023). Hence, the disease is impactful on long-term health and living conditions of people.



Figure 1: The normal ability of the patient is being hampered by MS

(Source: WHO, 2023)

According to the definition of the National Health Service (NHS) in the UK, multiple sclerosis (MS) is a condition affecting the brain and the spinal cord. It cannot be cured, but with treatment, it can often be managed (NHS, 2024). The common symptoms of MS in the UK are feeling tired, problems with eyes and vision, such as blurred vision, eye pain. Muscle cramps, tingling sensations, and feeling off balance are some of the common symptoms of MS (NHS, 2024).

Hence, people are to reach out to the doctors when such symptoms appear.



Figure 2: Common symptoms of multiple sclerosis in people

(Source: Cleveland Clinic, 2024)

Prevalence and burden of multiple sclerosis

According to the World Health Organization (WHO, 2023), MS is a global health concern. 1.8 million people globally are affected by MS. While people of all ages can be affected by MS, young adults and females are mostly affected by the condition (WHO, 2023). In the UK, MS is concerning because the autoimmune condition affects the central nervous system (CNS) of the body, and currently, more than 150000 people living in the UK have MS (Nicholas, 2026). The concerning case of prevalence regarding MS in the UK is that its existence has increased by 13% within 2019 and 2024. In 2019, 130,000 people had MS in the UK, which had increased to 150,000 in 2024 (MS-UK, 2024). The UK belongs to the northern latitude where the sunlight exposure is low, leading to lower vitamin D levels. Lack of vitamin D is a risk factor of MS and for this reason, MS burden is high in the UK (Oliver, Santana and Ribeiro, 2023). Like the global incidence of high MS rate in women, 71% of the

MS cases in the UK are reported from women, and most of them are thirty to forty years old (WHO, 2023; MS-UK, 2024).

Hence, it can be said that globally and in the UK, women are more affected by MS than men.

Burden of Disease Global and National

Several research studies have been conducted to understand the Global burden of MS in the UK. According to Royle *et al.* (2018), using the data from the Clinical Practice Research Datalink (CPRD), it has been observed that 19.4 million person/years. Within a 20-year-old study period, the peak age of the onset is 55-69 years. The UK prevalence of MS in the UK population is 307 per million in the 70-84 years aged people in the UK (Royle *et al.*, 2018). All four nations of the UK have a prevalence of MS. 15% increase in MS incidence can be reported from England, 10% incidence is reported from Scotland, 9% is reported from Northern Ireland, and 8% is reported from Wales (MS Trust, 2024). Total 150,000 people in the UK are presently having MS

(MS Trust, 2024). Each year, 7,100 people are diagnosed with MS. The trend of MS in the UK is such that 71% of the people with MS are women, and women are 2.5 times more likely than men to be diagnosed with MS (MS Trust, 2024). Middle-aged people within the age range of 30s and 40s are more likely to be affected by MS in the UK (MS Trust, 2024). Hence, it can be said that increased cases of MS in the UK are a concern that is making addressing the issue effectively.

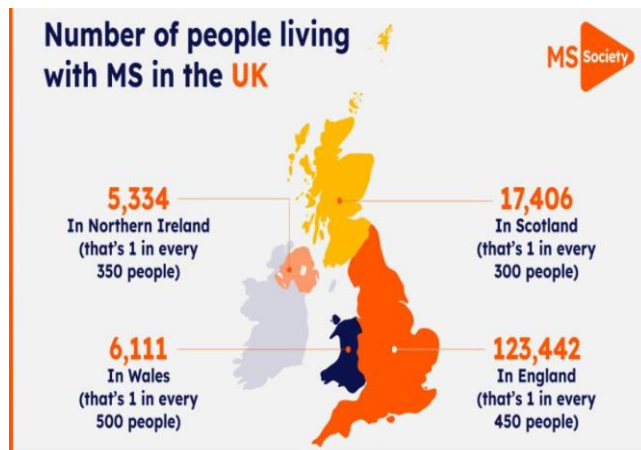


Figure 3: Prevalence of MS in different parts of the UK

(Source: MS Society, 2024)

Aetiology or risk factors of the health condition

MS is considered to be a concerning health condition because of its autoimmune nature. According to Taan *et al.* (2021), family history of MS, vitamin D deficiency since childhood, smoking and even persistent migraine are the possible risk factors of developing MS. In the UK, the risk factors of MS are more or less similar to those of the global risk factors. Common infections and vitamin D deficiency are directly linked with developing MS (MS Society, (n.d.) 2026). Hence, these are the risk factors associated with MS complications.

Aetiology helps in understanding the reasons, origins and causes behind the disease and the abnormal conditions. According to Boutitah-Benyaich *et al.* (2025), genetic factors are often related to the progression of disease in the adult state. MS generation is primarily led by immunological mechanisms associated with the adaptive arm of the immune system (Boutitah-Benyaich *et al.*, 2025). MS also has environmental

triggers. Certain environmental disease exposures often increase the chance of developing MS, such as **Epstein-Barr virus** (EBV) infection. The people who live at greater distances from the equator and have less sunlight exposure do not have enough **vitamin D production**. This leads to MS in people (Boutitah-Benyaich *et al.*, 2025). Other than these, **smoking** is a behavioural factor that is causing MS among people. Smoking increases the oxidative stress of the body, nitric oxide-induced axonal degeneration, chronic immune activation and increased permeability. All of these result in the prevalence of MS (Boutitah-Benyaich *et al.*, 2025). Other than the genetic or environmental causes, some previously existing health issues or diseases can increase the risk of having MS. Gianfrancesco and Barcellos (2016) have indicated that people who are obese have a high chance of developing MS, resulting in a 1.28 times increase in odds. Thus, obesity acts as a risk factor as well.

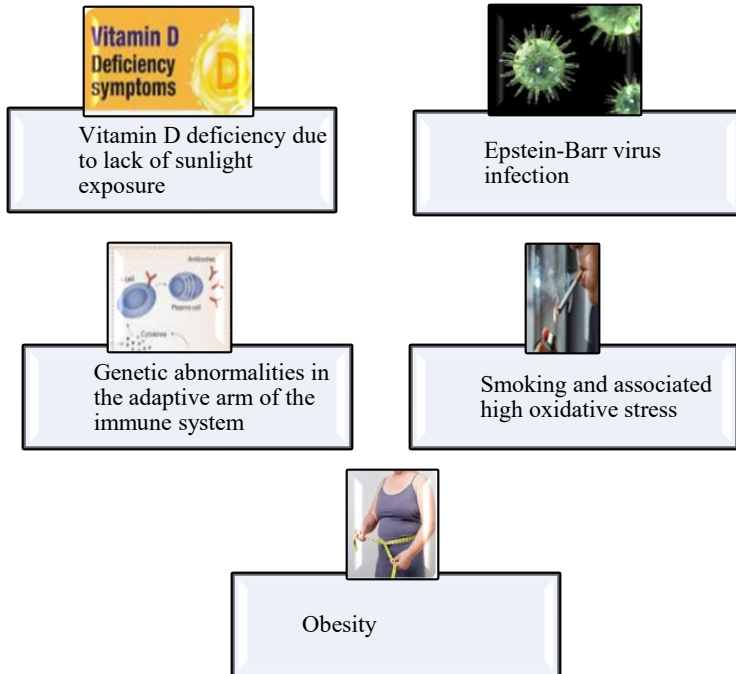


Figure 4: Risk factors giving rise to MS

(Source: self-created)

Physical health implications of MS

MS is a long-term chronic condition that has significant health implications. According to Young *et al.* (2024), often adults with MS face difficulties in conducting **physically demanding**

tasks. The mobility of the people gets hampered to a certain extent and often faces difficulty in **moving indoors.** As time passes, the physical difficulty increases and often affected people **face issues in performing leisure and social activities** (Young *et al.*, 2024). Other than the common health implications, Moore *et al.* (2022) have indicated the specific physical impact of MS. **Fatigue** is one of the common symptoms that is often observed among the affected people. Among the female affected people, fatigue is an important health concern (Moore *et al.*, 2022). As the fatigue issue increases, it gives rise to enhanced sedentary behaviour and higher mobility impairments (Moore *et al.*, 2022). Hence, several physical implications are reported due to the presence of MS, which hampers the common health of the people.

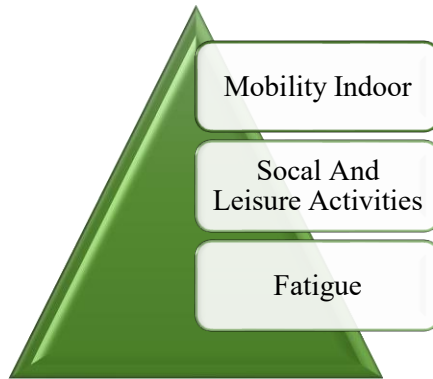


Figure 5: Physical impacts

(Source: Self-created)

Psychological health implications of MS

Other than the physical health implications, the long-term condition often has serious mental health implications. Young *et al.* (2024) have mentioned that MS often makes people mentally fatigued. Due to prolonged mental fatigue caused by the oxidative stress of MS, concentration issues occur which has an odds ratio of 0.82 (Young *et al.*, 2024). Lack of adverse health conditions impacts psychological health, which results in creating depressive symptoms among people (Young *et al.*, 2024). Moore *et al.* (2022),

in the case of the UK people, have also indicated that fatigue and depression coexist within them. 56% of the UK adults with MS have indicated that they faced mental health complications moderately or severely due to MS (MS Trust, 2023). The NHS have indicated that often people in the UK with MS complain about facing concentration difficulty, feeling they are losing memory (NHS, 2024). Hence, psychological implications in general and in the context of the UK are impacting the affected people on a long-term basis.

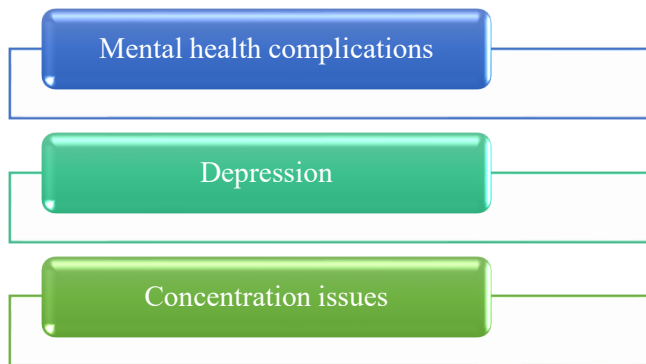


Figure 6: Psychological impacts of MS

(Source: Self-created)

Social implications of MS

The social implications of MS are complex. Having MS restricts several physical and psychological processes, hence the transition to a restricted social identity can have negative consequences (Moore *et al.*, 2022). Contrastingly, an MS diagnosis can have positive social connections as well because of the connectedness with other diagnosed people. The solidarity can improve mood as well (Moore *et al.*, 2022). Contrasting with the positive impacts, Ratajska *et al.* (2020) have indicated that MS diagnosed in early adulthood can interrupt the social connections and activities of the individual. MS causes psychological and physiological complications leading to adverse social implications like not getting desired employment, facing disease-related social stigma and social exclusion or pity for having a chronic condition (Ratajska *et al.*, 2020). Hence, the adverse social implications of MS are a concern for the livelihood of people with MS.

Strain on families

The family is the primary caregiver to any MS-affected individual. Ratajska *et al.* (2020) have indicated that MS management or coping with the physiological and psychological symptoms of MS directly creates strain on the family members. Often in the UK, when teenagers are diagnosed with MS, their family members become anxious about their future. The care providers and the family members both become scared about the long-term implications of the disease (MS Trust, 2022). The partners often feel hesitation in the sexual relationships because of the long-term conditions associated with MS (MS Trust, 2022). Hence, continuous strain and concerns are the adverse impacts on the families.

Evidence-based treatments of MS in the UK

The NHS has recommended several medicines for treating MS in the UK. **Steroid medicines** are used for reducing the swelling of MS. Often, the medicines tagged under the **disease-modifying**

therapies are used for reducing the relapse of multiple sclerosis (NHS, 2024). According to Smets *et al.* (2017), in the case of inflammation in the central nervous system (CNS), corticosteroids are often used. In 90% of the cases, corticosteroids are effective in reducing the relapses. Along with steroid medicines, disease-modifying therapies (DMTs) are utilised for treating MS in the UK. DMTs can be oral medicines or injectable medicines, which are often useful in modulating or suppressing the immune system (Smets *et al.*, 2017). Since 1993, DMTs have been considered the effective treatment of MS in for treating the relapsing form of MS (Smets *et al.*, 2017). In the UK, the NHS often utilises some drugs like natalizumab and fingolimod which are proved to reduce the relapse of MS (Great Ormond Street Hospital for Children, 2026). Hence, all these treatments being used by NHs are impactful.

In order to support the symptoms of MS, several interventions are being implemented by the NHS. Physiotherapy is provided to people for dealing

with mobility issues (NHS, 2024). According to Binshalan, Nair and McNeill (2022), physiotherapy helps improve gait impairment in MS. 78% of the MS-affected people are not involved in physical activity, and physiotherapy helps them in doing so. Hence, physiotherapy is an evidence-based intervention that is being utilised by NHs for treating MS and associated symptoms.

International models/frameworks for improved outcomes of MS

The international frameworks for dealing with long-term conditions like MS are several. Here, a specific MS-related framework has been chosen. According to Zaratin *et al.* (2024), the Multiple Sclerosis International Federation and European Charcot Foundation together have launched the Global Patient Reported Outcomes for MS (PROMS) initiative. The reported outcomes by the patients are being included in the clinical research and the care delivery. Therefore, the personal needs and the concerns of the patients can be better addressed through the Global PROMS

framework (Zaratin *et al.*, 2024). The framework/ Global PROMS model is ensuring that patient voices are being included alongside the clinical metrics, which involve pain, dexterity, cognition and fatigue. Zaratin *et al.* (2024) have also indicated that for improving the MS-related treatment among people, predictive measures are often implemented through Global PROMS. Based on the patient-reported symptoms, the disease is predicted (Zaratin *et al.*, 2024). Global PROMs is the framework focusing on personal needs and the care procedures of the people living with MS (Zaratin *et al.*, 2024). Zaratin *et al.* (2024) have indicated that mobile health (m-health) technology holds considerable promise for enhancing patient care, offering a way of monitoring health outside the traditional clinical environments (Zaratin *et al.*, 2024). Therefore, it can be said that Global PROMs is a personalised care process.

Patient-reported outcomes for MS are dependent on the **patient-centred theory**. Person-centred theory (PCT) refers to treating patients as

individuals and equal partners in the business process of healing (Coulter and Oldham, 2016). PCT refers to enabling, coordinated and personalised features for delivering effective care to the people who need special care regarding an outcome (Coulter and Oldham, 2016). Like the Global PROMS framework, where the patient-reported outcome is being prioritised regarding the next steps for treating MS, in PCT, also enabling coordinated and personalised features of care delivery are ensured (Zaratin *et al.*, 2024; Coulter and Oldham, 2016). Hence, the Global PROMS framework is being executed based on the person-centred care approach or theory.

UK-based models/frameworks for improved outcomes of MS

In the UK, there is a framework or model being executed for improving the outcomes of MS, which is a long-term condition. The National Institute for Health and Care Excellence (NICE) guideline has launched the framework called Multiple Sclerosis in the adults: management. The model recommendations prioritise referring and

early diagnosis of MS in the UK, so the treatments can be started earlier (NICE, 2022). The NICE guidelines framework also prioritises providing information and support regarding diagnosis and treatment (NICE, 2022). The NICE guideline model/framework enhances symptom management and rehabilitation of people suffering from MS. According to the NICE guideline, addressing modifiable risk factors of MS is being prioritised for halting further progression of MS (NICE, 2022). Hence, the underlying theory of the NICE Guideline is to be assessed here.

The first theory that is applicable here is **the evidence-based medicine framework**. Evidence-based medicine (EBM) theory emphasises applying relevant scientific evidence to the condition of the patients based on the values of the patients. In order to improve the medical outcome of the intervention, the theory is used (Tenny and Varacallo, 2018). Following the evidence-based framework, from diagnosis to screening, conducting clinical trials before

implementing interventions are done by the NICE guideline/framework for MS in the UK (NICE, 2022). The evidences from previous intervention, treatment strategies guide the future treatments of MS. Hence, the EBP theory is effective here.

Local, national political health and social care agendas

The national agenda for managing MS is the NHS Guideline for MS. The guideline is being implemented through the multidisciplinary care services being executed by the NHS (NICE, 2022). NICE Guidelines have been created for supporting the adult NHS services through evidence-based and person-centred care delivery (NICE, 2022). According to Tenny and Varacallo (2018), evidence-based treatment or approach increases the effectiveness of the intervention outcomes. Hence, evidence-based initiatives are strengthening the long-term management of MS. All the NHS trusts throughout the UK do not perform similarly; disparate care levels can be observed (Farrukh and Mayberry, 2023). Hence, unequal implementation is a weakness. NICE Guideline indicates that politically, the government is trying to holistically improve the MS condition.

The local agenda for long-term condition management is being executed by organisations

like the Multiple Sclerosis (MS) Society. MS Society provides local support, up and down the country, for the local groups to provide support, disease information and friendship (MS Society, n.d.). Moore *et al.* (2022) have indicated that when the MS-affected people within a community connect with each other, a sense of positive support develops, which improves healing (Moore *et al.*, 2022). Hence, at the local level, a friendly, supportive environment for treating MS is being created.

Already, it has been indicated that MS Society is providing local support services for MS management in the UK. Other than the MS Society, the MS Trust can provide social support (NHS, 2024). Hence, through local trusts and societies, the developmental initiatives for MS are being executed.

Conclusion

It can be concluded that MS is a long-term health condition which is a public health concern in the UK. The diseases have physical, psychological and social implications. Internationally, Global

PROMS, backed by person-centred care and in the UK, NICE Guidelines for MS, backed by evidence-based practice, are managing the issue. The recommendation for improving person-centred care in self-management is providing personalised care plans to the affected people so that specific needs can be fulfilled. In order to enhance the end-of-life care, integrating the palliative care team into the MS management process can be helpful, and it is recommended as well.

From the overall discussions, it can be said that identifying the disease symptoms and addressing those based on specific disease patterns are important for the care outcomes of the people. The national agenda for addressing MS is the NICE guidelines, MS Society based group discussions are the national and local level initiatives for executing MS care procedures.

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