SPASTICITY ASSOCIATED WITH MULTIPLE SCLEROSIS: THE IMPACT

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KEY MESSAGES

Spasticity is a common symptom associated with multiple sclerosis (MS) and is a major contributor to disability.

In a study, 84% of people with MS reported symptoms of spasticity. Moderate, severe or total spasticity is reported in 34% of individuals.

Spasticity has a detrimental effect on quality of life in people with multiple sclerosis, affecting many areas of life for example, mobility, sleep, washing, dressing, eating, mood and ability to work. Inability to work and the need for care can have economic consequences.

Caring for someone suffering with spasticity involves assisting with activities of daily living, mobility and transfers as well as dealing with the emotional, psychological, economic and social impact of the caregiver role. If the carer is a spouse and especially if there are children in the household, this may be particularly challenging.

People with MS and spasticity access many health professionals within the NHS, for example specialist nurses, physiotherapists and occupational therapists as well as clinicians. Aids and equipment to assist with mobility and self care may be supplied through the NHS, along with drug therapies to relieve symptoms. Initial pharmacological management of spasticity is with oral therapies such as baclofen or gabapentin (unlicensed use). If monotherapy fails then combination
therapy with oral agents may be tried. If these therapies fail to provide adequate relief or are intolerable, more costly, invasive therapies such as botulinum toxin or intrathecal baclofen may be tried\textsuperscript{8,9}. An effective, tolerable, non-invasive therapy would be advantageous when patients have not gained adequate relief with oral treatments or have suffered intolerable side effects and whose only option is invasive therapy.

Those with severe spasticity may require hospital stays for related problems e.g. pressure sores, which can be lengthy and costly\textsuperscript{2}.

There are many support services that are offered through social services, including home care, home adaptations and respite and these are available based on need. For these services, there may be a charge made for the client based on “means testing”.

In addition to a huge impact on quality of life of both the individual and the carer, spasticity in MS has considerable cost implications for the NHS, Personal Social Services (PSS) and society as a whole.
INTRODUCTION

Multiple sclerosis (MS) is a condition in which damage occurs within the central nervous system (CNS - brain and spinal cord). As the nerves of the CNS control the functions of the whole body, symptoms can affect many different areas.

MS is the most common disabling disease of the CNS affecting young adults and is usually diagnosed between the ages of 20 and 40 years. MS is twice as common in women than men and is at its peak in the most economically productive years of life and when the person affected may have a young family. There is an increased prevalence, and higher risk of MS, further north and south of the equator.

Spasticity is a common symptom experienced by people with MS. This document sets out the burden and impact of spasticity associated with MS, giving consideration to the impact on the patient, the caregiver, the NHS, social services and society as a whole – see Figure One below.

FIGURE ONE

- Prevalence
- Impact on family & caregivers: quality of life, financial, social
- Impact on social services
- Spasticity
- Impact on patients: quality of life, financial, social
- Impact on society
- Impact on NHS
WHAT IS SPASTICITY?

Spasticity is an involuntary muscle overactivity caused when nerves controlling muscle movement are damaged as a result of the disease process in MS.

Muscle tone is increased resulting in a feeling of stiffness and tightness in muscles. The muscles affected will determine the impact on the person in terms of restrictions of movement.

“It’s as if my muscles switch on and go rigid when I don’t want them to and I can’t switch them off again.”

Spasms or involuntary muscle contractions may also affect patients. Spasms can be described as:

- Flexor spasms – where the affected limb bends upwards towards the body
- Extensor spasms – where the affected limb shoots outwards from the body
- Adductor spasms – where the legs come together causing difficulty in separating the thighs
- Spasms affecting the trunk – the back or trunk can arch away from the back of a chair or off a bed

Any muscle can be affected but spasticity and spasms tend to predominantly affect a person’s limbs or trunk. Severe spasticity affecting the limbs can result in it being very difficult to move the limb at all. If the limb becomes fixed in one position it is known as a contracture.

Spasticity can affect just a few parts of the body (focal spasticity), or it can manifest in multiple places (generalised spasticity). The impact can range from insignificant to incapacitating. Spasticity may also contribute, directly or indirectly to other symptoms of MS such as bladder or bowel dysfunction.

Symptoms associated with spasticity include pain, weakness, clonus (repetitive, up and down movement, often of the feet), sleep disturbance, fatigue and loss of dexterity.
TRIGGER FACTORS

Factors that can exacerbate spasticity include\textsuperscript{1,4,6,16,18}:

- an increase in body temperature (e.g. due to a fever or excessive exercise)
- infections (e.g. bladder or chest infections)
- a relapse
- skin irritation (including pressure sores and ingrown toenails)
- a full bladder
- constipation
- renal or bladder stones
- menstruation
- overly tight strapping or clothes
- bone fractures
- problems with posture
- emotional stress
- excessive fatigue
Health ministers consider the management of people with long term conditions a priority for the NHS. This is evidenced through the publication of “Supporting People with Long Term Conditions – An NHS and Social Care Model to support local innovation and integration20”. MS features prominently in both this document and the National Service Framework for Long Term Conditions21.

“For many people living with conditions such as multiple sclerosis or Parkinson’s disease the main issue, until science can find a cure, is improving the quality of their lives, supporting them to manage their symptoms and live as independently as possible21.”

Quality Requirement two of the NSF for long-term conditions – “Early recognition, prompt diagnosis and treatment”, specifies prompt access to symptomatic treatment in these patients.

A project group was set up in Scotland in January 2008 to develop clinical standards for neurological health services. Condition-specific standards have been developed for MS and other neurological conditions and it has been identified that people with MS can benefit from access to services that manage motor problems including spasticity. NHS Quality Improvement Scotland (QIS) will assess services against these standards22.
The degree of spasticity and spasms can vary from person to person, and over time. Spasticity is a major contributor to disability in MS.

In a study, 84% of people with MS reported symptoms of spasticity, with the definitions for severity ranging from “minimal” to “total” (See Figure Two below).

In an on-line survey, a third of people with MS said their spasticity was constant, while 27.5% described it as intermittent and 27.1% found it was worsened by specific activities or situations.

As there are approximately 100,000 people with MS in the UK, the number affected by spasticity is 84,000.

There is an increased prevalence, and higher risk of MS, further north and south of the equator and this is reflected in the incidence and prevalence figures across the UK, with higher numbers in Scotland and Northern Ireland.

**FIGURE TWO**

Proportion of MS patients affected by spasticity

Where moderate = frequently affects activities, severe = daily forced to modify activities and total = prevents daily activities
IMPACT ON PATIENTS

In some cases, a degree of spasticity can be helpful. Some people use the stiffness of their spasticity or extensor spasms to assist them in transferring from bed to chair or to walk\textsuperscript{18}. However, for others, severe ongoing stiffness or frequent spasms can have a significant negative impact on day-to-day life\textsuperscript{16}. Severe spasticity can lead to complete immobility\textsuperscript{2}. Prolonged immobility may lead to pressure sores\textsuperscript{2} and thromboembolism\textsuperscript{27}.

Some of the detrimental consequences associated with spasticity include\textsuperscript{1,4-6}:

- interference with mobility, ability to exercise and the range of motion in joints
- negative impact on endurance and energy expenditure
- interference with the activities of daily living (e.g. picking up objects, washing, dressing, eating, and household activities)
- interference with sexual activity
- discomfort or pain
- sleep disturbance
- interference with participating in hobbies and family activities
- interference with ability to work
- interference with the ability to drive
- emotional impact on, for example, mood, self-image and motivation
- depression and anxiety

As spasticity can occur in any muscle in the body, it can also lead to a number of problems including difficulty with speech, swallowing and bladder control\textsuperscript{10}. Spasticity can also lead to the patient falling unexpectedly\textsuperscript{2}.

Spasticity in a leg can cause someone to alter the way they walk or alter their posture, which can result in added strain on the back or legs or arms\textsuperscript{10}.

Safety in sitting and lying can also be compromised due to spasms or persistent poor positioning which can lead to the development of contractures. This can potentially lead to restricted community mobility and contribute to social isolation\textsuperscript{1}.
“Many people tend to deny themselves things that they enjoy because they don’t want to be embarrassed. As an adult you don’t want to be fed in a restaurant so you stop going out.”

Once present, contractures are often difficult to treat and can have major functional implications, particularly in maintaining a person’s skin integrity, personal hygiene and positioning. Contractures and spasms can lead to the development of pressure sores, which in turn may increase the severity of spasms and spasticity.

Ongoing spasticity and spasms may be described by the person affected as painful, uncomfortable, annoying, exhausting, embarrassing and frustrating.

Spasticity can contribute to a decreased independence, a decreased quality of life and may impact on a person’s role within the family, such as being a parent.

“I want to support my wife and children but can’t work because of my MS. All I can do is to try to be as little a burden on her as possible…”

A clear reduction in quality of life has been reported with increasing spasticity in MS patients.

In addition, there is likely to be an economic impact for patients if their ability to work or continue with their chosen profession, is affected by spasticity. There may be a further economic impact from the need to pay for social care services and equipment (see overleaf).
IMPACT ON FAMILY AND CAREGIVERS

Partners and family members of people with MS often become caregivers. As the individual’s disease progresses, the ability to carry out activities of daily living may decrease adding to the caregiver burden. Caregiver burden encompasses the physical, psychological, emotional, social and economical aspects associated with the caregiver role.

Spasticity may result in many difficulties for carers e.g. transferring the patient. In a patient perspective survey the following activities were identified as being difficult - getting in and out of a car, transferring out of a wheelchair, getting into and out of bed or a bath.

“Just getting me in and out of a car takes 15 minutes. It's always difficult because it always triggers spasms and often I have to be shoe-horned into my seat because my legs are in spasm and my body just goes rigid.”

The carer may need to assist in carrying out the activities of daily living for example washing, dressing, cooking and cleaning. The caregiver will also be faced with the emotional impact that spasticity has on the person with MS.

If the carer is a spouse and sleeps in the same bed, their sleep is likely to be disturbed by the spasms. It is also likely that any sexual relationship will be affected.

“I’ve had spasms while sleeping which have left my husband with painful bruises.”

If spasticity restricts the person with MS in their ability or willingness to participate in social activities or holidays, this will ultimately have an impact not only of the person with MS, but also their carer and family.
The time spent in the caregiver role will impact on the time available to carry out activities that they might otherwise choose, for example, time with friends or spent on their hobbies. 

The caregiver may need to give up employment or change the number of hours they are able to work. This results in an economic impact for caregivers. If the caregiver needs to remain employed, care for children and run the household, the burden may be particularly challenging.

Spousal caregivers may feel that they have lost their partner, companion, support, income and lifestyle. Other feelings caregivers often experience are anger, resentment and inadequacy.

A systematic review investigating the impact of being a caregiver for someone with MS (not specifically spasticity) found that caregivers reported a decrease in their quality of life, a deficit in their physical health and a detrimental effect on psychological wellbeing.

“I care for my husband. I’m happy to do it but it does put a strain on our relationship at times.”

Studies investigating the cost of MS (not specifically spasticity) commonly find that a large proportion of the economic burden is borne by informal caregivers.
IMPACT ON NHS

HEALTHCARE PROFESSIONALS

There are a number of healthcare professionals involved in the management of spasticity associated with MS. These include:

- MS nurse
- Neurologist
- Physiotherapist (neurophysiotherapist where available)
- Occupational therapist
- Speech therapist
- Rehabilitation specialist

In addition, the person affected by spasticity will be supported by various health professionals in primary care including their GP, practice nurse and district nurse.

The annual cost of consultations associated with the general management of spasticity was reported to be £894 per patient in the year 2000. As MS is a long term condition, the multidisciplinary team is likely to be accessed over a prolonged period. Disability resulting from spasticity can lead to patients requiring extensive nursing care.

AIDS AND EQUIPMENT

Aids or equipment can assist with the management of spasticity in MS. Braces and splints may be used to hold a muscle in place for a period of time which can be helpful if a muscle would otherwise be fixed in one position, making carrying out activities of daily living difficult. Standing frames or sticks may be suitable for some patients. Other aids include seating aids, spinal jackets and orthoses (e.g. special footwear).

Wheelchairs and accessories are provided through a number of different routes. In England, for example, the NHS Wheelchair Service is responsible for assessing and providing wheelchairs to those who have permanent difficulties with walking. In Wales, the Artificial Limb and Appliance Service is responsible for assessment and provision of wheelchairs. Exactly what is provided will vary from place to place. Manual wheelchairs...
are the most common wheelchairs provided however, many people choose to use their Disability Living Allowance (see below) to hire or purchase a powered wheelchair or scooter from the Motability Scheme\(^3\). The cost per year of a wheelchair varies depending on type\(^3\):

- Self or attendant propelled - £81
- “Active user” (a lighter type of chair) - £163
- Powered - £376

There are currently five wheelchair and seating centres in Scotland that provide multidisciplinary assessment and provision to wheelchair users and their carers in Scotland\(^3\).

**DRUG TREATMENTS**

There are currently several treatments used for spasticity in the UK, some of which are unlicensed in this indication. Initial pharmacological management is with an oral therapy such as baclofen or gabapentin (unlicensed use). If monotherapy fails then combination therapy with oral agents may be tried\(^5\). It has been reported that 35% of people with moderate spasticity and 46% with severe/total spasticity require combination therapy with more than one oral agent\(^5\). If oral therapies fail to provide adequate relief or are intolerable, more costly, invasive therapies such as botulinum toxin, phenol injection (unlicensed use) and continuous intrathecal baclofen infusion may be tried\(^8,9\). Whilst these therapies are effective in some patients\(^2\), they have a number of disadvantages:

- Invasive
- Intrathecal treatments require a detailed clinical governance framework to ensure safety of administration\(^1\)
- With both phenol and botulinum toxin, the effects are temporary and may require frequent injections
- Individuals can build up antibodies to botulinum toxin over time, making it ineffective\(^4\)
- Cost – of the treatment and also the administration and multidisciplinary care costs
The following chart sets out the costs of the drug therapies used in the management of spasticity.

**FIGURE THREE**

<table>
<thead>
<tr>
<th>Drug Treatment</th>
<th>Minimum Cost</th>
<th>Maximum Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>Baclofen intrathecal</td>
<td>£0</td>
<td>£4,500</td>
</tr>
<tr>
<td>Botulinum toxin</td>
<td>£0</td>
<td>£1,500</td>
</tr>
<tr>
<td>Phenol injection</td>
<td>£0</td>
<td>£1,000</td>
</tr>
<tr>
<td>Dantrolene</td>
<td>£0</td>
<td>£1,000</td>
</tr>
<tr>
<td>Clonazepam</td>
<td>£0</td>
<td>£1,000</td>
</tr>
<tr>
<td>Diazepam</td>
<td>£0</td>
<td>£1,000</td>
</tr>
<tr>
<td>Tizanidine</td>
<td>£0</td>
<td>£1,000</td>
</tr>
<tr>
<td>Gabapentin</td>
<td>£0</td>
<td>£1,000</td>
</tr>
<tr>
<td>Baclofen oral</td>
<td>£0</td>
<td>£2,000</td>
</tr>
</tbody>
</table>

NB Some doses used to calculate cost exceed those recommended in the product SPCs and some products are unlicensed in this indication. Refer to the latest drug tariff/MIMS for the most up to date pricing.

It has been estimated that the total cost of a single treatment with botulinum toxin, taking account of the drug, consumables, availability of splinting materials, imaging, equipment and staff is approximately £950 - £1,00015.

Intrathecal baclofen is particularly costly and a recent document from a specialised commissioning group, estimates the total annual NHS cost of this intervention per adult patient to be £12,771 in the year of implantation39. This cost includes the surgical implant procedure (including work-up), the device, catheters and refills. There is a life long follow-up for pump refills, estimated at a cost of £2,130 per year and the device needs replacing approximately every seven years39.

The invasive nature and ongoing maintenance of intrathecal baclofen therapy means that embarking on this therapy is not a simple decision to make for the person with spasticity18.
It is reported\textsuperscript{48} that recreational (street) cannabis is used by MS patients for relief of symptoms including spasticity.

An effective, tolerable, non-invasive therapy would be advantageous when patients have not gained adequate relief with oral treatments or have suffered intolerable side effects and whose only option is invasive therapy.

If drug treatments fail to control the symptoms of spasticity, there is likely to be an increased need for consultations with the multidisciplinary team and use of drugs unlicensed for spasticity e.g. gabapentin or clonazepam\textsuperscript{9}.

\textbf{HOSPITAL ADMISSIONS}

Patients with severe spasticity frequently require a hospital stay for the treatment of related problems. These include the management of pressure sores as a result of long-term immobility. Hospital stays can be for several months and the costs can be substantial\textsuperscript{2}.

A review of the economic evidence relating to the treatment of spasticity associated with MS found three estimates of bed days used for patients without or prior to continuous intrathecal baclofen infusion: 19 days, 32 days (63 days over 2 years) and 84 days\textsuperscript{2}. Using the information in the 2009/10 National Tariff\textsuperscript{49}, the non-elective spell tariff for multiple sclerosis is £2,331. The trimpoint is 37 days for MS and therefore the per day long stay payment can be applied for days exceeding this trimpoint. The long stay payment for MS is £207. The bed days quoted would therefore be charged between £2,331 and £12,060.

It has been estimated that the cost of treating a pressure sore varies between £1,064 to £10,551 depending on grade and complications, using NHS unit costs at 2000 prices\textsuperscript{50}.

\textbf{ELECTRICAL STIMULATION THERAPIES}\textsuperscript{16}

These therapies use electrical stimulation of the nerves and muscles affected by spasticity but are not universally available:

- Functional electrical stimulation (FES)
- Transcutaneous electrical nerve stimulation (TENS)
IMPACT ON SOCIAL SERVICES

For a person and their carer to gain support from the local social services department, they must undergo an assessment of their needs.

Unlike health care, an individual and their carer may be expected to pay for social care services. They are likely to be asked about their income, benefits and savings.

Services provided which may be appropriate for people with MS and specifically spasticity include:

- **Home care support** – practical help and support to people at home with essential tasks they are unable to manage safely for themselves. For example, assisting someone to get up or go to bed, to get washed, shaved or to get dressed, or help with shopping. The typical cost of a home care package if all hours are provided by the local authority is £191 per week (2007/08 costs).

- **Home adaptations** – common adaptations include widening doors, installing ramps, a stair lift or handrails. The costs of these adaptations vary widely. The following are median annuitised costs:
  - Grab rail - £6
  - Hoist - £308
  - Stairlift - £388
  - New bath/shower room - £1,757

- **Sitting services and respite** – this service can be provided to give the carer a break from their caregiving responsibilities.

- **Day centres** – providing somewhere for the person with MS to go during the day if they are unable to be out of the house unaccompanied. It gives the individual a social opportunity and the carers a break and the chance to meet other carers.
- **Residential care** – if an individual has high care needs, it may be suggested that they need 24 hour care in a residential facility\(^{31}\).
  - The weekly cost of care in a high dependency care home has been estimated to be £1,309 (2007/08 costs)\(^{34}\).
  - The weekly cost of accommodation in a special needs flat with on-site support and a comprehensive package including external services and all living expenses has been estimated to be £891 (2007/08 costs)\(^{34}\).

Moving and handling aids such as hoists, sliding sheets, transfer boards, bath seat, bed rails and pressure relief mattresses may be helpful for carers in some cases and may be provided by the social service team or community nursing team\(^{33}\).
IMPACT ON SOCIETY

The previous sections highlight the impact of MS and specifically spasticity, on the NHS and social services. The associated costs are borne by society through taxation and national insurance payments.

People with MS may need to change their career, hours of work or give up work entirely. The same can be said for their caregivers'. This has an impact on both employers and colleagues.

In addition, there are a number of benefits that people with MS and/ or their carers may be eligible to apply for, including:

• Employment and support allowance (ESA)
• Incapacity benefit and income support (replaced by ESA)
• Disability Living Allowance (DLA)
• Attendance Allowance
• Carer’s allowance
• Housing benefit
• Council Tax benefit/council tax disability reduction scheme
• Pension credit
• Jobseekers allowance
• Statutory sick pay
• Working tax credit
• Community care grant
• Disabled facilities grant
IMPACT OF DISEASE SEVERITY ON COST

There is a relationship between disease severity in MS, as measured by the EDSS (Expanded Disability Status Scale) and increasing cost\(^5^3\) (see figure four below). The EDSS scale ranges from 0 to 10 in 0.5 unit increments that represent higher levels of disability where a score of 1.0 represents “no disability, minimal signs in one functional system” and 9.5 represents “totally helpless bed patient; unable to communicate effectively or eat/swallow”\(^6^4\). As spasticity is a major contributor to disability in MS\(^5\), it seems reasonable to extrapolate that as spasticity progresses, costs increase.

**FIGURE FOUR\(^5^3\)**

Mean cost per patient by disease severity

![Mean cost per patient by disease severity graph](image-url)

- Indirect costs
- Informal care
- Services/Investments
- Direct healthcare costs

All costs are for 2005

Adapted from reference 53
CONCLUSIONS

- Spasticity is a common symptom associated with MS\(^1\) and is a major contributor to disability\(^2\).

- Spasticity associated with MS has an impact, not only on the affected individual, but to the caregiver, the NHS, social care and society as a whole.

- As this is a long-term condition, the impact is often over an extended period.

- Effectively managed spasticity has the potential to:
  - improve functional independence and the quality of life of the individual, their carers and family
  - reduce the amount of NHS resources that are consumed
  - reduce the amount of social care support required

- An effective, tolerable, non-invasive therapy would be advantageous when patients have not gained adequate relief with oral treatments or have suffered intolerable side effects and whose only option is invasive therapy.