



# MS Society policy position statement

## MS treatment and care

UPDATED July 2017

### Issue

People with MS require access to professionals across the totality of health and social care to best manage their condition. We believe people with MS should have timely access to professionals and be at the centre of decision-making about their treatment and care.

Published in 2016, the NICE Quality Standard for MS recommends that people with MS have access to care from a multidisciplinary team with expertise in MS. This team can be comprised of a range of professionals including neurologists, MS specialist nurses, physiotherapists and occupational therapists, speech and language therapists, psychologists, dietitians, social care, continence specialists and GPs.

In addition, people with relapsing forms of MS can be prescribed Disease Modifying Therapies (DMTs) and there are now 11 licensed DMTs in England. These can decrease the number and severity of relapses, delay the progression of disability and slow the speed at which it happens for people with relapsing remitting forms of MS. Added to this, there is now consensus among the MS and clinical community that early treatment with a DMT can improve long-term outcomes.

Since the 2012 Health and Social Care Act, commissioning responsibilities for MS and other neurological conditions have been split between NHS England (NHSE) Clinical Commissioning Groups (CCGs). Under this structure NHSE have had responsibility for the specialised aspects of MS care, such as DMTs and activity carried out in neuroscience centres, while CCGs responsibilities include community services provided across a multidisciplinary team.

This divide is set to end, with NHSE publishing their **Strategic Framework for Specialised Services** towards the end of May 2016. The vision set out in the Framework is that of further collaboration between national and local commissioning, with CCGs required to take more responsibility for a range of specialised services. This should have the benefit of allowing commissioners to take a whole system view and create more integrated pathways for people affected by MS.

The Neurosciences Clinical Reference Group is also scheduled to develop a new service specification for neurological conditions, which should aim to clarify commissioning responsibilities.

## Evidence/Findings

Key findings from our 2016 My MS My Needs research included:

- In England, 56% of those who could potentially benefit from taking a DMT are doing so (an increase from 40% in 2013).
- Access to health professionals and the right information are key to access to a DMT – 81% of people who have access to MS specialists and the right information are taking a DMT. Just 10% of people who could benefit from these treatments but did not access any of these services are taking one.  
86% of respondents had their need for access to a neurologist met. 83% of respondents had not been offered a care plan or a care plan review for their health care.
- 17% of survey respondents answered “not at all” when asked if they felt that the professionals who help plan their care worked well together.
- The most common key contact for health care and support in relation to MS was a specialist nurse (45%). One in five identified their GP as their key contact for health care and support in relation to their MS. A quarter of respondents (26%) required support to remain physically active in the past 12 months but had not received any.
- One in five of respondents required emotional support but had not received this.

Anecdotal feedback from policy roundtables held across England (2016-17) with local commissioners, clinicians and healthcare providers, and people living with MS, indicates that the current split in commissioning can negatively impact on the delivery of MS services. This can be through services not being picked up (including MS nurses) as NHSE and CCGs feel the other is responsible.

## Recommendations

- Conversations about treatment options, including DMTs, should begin close to diagnosis, with follow-up after diagnosis within six weeks and again within six months.
- All licensed treatments for MS should be made available on the NHS in England.
- People with MS should be offered a comprehensive review of their care at least once a year that draws on expertise across a multidisciplinary team.
- People with MS should be offered information and support at diagnosis to understand their condition and how it can be best managed. Their information and support needs should be reviewed regularly.
- People with MS should be offered support from a multidisciplinary team, including emotional support, continence advice and support to remain physically active.
- People with MS should be offered a care plan or care plan review – this presents a key opportunity to involve people in their care.
- People with MS should have a single point of contact for their care, who coordinates care across a wider multidisciplinary team.
- A revised Neurosciences Service Specification should be developed and clearly set out commissioning responsibilities for MS care and treatment.