

The role of the Advanced MS Champion: Executive summary



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Identifying the gaps in service provision for people with advanced Multiple Sclerosis (MS)

A report published by the MS Trust in 2016, highlighted the many inequities in service provision for people with advanced MS (pwAMS) (Roberts et al, 2016). This gap in service provision has developed as a result of the changing workload of MS teams as detailed in MS Forward View (Croft et al, 2016).

Defining advanced MS and why it matters

People with advanced MS have multiple, complex symptoms relating to their disease; are dependent for some or all of their care needs and experience significant impairment of function (Roberts et al, 2016). Many people living with advanced MS experience repeated non-elective (i.e., emergency) admissions due to complications of their MS. The majority of these admissions are avoidable with provision of proactive, specialist care (Leary et al, 2015).

Data looking at emergency admissions of all people with MS (pwMS) in England during 2018/19 (Raising the bar, 2020) showed that emergency admissions for pwMS have risen by 15.6% since 2016/17. The total cost of emergency admissions during 2018/19 was £86 million, with an average cost per admission of £2,844. Emergency admissions for pwMS are not only costly and take up medical beds which are in short supply but also have a huge negative impact on the quality of life of pwMS and their families.

Since the MS Trust started this programme, the AMSC role has been advocated by NHS England (NHS RightCare, 2019) and within the Optimum Care Pathway for MS (Coles et al, 2019).

Advanced MS Champion pilot programme

Following a period of extended consultation and scoping, the MS Trust developed the role of the Advanced MS Champion to address the gaps in service provision for this group of people, improve access to specialist, proactive care and reduce unnecessary emergency admissions. The MS Trust was successful in being awarded transformational funding from The October Club in 2017 to run the pilot.

The pilot programme established six Advanced MS Champions (AMSC) in different sites across the UK between 2018-2020. The MS Trust provided 90% of the funding for the roles first 15 months in post, alongside facilitation of peer support, mentoring and a rigorous evaluation at each site.

The AMSC role was open to any MS health professional, there were two nurses and four therapists in the roles, all at a specialist Band 7.

The impact of the AMSC in each site was evaluated based on a set of core key performance indicators (KPIs) and specific, local KPIs relating to local needs and services; feedback from pwAMS, their carers and families and other health and social care professionals working with them was also gathered.



Due to the impact of Covid-19 on staffing levels and services both within the NHS and the MS Trust, the evaluation took the form of a pragmatic service review. Key findings are listed below, for more detailed findings and discussion please contact the MS Trust on hpteam@mstrust.org.uk.

Key findings

AMSC caseloads:

- An AMSC caseload consists of people with the most complex needs across physical, social, cognitive, mental health, environmental and financial domains with an Expanded Disability Status Scale (EDSS) range of 6.0–9.5.
- Given the complex needs of pwAMS, the recommended caseload per AMSC is 100 pwAMS, assuming that the AMSC post sits within a supportive MS team and has ready access to neurologist and/or neurorehabilitation consultants for clinical supervision and support.
- Establishing an AMSC within an MS team increases the types of appointment available, improving access to services for everyone with MS. Home Visits are particularly important given the complex disabilities pwAMS are living with.

Impact of the AMSC on emergency admissions:

- Using Hospital Episode Statistics (HES) data we have been able to show:
 - » A reduction of 52 emergency admissions of pwMS per site, per year
 - » A reduced spend on emergency admissions of pwMS of £465,376 per site, per year
 - » A reduction in number of emergency bed days for pwMS of 403 per site per year
 - » Mean length of stay is fairly static with a reduction of 0.4 days per emergency admission

- » A consistent reduction in the number of pwMS requiring two or more emergency admissions during a 12-month period.

Results from other Key Performance Indicators (KPIs):

- People with AMS who have access to an AMSC require fewer GP appointments with 115 GP appointments saved per year across an AMSC caseload.
- Establishing an AMSC within an existing team of MS specialist nurses releases significant MS nurse resource and capacity, enabling the MS specialist nurses to provide more proactive care to more people with MS with an average of 91 MSSN appointments saved per year per site.
- Many pwAMS become disengaged from specialist services over the years, establishing an AMSC role has been pivotal in re-engaging patients in this most vulnerable group with 10% of AMSC referrals being pwAMS who have been lost to service.
- People living with advanced MS have unequivocally found the AMSC role to be hugely helpful to them and their families, improving their experience and often their outcomes.

The aim of the pilot was to demonstrate the viability and impact of the AMSC roles and to ensure that no one has to cope with MS alone.

Despite the limitations imposed on the pilot by Covid-19, the MS Trust has demonstrated that the AMSC post is financially viable, improves patient flow within acute trusts, improves outcomes and patient experience for pwAMS and their families and is welcomed by other health and social care professionals.

Whilst many more of these posts and other MS specialist roles are needed across the UK (Roberts et al, 2022), it is clear that the AMSC role is a valuable addition to the MS team and should be a requirement for every MS service



to ensure they are meeting the needs of everyone with MS in their locality. The MS Trust is planning a 2nd wave pilot which will build on the findings of this one.

References

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Having an MS champion involved in my life has helped and assisted me tremendously. Contacting my AMSC allows me to discuss any issue with her and my issue is dealt with efficiently and effectively. Having the MS champion supporting me, floods me with confidence to live my life not just survive. I realised not all superhero's wear capes – but face masks seem to be popular choice!

Person living with Advanced MS
