

MS Trust Advanced MS Champion Programme

Welcome to the MS Trust's Advanced MS Champion Programme

Our Advanced MS Champion (AMSC) programme works with NHS organisations to fund multiple sclerosis specialist practitioners who champion the needs of people living with advanced MS (AMS).

The number of people living with MS at any one time is now estimated to be over 150,000. Based on the UK MS Register's data from 2024, we estimate that 32% of people diagnosed with MS, approximately 48,000 people, are living with AMS.

MS Trust research revealed that many people with advanced MS (pwAMS) report losing contact with MS specialist services as their condition gets worse and leaving them to rely on informal care from family and friends. When these support networks are absent or break down, people with advanced MS become forced to manage their condition alone. MS health professionals often become aware of people with advanced MS when they have hit crisis point.

Following the successful pilot programme and further successful AMSC posts, we are now assessing sites for the next AMSC post in the UK.

We believe everyone with advanced MS should feel supported, informed and in control – today and every day.

The context for an Advanced MS Champion

In October 2025, MS Trust launched a new organisational strategy centred on helping people with MS feel more in control, today and every day. This strategy reflects the diversity and complexity of experiences across the MS community.

The strategy is built around three core priorities:

- Providing trusted information and compassionate support
- Driving excellence, equity and consistency in treatment and care
- Delivering research rooted in real experience and translating it into action

The Advanced MS Champion (AMSC) programme sits at the heart of the MS Trust's organisational strategy to ensure that everyone living with MS, including those with advanced and complex needs, can access high-quality, coordinated and compassionate care.

What is an Advanced MS champion?

An Advanced MS Champion (AMSC) is a specialist health professional who plays a critical role in delivering care for people living with advanced MS. Working as part of an MS team, the AMSC supports people with advanced MS to feel informed, supported and more in control, even as their

needs become increasingly complex and they become more isolated from healthcare and their community.

As part of the role an AMSC will:

- provide specialist, proactive and individualised care to people with advanced MS and their families, helping them understand their condition, manage symptoms, and identify problems.
- coordinate care for people with advanced MS across different services, ensuring timely referrals to relevant health and social care professionals.
- work across boundaries within the NHS and social care to implement change and ensure delivery of joined-up care.

“The role of the AMSC is worth its weight in gold. There are so many people involved in my mother’s care, all focusing on different parts of her body rather than treating her as a whole person. The AMSC role oversees all the areas and supports her in dealing with the many professionals involved.

This role is needed more than ever when someone has such complex disability”.

- Relative of person with AMS

Evidence from the Pilot

Evidence from the AMSC pilot demonstrates how targeted, specialist roles can reduce health inequalities, improve quality of life and deliver value for the NHS. This aligns with the MS Trust’s strategic focus on improving consistency of care and addressing systemic gaps experienced by people with advanced MS.

Not only do AMSCs make a tremendous impact to the lives of people with advanced MS but results from our pilot demonstrate that the role is financially viable in a challenging NHS landscape:

- The recommended caseload number for an AMSC is **100** people with AMS, due to the complex needs of pwAMS. This assumes that the post sits within a supportive MS team with good links to community services.
- On average an AMSC prevents **64** avoidable admissions a year.
- Hospital Episode Statistics (HES) data shows that a single AMSC saves **£465,376** on emergency admissions of pwMS and **403** emergency bed days for pwMS, per site, per year.
- An AMSC saves an average of **91 MSSN appointments** per site, per year.
- AMSCs re-engage people with advanced MS lost to services with **10%** of referrals being from pwAMS who had been lost to service.
- Qualitative data shows that people with advanced MS and their families have found AMSCs invaluable, especially in co-ordinating care and advocating for their needs.

How the Programme works

The MS Trust provides:	The employing/host organisation provides:
80% of funding for each AMSC post for 15 months	The remaining % funding of the AMSC post
Professional development support for each AMSC including mentorship, pastoral care, education and facilitating peer support	An approved business case and baseline patient satisfaction survey before commencing recruitment
A fully funded place at our Development module and one MS Trust conference	Agreement that the AMSC post will continue to be funded by the NHS following the cessation of MS Trust funding