



Evidence for MS Specialist Services:

Findings from the GEMSS MS specialist nurse project

This is an executive summary. Read the full report and references at www.mstrust.org.uk/GEMSS



What is GEMSS?

GEMSS (Generating Evidence in MS Services) is a national programme of work, funded and facilitated by the MStrust, to help health professionals working in MS evaluate and improve their services and to demonstrate what works best to meet the needs of people with MS. This report summarises the data and findings from a project to evaluate MS specialist nurse teams across the UK.

What are the main conclusions from the GEMSS evaluation of MS specialist nurses?

For people with MS	MS specialist nurses are the health professionals most consulted about MS and play a vital role in the overall coordination of care. Their specialist expertise and continuity of availability enables them to improve outcomes for pwMS across all five domains of the NHS outcomes framework.
For other health professionals in the NHS	MS specialist nurses make a major contribution to increasing the capacity of other staff (particularly neurologists) and to building the skills and knowledge of other, less specialist professionals working with pwMS, including GPs, social care staff, other nurses and therapists, indirectly improving outcomes for PwMS.
For NHS commissioners	MS specialist nurses save costs elsewhere in the health system, both in ambulatory care costs (GP, A&E and neurology attendances) and prevention of unplanned hospital admissions resulting from complications of MS including MS relapses, bladder and bowel problems and respiratory infections.
For wider society	MS specialist nurses improve quality of life for pwMS and thereby help them to live full and active lives, including staying in work where this is possible. This benefits the economy and is of wider value to the families and carers of pwMS.



Who took part in GEMSS?

The GEMSS teams were chosen through a competitive process and selected to represent a wide range of MS services from across the UK. Working with the MS Trust GEMSS facilitators, 15 teams collected service and user experience data from April 2014 - March 2015¹.

The MS Specialist Nurses (MSSNs) in these teams had a combined caseload of over 15,000 pwMS. Based on recent prevalence estimates the teams' caseloads represent approximately 12-15% of pwMS in England and Scotland.

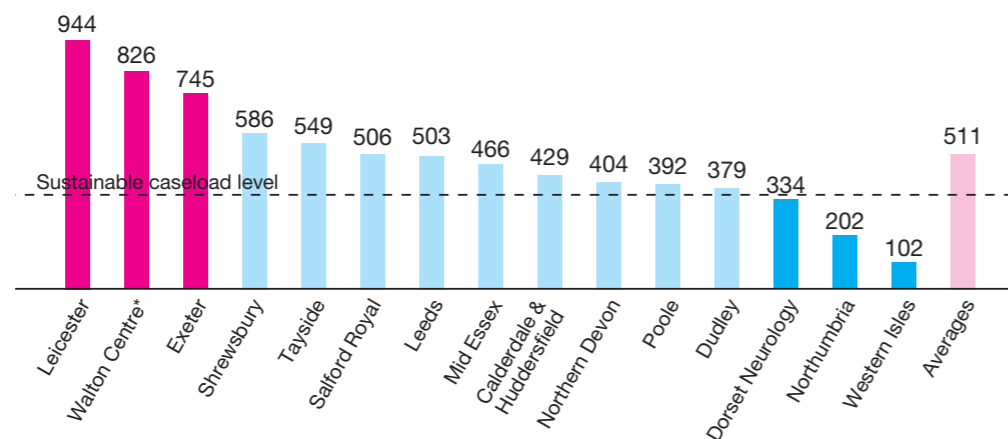
The project benefitted from the involvement of allied health professionals (AHPs) from some of the participating teams. This has strengthened the insights arising from the project and reinforced the importance of a multidisciplinary service to comprehensively meet the needs of people with MS. None of the health or social care professionals who work with people affected by MS can be fully effective in isolation.

What are the key findings?

The GEMSS teams

- The average caseload of the GEMSS teams is 511 people with MS per whole time MSSN, far in excess of the 358 'sustainable' caseload recommended by the MS Trust. Three teams have more than twice the sustainable caseload per MS nurse.
- Only around a quarter of MSSNs in GEMSS are nurse prescribers, but those who are cite major benefits in terms of their ability to manage whole episodes of care.

Caseload per WTE MSSN



¹ See page 10 for list of all participating teams

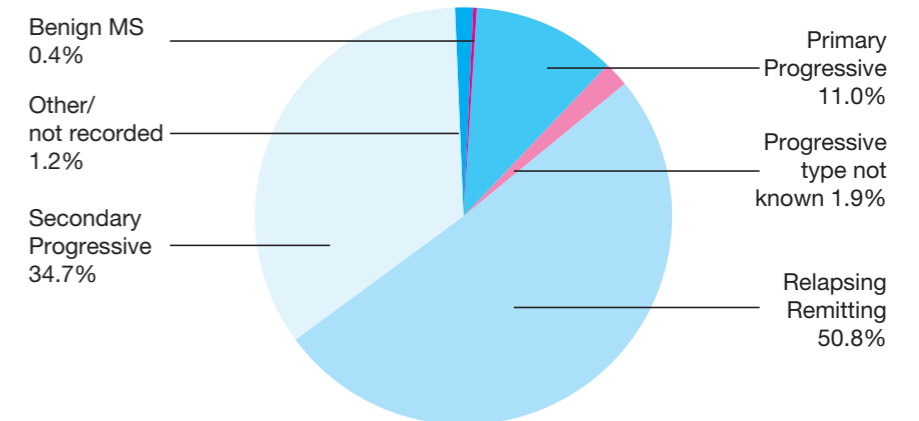
* Caseload relates to pwMS in contact with the MSSNs and AHPs in the past year, which is a subset of the full caseload of the Walton Centre of pwMS.



MS specialist nurse caseload and casemix

- 51% of the combined caseload have relapsing remitting MS (RRMS) and 46% have a progressive form of MS.
- 38% of pwMS on the combined caseload rely on a stick, frame or wheelchair, and a further 16% have severe disability and are immobile.
- 27% of the combined caseload is taking a DMD. This equates to 52% of those with RRMS. These prescribing rates are low relative to the European average.
- The rates of DMD prescribing within caseloads, and the types of DMD used, vary widely.
- Around half of working age people with MS who were diagnosed more than 10 years ago report that they have stopped work early on ill health grounds.
- MS specialist nurses are the professionals that the greatest number of people with MS (78%) have seen about their MS in the past year.
- People with progressive forms of MS had less contact with MSSNs and neurologists in the past year than those with RRMS, but were more likely to have seen a therapist, social worker or community nurse.

Type of MS within combined 'representative' caseloads



"I have suffered very low moods and low self esteem in the last few months and my MS nurse has been very supportive and helped me to be positive. She is one of the few people who understands the frustration of MS without having to go into long explanations."

61 year old woman with SPMS, diagnosed 10-20 years ago

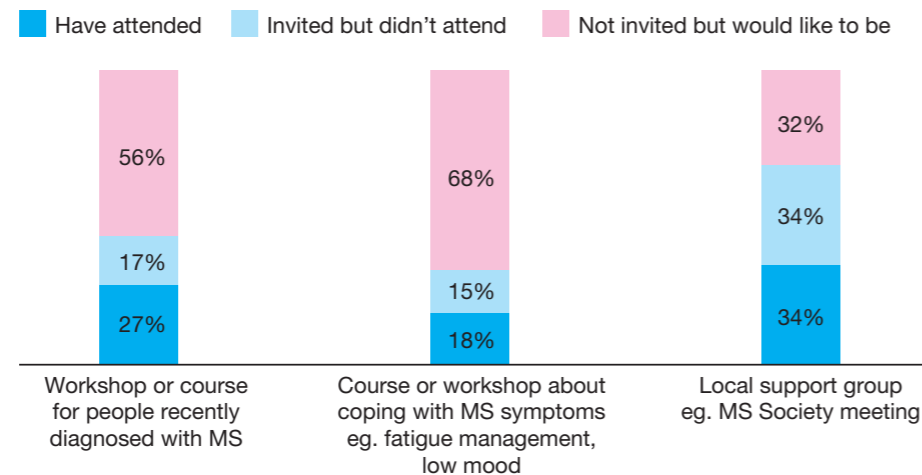


Activity, productivity and responsiveness

- PwMS on average had 1.4 face to face consultations and 1.5 telephone contacts with an MSSN during the year, with substantial variation between individuals. The fact that nearly a quarter of pwMS did not see an MSSN in the past year reflects high caseloads.
- PwMS who are on DMDs get more contact from MSSNs than those who are not, suggesting that those with progressive forms of MS may be missing out on the care they need.
- There is significant unmet demand from pwMS for more self-management programmes. 68% of pwMS responding to the GEMSS survey said that they had not been invited to a course about managing MS symptoms but would like to be.
- Responsive telephone work constitutes a large proportion of MSSN activity. 78% of pwMS were able to speak to an MSSN the same or next working day last time they phoned, but 11% said it was generally not easy enough to get hold of their MSSN.
- Activity per WTE nurse varies greatly between teams and can be improved by using key productivity levers and having sufficient, effective administrative support.

Respondents' use of self management support

Have you been invited to or attended any of these types of support to help you manage your MS in the past 3 years? (n=1254)

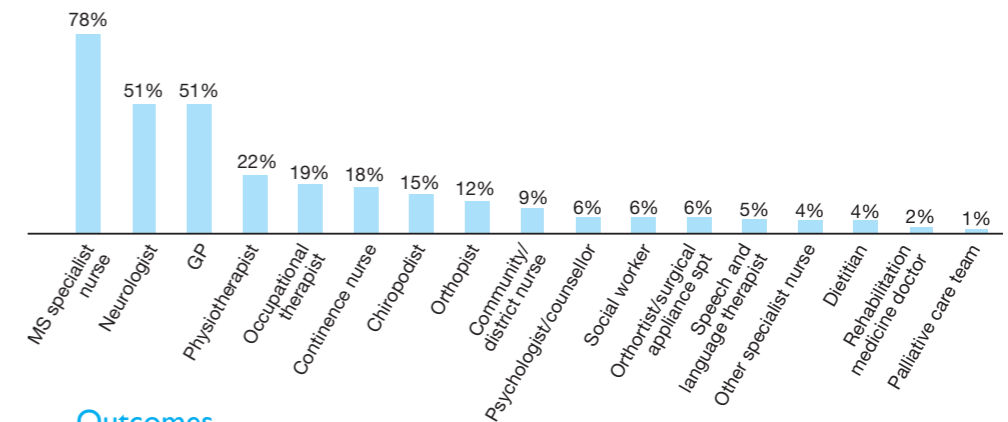


" My MS nurse makes the world of difference to my care... By having telephone support I can ... avoid hospital treatment. MS requires quick decisions about managing relapses and the MS nurse is best placed to do them."

35 year old woman with RRMS diagnosed 5-10 years ago



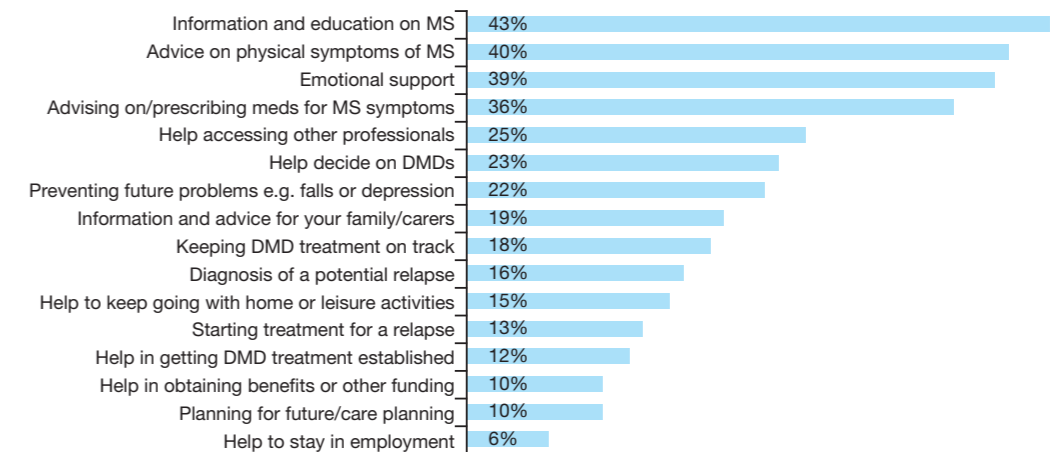
Proportion of survey respondents who had seen this type of professional about their MS at least once in the past year (n=1254 pwMS)



Outcomes

- 73% of pwMS thought that having an MSSN had improved the overall coordination of their care.
- 47% of pwMS diagnosed in the past year reported that their MSSN had helped them make an informed decision about DMD treatment.
- MSSNs perform well against national measures of patient experience. 95% of pwMS said they were definitely treated with dignity and respect by their MSSN and 90% that they definitely had trust and confidence in their MSSN. 71% of pwMS said they would be 'extremely likely' to recommend the service to friends or family in a similar situation.
- Features of MSSN services particularly valued by pwMS were consistent availability and accessibility, a positive and empathetic attitude, specialist expertise and knowledge and accessibility of consultation location.
- MSSNs increase the capacity of other health professionals (particularly neurologists and GPs) and can play a valuable role in improving the MS-related skills and knowledge of other, non-MS-specialist health and social care professionals.

What, if any difference did the MSSN make to you over the past year (tick all that apply?) (n=1254 pwMS)





“The main positive difference made by my MS nurse team was providing me with plenty of information and talking through my diagnosis. MS nurses take time to listen and always make me feel at ease. There is never the feeling of a slightly rushed appointment, in comparison to a regular GP visit. In addition they give constant reassurance about the ease of contacting any of them should I need to do so.”

34 year old woman with RRMS diagnosed 1-2 years ago

Economic effectiveness

- Using conservative assumptions, GEMSS data suggests that each WTE MSSN participating in GEMSS saved £77.4k in ambulatory care costs during the year.
- MSSNs also reduce hospital admissions and the savings generated are likely to far exceed the costs of employing them.
- 6% of working age pwMS said that their MSSN had helped them remain in paid employment in the past year, resulting in personal and wider societal economic benefit.

“[The MSSN service] has enabled my mother to stay at her family home and also helped to manage all health concerns. MS nurse has supported her to be assessed by other relevant professionals.”

Daughter of 63 year old woman with SPMS, diagnosed more than 20 years ago

“I've known I could contact her if I so wished and she has supported me in making the difficult transition to long-term nursing care and helped inform the whole process.”

47 year old female with PPMS diagnosed 10-20 years ago

“I had a useful discussion at routine interferon monitoring appointment about new oral medication option and planning to have a family.”

32 year old female with RRMS, diagnosed 1-2 years ago



What are the recommendations from GEMSS for improving MS specialist nursing services?

Increase the MSSN workforce so that MSSN caseloads are sustainable

Earlier work by the MS Trust in 2014 showed that, across the UK, 62 WTE MSSNs are needed in addition to the 234 WTEs in post in order to enable all MSSNs to have caseloads within the 'sustainable' level of 358 pwMS per whole time nurse. The GEMSS project has confirmed the need for manageable caseloads.

Focus on service equity so everyone with MS has access to care

Resources of MSSN services are being pulled increasingly toward those with RRMS. A service-wide commitment to ensuring that there is equitable access to MSSNs for everyone with MS is required to ensure that those with progressive disease are not disadvantaged.

Describe and create more rational funding models for services

The very complex commissioning landscape for MS services in England makes it very challenging to identify funding flows for MSSN services. Commissioning arrangements do not necessarily incentivise providers to invest in or improve services.

Increase autonomy and advanced practice amongst MSSNs

There are opportunities for MS specialist nurses to work more consistently at advanced practitioner level, including as independent prescribers. MSSNs also need to be freed from tasks which do not require their training, such as non-clinical administration.

Effect a step-change increase in support for self-management

Supporting self-management is a core element of every MS consultation, but the number of people reached by organised group education programmes about MS and its symptoms is small and there is significant unmet demand.

Improve use of information and undertake proactive case management

There is an opportunity to improve consistency of care by greater use of pathways and proactive case management. Every MS service needs a register of everyone on their caseload which is continuously updated, ideally integrated into NHS information systems. Accurate information about the national and local prevalence of MS is also needed.

Improve the productivity of MS specialist nurses

GEMSS reveals wide variations in the number of pwMS seen by MS specialist nurses working in different settings. There are multiple levers which could improve productivity, as described in the full report.

Make full and effective use of the multidisciplinary team

MS specialist nurses work with varying access to multidisciplinary services with expertise in MS. Multidisciplinary models of MS care are essential to ensuring an equitable and comprehensive service.



How do MS specialist nurses fit into multidisciplinary models of care?

GEMSS has highlighted the vital importance of expertise from a wide range of specialists to help pwMS to manage the complex range of issues which MS can bring. This works best when there is close working between MSSNs and other members of the MDT to ensure that roles are clear and that the needs of pwMS are met without undue duplication.

Many of the GEMSS teams demonstrated this close, joined up working, even across organisational boundaries. For example:

The Walton Centre MS team is made up of five MS-specialist neurologists, three² MSSNs, two MS-specialist physiotherapists (1 WTE), two MS-specialist occupational therapists (1 WTE) and an MS-specialist orthoptist (0.2 WTE), all working closely together in a single department with a shared office and regular team/service development meetings. This allows for shared clinical working, including a weekly multi-disciplinary relapse clinic at which pwMS with suspected relapses can be jointly assessed and advised, self-management groups run jointly by MSSNs and AHPs and the development of joint treatment plans for pwMS involving medical, nursing and therapy input to address problems.

The Calderdale and Huddersfield MSSN service runs two joint sessions per month with the physiotherapist and occupational therapist (alternately) from the local community rehabilitation team. This enables the MSSN to identify pwMS who would benefit from rehabilitation and then see them jointly with the most appropriate therapist, either in clinic or at home, and create a joint plan of action for the management of difficult symptoms. As the team is able to manage whole episodes of care.

The Dundee MS service consists of a consultant neurologist, three MSSNs and an MS specialist physiotherapist, all working within Ninewells Hospital in Dundee, and an MS specialist social worker based in Dundee City Council. The service provides pwMS with a dedicated team that promotes and supports an inter-professional approach, and this is achieved by joint meetings and close communication.

The Dorset Community Neurology service is an integrated MDT of nurses, physiotherapist and occupational therapist, working closely with a rehabilitation medicine consultant. Their caseload encompasses other long term neurological conditions besides MS. The service uses a 'neuro-practitioner' approach to provide a single access point for patients, streamline roles and avoid duplication. All team members have the expertise to deliver holistic neurological assessment and case management but also practice in their primary professional capacity based on a system of internal team referral.

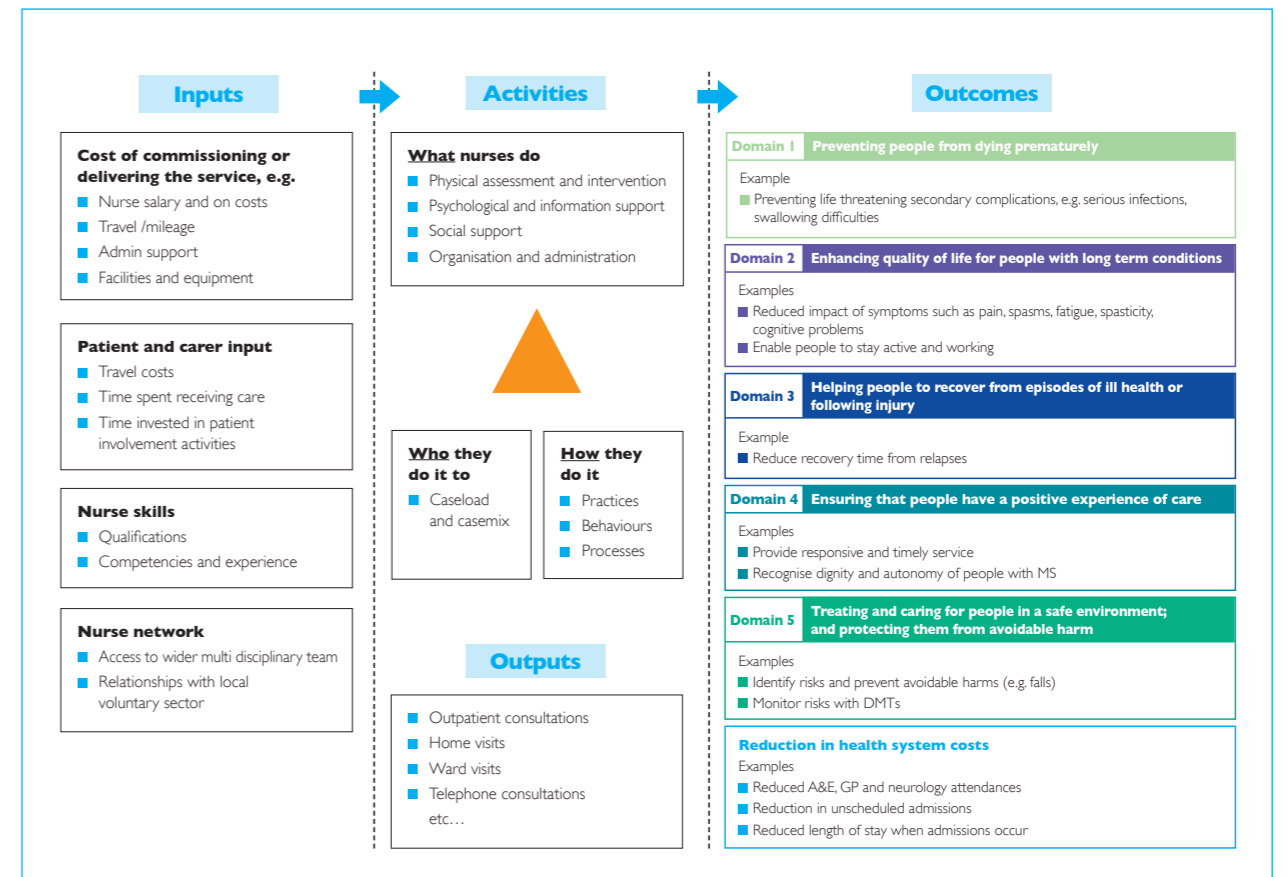
However, whilst GEMSS provides examples of good practice, there are challenges. In many areas, MSSNs reported an absence of local provision in certain professions, very long waiting lists or an absence of neuro-specialist provision. In other instances, the challenges of working across multiple organisational boundaries across large geographic areas make joint working hard to achieve.

² Recently increased to four



How were MS nursing services evaluated?

An evaluation framework for MS specialist nursing (see below) was developed jointly with teams taking part in GEMSS and the GEMSS Advisory Group.





Who were the GEMSS teams?

Team	GEMSS Lead(s)
Calderdale & Huddersfield NHS FT	Audrey Owen, Denise Winterbottom
Leeds Teaching Hospitals NHS Trust	Gale Metcalfe, Julie Taylor
Mid Essex Hospital Services NHS Trust	Helen Willis, Julie Webster
Northern Devon Healthcare NHS Trust	Carol Turner
Royal Devon and Exeter NHS FT	Louise Jarrett
Salford Royal NHS FT	Karen Vernon, Will Lusher, Alison Bradford
The Shrewsbury and Telford Hospital NHS Trust	Kate Womersley, Denise Cooper
Tayside and North Fife Regional MS Service*	Shona Flucker, Pam Walker
The Walton Centre NHS FT*	Carolyn Cairns, Helen Curran
University Hospitals of Leicester NHS Trust	Deborah Wilkinson, Fiona Cray, Allison Smith
NHS Western Isles	Rachel Morrison
Poole Hospital NHS FT	Caroline Chandler, Cheryl King
Northumbria Healthcare NHS Trust	Jane Metcalfe, Miriam Forster
The Dudley Group NHS FT	Tracy Dean
Dorset Healthcare University NHS FT*	Michelle Davies, Tracy Evans
Sheffield Teaching Hospitals NHS FT**	Daisy Cam, Helen Parry

* multidisciplinary teams

** GEMSS 1 only (2012/13)



A brief introduction to MS

The range of symptoms and disabilities caused by MS, and the unpredictable course of the disease, make it particularly complex and challenging to manage.

There are three main types of MS:

- 85% of those people diagnosed have **relapsing-remitting MS (RRMS)** at onset. When experiencing a relapse, people with MS can become very unwell for a period of days, weeks or months. They may recover completely, but around half of relapses leave some form of residual disability. Many people with relapsing remitting MS are treated with **disease modifying drugs (DMDs)**, typically beginning soon after diagnosis. There are currently no DMDs that work in the other forms of MS.
- Around 58% of those with relapsing remitting MS will develop **secondary progressive MS (SPMS)**, a median of 19 years after diagnosis, where there is a sustained increase of disability, independent of relapses.
- 10-15% of people with MS are diagnosed primary **progressive MS (PPMS)**, where symptoms get progressively worse over time from the outset, rather than appearing as relapses.

All types of MS have symptoms which can include fatigue, pain, vision problems, walking difficulties, numbness, pins and needles and burning sensations, cognitive problems, continence issues, depression, sexual difficulties, speech and swallowing difficulties, spasticity and tremors. Those people who develop advanced MS may be confined to wheelchair or bed, have severe cognitive difficulties and significant problems with speech and swallowing. Symptoms can come and go throughout the course of the disease.

Many people with MS end up being admitted to hospital each year. Based on Hospital Episode Statistic data, in 2013/14 around 17% of people with MS in England were admitted to hospital as an emergency at least once, and there were 0.26 emergency admissions per person with MS. The most common reasons were bladder and bowel related complications and respiratory infections, some of which could be prevented or managed at home with expert early intervention and treatment.



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About the MS Trust

The MS Trust is a small charity which works to make a difference today for the more than 100,000 people living with MS in the UK.

We work to make sure everyone affected by MS can access good quality care from specialists with an interest in MS, and offer education and professional development. Through our innovative GEMSS programme, we support evidence-based service improvement in MS care. Our approach is always to work in partnership with health professionals and people affected by MS to improve MS services now and in the future.

We also produce practical, reliable information, online and in print, and offer a telephone and email enquiry service to anyone who needs to know more about MS. Our materials are widely used by MS services across the UK.

We rely on donations to fund our vital services.

To find out more about our work, how we can help you and how you can get involved

Visit www.mstrust.org.uk

Call 01462 476700

Or email info@mstrust.org.uk



Multiple Sclerosis Trust
Spirella Building, Bridge Road
Letchworth Garden City
Hertfordshire SG6 4ET

T. **01462 476700**
T. **0800 032 3839**
E. info@mstrust.org.uk
www.mstrust.org.uk

Registered charity no. 1088353

