

## Rehabilitation and MS

Rehabilitation is a key component of a comprehensive MS service. People with MS may experience periods of impaired function related to a relapse and require rehabilitation to recover and regain function. Those with progressive MS require specialised support to maximise their abilities and continue to participate as fully as possible in the activities that matter most to them. Whether it is physical, occupational or cognitive, rehabilitation represents a commitment to autonomy, independence and engagement for people living with MS.

Over the years, the MS Trust has highlighted that access to rehabilitation services for people with MS could and should be greater. In 2011, an audit of services conducted by the MS Trust and the Royal College of Physicians<sup>1</sup>, found that only 30% of community providers and 22% of hospital providers had specialist neurological rehabilitation services that met recognised standards. This means that too many people with MS are missing out on this vital element of their care.

The MS Trust is committed to ensuring that people with MS have access to the specialist services and practitioners that they need. Raising the profile of rehabilitation as a vital area of specialist practice and supporting the needs of rehabilitation therapists and researchers is a core activity for us and we are delighted to be able to announce an exciting new opportunity for UK practitioners.

In partnership with RiMS, the European Network for Rehabilitation in MS, and the National Hospital for Neurology and Neurosurgery in London, the MS Trust will be hosting a Europe-wide conference on rehabilitation and MS. The two day conference will be held in Brighton on 6–7 June 2014, with an optional additional day of specialist teaching held on-site at the National Hospital for Neurology and Neurosurgery on 5 June 2014.

RiMS aims to:

- raise the profile of rehabilitation in MS and attract the best researchers and practitioners
- improve the understanding of rehabilitation and its relevance at every stage of MS
- facilitate interaction between researchers and practitioners to generate new evidence on rehabilitation in MS
- stimulate the implementation of new and existing evidence-based rehabilitation
- educate and train practitioners to integrate evidence into clinical practice.



The 19th Annual RiMS Conference will bring together therapists, nurses, neuropsychologists, neurologists, rehabilitationists, service providers, academics and researchers to raise the profile and standard of MS rehabilitation services and to participate in a wider network of interest in this area of practice. The MS Trust is proud to be bringing this exciting event to the UK for the first time. Please watch both the MS Trust [www.mstrust.org.uk](http://www.mstrust.org.uk) and RiMS [www.eurims.org](http://www.eurims.org) websites for updates.

**Reference:**

1. The Royal College of Physicians, Multiple Sclerosis Trust. The national audit of services for people with multiple sclerosis 2011. London: RCP, MS Trust; 2011.

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# Research news



## MS research showcased at AAN meeting

The 65th annual meeting of the American Academy of Neurology (AAN) took place in San Diego in March. Over 12,000 neurologists and other researchers met to share progress in understanding and treating neurological diseases including MS.

The results of key clinical trials for many of the new disease modifying treatments had previously been reported, so presentations focused on longer-term efficacy and safety data.

The AAN website has the abstracts and a webcast of the plenary session at [www.aan.com/go/am13](http://www.aan.com/go/am13). There is also the option to view the posters which have been uploaded to an interactive, fully searchable database. You can magnify the content, contact the author directly with comments or questions, and bookmark abstracts. The posters are very easy to view – go to [www.aan.posterview.com/](http://www.aan.posterview.com/) to register or look round as a guest.

## Teriflunomide and BG-12

In March 2013, teriflunomide (Aubagio) and BG-12 (Tecfidera or dimethyl fumarate), both oral disease modifying treatments, moved closer to receiving a licence for relapsing remitting MS.

The Committee for Medicinal Products for Human Use (CHMP) assessed these drugs for quality, safety and efficacy and recommended to the European Medicines Agency (EMA) that they should be licensed. The final licences should be issued in the second half of 2013.

In anticipation of licensing, NICE is beginning its appraisal to decide whether it will be cost effective for the NHS to provide these treatments. A decision is expected in January 2014.

Teriflunomide reduces the relapse rate by about one third compared to placebo and BG-12 reduces the relapse rate by about half. Both are already licensed in the USA.

Two other disease modifying drugs are also currently going through the licensing process. Decisions on alemtuzumab (Lemtrada) and laquinimod are expected later this year.

You can read more about these drugs in the A to Z of MS [www.mstrust.org.uk/atoz/](http://www.mstrust.org.uk/atoz/) or order our factsheets on the back page.

## PML with drug similar to BG-12

Four cases of PML (progressive multifocal leukoencephalopathy) have been found in people taking a drug similar to BG-12 (Tecfidera or dimethyl fumarate).

The New England Journal of Medicine has reported two cases of PML, a rare but serious viral disease of the brain, and the manufacturer, Biogen, has said that it is aware of two more cases. All four were taking long-established fumarate-based treatments for psoriasis.

However, the picture is not straightforward as the psoriasis treatments also contain other active ingredients which are not found in BG-12. Also, those diagnosed with PML had additional risk factors including prolonged periods of abnormally low levels of white blood cells while on treatment and prior use of immunosuppressants.

Consequently, it is not possible to draw exact parallels with BG-12, especially as PML was not seen in clinical trials of BG-12 which included 2,600 people with MS who were treated for up to four years.

PML is of concern for people with MS as it has been seen in a very small number of people taking another disease modifying treatment, natalizumab (Tysabri).

**Reference:**  
N Engl J Med 2013; 368: 1657-1661.

## NICE changes its name (but is still NICE)

NICE is the independent organisation responsible for providing national guidance and advice to improve health and social care in England and Wales. It was established as the National Institute for Clinical Excellence in 1999 but was combined with the Health Development Agency to form the National Institute for Health and Clinical Excellence (still abbreviated to NICE) in 2005.

In March 2013, the remit of NICE was extended to include social care services and the name was changed to the National Institute for Health and Care Excellence (but the acronym NICE has still been retained).

# Modafinil for fatigue - evidence summary from NICE

NICE has launched a series of evidence summaries for selected medicines which are unlicensed or prescribed off label. These summaries review the published evidence for medicines which are considered of significance to the NHS, but where there are no clinically appropriate licensed alternatives. The summaries provide information for clinicians and patients to inform their decision making and to support the construction and updating of local formularies. They do not constitute formal NICE guidance.

One of these evidence summaries concerns modafinil (Provigil) which is sometimes prescribed off label for fatigue in MS. NICE reviewed two small randomised placebo controlled clinical trials but did not find any statistically significant evidence that modafinil improved fatigue in adults with MS after 35 days or eight weeks of treatment. These trials did not provide any evidence on the longer-term safety and efficacy of modafinil.

Modafinil can cause serious adverse effects including psychiatric disorders, cardiovascular symptoms, and serious skin and multi-organ hypersensitivity reactions. In January 2011, the European Medicines Agency's (EMA) Committee for Medicinal Products for Human Use (CHMP) concluded that the benefits of modafinil could only be considered to outweigh the risks when used to treat narcolepsy.

The evidence summary concludes that, if a prescriber wants to use modafinil as an unlicensed or off label medicine, they must follow their professional guidance. This includes giving information about the treatment and discussing the possible benefits and harms so that the patient has enough information to decide whether or not to have the treatment. It notes that no other drugs have marketing authorisation for MS-related fatigue, although off label use of amantadine may also be considered

## NHS England [www.england.nhs.uk](http://www.england.nhs.uk)

The NHS Commissioning Board, established in October 2012, has been renamed NHS England. It is intended to be an independent body, at arm's length to Government but, at the same time, has been given "a key role in the Government's vision to modernise the health service with the key aim of securing the best possible health outcomes for patients by prioritising them in every decision it makes".

### Clinical commissioning policies

One role of NHS England is to develop clinical commissioning policies to underpin the commissioning of specialised services. These policies are important in defining what NHS England expects to be in place for providers to offer evidence-based, safe and effective services with equal

access across the country. Some documents relevant to MS have been published and will be adopted by NHS England for the 2013/14 annual commissioning round.

### Disease modifying treatments

This policy provides detailed guidance on the use of DMTs, in particular, it identifies starting and stopping criteria for the use of these drugs and clarifies the definitions of the terms used to describe different presentations of MS. This policy provides definitions to be adopted across England which will allow beta interferon, glatiramer acetate, natalizumab and fingolimod to be commissioned without the need for prior approval. (NHSCB/D04/P/a)

### Intrathecal baclofen

This policy supports the use of intrathecal baclofen for the groups for which it is most cost effective, where other options are exhausted, and where patient and carer evidence shows a real likelihood of success. MS is not specifically discussed. (NHSCB/D04/P/c)

### Hyperbaric oxygen

Some people with MS find hyperbaric oxygen therapy (HBOT) beneficial and it is most often accessed at MS therapy centres. The NHS is willing to commission HBOT for decompression illness, gas embolism and acute carbon monoxide (CO) poisoning. It will not be commissioned routinely for other indications including MS. (NHSCB/D11/P/a)

### Trigeminal neuralgia

Stereotactic radiosurgery will be commissioned when all other treatments have been tried unsuccessfully or deemed inappropriate. (NHSCB/D05/P/b)

### Clinical policy statements

NHS England also issues clinical policy statements. These are interim statements which set out NHS England's current position in relation to these services:

### Fampridine

Fampridine is licensed for the improvement of walking in adult patients with MS with walking disability (EDSS 4-7). Overall, the clinical benefit of the medicine was thought to be marginal and unlikely to be cost-effective. Consequently, they recommended that fampridine was not routinely funded. (NHSCB/D04/PS/d)

### Deep Brain Stimulation (DBS)

The policy states that the evidence does not support the routine funding of DBS on the basis of clinical effectiveness for coma, depression, pain and Tourette's Syndrome. MS is not discussed but the policy states that, pending further evidence of clinical effectiveness, this commissioning policy will apply to all indications for DBS except the movement disorders outlined in a separate policy. (NHSCB/D03/PS/c)

## Keep up to date with research news

Sign up for our weekly research update email alert at [www.mstrust.org.uk/research-updates](http://www.mstrust.org.uk/research-updates)

# Policy and campaigning



## A brave new world for England – business as usual elsewhere...

The new world of the NHS in England is well and truly upon us, but it hasn't stopped the policy makers from publishing directives that have a direct impact on how care is provided for people with MS.

### DMTs in appraisal

As mentioned in the research news, NICE is appraising four new drugs for MS: BG-12, teriflunomide, laquinimod and alemtuzumab, with a view to producing guidance next year. After some 'to-ing and fro-ing' about whether to appraise all four treatments together, they chose to review each individually in a 'single technology appraisal' or STA.

NICE guidance is mandatory in England and Wales. Northern Ireland often follows NICE guidance, reviewing the evidence in its own system, although the rhetoric recently indicates that more expensive treatments may not be available in the province. The Scottish Medicines Consortium will wait for the NICE decision and then review its evidence. There has been a recent history of the SMC rejecting NICE appraisal decisions for MS on first submission, followed by successful appeals. All of this means there will be a gap in providing the new treatments in Scotland and Northern Ireland, assuming NICE rules in favour of them in England.

NICE's original comparator for the treatments in the draft scope was between the drug in question and 'best supportive care'. 'Best supportive care' was never well defined, and risked being 'no care', or, at least, no drug therapy. It also risked making any cost comparison between treatments very unfavourable to any new therapy. We devised a statement, together with the MS Society and the UK MS Specialist Nurse Association (UKMSSNA), on the pitfalls of 'best supportive care' as a comparator, and were delighted to see that NICE has dropped this from all its subsequent appraisal documentation.

NICE works slowly: the next round of documentation for consultation will come out in August at the earliest.

One of the big issues following the NICE appraisals is whether this new generation of first-line oral drug treatments in MS will change the landscape of MS service provision. There is a risk that, as money gets tighter; commissioners will consider that MS nurses can take on bigger caseloads if they need to undertake

less teaching and monitoring of patients on injectable medication, or whether fewer posts are necessary. It's a good time to consider whether individual nurses can raise the profile of their posts and the value of what they offer. The Generating Evidence in Multiple Sclerosis Services (GEMSS) programme, which was launched in 2012 by the MS Trust, is aiming to help health professionals who work with people with MS to do just that (see pages 6-7 for more information on GEMSS).

### Who pays for MS services?

"Specialised services commissioning" is becoming more and more relevant in England to MS services.

Under the old system, PCTs were given money for all their patients, and some went with the person with MS to either a neurology service at their local hospital, or to the neuroscience centre.

Under the new system, NHS England (the new name for the NHS Commissioning Board) is responsible for providing services out of neuroscience centres, and holds the budget for doing this.

NHS England's main aim is to standardise services across England, to eliminate postcode prescribing and to ensure that anyone with MS receives the same standard of care wherever they live.

To do this, they have published a number of policies on what can, and cannot, be funded, and service specifications on what a neuroscience service should provide. The policies were put out to consultation in a huge hurry, with a very short turnaround, and it would appear that no comments have been taken into consideration in the final versions.



Policies relevant to MS include the Disease Modifying Therapies, intrathecal baclofen and fampridine (see the research news on page 3 for more information). A generic policy on Individual Funding Requests (IFRs) has also been put together. While IFRs are still possible, five IFRs for the same drug treatment in the same circumstances will trigger a national policy. Our fear is that this will tend to trigger a blanket 'no', although technically it should be possible for a drug to be recommended at this stage.

The draft service specification for neurosciences recommended a hub-and-spoke model of care, from the neuroscience centres currently existing in England. The hub-and-spoke model assumes a teaching hospital at its centre from which neurologists and/or MS nurses and allied health professionals run satellite clinics at District General Hospitals in the local area.

This continues the model of care on offer in many parts of the country, but not all, and contains significant issues to which we do not yet have answers:

- we know there are some DMT clinics and associated services running from general neurology services – what will happen to these? For example, will the hospital be required to expand to offer a full neuroscience service – which they may not be in a position to do – or required to close the DMT service (which appears to be what the document is saying)?
- will this mean that, in practice, local commissioners expect all MS services to run from a neuroscience centre? There is resentment among some Clinical Commissioning Groups that money for specialised services has been top-sliced from their budget. While NHS England assumes that general neurology will continue to be locally funded, there is a risk that local commissioners will see it differently.

The Specialised Healthcare Alliance (of which we are a member) is working hard to get clarification in this area.

Clearly we were not alone in taking issue with the draft Service Specifications so the good news is that their implementation is being delayed until October. We've yet to see whether the revised Service Specifications will contain significant changes to these draft plans. Full versions can be viewed on the NHS England website.

### Concerned? So are they

The better news in England is that the Health Select Committee in the House of Commons is reviewing the way the Health & Social Care Act 2012 changes were brought in, and management of long-term conditions in health and social care. We are responding to both, and hope that they will be able to bring pressure to bear in both areas.

## Other regions

### Northern Ireland

The Government in Northern Ireland has brought out their vision of how Health and Social Care in the province will change, following on from **Transforming your care**. Unlike the original proposals, no hospitals will close, but some will be downgraded, losing their A&E departments and maternity care.

It is establishing 17 Integrated Care Partnerships in primary care, which will see doctors, nurses, social workers, other healthcare professionals such as physiotherapists and occupational therapists, working together to keep people healthy and able in the community.

A large part of the strategy is concerned with care. Northern Ireland's population is growing mainly from increased life expectancy, with all the pressures on care and support that brings. So the strategy promises a greater focus on how carers are involved in the provision of care, and a move away from social care provision being primarily in residential care, and a move to social care provision at home. This means some residential homes will close.

### Wales

Wales has published its 'Well-being Statement', which sets out what people receiving care and support can expect in their everyday lives. This includes statements such as 'participation in society', and the 'right to have a voice in decisions that affect them'. A new end of life delivery plan is also published.

### Scotland

Things have been much quieter in Scotland, where a number of regulations relating to the Self-Direct Support (Scotland) Act are out for review, but other major changes are not apparent.



## Keep up to date with government policy

For all the latest policy news, and to read our Action for MS blog, go to:  
[www.mstrust.org.uk/action-for-ms](http://www.mstrust.org.uk/action-for-ms)

# GEMSS: the next stage



## Introduction

In 2010-11, a scoping study was undertaken for the MS Trust to assess the evidence for the value of MS specialist nurses. The outcome was a report, *Defining the Value of MS Specialist Nurses*, which highlighted that although anecdotally there is a lot of evidence that MS nurses are valued highly by patients, neurologists, GPs and other health professionals, they are short on robust evidence to show that their services are cost effective. The report also established that nurses are not collecting evaluation data for a variety of reasons: lack of time, tools and evaluation skills.

As a result of the report, in April 2012, the MS Trust launched GEMSS (Generating Evidence in Multiple Sclerosis Services), a project aiming to help MS nursing teams to evaluate their services, and to demonstrate what works best to meet the needs of people with MS and their families.

## GEMSS: the first phase

In the first phase of GEMSS, the MS Trust supported four teams, representing a total of 13 MS nurses and one physiotherapist:

- Dorset (Poole Hospital NHSFT and Dorset Disability Action, part of Dorset Healthcare University NHSFT)
- Sheffield Teaching Hospitals NHSFT
- Dudley Group of Hospitals NHSFT
- Northumbria Healthcare NHSFT.

The teams were selected to reflect the broad range of team structures around the UK: acute Trust and community based, urban and rural, large and small. The project had both a professional development component – building the skills and capabilities of the nurses involved; and a service development component – developing an improvement culture in the



services. Additionally, the project aimed to leave a lasting legacy by developing a set of common quality standards and tools that could be used by other MS nursing teams.

At a two day workshop in May 2012, the nurses and GEMSS facilitators worked together to refine a draft evaluation framework for MS specialist nursing and develop a set of quality indicators that they agreed services should aim for. They learned about evaluation and developed the practical skills needed to collect and analyse data on:

- caseload
- activity
- performance against key process indicators
- patient experience of the service
- views of other stakeholders (GPs, neurologists).

The evaluation framework includes an agreed set of objectives for MSSN services, which were mapped to the NHS outcomes framework to demonstrate how MS specialist nurses add value. Examples of objectives include:

- reducing the impact of symptoms such as pain, spasticity, depression
- enabling people to stay in their own home for longer
- reducing the physical and emotional impact of MS on the family and carers.

## So how was it?

At the March 2013 MS Trust MS Specialist Nurse Meeting in Crewe, some of the MS specialist nurses involved shared their perspective on what it had been like to participate in the project.

The teams described how they:

- had created documents to describe their service configuration and staff skills and experience
- used different tools to analyse their work patterns, monitor their caseloads and analyse their activity (appointments, phone calls, home visits)
- used patient surveys and case studies to provide evidence of outcomes
- monitored between four and six key process indicators (quantitative markers that show whether your objectives are being met) on a monthly basis.

Although each of the teams utilised all of the above tools during their service evaluation, each group went on to describe one particular aspect of their evaluation.

The Sheffield team described how they had used the caseload database tool to gain a better understanding of the relative size and complexity of their individual caseloads by plotting patients according to:

- age
- gender
- type of MS
- severity of disability
- self management/dependency rating.

The MS nurse from Dudley talked about the cost drivers within her service after analysing activities such as the time spent on travelling and administration versus patient contact. The team in Northumbria described how qualitative (case studies) and quantitative (survey) methods highlighted how much their service is valued, with 95% of patients accessing their MS nurse for advice about their MS in the past year, compared to 71% seeing their neurologist and 57% their GP.

The Dorset team talked about some of the process indicators they had used to measure their performance against, including:

- the percentage of new patients who were contacted by the service within two weeks for pre-consultation triage
- the percentage of patients with acute deteriorating symptoms (including suspected relapse) contacted for assessment and appropriate management within one working day.

At the end of the data collection period, the teams were further supported to write site specific evaluation reports for senior managers, or commissioners, within their individual organisations.

All the teams agreed it had been a worthwhile experience being involved in the project and that they would carry on collecting data on their services to ensure they were in a good position to make the case for safeguarding their service.

**Tracy Dean, MS nurse in Dudley, said**

**I feel privileged and inspired being part of the GEMSS project. It has been challenging but very rewarding. It's been really useful to have a database with graphics to use in my business plans for the service, which can be used to highlight to others what my role entails and the proportion of time spent on different activities."**

**Jane Metcalfe, MSSN in Northumbria, said**

**GEMSS has given a clearer understanding of how our service works. The GEMSS database has, for the first time enabled us to provide an accurate breakdown of our patient case load and demographics. By evidencing our role and the service we provide we hope to be able to secure, and hopefully improve and expand the service."**

## Looking forward: involving allied health professionals

We are now in the process of asking allied health professionals (AHPs) to contribute to a scoping report, 'Defining the Value of Specialist Allied Health Professionals in MS'. The aim is to articulate the case for the value and impact of AHPs in providing a comprehensive, high quality

service for people with MS across the whole disease trajectory. We want to determine what evidence is already available, and what new data needs to be gathered to establish the case for the cost effectiveness of AHPs in MS services. The report will be published in November 2013.

## GEMSS II: the next phase

For the next phase of the GEMSS project we are looking to recruit ten new teams who work with people with MS. We will continue to focus on MS nursing, but additionally, at least two of the teams recruited will be integrated multidisciplinary teams, which will enable greater focus on the role of AHPs working alongside MS nurses. In addition to using the tools and methodology developed in the first project, we will also develop new tools to audit admission avoidance and describe the economics of the services. We will be writing to all MS teams in September inviting applications. The ten teams will be recruited shortly after the MS Trust Annual Conference in November 2013; training will be carried out in early 2014 and data collection will begin in April 2014.

If your team is interested in participating in the next phase of GEMSS, please look out for the communication from us in mid-September ([www.mstrust.org.uk/GEMSS](http://www.mstrust.org.uk/GEMSS)) or contact Amy Bowen, Director of Service Development at the MS Trust ([amy.bowen@mstrust.org.uk](mailto:amy.bowen@mstrust.org.uk)) to register your interest.

## NeLM gives way to NHS Evidence

The National electronic Library for Medicines (NeLM), originally known as DrugInfoZone, was created to deliver medicine information updates to health professionals who used the Regional Medicines Information Service based at Guy's Hospital. The website's reputation grew for providing timely and useful information about medicines quickly, so, in collaboration with the UK Medicines Information (UKMi) service and with the support of the Department of Health, it relaunched as NeLM, where it developed to become one of the busiest sites run by the NHS, generating downloads of over four million records a year.

As of April 2013, the NeLM website ceased to exist. All evidence that could previously be found on NeLM is now only accessible via NHS Evidence [www.evidence.nhs.uk](http://www.evidence.nhs.uk) which is provided by NICE. NICE has worked with UKMi to bring medicines information together into one place, making it simpler for those with medicines and prescribing responsibilities to view, search and filter high quality evidence-based information. A new personalised daily and weekly medicines awareness service was also launched in April 2013 to replace the existing NeLM newsletter.

# Oswestry standing frames

A mixed methods investigation of the use of Oswestry standing frames in the homes of nine people with severe multiple sclerosis.



Dr Wendy Hendrie, Specialist Physiotherapist in MS, Norwich MS Centre, Norwich, Norfolk.

## Introduction

From the time when our ancestors first adopted the upright posture, standing has been an integral part of what it is to be human. Standing allows us to carry out a multitude of activities and enables us to interact with people eye-to-eye, which may contribute to our sense of identity. Standing is important, yet weakness and poor balance can often limit the quantity, or quality, of standing for many people with MS. The aim of this study was to explore the physical and psychological impact of regular standing in an Oswestry standing frame (Figure 1) in people with MS who were either walking a few metres with bilateral support (EDSS 7.0) or were unable to walk (EDSS 7.5 or 8.0).

## Figure 1. Standing in an Oswestry standing frame



## Background

The idea for this study arose from clinical experience whilst working as a physiotherapist at an MS Therapy Centre. One of the most therapeutically challenging stages occurs when a patient has begun to use a wheelchair. At this stage, balance is often poor, and engagement with activities involving standing is often precarious; as a result, many spend much of their day sitting. This often leads to de-conditioning, or secondary complications of immobility such as pain, constipation and increased spasms. These problems accelerate the loss of the ability to perform activities of daily living (ADL), and impacts negatively upon quality of life and self-identity. Oswestry standing frames are used in the clinic to provide a safe environment in which people with severe MS can carry out exercises and activities.

Following periods of regular standing, improvements were observed in patients in both strength and ability to perform ADL. Patients also expressed increased wellbeing when standing again in a fully upright position. After initially carrying out a single case study<sup>1</sup>, I decided to undertake a larger investigation to evaluate the impact of frame standing in people with severe MS.

## Method

The aim of the study was to explore the objective (quantitative) and subjective (qualitative) impact of standing. A mixed methods study was undertaken over 48 weeks, with nine people with MS. The sample consisted of six women and three men. Their mean age was 54 years (range 33-68 years) and average time since diagnosis was 11.6 years (range 5-18 years).

Single case experiments were used for the quantitative strand. Outcomes used were the Amended Motor Club Assessment Scale<sup>2</sup> (motor function), the Canadian Occupational Performance Measure<sup>3,4</sup> (ADL), spasm frequency<sup>5,6</sup>, bowel frequency<sup>7</sup> and pain<sup>8</sup>. Repeated measures were taken over two phases lasting 36 weeks: A (baseline) and B (intervention) – participants were asked to stand for at least 30 minutes, three times a week. A third, optional Phase C (12 weeks) was included to evaluate the feasibility of self-management.

The qualitative strand consisted of three semi-structured interviews to explore the lived experience of standing, within the context of having severe MS, and self-management of frame use at home.

## Findings

One of the participants was unable to use the frame due to illness. The remaining eight participants showed statistically significant improvements ( $p < 0.05$ ) in motor ability. Seven participants demonstrated statistically significant improvements in ADL. Of the seven participants who recorded spasms, two showed a statistically significant improvement following standing. No improvements were seen in bowel frequency in the four participants who reported having constipation, and no change was detected in the one individual who reported back pain. Subjective improvements were reported in bladder and bowel control, clonus and fall rate.

Themes which arose from the interviews associated with the experience of living with severe MS, centred on the loss of ability to perform ADL, diminution of life roles and fear for the future. Whilst themes that arose around the experience of standing, focused on changes brought about by being safely upright again, or by being strengthened by standing. Standing enabled participants to engage in activities requiring two hands, Joan said: **"I chopped a cauliflower the other day when I was standing in the frame; you can't do that properly when you're sitting."**

Improvements were reported in many areas of personal and domestic ADL, mobility and transfers, and leisure activities. The quality of the upright position in the frame led to participants feeling like their old selves, John said: **"You feel you're standing ten feet tall, you just feel you're normal again, five foot eleven rather than five foot eight"**. Many re-established themselves in previous life roles, such as being a wife, Louise said: **"We now kiss when standing again how we used to, it's lovely"**. They also felt that standing connected them with the world again, Sue said: **"When you stand you can see everything and that's great, you feel more included, involved"**. These experiences led them to feel more in control and less fearful for the future.

## Discussion and conclusion

Regular frame standing was feasible in the home environment and improved motor ability, ADL and spasms in people with severe MS, with subjective improvements in bladder and bowel control, clonus and fall rate. Standing reinstated a sense of belonging and optimism about the future by restoring important life roles, and feelings of normality as participants regained previous valued activities.

This study is one of the first studies to look at the impact of regular activity on people with severe MS. To minimise the debilitating effects of inactivity, such as muscle wasting, it is important that people with MS, at all stages of the disease, incorporate regular, long-term activity into their lifestyles. Frame standing may enable people with severe MS to keep active, maximise their functional ability and may also improve wellbeing.

## Clinical recommendations

This small study gave rise to a number of issues which clinicians may find useful.

- **Selecting appropriate patients** - regular frame standing may benefit people with MS who are limited in their ability to walk. To comply with manual handling regulations, however, people using frames at home will require the help of a standing assistant (eg. spouse) and should be able to stand with minimal help.
- **Appropriate standing contexts** - self-managed frame standing within the home context is feasible. The participants and assistants received one training session and a written instruction sheet. No problems were encountered during the 48 week study period, although space was an issue for one participant. Standing could be offered in an outpatient setting. However, maximum change in motor ability was not seen in the more able group (EDSS 7.0) until nine weeks at the earliest, and took up to 22 weeks in the more disabled group (EDSS 7.5 and 8.0). This latency of effect could mean that patients would need to attend over a long period.
- **Adverse effects** - four participants reported transient back or leg pain during the first few days of standing which resolved quickly. One participant felt that tiredness limited standing time.
- **Time spent standing** - only two of the more able participants could stand for more than 30 minutes three times a week. This indicates that people with severe MS may be unable to tolerate long periods of frame standing. However, significant improvements in motor ability were seen in all of the participants, including one who only stood for an average of 15 minutes per week. Time spent standing must ultimately be decided by the individual based on their own tolerance levels and availability of help.

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# Palliative care in advanced MS



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## Introduction

In the January issue of *Way Ahead* we reported the results from a survey we carried out at our MS specialist nurse meeting in 2012. We asked the 100 delegates to complete a questionnaire to give us an indication of the number of MS specialist nurses involved in providing services to people severely affected by MS. 97% of respondents indicated that they had a role in caring for people with advanced MS. However, many nurses felt they lacked experience in areas such as when to open up discussions about end of life (EoL) care in a timely and sensitive way, and supporting the family.

In the following article, Debi Adams and Colin Campbell look at some of the issues that people with advanced MS face, how palliative care can help and how to identify the triggers that can be an indication that discussions about EoL care and life prolonging treatments could be useful.

## What is advanced MS?

Defining when a person with MS has entered an advanced stage of their disease - when a palliative approach to care may be required - can be both complex and emotional. It is estimated that around 15% of those living with MS are at an advanced stage. There is no clinical definition of advanced MS, but it would be reasonable to include people with an Expanded Disability Status Scale (EDSS) score of eight or greater, where mobility is very limited and the person is dependent on others for most aspects of care and support.

Typically, in advanced MS, the person will have a complex range of symptoms, including cognitive impairment, spasticity, swallowing and communication problems. Combinations of these symptoms can increase the risk of complications, in particular pressure sores, contractures and infections. These complications can be life threatening and for some people in the advanced stages of MS, their lives may be shortened by the disease.

MS professionals may feel skilled in recognising that a person has advanced MS, but less confident to acknowledge that the person may in fact be in their last year or so of life. This important link is often missed and therefore the opportunity to understand important wishes, prepare people for the future and support a good death may be lost.

The NHS End of Life (EOL) care programme produced a framework for end of life care in neurological conditions<sup>1</sup>. This national guidance identifies a set of triggers which indicate when a person with any neurological condition, including MS, is entering the last year or so of life. These triggers are invaluable pointers that a person is in an advanced stage and palliative care should be considered:

- swallowing problems
- recurring infection
- marked decline in physical status or weight loss
- first episode of aspiration pneumonia
- severe cognitive difficulties
- significant complex symptoms.

Inevitably there is also an increased burden on the individual's family, particularly if they are providing a high level of care support. Often these unsung heroes are physically and emotionally exhausted, leaving them prone to burnout. They need and deserve support, with many valuing a period of respite. Unfortunately, it is still very difficult for people with MS to access specialist palliative care.

## MS, life expectancy and mortality

Long-term studies suggest that overall MS only has a relatively small impact on life expectancy. A study in Canada<sup>2</sup> found that life expectancy for those people whose experience of MS ranged from no symptoms to full time use of a manual wheelchair (less than or equal to 7.0 on the Expanded Disability Status Scale (EDSS)) was only slightly reduced.

However, the research also found that people with more complex disability (EDSS greater than or equal to 7.5) were more at risk of potentially life threatening complications - such as respiratory or cardiovascular problems, and had an increased susceptibility to infection. In fact the mortality rates seen in those with more complex disability were more than twice those for patients with an EDSS less than or equal to 7.0. This affected the overall life expectancy figures, but even with this group included, overall life expectancy for people with MS was about six to seven years less than that for the general population.

Looking at all the various studies as a whole<sup>2,3,4</sup>, a five to ten year reduction in life expectancy is estimated,

compared with the general population. However there is a small cohort of people for whom MS shortens their life more significantly.

The most common causes of death in advanced MS are:

- aspiration pneumonia
- sepsis due to infection (UTI, chest infections and pressure sores).

In advanced MS these causes can be attributed to the disease, for example someone with severe swallowing problems cannot be completely protected from aspiration.

In 1991, in the pre-disease modifying therapy era, a Canadian study<sup>5</sup> reported that out of 119 people with MS for whom the cause of death could be determined, 52 deaths (43.7%) could be attributed to complications of MS. The true figure of deaths attributable to MS may be higher still in this cohort, as it excluded those deaths due to suicide.

Identifying those for whom life expectancy may be reduced can promote good communication and care to prepare the person and their family for the end of life.

## How can we make the experience better for people with advanced MS?

There is a growing awareness that for those at the end of life, the last year of life is characterised by repeated unplanned hospital admissions. Lyons and Verne<sup>6</sup> found the mean frequency of admissions to hospital in the last year of life, for all diseases, in the UK was 3.5 per patient per annum. All too often the experience of hospitalisation for a person with advanced MS is one of discomfort and distress away from their well-planned home care environment.

Identifying that a person may be in the last year or so of life and adopting a palliative care approach may go some way to preventing futile and distressing hospitalisations and other unwanted interventions. The opportunity to openly discuss the likely course of the disease, and the options for care and support available at home at the end of life, can allow people with MS and their loved ones to make an active choice, for example to be cared for at home in any situation.

### First steps: “Listen to me!”

One of the most useful roles of the health professionals involved in the care of someone with advanced MS is to actively seek out what is important to the person. Listening to their story may be the first step in handing them back some control over their life. Here are some open questions that may help start a discussion:

- “Can you tell me what’s most important to you now?”
- “How do you feel about what’s been happening to you?”
- “Can I ask you what you would like to see happen?”
- “Can I ask you what the worst thing about all of this is for you?”

Advanced MS can threaten who the person is. It can undermine a person’s identity and self-esteem in a variety of ways. It can compromise speech and swallowing, bladder and bowel continence, and often one of the most deleterious effects can be the intrusion of cognitive difficulties into a person’s relationships. Each of these facets can gradually erode the control someone has over their life. Therefore, listening to the person’s story, and hearing their agenda, is the first step to learning which symptoms need to be tackled. Setting future plans in place can help the individual feel they are in the driving seat again.

## How can palliative care help people with advanced MS?

Ideally, important conversations about what matters to the person and what they would like to influence, are best carried out before cognitive difficulties have a significant impact. The end of life triggers (see earlier) are a good indication that the disease is at a stage where future care discussions should be initiated. One of the key areas where it is possible for an individual to influence their future care is through advance care planning, or advance directives to refuse treatment. Some may take comfort from directing that they will not receive treatment to prolong their life against their expressed wishes, for example by gastrostomy feeding. Many may feel a sense of renewed control over their lives in being able to assert their wishes, for example to be cared for and die at home.

Importantly people need to know what support and care is available should they express a wish to die at home and not wish to be admitted to hospital for life prolonging intervention. There should be no barrier to excellent end of life care in the person’s own home. This requires a shared acknowledgement between the person with MS, their loved ones and their health care teams that they are near the end of life. With good partnership working, primary care and community palliative care teams can provide a range of support to ensure that people can remain in their own home without fear of suffering. This may include medication to reduce distress and access to additional care support (eg Marie Curie care, NHS fast track care funding, day hospice care). For some, a short stay in their local hospice to manage symptoms, or for carers’ respite, may be available.

In many cases, people with advanced MS have developed profound cognitive problems before their end of life care wishes have been discussed. When it is becoming clear that time may be short, the person may no longer have the required mental capacity to make complex decisions about their own future care. In these situations, important decisions can still be taken to protect the person and ensure that care is provided in their ‘best interest’. The best practice principles given in the Mental Capacity Act<sup>7</sup> guide these important discussions and decisions, in particular that close family and loved ones are involved in any decisions.

Patients and families who are aware that time may be limited can be better prepared psychologically, which may facilitate a reordering of priorities (see clinical scenario).

Optimum symptomatic treatment of the patient at the end of life is beyond the scope of this article, but is a well-established part of good care in any setting, with the Liverpool care of the dying pathway<sup>8,9</sup> providing clear guidance on managing this.

## Clinical scenario

Betty was a 54 year old with advanced MS. She had become unable to communicate her wishes effectively, and her cognitive function had deteriorated to the extent that she barely recognised her husband John. Six weeks previously Betty had been admitted to hospital to receive intravenous (IV) antibiotics for an episode of aspiration pneumonia. Speech and language therapy assessment confirmed she was at high risk of aspirating again.

In the context of advanced MS with the presence of end of life triggers, the specialist palliative care nurse discussed important end of life decisions with Betty's family, her GP, neurologist and MS nurse.

The following 'best interests' decision was reached with agreement from all key parties:

- not to attempt resuscitation (DNACPR form completed)
- to avoid admission to hospital
- not to administer IV antibiotics in the event of a serious infection
- in the event that Betty is unwell 'out of hours', phone St Catherine's Hospice out of hours telephone advice service as first contact
- preferred place of care is home, but if necessary admission to St Catherine's Hospice or the Palliative Care Unit at the local hospital should be considered
- injectable palliative medication is to be available at home to ensure Betty is not in pain or distress.

This information was shared with the family, GP, out of hours GP service, ambulance service, care agency, local hospital and most importantly, copies were kept with Betty at all times.

Two weeks later Betty became distressed one evening. John phoned the hospice and an on-call GP was asked to visit. The GP understood and accepted Betty's end of life care plan and agreed not to treat the suspected chest infection with antibiotics. Instead she started a syringe driver with Buscopan (to dry chest secretions), and a small amount of midazolam (to relieve potentially frightening breathlessness) to ensure Betty was comfortable and distress free. Betty quickly settled and slept.

Over the next three days, Betty's usual GP visited daily, district nurses attended twice a day and the Marie Curie nurses came when they could at night. The specialist palliative care nurse remained in close contact with Betty's family and the rest of the care team. Betty died peacefully at home with her family around her.

## What have we learnt at St Catherine's Hospice?

Listening to people with MS and their families, we hear a number of common themes pointing to where things can go wrong in the care in advanced MS. People don't like it when they:

- feel their concerns are not being addressed
- feel that they have to 'fight for everything'
- perceive a lack of information, continuity and coordination of care.

People value:

- being listened to
- getting help to make sense of what is happening to them
- continuity and coordination of care
- access to specialist care, treatment and equipment
- help to plan for the future and make those difficult end of life decisions.

The wife of one man with advanced MS told her palliative neurology nurse, "You look at the whole person and the whole picture" and "You don't just look after Peter, you look after me too."

As Fiona Godlee succinctly put it in a recent editorial in the BMJ, health professionals "can do a great deal to help patients achieve a good death. Early identification of the dying phase, good communication with patients and relatives, sensible prescribing, effective management of physical symptoms, and understanding of the patient's social, psychological, and spiritual needs must all play their part."<sup>10</sup>

\*Names and personal details have been changed to protect the person's identity.

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**The MS Trust will be running three study days on end of life issues around the country (London, North West England and Scotland) in early 2014. For more information on how to register your interest go to the Professional Development section on pages 14-15.**

# Information news



## Information for the newly diagnosed

In 2012, the MS Trust commissioned research into the information needs of people with MS around the time of diagnosis. We found that the appetite for information varied considerably from one person to another. Also, most individuals had phases of seeking information and times when they wanted to avoid the subject of MS. People wanted to choose how much information they accessed at any particular time, personalise it and be supported to use it.

The results of this research were considered by a group of people affected by MS, together with a range of health professionals involved with patients around the time of diagnosis. This group suggested that two resources should be developed for the newly diagnosed:

- the first would be a resource which could be given out at the time of diagnosis. It would answer some initial questions about MS and signpost to further information either online, in printed form, or through the MS Trust Enquiry Service. It would be very discrete and could easily be tucked into a pocket or handbag as someone left the clinic. This initial resource would include options to acquire further information, either straight away, or bit by bit, when needed or wanted
- further information could be available as information sheets, either printed or held electronically, which could be kept for reference, as well as supporting web content such as videos.

### Can you help?

The MS Trust has begun to develop these resources and is keen to hear from any health professionals who might be able to help. We need people to read drafts and look at designs to see if the information is appropriate, clear and helpful.

In addition, we would welcome input on the logistics of making the initial resource available in MS clinics so that it is given to people at the point of diagnosis, or very soon after.

If you can help, please email [infoteam@mstrust.org.uk](mailto:infoteam@mstrust.org.uk) or call **01462 476700**.

The MS Trust Information Team can provide comprehensive reference lists that support general MS services; MS nursing services; multidisciplinary or rehabilitation teams; physiotherapy and many other areas of practice that have a direct impact upon the quality of life for people with MS. Health professionals are encouraged to contact the team if they require literature searches to support any aspect of service development: **email [infoteam@mstrust.org.uk](mailto:infoteam@mstrust.org.uk) or phone **01462 476700**.**

## The new-look Open Door

We hope you've had an opportunity to have a look at the latest edition of our free supporters' newsletter, Open Door. The May issue was the first edition in an expanded format, including all the latest news, research and practical therapies we've always featured, whilst also letting people know more about the MS Trust's work and how they can get involved.



We've already had lots of positive feedback and we hope to incorporate comments into our next issue which will be published in August.

**"Thanks for the latest Open Door newsletter. Love the new look – informative, relevant and easy to read."**  
**MS Trust supporter.**

If you don't currently receive Open Door but would like to in the future, sign up at [www.mstrust.org.uk/opendoor](http://www.mstrust.org.uk/opendoor) and don't forget to tell your patients about Open Door too!

## TONiC study

In the January issue of Open Door, we reported on the Trajectories of Outcome in Neurological Conditions (TONiC) quality of life study being conducted at the Walton Centre Foundation Trust, Liverpool. In the article, Benjamin O'Sullivan and Carolyn Young appealed to you as health professionals to become involved. Following publication of the article we were made aware that there were problems with the study website, these have now been resolved, so we encourage you to revisit the site and feedback your experiences [www.tonicstudy.org](http://www.tonicstudy.org)

# Professional development



One of the ways in which the MS Trust is dedicated to making life better for people living with multiple sclerosis is by supporting the health professionals who provide MS-related services. The MS Trust Professional Development team runs a range of programmes aimed at ensuring that every health professional that provides care to someone with MS has the skills and knowledge they need to provide the highest quality service.

## MS Trust Annual Conference, 3 - 5 November 2013

Don't miss this flagship event for those working with people with MS.

Who the conference is for:

- MS specialist nurses and allied health professionals
- acute or primary care nurses who care for people with MS
- allied health professionals with an interest in neurology or rehabilitation
- neurologists
- students
- researchers
- GPs.

Topics for 2013 include:

- Transition to secondary progressive MS
- Acceptance and commitment therapies
- Therapy tips for nurses
- Smoking and MS
- Exercise, fatigue and MS



- Update on latest disease modifying drugs
- Research for progressive MS.

Keynote plenary speakers include:

- Professor Alan Thompson, Consultant Neurologist, Hospital for Neurology and Neurosurgery
- Dr David Rog, Consultant Neurologist, Salford Royal Foundation Trust
- Alex Cowan, Expert Patient, Sex and Disability Advisor
- Dr Jeremy Chataway, Consultant Neurologist, St Mary's Hospital, Paddington.

The MS Trust administers professional development bursaries of up to 75% for health professionals who are working in a clinical role with people with MS. That means that, with a bursary, the cost would be less than £150 (plus VAT), which is great value for a three day residential conference. The bursary funds are limited so ensure you apply as soon as possible to avoid disappointment.

Further details on applying for a bursary, the full conference programme, and how to book your place can be found on the conference website [www.mstrust.org.uk/conference](http://www.mstrust.org.uk/conference)

## A call for posters - research and development showcase

The R&D showcase is a chance to celebrate your work. No project is too small and posters do not have to be professionally produced. All well-presented work which highlights ways in which you have generated evidence, or improved services, for the benefit of people with MS is welcomed.



Developing and submitting posters can be daunting, so we have developed some top tips, guidelines and examples to help you with your poster submissions. See [www.mstrust.org.uk/conference](http://www.mstrust.org.uk/conference) for more information.

## MS and End of Life Study Days

The needs of people at the end of their lives have been the subject of increased focus in policy and service provision. Our work with people with MS suggests that they, and their families and carers, often struggle to get the support they need as their lives draw to a close.

A recent survey of MS specialist nurses showed that many did not feel wholly confident about this aspect of their role. Many also felt that MS, with its complex and sometimes rapidly-changing symptoms, was difficult to fit into the standard care models that were available.

**“We need to understand how to be transparent and support people to deal honestly with this stage of illness. There are elements of fear about how much we can bring to the care at end of life – fear about opening a can of worms.”** [Anonymous - survey respondent](#)

In this issue of Way Ahead, Debi Adams and Colin Campbell from St Catherine’s Hospice in Scarborough, look at some of the issues that people with advanced MS face, how palliative care can help and how to identify the triggers that can be an indication that discussions about end of life care and life prolonging treatments could be useful.

We also plan to run three study days on end of life issues which will follow a well established format of sessions headed by experts in the field who can offer practical advice that delegates can use immediately to improve the care of their patients.

The study days will be spread across the country (London, North West England and Scotland) and will take place early in 2014. To register your interest, please email [education@mstrust.org.uk](mailto:education@mstrust.org.uk) and watch the MS Trust website for more details.

## Development of multiple sclerosis care and management for specialists module

This course is designed for new in post MS specialist nurses and other professionals who specialise in supporting people with MS. MS specialist nurses can receive a fully funded place on the course and substantial bursaries are available for allied health professionals and other health professionals interested in improving their knowledge and skills in MS care.

The course runs for a full residential week and covers a host of clinical and professional issues relevant to people undertaking a specialist role. The course is accredited by Birmingham City University and participants can gain 15 credits at level 6.

The next course is taking place from 14-18 October 2013 at the Priory in Hitchin, Hertfordshire.

For further information, contact the Professional Development team [education@mstrust.org.uk](mailto:education@mstrust.org.uk) or see [www.mstrust.org.uk/professional-development](http://www.mstrust.org.uk/professional-development)

## MS Therapists Education Fund

Therapists, both specialist and generalist, play a pivotal role in improving the quality of life of people affected by MS. With the current financial constraints within the NHS it is often very difficult for therapists to get financial support to attend education courses to help with their professional development. This lack of financial support means that they can be working without the ability to develop their clinical expertise, evidence-based practice and management skills.

The MS Therapists Education Fund has been set up with equal investments from Biogen Idec Ltd, Bayer Healthcare, Merck Serono, Novartis, Genzyme and the MS Trust.

The purpose of the fund is to enable therapists to best meet the needs of people with MS by expanding their MS knowledge and skills, and to enable therapists to develop services in their locality. The fund is aimed primarily at physiotherapists, occupational therapists, speech and language therapists and psychologists, although applications from other therapists will be considered. Specifically it will enable those who are working in a clinical role with people with MS to attend academic courses, conferences and study days to develop their clinical expertise and expand their skills base.

For further details, rules and to download an application form see our website:  
[www.mstrust.org.uk/professional-development](http://www.mstrust.org.uk/professional-development)

## Accessible education

**Do you work in Neurology?**

**Are you finding it hard to attend educational courses and or conferences?**

**The MS Trust wants to hear from you!**

The MS Trust, in conjunction with the Therapists in MS (TiMS) Networking Group, have an ongoing commitment to providing up to date, evidence-based education to allied health professionals with a specialist interest in MS. The current financial climate has put increasing amounts of pressure on services, thus limiting opportunities for staff to attend traditional educational courses and training opportunities. We would like your assistance to inform us of new, up to date, and accessible ways to meet your learning needs.

Please take a few moments to complete the survey monkey [www.mstrust.org.uk/education-survey](http://www.mstrust.org.uk/education-survey)  
Please offer as much detail as possible regarding the specific topics you would like education on.

For further information on any of our professional development courses, please contact Delia Britter on **01462 476700**, or email [education@mstrust.org.uk](mailto:education@mstrust.org.uk)

## Publications

For a complete listing of all our publications and factsheets visit our website at [www.mstrust.org.uk](http://www.mstrust.org.uk)

### Publications for health and social care professionals

- MS information for health and social care professionals  
4th EDITION
- Spasticity care pathway

### Publications for people with MS – (a sample)

- 2013 publication list
- Disease modifying drug therapy
- Living with fatigue
- MS and me

### Postcards

- At work with MS
- Posture
- StayingActive

### Factsheets – (a sample)

- Alemtuzumab
- BG-12
- Laquinimod
- Teriflunomide
- Vitamin D REVISED
- Sativex

All items are free, but if you would like to make a donation towards our costs, we would be very grateful.

- I enclose a cheque made payable to the MS Trust

I want the MS Trust to treat this donation and all donations I have made for the four years prior to this year and all donations I make from the date of this declaration until I notify you otherwise, as Gift Aid donations. Date: \_\_\_/\_\_\_/\_\_\_ Signed \_\_\_\_\_

I confirm that I will pay an amount of Income Tax and/or Capital Gains Tax in each tax year (6th April to 5th April) that is at least equal to the amount of tax that all the charities or CASCs that I donate to will reclaim on my gifts for that tax year. I understand that other taxes such as VAT and Council Tax do not qualify. I understand the charity will reclaim 25p of tax on every £1 that I give on or after 6 April 2008. Please notify us if you change your name or address.

Name \_\_\_\_\_

Job title \_\_\_\_\_

Address \_\_\_\_\_

Postcode \_\_\_\_\_

Telephone number \_\_\_\_\_

- I am happy to be contacted by email:

email address \_\_\_\_\_

**Return to: MS Trust, Spirella Building, Letchworth Garden City, Herts, SG6 4ET**

The MS Trust will use your details:

- to keep you informed about our work, including our fundraising
- to pass to our wholly owned subsidiary companies MS Trust (Education) Ltd and MS Trust (Trading) Ltd which exist only to carry out our educational objectives and to raise funds for the MS Trust.

We will not sell or pass your details to anyone else (unless we are required to by law). If you object to either use of your details, please let us know.

## Supporting the MS Trust

We rely on donations to keep providing support for people with MS and for professionals working in MS. If you value the MS Trust and would like to help us by fundraising, it's not too late to take part in one of our fun events this summer...

### My Garden for MS

If an afternoon with tea, coffee, champagne, cake and spending time with friends and family sounds up your street, then our 'My Garden' campaign is an ideal way to get involved and raise funds. We've put together a fundraising pack containing all you need to help you plan your event, big or small [www.mstrust.org.uk/mygarden](http://www.mstrust.org.uk/mygarden)



### Skydiving

You can skydive for the MS Trust all year round at centres across the UK. We offer tandem jumps, where you are strapped to an instructor who will open and control the parachute, so you can just relax and enjoy the view! Raise £395 and your jump will be free.

Visit [www.mstrust.org.uk/jump](http://www.mstrust.org.uk/jump) to find out more.



There are many ways to support the MS Trust's work. If you would like to get involved with fundraising, please contact us on 01462 476707, email [fundraising@mstrust.org.uk](mailto:fundraising@mstrust.org.uk) or visit [www.mstrust.org.uk/fundraising](http://www.mstrust.org.uk/fundraising)



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