Welcome to the first edition of Open Door in 2013

We believe the best care for people with MS comes from a specialist healthcare team which understands the complexity and uncertainty of MS. MS specialist nurses play an essential part in this team and over the last 20 years the MS Trust has championed their role.

During this time however the NHS landscape has dramatically changed and NHS managers now want hard evidence to prove the added value of MS specialist services. MS nurses are now expected to collect and evaluate data to prove their service provides value for money as well as providing the best care possible.

In May 2012 the MS Trust launched the Generating Evidence in MS Services (GEMSS) project working with four teams to develop a range of tools to help nurses evaluate their service. This work has proved invaluable for these teams and we now need to ensure that more MS nurses can benefit.

We would not normally include an appeal with Open Door, but the GEMSS project, highlighted in our letter enclosed, is vital to ensure we can continue to support MS nursing posts in the UK. We would be very grateful for any help you can give.

We have also enclosed a copy of our latest publication leaflet detailing all of our publications and website resources for people with MS. We hope you find it useful, or can pass it on to someone else who will.

Thank you for supporting our work and please accept our very best wishes for 2013.

Pam Macfarlane
Chief Executive

MS Awareness Week
MS Awareness Week is our chance to raise the profile of MS. Keep an eye on www.mswarenessweek.org.uk to find out how you can get involved. We’re asking our supporters to Be Bold in Blue - more on page 14

www.mstrust.org.uk  Freephone: 0800 032 3839
Where does vitamin D come from?

Vitamin D (vitamin D3) is created in the skin when exposed to ultraviolet B radiation in sunlight. In the UK, between May and September, about 20 to 30 minutes a day spent outdoors in direct sunshine in the middle of the day will meet vitamin D needs for most fair skinned people. Factors such as darker skin, the use of sunscreen, levels of pollution and the unpredictability of the British summer can all lower availability and between October and April, the level of ultraviolet is too low for vitamin D to be made.

There are dietary sources of vitamin D3 from fish and dairy products and vitamin D2 from plant sources, but at much lower levels than from sunlight.

As a result, levels of vitamin D in the UK are generally low. The Department of Health reports that a quarter of the population have no more than a third of what is considered an adequate level.

What is known of vitamin D in people who have MS?

Research has suggested a possible association between vitamin D levels and the risk of developing MS. But what of vitamin D in people who already have MS?

A Dutch study of 267 people with MS found that higher levels of vitamin D were associated with a lower relapse rate. People with progressive forms of MS had lower levels than those with relapsing remitting MS.

This pattern was reflected in an Australian study that found that people with higher disability scores were more likely to have lower levels of vitamin D. Another Dutch study found those with lower levels of vitamin D had a greater risk of experiencing a relapse.

Although there seems to be an association between more active MS and low vitamin D levels, the nature of this association is difficult to determine. Are reduced vitamin D levels a cause of MS activity or a result of it? Research in other conditions has shown that inflammation significantly reduces levels of vitamin D. More research is needed in MS to see if the inflammation that drives relapses is also affecting vitamin levels in the blood.

Vitamin D as a treatment in MS?

There have been studies looking at vitamin D as a treatment in MS. Although there were indications of an effect on the number of relapses experienced, these trials were relatively small, involving 10-62 people, and used doses ranging from 1,000 - 40,000IU per day. (40IU or international units is equal to 1 microgram of vitamin D3)

Several larger trials are looking at vitamin D3 supplementation combined with beta interferon.

A Finnish study found that people taking supplements showed fewer new areas of scarring on MRI scans, although there was no difference in the relapse rate between the supplement group and those taking a placebo.

Two larger studies, SOLAR and CHOLINE, involving about 250 people each, are still ongoing. These are testing whether vitamin D supplementation will reduce the number of relapses someone experiences.

How much should you take?

The recommended daily intake in the UK (400IU) is based on reducing the risk of rickets and is widely considered to be too low. In August 2012, the European Food Safety Authority increased the Tolerable Upper Intake Levels (the levels that can be taken daily without causing harm) to 4000IU. Some authors feel this is also too low.

NICE has begun to consider the implementation of existing guidance on vitamin D, a review that will look at its role in general rather than specifically in MS. A consultation on the draft version of this is expected towards the end of the year.

To order the Vitamin D factsheet visit www.mstrust.org.uk/vitamin-d

For a longer version of this article and to see the list of references, visit www.mstrust.org.uk/open-door-vitamin-d
Developing information for people newly diagnosed

In 2012, the MS Trust funded research into the information needed by people newly diagnosed with MS, their friends and family and the health professionals who support them. A number of key themes emerged including the importance of:

- knowing that the information was reliable and up to date
- having a choice of formats, for example, online, printed or video
- choosing how much or how little information was acquired at any particular time
- having information that was relevant to the individual rather than too wide ranging
- being encouraged to take an active role in managing MS
- being supported to use the information, for example, when making choices about treatment

More information about this research is available in the November 2012 edition of Open Door and is available online at www.mstrust.org.uk/info-needs

In October 2012, the MS Trust held a workshop to consider how the research findings could be translated into new information resources for people newly diagnosed with MS. The workshop participants included:

- people with MS
- people with MS in their family
- health and social care professionals including MS nurses, a neurologist and a GP
- designers working in health information delivery
- MS Trust staff who will be involved in developing the new resources

We plan to use the results of this workshop to improve our services for the newly diagnosed including online and printed information and the support our Information Team provides over the phone. The new resources will also help health professionals who are involved at the time of diagnosis, particularly neurologists and MS specialist nurses.

Information about MS is available at www.mstrust.org.uk/information

If you have a question about MS, contact the Information Team on 0800 032 3839 or infoteam@mstrust.org.uk

Personal health budgets

The government has announced that, following the completion of pilot studies, personal health budgets will be rolled out across England. Evaluation of the pilot schemes showed that people reported better quality of life and had fewer periods in hospital. People with greater health needs benefited more and so the scheme will initially be extended to people on the NHS Continuing Healthcare scheme. By 2014, 56,000 people with complex medical conditions and who require a lot of care and support will have financial control over some aspects of their care. A similar scheme has been giving people control of some of their social care budget for several years.

Department of Health - www.dh.gov.uk/health/2012/11/phb/

Alemtuzumab update

The results of phase III clinical trials of alemtuzumab (Lemtrada) were published in the Lancet in November. These results showed that alemtuzumab was twice as effective as beta interferon in reducing relapses in people with relapsing remitting MS who had not received any treatment previously. After the two years of a comparison trial, half of those on beta interferon had relapsed but only a third of those in the alemtuzumab group. However, more people taking alemtuzumab experienced side effects, some of which were serious.

Alemtuzumab is currently being appraised by the EMA, the body that licenses drugs in the European Union. A decision is expected this year.

Genzyme, the manufacturer of alemtuzumab, has attracted criticism from a number of sources for withdrawing its licence for alemtuzumab as a treatment for leukaemia (under the name MabCampath) with the intention of relaunching it once a licence for multiple sclerosis has been granted.

Cohen JA, et al.


To order the Alemtuzumab (Lemtrada) factsheet visit www.mstrust.org.uk/alemtuzumab

Freephone: 0800 032 3839
The gorilla in the room

Problems with concentration are common in MS. This research looked at an aspect of concentration called inattentional blindness, which is when someone does not notice something even though it is plainly visible.

The ‘gorilla in the room’ is a famous psychology experiment. Participants were asked to watch a video of people passing a basketball and to count the number of passes made by the players wearing white shirts. Half way through the video, someone wearing a gorilla suit strolls through the middle of the game. A large proportion of the participants did not notice the gorilla because they were concentrating so hard on the ball and the players in white shirts.

68 people with MS completed a series of psychological tests to assess information processing speed and flexibility. They also did the gorilla in the room test.

The researchers found that people with MS who scored poorly on the psychological tests were more likely to notice the gorilla but were also more likely to detect fewer ball passes. They concluded that people with MS had less inattentional blindness (they were better at spotting the gorilla) but were less focused on the task (they missed some of the ball passes).

Less fatigue and better sleep

This study found that the Progressive Muscle Relaxation Technique (PMRT) helped with fatigue and sleep problems which are commonly experienced by people with MS.

PMRT involves closing your eyes before tensing a particular muscle group then relaxing again. Different muscle groups are tensed then relaxed in turn. You are asked to concentrate on the feeling of the tense muscles before relaxing them. The physical relaxation is accompanied by a mental relaxation which decreases anxiety and helps sleep. Better sleep decreases fatigue the next day.

32 people with MS who had difficulties with sleep and fatigue completed questionnaires to assess their level of fatigue and the quality of their sleep before learning PMRT. They completed the questionnaires again after practicing PMRT every day for six weeks.

The researchers found that there was a significant improvement in sleep quality and a decrease in levels of fatigue.

Feinstein A, et al.

Dayapoglu N, et al.

PMRT can take a bit of practice, like learning any new skill, but can bring substantial benefits. You can try PMRT for yourself using the 8 minute video on the MS Trust website. There is also a 12 minute audio relaxation session that you can either listen to online or download.

Go to www.mstrust.org.uk/exercises and click on the Relaxation tab.

You can read more about fatigue and sleep, including common reasons for poor sleep and ways to improve sleep quality, in the A-Z of MS - www.mstrust.org.uk/atoz

Our book Living with fatigue can be ordered or read online at www.mstrust.org.uk/fatigue

Problems with memory, concentration and planning are common in MS.

This research is relevant to tasks in everyday life where concentration is important such as when driving, cooking or at work. However, less inattentional blindness could be an advantage when it is important to spot something unexpected (not often a gorilla!).

StayingSmart is an MS Trust website that has tips for coping with day to day memory, concentration, planning and other cognitive problems - www.stayingsmart.org.uk
Migraine more likely in MS

Migraine is a severe headache usually felt as a throbbing pain at the front or on one side of the head. It can be accompanied by nausea and sensitivity to light. Migraine is common in the general population, affecting about one in seven people.

People who have MS have several factors in common with people who experience migraines: they are more likely to be women, more likely to be relatively young when symptoms begin and more likely to be from Caucasian rather than African or Asian populations.

This study was a meta-analysis which combined the results from previous studies of migraine in MS. The eight studies reviewed included 1,864 people with MS and 261,563 controls. The analysis found that migraine was more than twice as common in people with MS than it was in controls. The authors suggest that migraine may be more common in MS than previously realised and may contribute to a reduced quality of life. Consequently, it may be important for health professionals to actively look for and treat migraine in people with MS.


Risk of MS in the family

MS is not hereditary as it is not passed on in a predictable way like some conditions. However, genes do play a part in susceptibility to MS but environmental factors are also involved. This study combined the results of 18 previous studies to get a better estimate of the risk of MS in family members.

In families where one member was already diagnosed with MS, the risk was highest for more closely related members.

Lifetime risk of MS by relationship to someone with MS:
- Identical twin - 1 in 6
- Non-identical twin - 1 in 22
- Other brothers or sisters - 1 in 37
- Parent - 1 in 67
- Child - 1 in 48
- Relatives that were less closely related had a lower risk.

The research team calculated that genes contributed just over half (54%) of the risk factors. The remainder would probably be due to environmental factors.


It can be worth comparing the risk of MS with the risk of having other conditions. For example, in the UK:
- 1 in 3 people will develop some form of cancer
- 1 in 22 people have chronic heart disease
- 1 in 33 people have diabetes
- 1 in 500 people have Parkinson’s disease
- 1 in 625 people have multiple sclerosis

MS Trust resources

Living with fatigue
Order or read online at www.mstrust.org.uk/fatigue

StayingSmart
A website for people with cognition symptoms such as poor memory, concentration or attention span - www.stayingsmart.org.uk

Keep up to date with research news
Sign up for our weekly research email alert at www.mstrust.org.uk/research-updates

Migraine headaches can be very disabling. Some people experience changes in mood, energy levels, behaviour and appetite, and sometimes aches and pains, several hours or days before an attack. Most attacks gradually fade away and sleep often relieves the symptoms.

You can read more about migraine, including treatments, on the NHS Choices website www.nhs.uk/Conditions/Migraine

Freephone: 0800 032 3839
Changes to walking and balance
How can physiotherapy help?

Alison Clarke, Clinical Specialist Physiotherapist, Mobility and Specialised Rehabilitation Centre, Northern General Hospital, Sheffield

Walking around the house, the garden, to the shops and in the office should be automatic and effortless. It is often only when things go wrong that we realise how complex all the aspects of our balance and walking are.

How does MS affect walking?
The wide ranging nature of the symptoms that people with MS experience often means that walking problems vary considerably from person to person. Anyone with changes to their walking should see a physiotherapist for a review. This is equally important whether you are experiencing your first walking problems or if you have existing difficulties that might be altering.

Some of the things that you might notice are:
- Unsteadiness on walking or turning
- Slower, shorter steps
- Less confidence
- Needing support from walls, furniture or other people
- Tripping and stumbling
- A heavy feeling in your legs when stepping forward
- Weakness of the leg when your weight is on it
- Difficulty placing your foot on the ground

Many of these problems are initially caused by the slowed or altered nerve conduction, which results in muscle weakness, spasm and sensory changes. However, other MS symptoms can have a large impact on walking, such as pain, tremor, dizziness and visual problems. For example, vision that is double, blurred or has altered depth perception can make it difficult to place your feet or judge steps and kerbs.

What can you do?
Experience has shown that the sooner new problems are identified, the more chance there is of correcting or minimising them and reducing the risk of secondary problems such as muscle wasting, poor circulation or weaker bones.

It is not inevitable that walking will deteriorate rapidly if you have MS and some problems may be reversible. It is important to see a physiotherapist who understands MS. If you do not have one of these, a doctor or specialist nurse can put you in touch.

What is the physiotherapist looking for?
Physiotherapists understand the components needed for a normal walking pattern. They will evaluate your strength, muscle tone and spasm, coordination, sensation and balance. They can improve the efficiency of your walking and also, very importantly, anticipate the consequences of treatment. For example, reducing muscle tone with medication or giving a foot splint can be helpful but occasionally can have an effect on other aspects of gait, creating different problems.

Physical capabilities are a significant part of an assessment but equally important is to consider your usual walking environment - the level of noise, distraction or busyness of frequently used routes. People often notice that it becomes harder to do tasks when walking such as talking, looking around or carrying things because their walking requires all of their concentration. A person’s mood can also have an effect as depression has been shown to have an impact on walking pattern.

Some people develop other movement strategies to compensate for walking difficulties. The most commonly seen are hip hitch, circumduction (swinging the leg out to the side to clear the ground), leaning to one side, vaulting (excessively pushing-off from the weight bearing leg to clear the floor with the other one), high step and foot drag. These strategies can in themselves lead to further problems such as back pain or compromised balance. This then sets up a vicious circle of increasing pain and weakness and so is important to resolve.
What is there that might help?

A smaller number of focussed exercises for your specific problem are often preferable to a long list that you do not have time to keep up and that may worsen fatigue. It is very important to keep doing exercises you are given, or go back for a review if you do not think they are still useful. People often are enthusiastic at the beginning but stop doing exercises after a while. Muscle weakens very quickly if it is not used and balance mechanisms become less efficient, so it is important to keep up an exercise programme that includes:

- strength training - research shows this has a positive effect on walking in MS
- coordination work - it is essential that muscles are working in the right order
- stretches for stiff joints and shortened muscles
- strategies to help with the management of muscle tone and spasms.

Walking is complex and a gait assessment by a therapist is very involved. You could simplify this for yourself by thinking about walking in three main stages:

1. Acceptance - foot placement and control on the ground
2. Support - balance and strength in the stance (supporting) leg
3. Advancement - ability to swing a leg forward

Arguably the most important of these is acceptance. If your foot is in the optimum position when it makes contact with the ground, the balance and muscle control through your leg will be better when you put your weight on it. However, if the foot is not in a good position, this has a knock-on effect of making the next steps more difficult and effortful.

Functional electrical stimulation (FES) is often very successful in addressing walking problems in MS. A small electrical signal is sent to muscles by a battery powered box. Most referrals to our clinics are for foot drop and turning in (inversion) of the foot. People with MS who use FES often notice significant changes to their walking including greater confidence and speed, less effort involved and fewer stumbles.

There is a huge range of foot and knee splints that may help with walking. Some are rigid and some made of soft materials. Each has their pluses and minuses for an individual and a specialist in orthotics can assess and advise regarding this.

Sometimes medications may help with walking. If you experience difficulties because of spasms and stiff muscles, some medications can ease this, however, too much can sometimes lead to drowsiness and muscle weakness. If fatigue or neuropathic pain, such as burning or tingling, are a particular problem for you, then treatments that address these symptoms might be helpful and can be discussed with your doctor or specialist nurse.

Physiotherapists will also be able to advise about walking aids, such as sticks, crutches and walking frames. There are various opinions in the literature regarding use of walking aids as dependence can lead to reduced balance reactions and some muscle weakness. A good rule of thumb is to use the minimum support required to ensure that you are safe and confident. The most important factor is to keep walking and be as active as possible - walking aids may be the way for you to do this.

In summary

If you notice any changes to walking and balance ask for an assessment by a physiotherapist who will look at all aspects of walking including physical, emotional and environmental. They can give you individual advice that is both helpful and realistic. It is important to keep as fit as possible by continuing with any given exercise regime.

To order the FES factsheet visit
www.mstrust.org.uk/fes

The MS Trust funded the pilot study that showed FES and physiotherapy improved walking for people with MS. To find out more about the research we fund and how you can support this work, please visit
www.mstrust.org.uk/mstrustprojects
Journey into poetry

Christine Moran

I wouldn’t describe myself as a walker or rambler yet the idea always held a hidden attraction somewhere deep in the recess of my psyche. So in 2004, three children having grown up and flown the nest, I decided to pull the attraction from the depths and put it into action. And what better incentive than to do this with a special friend, one who would be prepared to listen to my opinions and woes without uttering a word in reply. Enter Jack, a golden retriever puppy, who has now been my very close companion for the past eight years.

I began at the very beginning and kitted myself out - sturdy walking boots, chunky socks and, of course, waterproofs for the ever unpredictable English weather. I was all set to go. So on a not so sunny morning in February 2005, Jack and I set off armed with sandwiches, a flask of tea for me and several biscuits and water for him. It would be a fairly short walk, duration of no more than two hours - he was only seven months old and still growing his land legs. We skirted the periphery of part of the Chevin, our local moor, and took a well earned rest on a large rock. It was perfect.

Diagnosis

I had no idea this was going to be our one and only long walk together. On the way back and as we were nearing home my right foot began to misbehave, wanting to walk out to the side instead of straight. I mentioned this to the family but we dismissed it as ‘one of those things’. But on subsequent short walks I began to trip, sometimes resulting in falling. The falls became a feature of the walks, often resulting in bad cuts and bruises and even black eyes. Jack would sit patiently by my side licking my wounds while I pulled myself upright.

After a while a referral was made to an orthopaedic doctor and an MRI done which revealed torn ligaments and a ruptured tendon. These were operated on and we all felt sure I was on the mend. We now know that the torn ligaments were caused by the falls whereas at first we thought it was the other way round. It has since become apparent that MS was the reason for the falls.

After a few months of recovery it was evident the symptoms hadn’t gone away but I kept on hoping. Then in 2007, while Jack and I were out, my right leg began to drag and I had difficulty walking home. I was admitted to hospital with a suspected TIA (transient ischemic attack, a mini stroke) and had tests which were inconclusive. Time passed and the foot became weaker. In late 2009 I noticed the weakness had spread to my right hand. In 2010 an appointment was made with a neurologist who embarked on a series of tests including a lumbar puncture and MRI. The conclusion was an inflammatory disorder and, shock horror, I was referred to an MS neurologist. She quite calmly but definitely confirmed secondary progressive MS. I felt as though a great boulder had dropped on top of me but at the same time was relieved to have an explanation.

When my medical history was gathered together it became apparent that I have had MS for about thirty years. I had many weird and unexplained symptoms back in the 80s and 90s which were then put down to stress. It was, apparently, at that time, relapsing remitting. I had no further symptoms until 2005, which was a blessing as I was able to bring three children up almost symptom free.

Jack waiting for cake!

www.mstrust.org.uk
Learning to live with MS

So, where on earth did I go from here? I was given lots of support from the MS team at the hospital and attended a series of talks for newly diagnosed people. Chatting there to others in the same boat helped enormously and I also found, and still find, the internet a great source of support too, joining MS groups etc. I am meeting so many people I would never have come across. And the wonderful information I was provided with by The MS Trust was an absolute godsend. Everything was beautifully presented in bright, colourful booklets, explained in simple terms and not frightening in any way. I would have been lost without this information.

Acceptance, which is something I used to think of as a one off single act, is, I have found, complex and a very gradual process - some days I seem to take steps back and have to work harder with it. But, having been faced with a condition such as this, which at times seems as though it has robbed me of who I was, I have also discovered that I have to try my best to help myself by pushing new doors open. Amazingly for me, one of those doors has led me to writing poetry, something I never imagined I could ever do. I am finding this very therapeutic as an outlet for my feelings and frustrations and also it is simply fun to do. I have my own website, and once again, here I have met some lovely people and made new friends. And if, by putting my poems out there, they may help a few people to come to terms with the ups and downs of this difficult condition, then that is a great bonus for me.

My main difficulty has been coming to terms with how quickly my mobility has decreased, leading to my having to walk with a four wheeled aid. I wrote a poem about this which I would like to share with you (right).

I try to stay as positive as I can and this is made much easier by the huge support of a loving family. I am very blessed and, as I keep saying, I am meeting some wonderful people along this new path, many of whom are a great inspiration to me. MS is a huge pill to swallow and sometimes gets well and truly stuck in the throat. But the bad days always pass and there is so much life yet to be lived and I intend to live it, along with family and my faithful companion, Jack, who has been with me every step of the way.

My next aim is to acquire a mobility scooter so we may be able to resume our walks together. Perhaps not on the moors but round the block will be quite acceptable. To be outside with him again, just the two of us, as we had planned.

Christine’s website is
www.journeyintopoetry.wordpress.com

Befriending the enemy

It stands, redundant, in the hallway; I’ve been looking at it for weeks, its incongruence, its blackness. But I suppose if you really needed to use one, the seat could be quite handy, plus the shopping basket on the front and, of course, walking without falling could be a significant point in favour.

But it smacks so of disability, infirmity, ageing, inviting strange looks from other people, requiring ‘parking’ in cafes etc, not to mention the self-conscious image I’ve always presented, designer heels, jeans just a touch too long, to lengthen the walk.

And yet the deep violet velvety blossom that I noticed from the car window yesterday, in a garden at the top of the road, cries longingly to be caressed, and I ache to touch it.
Stepping out in style

Dawn Banton

I'm 38 now, though in my heart I'm still 18. I was a professional singer and dancer for 14 years - I've always loved the big hairdos, the costumes, the make-up, the glamour, the glitz. My dad took me everywhere - he was my driver and roadie until he couldn't manage it anymore. He's 75 now and has had MS for more than 30 years. He's struggled very hard with all that MS brings but keeps on fighting it. My mum has been battling with breast cancer for seven years. I'm very close to both my parents and do everything I can to help them. My partner, Chris, and I have been together for 17 years and we have a little girl, she's 7 years old. My family is everything to me.

MS started for me literally overnight. One morning, I woke up with no vision in one eye. I went down to casualty, had all sorts of tests and was sent home with the reassurance that "it's probably nothing but we'll send you an appointment for the eye clinic." Before the appointment came through, my left side had started to go numb. What with Dad's history and what I knew about MS, I could put two and two together. Sure enough, within a couple of months my neurologist confirmed that I had MS.

I was devastated. Me? Have MS? No way. I couldn't believe it, I thought they must be wrong - I was never going to get the same thing as my dad. It was so hard for Dad to see me diagnosed with MS - he was devastated too. I knew a lot about MS, though I'm not sure whether that was a good thing or not.

Coping with changes

Soon after my diagnosis I had a bad relapse which greatly affected both of my legs. I went from being a really active person to being hardly able to walk. After a few near misses I realised that it was either use a walking stick or break my leg. I borrowed a nasty grey NHS stick from Mum.

I really didn't want to use a walking stick, it made me feel bad about myself. There's a real stigma attached to a walking aid, especially for a younger person. Other people just don't understand why you should need one.

Younger people tend to keep their MS to themselves, rather than tell their friends. It's not sexy to have MS.

Setting up a business

I was getting so many requests that I began to think I could make this into a business. Here was something I could work hard at and make a success of. It felt so good to be turning the negatives of MS into positives, washing away the stigma of having to use a walking aid.
I launched an eBay shop and set up a Facebook page. They went well so I decided to really go for it and now it's become full-on. During the last two months I've set up a business. I contacted Business Link for advice but that was about it. Although I've always wanted to be my own boss, I'm the creative sort and not keen on all the red tape. But I'm doing all of it now and learning as I go.

I'm continually planning and trying out new designs. People send me fabric samples so that I can make a special stick for a special outfit, particularly wedding dresses, and the stick becomes a treasured keepsake. All sorts of people buy them, including burlesque dancers! Some customers send me designs to be made up and I've been asked to do crutches too. Customer service is really important to me; I've made friends with many of the people who've bought sticks from me.

Working for myself

I was faster before I had MS. My eyesight has improved but I still have only 20% vision in my left eye, so I've had to work more slowly. You can't rush it - crystal placing is tricky and I want to be sure my work is well-finished.

Working for myself has been good. I haven't learnt to say no yet but customers are flexible and understand that each piece is made to order and may take a bit longer to send out. I've set despatch time to around 16-18 days which I meet 99% of the time. Good communication takes care of the rest. Things got a little crazy before Christmas, so I set a deadline for Xmas orders.

I'm just recovering from a relapse and while I'm getting better and better, I do worry about coping if I have another relapse. Now I'm training up my chap - he's thinking of working with me full time. There's so much happening at the moment, at the end of a busy day my head is buzzing and sometimes it's difficult to turn off. I find that my MS gets worse when I'm stressed, so I try hard not to get too hassled by it all.

Confidence to step out

What I've found, and other people tell me this too, is that my sparkly sticks make me feel good about myself; MS had taken a lot of that away.

Young people are fashion conscious and don't want to use a walking stick. They might ask for a fairly plain one at first but once they start using one, they go to the other extreme and want all the sparkle and bling they can get.

One of my friends really didn't want anyone to know she had MS and had stopped going out. She found that her walking stick was a great ice breaker and she got loads of compliments. People would ask, “why are you using a walking stick?” It made it so much easier to explain about MS and has given her back her confidence. Now she can't wait to get out and use it.

I love doing what I do. The best days are those when I pretend I don't have MS, when I get through the day without thinking about it. I get so much satisfaction from making my designs that I feel more positive about life in general and know that no matter what MS throws at me, I have achieved my dream of a successful business.

For me it feels like a light at the end of the tunnel. It's meant so much for the rest of my family too, especially my dad who's so proud of what I've achieved.

More about Dawn's sticks at www.blingsticks.com or www.facebook.com/blingsticks
Since the first MS nurses were appointed back in the 1990s, the MS Trust has been at the forefront of developing the MS nurse workforce. We believe that everyone with MS should have access to a specialist nurse. However, with the NHS currently needing to make big savings, the future of MS nursing is at risk and so we've had to take a tough look at how best to defend nurse posts against cost-saving measures.

As well as the obvious benefits specialist nurses can bring to people with MS, research has proven that they can actually save the NHS money. By making sure people with MS get the right care at the right time, MS nurses often prevent unnecessary hospital admissions and doctor consultations. But in order to secure funding for specialist posts when budgets are tight, commissioners need hard evidence that this is happening in practice - something many nursing services just don't have.

To tackle this problem head on, the MS Trust is working with four MS nurse teams across the UK to find the best ways to gather the evidence they need. We're arming nurses with tools to collect data as part of their regular routine and the skills to use that data to show how their services are making a difference. Once we have completed this initial stage, our GEMSS project (Generating Evidence in Multiple Sclerosis Services) will be rolled out to MS nurses across the UK. By understanding how to capture strong evidence of their quality and cost-effectiveness, MS nurses will be in a much better position to secure their services over the long term.

“Specialist nursing roles are very valuable and no one wants to see them go - you just have to make it ‘easy’ for people to say yes to employing them, based on real data” - Commissioner

In a recent survey of 58 specialist nurses, two thirds believed better data would help them defend against potential threats or cuts. Three quarters of them felt that they would be able to provide a better service if they could properly evaluate what they're doing. 90% of the nurses surveyed were interested in using the tools from our GEMSS project within their own services.

“The GEMSS programme has been an extremely useful tool for evidence, to highlight to others what our role entails. I feel privileged and inspired being part of the project.”

MS nurse and GEMSS project participant

We will continue to fight for MS nurses and assist them in defending and developing their own services, but we can only do this with your support. We have recently launched an appeal to help fund this urgent work; if you would like to make a contribution, please get in touch or visit www.mstrust.org.uk/nurses

For more on the GEMSS project, visit www.mstrust.org.uk/gemss

Laura Percival talks to MS nurse Judith Brassington, winner of the 2012 My Super Nurse award

How did you get into nursing?

My nursing career started in 1982 as an auxiliary nurse in Kendal and I began my nursing training the following year in Newcastle-upon-Tyne. My interest in MS stems back to my stepfather having the condition. He was diagnosed in the early 1980s when there wasn’t much in the way of MS treatment or services. Over the years things have changed a lot, but I’ve always been passionate about MS. I did my Professional Diploma in MS Care in 2009, with funding from the MS Trust.

Being local to Cumbria, I was aware of the lack of MS services here. Fortunately, Dr Footit, a consultant neurologist, came along in 2009 and pushed for an MS specialist nurse in South Cumbria. Talk about being in the right place at the right time - I was very fortunate to get the job. We’re a very small service, just Dr Footit, his secretary and myself.

The job was extremely challenging at the start as we were building the service from scratch. I went to check out the office space and there was nothing there apart from a chair - no desk, no phone, nothing. Dr Footit had to lend me a desk from his cellar. I knew the area though and had worked locally, so I could knuckle down and get on with it.

It’s been difficult to find all the people with MS in the area - many hadn’t been seeing a neurologist and had just fallen out of the system. We contacted GPs to try and find people and to let them know there was an MS nurse. I’ve now managed to identify more than 320 people with MS and I’m quite determined I will find everybody!

How do you help people?

I support people with absolutely everything MS related. When I see them for the first time we do a detailed assessment looking at every aspect of their lives. If people are having problems with work, I can give them information about where they stand. I’ve been for meetings with their employers and I’ve been to Job Centres with people who have been wrongly assessed as being fit for work.

How did it feel to win this award?

I couldn’t believe it when I was nominated for the MS Trust’s My Super Nurse award. It was so lovely that people had taken the time to do it. It reflects really well on the service as a whole and all the health professionals who support us. We’re hoping to develop the service much more in Cumbria and it’s good to see that it is already being recognised. Getting local media coverage has been a great boost.

It is really important for people with MS to have an MS nurse - we’re their first line of contact when problems arise. Where posts are at risk, people should be made aware and it’s important that they fight hard to ensure that they’re secured. Having access to an MS nurse can greatly improve quality of life for people with MS and their families and carers.

“Judith is our first MS nurse for our area. She shows outstanding commitment to her patients and we would certainly be lost without her”

I do a lot of home visits because of the rural nature of my patch. By going to people’s homes you can sometimes see the problems they are facing first hand and look at possible improvements. One important aspect is supporting carers. A lot of people aren’t aware of the local carers association. It can give them peace of mind to know that there is back up support if needed.

A big part of my job is directing people and their families to other services that can make their lives easier. For example, I’ve got someone who’s started going to a local hydrotherapy session at the swimming pool. It’s lifting her mood and helping physically and mentally. Small things like this can make a big difference.

“Judith has been a lifeline for me, nothing is any trouble. The world needs more Judith Brassingtons”

Freephone: 0800 032 3839
Supporting the MS Trust

It's time to be BLUE!

MS Awareness Week  
29 April - 3 May 2013

It is that time again when we need all our supporters to Be Bold in Blue! Get the dates in your diary now so you can get involved and be part of the MS Trust’s blue army during MS Awareness Week 2013.

MS Awareness Week is a great opportunity to shout about MS and raise much needed awareness and funds. There are many ways to Be Bold in Blue. It can be as simple as baking blueberry muffins and selling them at work, or dressing up in blue for a day. It could also be as big as a blue themed dinner party or gala ball, or even dying your hair blue! It really is down to you, so feel free to be creative.

The main thing to remember is that whatever you do, no matter how big or small, the money you raise really will make a difference for people with MS.

“I would encourage everyone to Be Bold in Blue. Not only is it great fun but it's such an easy thing to do to raise money for the MS Trust. I made cakes and sold them at work. I was very proud when I realised we had raised £140”

Kaye Robinson, Surrey - MS Trust fundraiser

The more people who know about our Be Bold in Blue campaign, the more money we can raise. Ask friends and family if they can take part, ask local schools to sign up, put up posters in your local area. Any help you can offer would be much appreciated.

MS Awareness Week is our chance to raise the profile of MS. If you want to get involved, please contact us or visit www.mstrust.org.uk/blue

Run for the MS Trust in 2013

DIFC Super Hero Run, London - 19 May

5K and 10K fun runs in Regent's Park, with free super hero fancy dress costumes! Open to all, including wheelchair entrants and children over eight.

www.mstrust.org.uk/superhero

British 10K London Run - 14 July

Run 10,000m in London and win gold for people with MS. The route takes you past some of London’s most iconic sights. Discounts for team entry.

www.mstrust.org.uk/british10k

Virgin Active London Triathlon - 27 and 28 July

Swim, cycle and run. Various distances available depending on your fitness level, there is also a relay option for teams of three people.

www.mstrust.org.uk/londontriathlon

Great North Run - 15 September

Support the MS Trust in the world's biggest half marathon. Run 13.1 miles from Newcastle to South Shields amongst tens of thousands of other runners.

www.mstrust.org.uk/greatnorth

Get ready for Monster Ski

Our sponsored ski and snowboard challenge is back for the winter 2013/14 season. Monster Ski is an endurance challenge, open to experienced skiers and boarders who are confident on a red run. We’d love to hear from anyone who might be interested in taking part or in helping us promote this exciting event.

Call us or visit www.mstrust.org.uk/monsterski to find out more.
MS nurse John gets on his bike
MS specialist nurse John Pohorely has raised over £2,600 for the MS Trust by taking part in two very different cycling challenges: the London to Paris cycle ride and the MS Circuit Challenge at Goodwood.

John has supported the MS Trust since he attended our training course for new MS nurses in 2004. He says that the MS Trust’s training has been fundamental to the service he now delivers and that our publications are “second to none”, adding “I’ve tried my best to give back what I can - I can’t produce a book but I can cycle from London to Paris.”

For John, one of the best things about the ride was meeting the other cyclists. He says, “The ride was excellently organised and I met a really good bunch of people. Stopping the traffic with hundreds of other cyclists in Paris is a pretty cool way to finish. Definitely one ticked off the bucket list!”

John has also supported our MS Circuit Challenge at Goodwood, cycling around the motor circuit on two occasions. He says, “The event has a really nice friendly feel. Everything is in place to help you succeed, in a very historic setting - a lovely day out”.

Want to follow in John's tracks?
We’re now taking bookings for the 2013 London to Paris cycle ride, which takes place from 19 to 23 June. It costs £99 to register and the minimum sponsorship is £1,450. Contact us to find out more or visit www.mstrust.org.uk/londontoparis

The MS Circuit Challenge at Goodwood in West Sussex will take place on Sunday 12 May. Come along and join us for the morning cycle challenge - 21 laps (50 miles) of the famous motor circuit. Great prizes will be on offer to the winners of various categories. £17.50 for advance registrations, £20 on the day.

Alternatively, take part in the afternoon family fun event and complete the 2.38 mile circuit ‘by any means’ - walking, cycling, on roller skates, in fancy dress - it’s open to all ages and abilities and is all about having fun! The flat motor circuit makes it ideal for mobility scooters and wheelchairs. Just £5 per person or £10 per family.

For more information and to register, visit www.mstrust.org.uk/goodwood

Coming soon to an airfield near you...
Are you looking for something to shake off the cobwebs? We need 100 daring individuals to come forward and sign up for our Jump in June skydiving month!

You can jump for the MS Trust at one of 21 airfields across the UK. For every one person that takes part in a sponsored parachute jump, at least 32 people with MS can receive their free copies of Open Door for a year.

"It feels astounding to do something so exhilarating and help such a worthy cause"
Roya, MS Trust supporter

Roya (pictured) Jumped in June to support the MS Trust and raised over £800. Sign up today and you could join Roya, and many others like her, making a real difference for people living with MS in the UK.

Call us or visit www.mstrust.org.uk/jump to get your free information pack.
MS Trust website resources
As well as our list of printed books and factsheets, the MS Trust has a number of resources available on our website

At work with MS
An online resource for people with MS in the workplace. These pages look at what adjustments can be made to help people remain in employment, people's employment rights under the Equality Act and also ways to manage symptoms at work www.mstrust.org.uk/work

Posture
Maintaining a good posture can be challenging for people with MS but simple changes can be incorporated into everyday activities to help achieve better posture. These web pages explain what posture is all about, why good posture is so important and include suggestions to improve posture in everyday situations www.mstrust.org.uk/posture

Exercises for people with MS
A collection of exercises designed for people with MS, together with extracts from the Move It For MS DVD led by Mr Motivator, core stability exercises and a relaxation session to help you unwind www.mstrust.org.uk/exercises

StayingActive
An online directory of sports and leisure activities for people with MS, including links to key organisations and personal stories of experiences with sports. There's something for everyone in our StayingActive pages www.mstrust.org.uk/stayactive

StayingSmart
Can't concentrate? Find you are forgetting things? Can't find the right word? Have a look at the StayingSmart website. Written with the help of a neuropsychologist and illustrated with tips for coping with day to day situations sent in by people with MS, StayingSmart is an important resource for people living with cognition symptoms www.stayingsmart.org.uk

Spasticity triggers
Muscle stiffness and spasms can be made worse by complicating factors such as bladder and bowel problems, skin damage and infections. Treating these trigger factors is important when trying to manage symptoms effectively. Spasticity triggers allows readers to build up a list of the factors that may be affecting their own symptoms and includes a diary to help spot patterns that may help identify triggers.

An interactive version on the MS Trust website helps readers build up their list of triggers online www.mstrust.org.uk/spasticity-triggers

Help us with new publications
Would you like to help the MS Trust in developing information resources? To find out more and join our readers' panel email info@mstrust.org.uk or call the Information Team on 01462 476700

Managing continence
We are developing resources about managing continence and would really value your help. If you are managing bladder or bowel symptoms as part of your MS and would like to be involved, please get in touch or visit www.mstrust.org.uk/continence

Secondary progressive MS
The MS Trust is planning a new resource about secondary progressive MS that we expect to publish at the start of 2014. To help us make the contents and design as helpful as possible, we are asking people to complete a brief survey about topics the resource should cover and how this might be best presented.

Visit www.mstrust.org.uk/spms-survey or contact the MS Trust on 01462 476700

The Information Standard
Evidence based information has been at the heart of the MS Trust’s work since our foundation in 1993 and so we are delighted to have been certified to carry The Information Standard quality mark on our publications.

The Information Standard was devised by the Department of Health to allow people seeking health information to identify resources that are accurate, based on good evidence, up-to-date and unbiased. Information providers who meet the Standard have demonstrated how information fits into the aims of the organisation, how evidence for a particular publication is identified and assessed and how the target audience and expert reviewers are included in developing information.

High quality information is vital to the successful management of MS - increasing confidence and involvement in making decisions, reducing isolation and anxiety and improving clinical outcomes. The Information Standard mark is an easy way to recognise health information you can trust.