

Finding Harmony

Life with an
assistance dog

Get active!
Exercising with MS

Carers column:
McFly support
young carers

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Getting loud about benefits: MS Society Scotland staff and members at the Hardest Hit rally in Edinburgh

We've been very busy promoting the Society, running training courses, campaigning (see picture above of the Hardest Hit rally in Edinburgh) and working on publications. We finally experienced a late summer with that little burst of Mediterranean heat at the end of September! Lots of people visited our stand at the Naidex event in Glasgow in September, and vast numbers of our publications flew off our tables. Very gratifying, as a lot of work goes into the production of the Society's information leaflets.

Now we have a new Scottish Council, MS support is being developed across the UK and MS Life is on target for

Manchester in April 2012. More details within.

Our book reviewer returned her review copy of *What nurses know...* - with reluctance :(- so you can read about this and some new and updated publications on the back page.

At the Society AGM in September, some changes were made to the constitution.

To read the updated constitution please go to our website at <http://www.mssociety.org.uk/ms-resources/ms-society-constitution>

Finally, if our hot topic – exercise – does not get you rushing out the door to find your nearest fitness class, then get hold of a copy of our exercise

“...get hold of a copy of our exercise DVD and do some lovely movement in the comfort of your own home!”

DVD and try out some lovely movement in the comfort of your own home! It will keep you warm until our next edition, which we hope to have with you in March.

Season's greetings from all of us at MS Society Scotland, and we look forward to a bright 2012.

Jenny

Jenny, on behalf of the magazine team

Our first AGM held as new charitable company

We held our first Annual General Meeting (AGM) as a charitable company, following the recent governance review and changes, on 10 September at the Crowne Plaza Hotel in London. It was Tony Kennan's last AGM as Chair of the Society and he steps down after six years in the role. Stuart Nixon is currently acting Chair of the Society until Hilary Sears joins us as our new Chair in January (see below).

Introducing the new Chair of the Society

We are delighted to welcome Hilary Sears, our new MS Society Chair. Tony Kennan, the retiring Chair, said: "I'm delighted the Society has appointed Hilary as my successor, and wish her well in the role. It has been a pleasure and a privilege to have been involved with such a fantastic organisation for so long, and I'd like to thank everyone at the Society for their hard work and support during my tenure."

Hilary, a senior business professional, brings with her a great deal of experience working with membership organisations. Her personal connection to MS is that her father, Clifford, was diagnosed with the condition in the early 1980s, only to be told eight years later that he was in fact suffering from a different condition which can present similar symptoms to MS.

"I'm honoured to have been appointed to this important position," said Hilary. "Although we eventually discovered my



Our new Chair, Hilary Sears

father didn't have MS, we lived for years in the belief that he did, and he spent many years undergoing treatments never really knowing if they were effective or not, as his condition deteriorated.

I know diagnosis and treatments have advanced a lot since then, thanks in part to research funded by the MS Society. I'm excited about playing my part in helping the Society advance our knowledge further, and support people affected by MS with their needs now, and in the future."

New Scottish Council members announced

The following people will serve on the new Scottish Council, formally taking up their roles on 1 January 2012:

Bryan Alexander

Ann Barnes

Judy Eglington

Michelle Logie

Linda Mason

Hew Mathewson

Angela McCormack

Angela Monteith

We are delighted to announce that Hew Mathewson has been appointed chair of the Scottish Council. Hew is a senior partner in an Edinburgh dental practice and is a member of the UK Advisory Committee on the Misuse of Drugs. He has been a member of the MS Society for 20 years.

We offer a warm welcome to the new Council, and many thanks to all who took part in the election. You can view footage from the AGM online at <http://www.voiceprompt.co.uk/mssociety/agma11/>

Look out for more information about your new council members in the next edition of MS Connect!

Developing MS Support

Following a successful pilot scheme, we are rolling out a new support volunteer role across the UK. The MS Society's MS support officers and volunteers are among the greatest strengths of our organisation. These volunteers aim to empower people affected by MS through giving information, providing emotional support, and signposting to available services.

The new MS support programme is designed to give support volunteers additional training and guidance to help them provide an even better service to people affected by MS.

This new approach will mean:

- recruitment of volunteers to this role
- a new four day training course for these volunteers
- the development of a team of support volunteers in each area with specific roles, led by a Lead Support Volunteer
- offering ongoing support and training



Representatives of the Angus, Perth and Stirling branches visited the Edinburgh Centre for Translational Research on 25 October after they donated over £30,000 to the work of the centre

In the New Year we will begin a recruitment campaign for new volunteers, and training will begin in April 2012.

Do you think you have the skills to help the MS Society provide this vital support to people affected by MS? If so, please contact our Volunteer Development Manager, **Lynda Boyce** on **0131 335 4050** or email **lboyce@mssociety.org.uk**

Success at the MS Society Awards



Isobel Craigie with Ainslie Harriet and Isobel's daughter Margaret

The MS Society Awards took place on 27 September in London to celebrate the stars of the MS community, and among the nominees were three valued entries from Scotland. Professor Charles French-Constant and Professor Robin Franklin won the award for Best MS Research of the Year for their work at the Edinburgh Centre for Translational Research and the Cambridge Centre for Myelin Repair. Thanks to their recent discoveries a treatment to repair the damage caused by MS to myelin could be available within the next 15 years. (See page 19 for our fundraising appeal for myelin repair research.)

Isobel Craigie, a.k.a. the Flying Granny, and Currie Balerno Rotary Club were also highly commended for their fundraising efforts. Isobel did a wing walk and a parachute jump all within two years of her 80th birthday. She also raises money by selling homemade jam, knitting and crafts, and has so far raised over £40,000 for the MS Society. Members of Currie Balerno Rotary Club wrote, edited and produced a cookbook in 2010 which featured recipes from famous chefs such as Gordon Ramsey and Nick Nairn. So far over 2,600 copies have been sold, raising over £26,000 for the MS Society Scotland.



Our biggest and brightest FREE event

On 14–15 April 2012, the MS Society’s biggest and brightest free event, MS Life, heads to Manchester. This lifestyle and MS knowledge event gives you direct access to leading **MS researchers** on hot topics such as myelin repair and stem cell research, and all the latest on drugs and treatments. You can ask questions to a range of MS health care professionals in our **Meet the Experts** area.

Over 40 workshops taking place across the weekend will cover various topics such as symptom management, benefits, employment, sex and relationships, and support for carers.

Our **lifestyle village** exhibition has a buzzing marketplace hosting everything from information and support to useful products and services. Visit the **MS Spa** to test drive some complementary therapies, and work up an appetite while watching some **live cookery demonstrations**.

Regarding **Getting Active** at MS Life, come and try seated yoga, Pilates or even accessible cycling. Discover how you can ‘Get Active’ for your MS community by getting involved in **fundraising, volunteering** and **campaigning**.

Learn about **online services and support** at the internet café or simply take some time out from the event to do some web surfing.

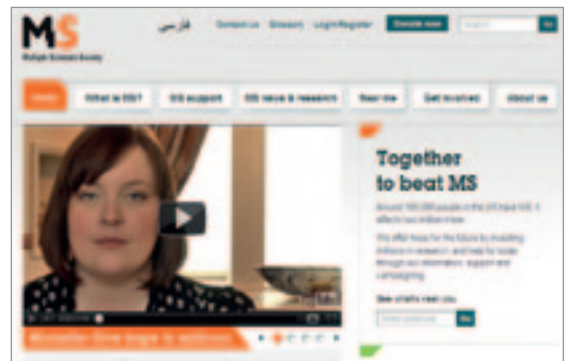
Drop the young ones off for some fun activities at the **free crèche** or bring them along to the **Wheel and Walk** fundraising event on Sunday 15 April.

For more information about MS Life please visit the website www.mssociety.org.uk/mslife or call the MS Life team on **020 8438 0941**.

Have you checked out our new website yet?

Our new website has been up and running for a few months now and there are lots of great new features, such as creating a personalised home page with content specific to your needs, interests and location. You can search for services near you on the ‘near me’ map, and the content from all four nations has been integrated into one, UK-wide site. There are some fantastic videos to watch, and in the community blog you can read the stories of others affected by MS. The MS forums, a popular feature on the old site, are as lively as ever.

Check it out at www.mssociety.org.uk





Almost 100 guests visit ms space Lanarkshire

What a day we had on Friday 30 September at ms space Lanarkshire! The day kicked off with a musical session led by Barbara Scott, a musician/performer/educator, who is also a carer for her husband who has MS.

The first presentation was delivered by the Director of the Centre for Regenerative Medicine and Co-director of the Centre for Translational Research (both at University of Edinburgh), Professor Charles french-Constant. He provided an absorbing update on how the latest research is proceeding to try to halt and/or repair the damage that causes MS. (See page 19 for information about our fundraising appeal for myelin repair research.) This was thoroughly explained and extremely thought provoking, leading to some interesting questions from the floor.

Secondly, Sue Allison, Strategic Lead for Carers for the MS Society

gave an overview of our work to establish a strategy for supporting carers, which will be launched during Carers Week 2012.

After lunch, Ben Hall from Shared Care Scotland spoke of improving access to quality short

Professor french-Constant provided an absorbing update on how the latest research is proceeding

breaks for people in Scotland. The MS Society's Julie Gilson joined him to talk about our Short Breaks and Activities Fund.

Next on the agenda, Matt Lancashire from Citizens Advice Scotland covered the major changes to Disability Living Allowance (DLA) and Employment and Support Allowance (ESA). Jo O'Neill, Policy Officer for MS Society Scotland, followed Matt with a rousing presentation on how people could take action by

sharing their stories, joining the MS Society's Policy Forum or writing to their MP/MSP. (See page 8 for the latest campaigns.)

Lynda Boyce, Volunteer Development Manager for MS Society Scotland, delivered the final presentation, providing an insight into the exciting new Support Volunteer role (see page 5) and the training programme for Scotland.

In addition to all this, therapists provided free taster sessions and local services hosted exhibition stands. Guests also enjoyed group sessions on self-management, exercise and relaxation techniques, and could 'meet the specialist' by visiting local MS nurses and a physiotherapist. Not to mention the chocolate fountain that certainly brought a smile to a few faces during the day!

Our thanks to everyone who made the day such a great success.



Getting loud about benefits!

The MS Society has been getting loud about the changes to disability benefits that could leave thousands of disabled people and their families without vital support.

Nearly a thousand people joined us at the Hardest Hit rally in Edinburgh last month, this was just one of many protests taking place across the UK.

It is estimated that disabled people and their families will be £9 billion worse off over the course of this parliament as they are the hardest hit by the UK government's cuts, losing out in multiple areas which have been hit by the benefit reforms and service cutbacks.

The MS Society is supporting the Hardest Hit campaign which intends to send a clear message to the government.

1. Stop cuts to Disability Living Allowance, a vital benefit that helps disabled people live independently.

2. Make sure Employment and Support Allowance, which replaces Incapacity Benefit, has a fair and effective assessment process, does its job and supports disabled people.

3. Stop cuts to services that are vital to disabled people, such as day-care services, transport services and respite-care services.

To find out what the changes could mean for you and how to get involved in our campaign please visit our website

<http://www.mssociety.org.uk/get-involved/campaigns/key-campaigns/uk>

Find out more about the Hardest Hit campaign here: <http://thehardesthit.wordpress.com/>

The Society at the SNP conference

Staff member Joanne Scott took centre stage at the conference, to speak about the importance of improving support for people with long-term conditions. Joanne, who lives with MS and coordinates our self management courses in the Highlands and Islands, was asked to speak at a fringe event held by the Long Term Conditions Alliance in Scotland (LTCAS).

Joanne told attendees, including the Minister for Public Health, Michael Matheson

(pictured with Joanne): "I want to have control of my life. I am the best person to make decisions regarding my own self management of my condition and the support I need to live my life".

The Scottish Government is keen for public services to be more joined up and people to have more choice over their support. It is proposing changes to the law so that more people are offered the option of directing their own support.



To find out more about self directed support contact Joanne O'Neill, Policy Officer at joneill@mssociety.org.uk



Get active!

Could 2012 be the year you get active? MS Connect considers how to find exercise which suits you.

Sticking to an exercise regime is hard, even without having MS. But exercising regularly can keep your body working to its full potential, helping you to manage and live with MS.

When Annette, from Midlothian, was diagnosed with MS she found herself in a “slump”, and exercise fell by the wayside. Her Pilates class became stressful because she felt she was keeping everyone else back, and she found it hard to motivate herself to do exercises at home provided by her physiotherapist.

Last year, however, Annette resolved to get active, joining a yoga class for people with chronic conditions. “I decided that I had to step up to the mark and make myself feel better. If not, I would be allowing MS to have even more of an impact on my life. I didn’t feel anxious about going to this class because I knew I’d be on an even keel with the others,” she says. “It’s been good: I like being part of a group because seeing the others improving encourages me and the exercises help with stress so I’m calmer. I don’t have so much ‘down time’ now. I can stand for longer and I have better upper body strength so I’m able to hold the hairdryer and do my hair. Now I’m adopting exercise as part of my daily life – even if I’m just doing the dishes I’ll do a bit of warm-up stretching!”

Getting started

“It’s really important for people with MS to exercise because it’s a case of ‘use it or lose it’,” says Jane Petty, the MS Society’s Strategic Lead for Physiotherapy. “If you haven’t been active for a while check with your GP or physiotherapist that there’s no reason why you can’t start exercising,” she advises. “Then start with something very gentle and gradually increase it. To really benefit from exercise though, you need to do something on a daily basis.”

Jane recommends the MS Society’s new exercise DVD, suitable for people with varying levels of mobility. The DVD is presented by athlete Sally Gunnell, who leads a small group of people with MS through a programme of gentle exercises and stretches. Nina, from Aberdeen, has been trying it out. “I tend to shy away from formal exercise classes and over-enthusiastic celebrity DVDs!” Nina admits. “But I have to say I was pleasantly surprised...I found it extremely appropriate. Sally has an understanding and practical approach and the routine is realistic and encouraging. I feel the benefit already.” You can order the free DVD from the MS Society’s website.

Joining an exercise class

If you’re finding it hard to motivate yourself, joining a class for people with MS or for people

with long-term conditions can help. Some MS Society branches and MS therapy centres run classes. Annette's yoga class, for example, is run by KICC (Keeping Fit with a Chronic Condition) in East Lothian. KICC was established by Janice Thomson from the local MS Society branch, (with the support of a Community Health Partnership Grant) when she couldn't find a suitable class near her.

Since starting in 2009, KICC has run 380 classes including yoga, Pilates, hydrotherapy and meditation. Janice has seen the members of the programme develop and change over time. "Many join for a short while before returning or progressing to mainstream classes. This rebuilding of confidence is one of the main benefits," she says.

Other examples of local classes include the following:

- In Glasgow, Revive MS Support offers a range of classes including yoga, Pilates and 'circuits for guys'.
- The MS Society's Borders Branch offers exercise classes in Tweedbank and Jedburgh.
- In Aberdeen, the MS Society's Stuart Resource Centre provides sessions on a MOTomed exercise bike, exercise classes, yoga and Tai Chi.

Contact your local branch or therapy centre to find out if there



"The exercise bike has benefitted my legs and when I've finished I feel better, knowing that I've cycled 1.5 miles!"

is a class near you – you can find details on our website or give us a call. Also check www.mstherapycentres.org.uk and www.revivescotland.org.uk

Working out at the gym

Of course classes aren't for everyone. "You might like to go to a gym and exercise on your own, but with the support of an instructor who knows about MS," says Jane. "Get in touch with your local gym and ask if they have anyone there who can support you to establish a suitable exercise regime, and if they have accessible equipment." Find out if your fitness instructor has joined the Register of Exercise

Professionals and what level they have trained to – ideally you'll want to find someone who has been trained to level 3. You can find more details and search for your instructor online at www.exerciseregister.org

Some MS Society groups and centres have purchased accessible gym equipment. Maureen, from Aberdeen, uses the MOTomed exercise bike at the Stuart Resource Centre. "The bike has benefitted my legs and when I've finished I feel better, knowing that I've cycled 1.5 miles!" she says. "If you can't operate the bike with your own power the bike can do all the work for you, so your legs and arms are still moving."

The MS Society is working with the fitness industry to make gyms more accessible. In conjunction with Oxford Brookes University the Society

offers distance learning in 'exercise rehabilitation for people with long-term neurological conditions'. Why not see if an instructor from your local gym is interested? Some MS Society branches have offered to fund someone from their local gym to do the course, in return for that person providing an exercise class for people with MS.

Find out more at

<http://www.mssociety.org.uk/ms-support/professionals/courses-and-learning-events/exercise-rehabilitation>.

In the swim

Water can be a particularly good environment for many exercises. Billy, from East Lothian, appreciates the chance to get out of his wheelchair and into the water. "I go swimming every week, using a hoist to get into the pool," Billy says. "You feel lighter in the pool."

Being in a pool doesn't just have to mean swimming – aqua aerobics classes are offered by many sports centres.

Exercising for wheelchair users

Power-chair user Billy exercises frequently. As well as swimming he goes to Pilates classes, uses an accessible gym (the Thistle Foundation gym in Edinburgh) and has physiotherapy at the MS Therapy Centre Lothian. "I started exercising because I needed some structure in my life,"



he says. "It's of mental benefit because there's a reason to go out every day. [Physically] I'm more composed in my chair now."

"People sometimes think that once you start using a wheelchair, that's it," says Jane. "But you can still exercise and you can still improve things like your sitting balance, your breathing and your arms. However severely affected you may be, there are still things you can do and be helped to do. Your physiotherapist can advise you on passive or assisted movements that you can do with a carer. Breathing exercises are also important."

Setting yourself goals

A good way to get motivated and gain the confidence to get back into exercising is to use the tools taught on a self management

The role of physiotherapy

If you have a specific problem or ongoing symptoms that are affecting day-to-day activities, mobility or independence, then physiotherapy can help. A physiotherapist will work with you to assess your physical difficulties, and help you to improve your movement and other functions of your body by helping you set achievable goals. Exercise is one of the key ways in which they do this.

Ideally your physiotherapist will work with you, so that once the course of treatment is finished you're able to maintain what you've achieved during your sessions. If MS is affecting the activities you are able to do, they might suggest new ways to stay fit, or ways to adapt your preferred exercises.

course. These free MS Society-run courses look at how you can manage your MS more effectively using techniques such as exercise. Val Johnston runs the programme in the West of Scotland and has MS. "During a course we look at the different types of exercise," she explains. "We look at how to monitor your physical activity, advising that people should find their moderate level.

"We use the FIT formula (frequency, intensity and time) to help plan exercise. With this in mind, and knowing your moderate level, you can set yourself a weekly action plan. You might set a very small goal at first, and week by week increase what you do. Making an action plan in a group is a real incentive to actually do it because you have to report back! But if you're not feeling well and you can't do it then everyone understands. Group members support each other."

Leading the course provides Val with the incentive to keep exercising herself. "Exercise is an important part of managing MS," she says. "It makes you feel better about yourself, it helps you sleep, it keeps the heart healthy, it's good for flexibility and helps reduce fatigue, it helps balance and coordination, it's good for depression, it helps your posture, it helps to prevent constipation, it can help people participate in family activities – there's loads of positives!"

Exercise

– finding out more

Read: MS Society Essentials 21, Exercise and physiotherapy, and 18, Complementary and alternative medicine. Both are available from our website or you can call 0131 335 4050 and ask for a copy. You can also check out this online guide to physical activity for people with neurological conditions: <http://www.shs.brookes.ac.uk/lifepass/>



Exercising with MS DVD: you can order this free from our website: <http://www.mssociety.org.uk/ms-resources/exercising-ms-dvd>

Branches and therapy centres: For your nearest branch or therapy centre,

check our website or give us a call. You can also visit www.mstherapycentres.org.uk and for Revive MS Support www.revivescotland.org.uk

KICC: For information about KICC classes in East and Mid Lothian, please contact **Janice Thomson** on **01875 619 805**.

Self management: Check our website to see if there is a class starting soon near you, contact **Ailsa** on **0131 335 4050** or email msscotland@mssociety.org.uk

For information about adapted sports in your area, you can contact Scottish Disability Sport <http://www.scottishdisabilitysport.com/sds/index.cfm/contact/sports-contacts/>

The Stuart Resource Centre, Aberdeen: Call **01224 692 777** for more information or email stuartresourcecentre@mssociety.org.uk.

The Thistle Gym, Edinburgh: <http://www.thistle.org.uk/our-services/health-wellbeing/thistle-gym>



My life with MS

As winter approaches Jenna Anderson will be keeping herself busy with some indoor activities.

I recently bought a new Kindle and was pointed to Shelfari – www.shelfari.com. It's a site where you can list all the books you're reading and have read, post reviews of the books, and follow your friends to see what they're reading – and you don't have to have a Kindle to use it. It's a great way of finding out what other people are reading, finding out about books you otherwise might not have heard about, and reading reviews of books before choosing whether to buy or not.

There are so many craft shops and websites out there, it's perfect timing to start making Christmas decorations, Christmas cards, parcel tags, a wreath for your door, and anything else you can think of! Craft projects like these are great for passing time indoors in the bad weather and can be great fun too. You might surprise yourself with the fab things you make!

Crocheting is the craft of the season this winter, and knitting was very popular last year. Although they bring to mind rather outdated items, there are loads of modern patterns out there, and the fingerless gloves in particular look great. They're something to keep you busy, and you'll be looking fab and keeping warm once you've finished! Great as gift ideas too.

There's nothing better than homemade goodies at Christmas. Whether it's condiments for the table, mincemeat for mince pies, sweets, mulled wine, or gifts to give to others, the kitchen's a

great place to spend a rainy day. BBC Good Food website (www.bbcgoodfood.com) has loads of recipes and kitchen gift ideas.

As making your own gifts and decorations has become rather fashionable recently, there are a lot of websites with ideas and patterns out there. Tipnut (www.tipnut.com) and House to Home (www.housetohome.co.uk)

are a couple of good ones. Google and you'll come up with a huge list of websites to pour over.

In a way, the poor weather's a bonus as it's a great incentive to make lovely things.

Get creating! And if you need help with your creations, get a buddy to help you do the tricky bits.

Jenna blogs at lifewithms.wordpress.com.



Forward
thinking today
can help us beat
MS tomorrow

If you would like information on how you can leave a gift to the MS Society in your Will, please contact **Hazel Johnstone** on **0131 335 4071** or email hjohnstone@mssociety.org.uk



Photographs by the Sunday Mail
and by Canine Partners.

Finding Harmony

In 2008 Edinburgh resident **Sally Hyder** found herself in a dark place. Her MS was worsening and she felt trapped. Three years on, she has reached the top of Ben Nevis and published a book. What changed? She found Harmony...

by **Hannah Maunder**

Before Sally found her assistance dog, Harmony, her floor was littered with dropped items. There they would stay until her husband got back from work or her daughter from school. Now, Harmony promptly retrieves them. She also helps Sally dress and undress, and helps with the household chores such as unloading the washing machine. Out shopping, Harmony will get goods off the shelves and hand over Sally's purse at the till. She keeps Sally safe: when Sally fell on the ice last winter, Harmony raised the alarm.

Sally found Harmony through the charity Canine Partners. The UK-wide organisation trains dogs to be the hard-working assistants, and companions, of people with disabilities. Their human partners speak of the life-changing impact of having such a dog. People have regained independence, and families and carers are put under less pressure.

For Sally, Harmony couldn't have entered her life at a more crucial time. Diagnosed with MS as an adventurous twenty-something, Sally says the condition initially had little impact on her life. She continued

working in a demanding job and gave birth to three children. However, a decade after diagnosis, she had a bad relapse and her symptoms worsened. "I went from crutches to a Zimmer, and then to a wheelchair. Everything became problematic," she says.

She gave up work to devote more time to her youngest daughter, Melissa, who is autistic, and found herself increasingly isolated, saying: "I'm very gregarious but I would go a whole week and not speak to anyone outside my family." In 2008 she hit rock-bottom.

“We had the worst summer possible,” she recalls. “Melissa was screaming non-stop and my MS was awful: I was permanently exhausted. I was relying on other people, like my husband and other children, to do things for me or Melissa. I was stuck in the house because I was scared to go out on my own with Melissa – if she ran off, how would I catch up with her? I was really depressed.”

She knew she had to seek extra help. After a google search she found Canine Partners and was instantly intrigued. “I grew up with dogs and the idea [of an assistance dog] appealed to me because it was a bit quirky,” she explains. “And it was clear they expected you to provide the dogs with a high standard of care; that gives you a real sense of self-esteem.”

After a few initial meetings she was asked to spend two days working with eight or nine different dogs, one of whom was Harmony. “They were looking for that ‘click’ between dog and human and I absolutely loved exercising her,” Sally says. She had found her perfect match, but she couldn’t take Harmony home there and then. After being partnered with their human, the dogs are put through advanced training, tailored to their human’s needs. Once Harmony had completed her training it was Sally’s turn – she spent two weeks at a residential centre



“She has made an indescribable difference... I re-discovered my love of being outdoors in the fresh air, getting muddy and wet!”

with Harmony, learning how to care for her and to understand her. She learnt how to call her so she would always come back.

Then Sally took Harmony home and her life changed.

“She has made an indescribable difference,” Sally says. “Suddenly I was out of the house because I had to take her for walks. I re-discovered my love of being outdoors in the fresh air, getting muddy and wet!

My scooter has been up and over tree roots and goodness knows what else. It’s about independence,” she continues. “I don’t have to rely on people to do the little tasks anymore, and that gives me dignity. The best example I can give is when I went shopping with Harmony and my handbag fell off my lap, spilling the contents everywhere. Harmony carefully picked everything up whilst a little crowd gathered around me, amazed at what this dog was doing!”

An unexpected benefit is that Harmony also helps Sally care for her daughter Melissa, who is soothed by the animal. “If she’s upset and having a panic attack she will get a cuddle from Harmony, and that stops her attack,” Sally says.

Harmony has provided Sally with a solution to her difficulties which is perfect for her personality and needs. She believes there needs to be more of this kind of creative thinking, pointing out that, in England, some councils allow people to use direct payments for the upkeep of an assistance dog. “It’s a really good use of money, the cost of an assistant would be so much more and Harmony is on call 24-7!” she says.

Sally is now on a mission to publicise the benefits of assistance dogs. She was given a great boost last year when publishers Harper True spotted a story she’d written online

and suggested that she wrote a book about her experiences. It took just three months for Sally to write her story and her book, 'Finding Harmony', has been a great success, reaching the Sunday Times bestseller list. In the subsequent whirl of publicity Sally and Harmony were flown down to London to star on This Morning (holding boarding passes is now one of Harmony's tasks).

Writing a book in three months is pretty impressive, but this year Sally completed her biggest challenge yet – reaching the top of Ben Nevis using a motorised wheelchair (the 'all-terrain' Boma). Supported by a crack team of friends, family, military personnel and Edinburgh fire fighters, she reached the summit after a five-and-a-half hour ascent – the first person to do so in a wheelchair that has not been lifted. The moment was all the more special as she had tried and failed to reach the summit the previous year. "But, with a bit more planning and organisation, I got there, and it was incredible! Everything is achievable with planning," Sally says.

Ironically, the woman who climbed a mountain in her wheelchair was recently almost unable to attend her own book-signing event, because of one small step. The bookshop hadn't provided a ramp, instantly disabling Sally. "I've become a bit of an advocate for accessible



places," Sally says. "Able-bodied people don't realise how incredibly difficult and frustrating life with a disability can be."

And although Sally's story is often described as inspirational, she has received many letters from readers of her book telling her how they value being given permission to be "hacked-off and upset about their disability". She is not afraid to speak candidly about being "in a dark phase", saying: "I'm a disabled person who deals with pain. If I'm having a bad week I'll get scared, upset, angry and fed up.

But I am able to pick myself up and keep going."

And her experiences demonstrate how, with the right support, you can adapt to difficult changes in your life and continue to enjoy the things you love. "Another person's Ben Nevis might be making it to their daughter's wedding," she says. "Sometimes you have to accept that things have got more complicated and you might need more help. That could just mean buying a tilted kettle so you can make yourself a cup of tea!"

For her, it meant finding Harmony.

Sally blogs at

<http://50thingsbefore50-sallyhyder.blogspot.com/>

Her book, *Finding Harmony*, is published by **HarperTrue**.

Canine Partners provide assistance dogs free of charge. Once an application has been successful the waiting list is, on average, 18 months. For more information about Canine Partners visit www.caninepartners.org.uk or call **08456 580 480**.

You can find out about other assistance dog organisations at www.assistedogs.org.uk



McFly make a surprise appearance at the Scottish Young Carers Festival

The state of caring



Marion MacNeil reports on what's going on for carers around Scotland.

Having just returned from a very busy, informative day at the **Carers Scotland Summit** in Glasgow, I am pleased to report some good examples of organisations working together to improve service outcomes and carers' experiences throughout their 'caring career'.

However, it is also apparent that the admirable aims of central and local government to help carers are still too often not resulting in tangible improvements on the ground. At a time of severe financial pressure in the public sector it must be remembered how much carers actually save the public purse in Scotland, £7.68 billion a year according to recent estimates. The gap between intention and outcome is frustrating, especially as it is an uneven gap with some local authorities offering better examples of integrated support

than others. Carers deserve a consistent level of support wherever they happen to be, not least because we all benefit from the incredible work that they do.

Carers appeared on TV on the evening of 31 Oct on Channel 5's *Celebrity Wish List*, featuring clips from the Scottish Young Carers Festival earlier in the year, thanks to the surprise appearance of boy band, **McFly**. In Scotland, over 100,000 young people provide unpaid care to a relative or loved one. They often take on practical or emotional caring responsibilities which would normally be expected from an adult, and these might include cooking, cleaning, shopping, dressing, managing the family budget and administering medication.

The Princess Royal Trust for Carers currently helps more than 4,000 Scottish young

carers through a network of centres and services. For the last three years, they have held a weekend festival which, for many young carers, is their only opportunity to spend some time away from their responsibilities at home. Over 500 of them travel from all over Scotland for a weekend of camping, outdoor activities, arts, crafts, discussions, games and socialising.

Within the MS Society, Sue Allison, **Strategic Lead for Carers**, is preparing an online consultation, to establish how the Society will provide support for all carers of people with MS in the future. If you want to know more about this, or the support available for young carers, contact the information team on Tel: **0131 335 4050** or Email: information-scotland@mssociety.org.uk.

MS Society Superstars

Thank you to all those who have helped support the 10,500 people with MS in Scotland.



Anna McKenzie opened her garden in Bridge of Weir to the public on 14 August and raised an impressive £590.



KRC International, a professional relocation management consultancy from Montrose, held a golf event on 11 July and raised £1,575.



Olive Patterson held a Tea Dance in aid of the MS Society on 27 August and raised £700. Since 1996 Olive and her very generous friends have raised over £7,900.



Rachel McLagan and Gemma Baillie presented the MS Society with a cheque for £4,000 in August. The money was raised at their Assemble & Leap highland dancing event in November 2010.



Lisa and Marco from the Fierce Valley Roller Girls found their skating legs and took part in the Goodwood Roller Half Marathon in August. Together they raised £526.



Martin Connelly and fellow sports enthusiasts from the village of Eaglesham raised £1,500 at a sportsman's dinner on 27 May.

A burning success



The first MS Society Firewalk was lit on Friday 30 September (despite pouring rain!) and after their two-hour training session, the 30 intrepid firewalkers took their first brave steps onto embers burning at over 1200 degrees Fahrenheit. Thank you to everyone who took part on the night and everyone who donated. The event has so far raised over an impressive £13,500 to help support people with MS in Scotland.

If you've done something amazing and would like to be an **MS Society Superstar**, send your photos to msfundraising@mssociety.org.uk

Stuart goes the extra mile at the Loch Ness Marathon

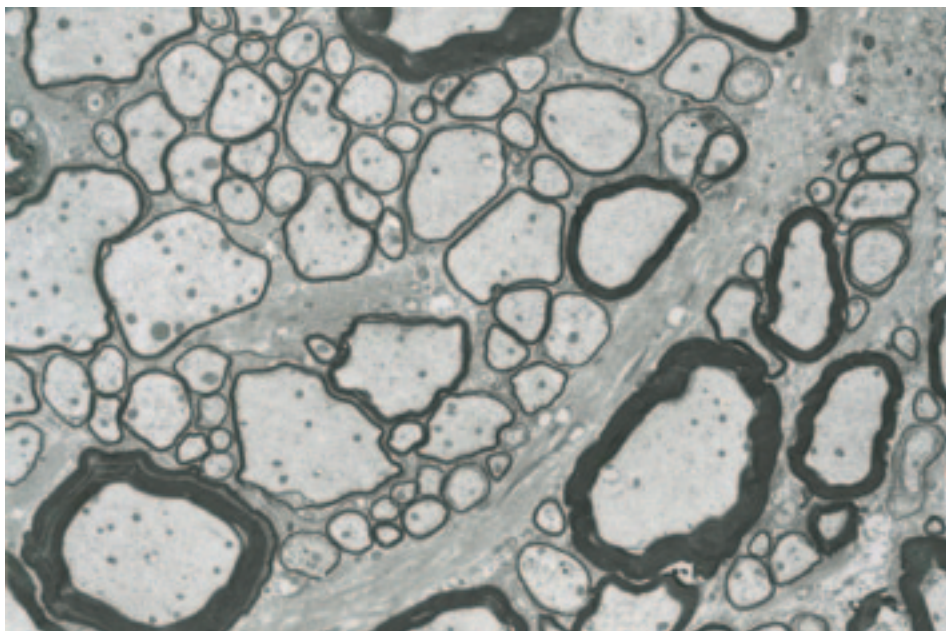


Just as he was starting to feel the burn at mile 18 of the Loch Ness Marathon, Stuart Rose was given the news he had been waiting for: he had hit his £5,000 fundraising target! Stuart completed his first marathon in an impressive 4 hours 58 minutes and 48 seconds. He says: “Seven years ago when I was diagnosed with MS I never thought this would be possible. I am absolutely

delighted at all the support I have received and the amount of money I have raised for this fantastic charity. Thank you to everyone who has donated.”

If you would like to follow in Stuart’s footsteps, why not join the MS Society team at the Rock n’ Roll Half Marathon on **15 April**, or the Edinburgh Marathon or Half Marathon on **27 May 2012**.

How you can help develop a treatment that could beat MS



Today, the pioneering work of MS Society-funded scientists has brought us to the verge of being able to beat multiple

sclerosis. Scientists from across the UK, led by the Cambridge Centre for Myelin Repair in collaboration with

the Centre for Translational Research in Edinburgh, have made a truly revolutionary discovery – they have proved in the laboratory that it is possible to repair myelin.

This breakthrough has given us real hope of beating MS and transforming the lives of the 10,500 people living with MS in Scotland, along with millions of people around the world, both now and for future generations.

We need your support to raise the funds needed for the next stage of research which could lead to clinical trials of potential MS treatments within three years. To make a donation visit www.mssociety.org.uk/hope or call **0131 335 4050**.



At your service

When **Andrew Johnston** started working for the MS Society Scotland as Service Development Manager, large areas of Scotland were without any specialist MS services. Six years on, there is an MS nurse post in every health board in Scotland and Andrew is setting his sights on social care. He speaks to MS Connect about why specialist services are so important.

What were MS services like in Scotland when you started working for the MS Society?

I was appalled by what people with MS told me about the lack of services. There were great areas in Scotland where there were no specialist posts whatsoever. I had a very clear remit: to turn the map 'red'.

Why do you believe specialist services are so important?

Specialists have an understanding of MS as a complex condition, and that gives people with MS confidence. People still tell me that many professionals don't understand MS; how it's a variable condition and that you can have good days and bad days.

What MS specialist services are available now?

There are 38 MS specialist posts in Scotland. There is an MS specialist nurse post in every health board, and we have also

widened the range of specialists. For example, there are now MS specialist clinical psychologist posts in Ayrshire and Arran, and in Lothian. They can understand the links between MS and depression and so forth, and work with the person with MS and their family. There are also specialist physiotherapists and occupational therapists. In the social care arena we have two MS specialist social work posts.

“People still tell me that many professionals don't understand MS”

How did you 'turn the map red'?

I have been very fortunate to be able to work closely with branch members and people with MS, empowering them to put pressure on the authorities. All the big successes have been made in conjunction with them. Networks are also very important

- I am the vice-chair of a health board, which has had a direct impact on the work I do for the MS Society. In this capacity I regularly meet senior NHS personnel and am able to lobby for issues around MS.

You must have had some battles...

We've had to persuade decision-makers that specialist services have both clinical and cost effectiveness. It's relatively easy to show clinical effectiveness, but managers look at cost issues as well and generic services that cover a variety of conditions can seem attractive to them.

The Western Isles was the last territorial health board to appoint an MS specialist and that post was not going to be continued, so we had to do some hard negotiating. But I am delighted that they have recently advertised for an MS nurse and hope that the post will be filled in the near future.

In England MS nurse posts are under threat – should we worry about nurse posts being cut in Scotland?

I think the balance in service development is going to change from gaining new posts to maintaining what we have. There is a good and rational argument for the preservation of these posts, especially in reference to the neurological standards, and although there have been times when we've had to campaign to ensure posts continue in Scotland we haven't lost a post yet.

You are also focusing more on social care, and have developed two MS social work posts. How do they improve care?

MS social workers directly support people with all non-medical aspects of their condition. That could be anything from supporting them to talk to their kids, to liaising with an OT to get a ramp installed. Because of their training and experience, they are able to understand how the particular symptoms of MS affect all aspects of a person's life.

In Dundee, Scotland's first MS specialist social worker post has recently been independently evaluated, and it has been magnificent hearing how that social worker has worked with his health colleagues to put together packages of care. Because of his specialist knowledge, he has speeded up



hospital discharge, prevented hospital admission, and so forth. We have sent the evaluation report to all directors of social work in Scotland. But there are still only two local authorities that have seen fit to establish a social work post for this very complex condition.

How can we convince local authorities of the benefits?

I think there is a realisation now that effective care means both social and health care and that services have to be joined up. So we are not there to put

extra pressure on them, we are there to help them improve their service. And now with this evaluation report we've got direct evidence of how it's a better service.

What's the next step?

We need to continue asking questions about why there isn't a specialist social worker in one area when there is in others. We need to send the evaluation report out as widely as possible. We've shown in the past that we can make a difference – there's no reason to believe that we can't in the future as well.

For a copy of the report, or to discuss services in your area, please contact Andrew Johnston on 0131 335 4050 or email ajohnston@mssociety.org.uk

Keeping specialists high on the political agenda

At the end of this month, **Rhoda Grant MSP** will host a debate in the Scottish Parliament on the provision of **better care for people living with MS**. Rhoda, who recently led a successful campaign to appoint an MS nurse in the Western Isles, will lead the discussion. As part of the debate, MSPs will discuss the Clinical Standards for Neurological Services, the contribution of MS specialists and specialist training for professionals. As financial constraints begin to bite, this debate will serve as an important reminder of why MS specialists are so crucial to people with MS.

To find out more about how you can get involved in this campaign please visit <http://www.mssociety.org.uk/get-involved/campaigns/scotland/health-care>

North of Scotland



The new chair of the MS Society's Ross-shire branch, **John McMurray**, introduces himself.

How did you first get involved with the MS Society?

My wife Linda's mum died of MS-related conditions before I got to know Linda. MS came to the foreground in our lives again

when Linda was diagnosed in 2007. Moving to Dornoch during 2009 we made contact with the Ross-shire Branch. Due to the welcome from these new friends, both of us decided the best way we could repay their kindness was to get more involved.

What experience do you bring to your new role?

I have worked in the voluntary sector for over 30 years running YMCAs as a General Secretary. I was a founder member and chair of the Renfrewshire Council of Voluntary Services for seven years. I am now working as a Community Outreach Worker in a new, small voluntary organisation with 90 volunteers covering the community around the Dornoch Firth.

What would you like to achieve while in post?

- To continue to develop and deepen the real friendship

and support that already exists between the members of the branch

- To identify and pursue strategies that will increase the comfort and reduce the hardship of those with MS in the local area
- To maintain a positive profile for MS locally
- To achieve a better-than-break-even financial performance each year

A final word about yourself?

Throughout my time in Scotland over the last 23 years I have maintained both my Belfast accent and my sense of humour; some are undecided if this is a good thing!

To contact the Ross-shire branch, please call our Area Development Officer Paula MacGillivray **07590 965 465** or contact branch secretary Gill McWhirter on gill.mcwh@uwclub.net

Southeast of Scotland

Borders Branch awarded £6,000

Congratulations to the Borders Branch which was recently awarded £6,000 by the Lloyds TSB Foundation for Scotland. The Branch will use the grant to provide physiotherapy and complementary therapies for people with

MS within the Central Borders area, to help improve their physical and mental well being, independence and quality of life.

You can find out more about the branch at www.msboundaries.org.uk or call **01896 823 694**

Southwest of Scotland

The Glasgow Early Days Group



Dr Meldum, clinical psychologist with (left) Carly Gillespie and (right) Lynn Cherry, MS specialist nurses.

Dr Steven Meldrum writes of this new service for people with MS in Glasgow

Being diagnosed with multiple sclerosis brings many changes to peoples' lives. Adapting to

this chronic disease can be difficult and this process is often accompanied by emotion; commonly sadness, worry and anger. Health care providers recognise that care is vital directly following diagnosis, and helping people adjust to illness is well recognised as being essential.

Group participation allows individuals who share a common illness to come together and share their experiences. Our new initiative is a clinical psychologist and MS specialist nurse-led service to help patients cope better in the early days after diagnosis. The aim is to teach enhanced coping skills, encourage discussion and new learning, and develop skills when

dealing with difficulties related to MS. We are using a small group format where patients attend two group sessions over two months. Sessions are held at the Southern General Hospital, Glasgow and involve teaching relaxation, coping styles, fatigue management, problem solving and communication. Patient input, reflection and discussion are also encouraged throughout. All aspects are led by a clinical psychologist experienced in MS and an MS specialist nurse. We have found already that attendees have welcomed the approach of the Early Days Group.

For further information please contact Dr Steven Meldrum on **0141 201 2600**.

Home & Interior Show in aid of Dumbarton & District Branch



Kilmacolm Home Show 2011

Angela Barr of Angela Barr Interiors recently organised a two-day Home & Interior Show in Kilmacolm with the help of the Dumbarton & District Branch. The event saw a wide range of exhibitors from fine art to architects and builders, and raised a fantastic £1,550 for the branch. Congratulations to everyone at the branch who made the event possible. Hopefully the event will be back again next year.

You can contact the branch on **01436 674 590**.

New publications

Research Matters Autumn 11

This edition focuses on research happening at the Translational Research Centre in Edinburgh, the Cambridge Centre for Myelin Repair, and the MS Tissue Bank. Latest news on disease modifying treatments, including CCSVI research, is included.



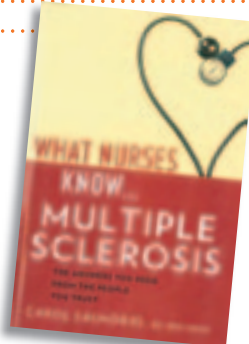
Short Breaks - A guide to short breaks and respite for people affected by MS.

This handy booklet aims to help you research your own break or activity, with or without care, for the length of time you wish. It covers such areas as payment, equipment and travel.

Book review

What Nurses Know ... Multiple Sclerosis

Carol Saunders, BA, BSN, MSCN.
Pub: DemosHealth, ISBN 978-1-932603-89-7
(Amazon £11.50)



“What a wonderful book!! Although written by an American MS Nurse, as a UK sufferer I found most of the information relevant, with clear and concise information on MS and related therapies.

The book is unique in that, as the nurse specialises in MS, asides are provided with answers to the most frequently asked questions and added insight.

As with other MS books it starts by explaining MS and follows through the progress of the illness, including chapters dedicated to helping you cope with the illness and on how to inform family/friends about your MS. Even the glossary gives clear definitions of the terms used.

As an MS sufferer I cannot recommend this book highly enough if you want a handy-sized MS reference book.”

Member Carol Humphries

Looking Ahead...

25 December 2011 - 3 January 2012 inclusive
Office for Scotland closed

25 January 2012

A Healthy Working Life with MS (professional event), Glasgow.
For details please call Mark Charlton on **0131 335 4058**.

14-15 April 2012

MS Life, Manchester

Recently updated publications



MS Essentials 09 *Benefits and MS*, **MS Essentials 14** *Fatigue* and **MS Essentials 16** *Support and planning ahead* – for people severely affected by MS.

For copies of the above, please see our website,

www.mssociety.org.uk,
or call the office in Scotland on **0131 335 4050**.