MSA NEWS

▶ ISSUE 34, 2012 | WWW.MSATRUST.ORG.UK

MULTIPLE SYSTEM ATROPHY TRUST MEMBERSHIP MAGAZINE |
MSA

MSA CLINICS
Find out what they do

The key to a healthy diet
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STAYING CLOSE
WITH SKYPE

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See our website, www.msatrust.org.uk

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MEMBERSHIP AT JUNE 2012

Current MSA members	922
Carers, relatives & friends	1,238
Healthcare professionals	1,644
Total	**3,804**
New MSA Members since 1 February 2012	97

MSA NEWS CONTENTS

Multiple System Atrophy Trust

Information, support, education and research. Free services for people with MSA, carers, family, health and social care professionals. **Our vision is a world free of MSA.**

SPECIALISED MSA CLINICS

Although it is usually the case in the UK for people with MSA to be seen in general neurology clinics, a specialised MSA clinic can provide more in-depth care for patients with MSA including accurate diagnosis, symptom management and ongoing support for the person with MSA as well as their families.

Consultant neurologist, Professor Henry Houlden, describes the role of his specialist MSA clinic at the National Hospital for Neurology and Neurosurgery in London.

Every patient is seen by me and the Nurse Specialists, to ensure that:

- Patients are seen quickly to give an accurate diagnosis or plan of investigations in a specialist centre.
- A plan is formulated on how to manage the individual symptoms of MSA.
- Patients and their families are given the time needed to discuss whatever they want in a one hour clinic appointment. If patients have to travel considerable distances, we are often able to give telephone appointments in between being seen. Often patients with MSA are only seen a few times to confirm diagnosis, or for a management plan to be set in place.
- The specialist clinic will facilitate the development of care pathways and involvement in treatment trials.

I am currently involved in a number of translational research projects that have been enthusiastically supported by the Trust. These include genetic analysis and risk factors for MSA, CSF biomarkers of MSA as a diagnostic aid, blood mRNA biomarkers of MSA and clinic-neuropathological MSA research. We plan future trials of imaging techniques in MSA: The development of the MSA clinic has allowed us to integrate patients into planned European drug trials such as the Rasagiline MSA trial.

ASSISTING OTHER DOCTORS INVOLVED WITH MSA

The main emphasis of our clinic is to achieve an accurate diagnosis of MSA, have expert follow-up management and to involve patients in treatment trials and research.

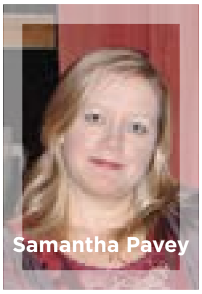
We will provide optimal care pathways for MSA patients, which are streamlined and cost effective, to enable a more joined-up service between primary and secondary care.

MSA is a rare, complex disorder and the clinic will help provide a framework for GPs to manage patients, although they will be unlikely to manage the condition without the bi-annual clinic visit.

We disseminate up-to-date information about the disease to patients, GPs and therapy services. The service provides a central source of evidence-based practice, but the aim is for this knowledge to be disseminated so that patients from all over the country could expect to receive the same level of care.

Our clinic also provides training for staff on the management of MSA, working closely with the Trust and its MSA Nurse Specialists, to give every patient the option to receive the best management of their condition, regardless of their location in the UK.

Q & A WITH MSA TRUST NURSES



Q: How does this type of clinic compare with a movement disorder clinic, or is it the same? How do the general neurology clinics fit in to this structure?

A: A general neurologist will cover many illnesses such as migraine, epilepsy, MS, but will not see many "movement disorders" (one of which is MSA).

Q: What clinics are attended by the Trust funded MSA Nurse Specialists, Katie Rigg and Samantha Pavey?

A: Samantha attends MSA clinics at:

- **Cambridge:** Addenbrookes Hospital with Dr James Rowe (three monthly)
- **Hove:** Poly Clinic with Dr Romi Saha (three monthly)
- **London:** The National Hospital with Professor Henry Houlden (three monthly)
- **Plymouth:** Mount Gould Hospital with Parkinson's Nurse Specialist (PNS), Fiona Murphy (six monthly)
- **Cardiff (possibly):** New clinic with Dr Huw Morris from September (then three monthly)

Katie attends MSA clinics at:

- **Manchester:** Salford Royal Hospital with Dr Alex Gerhard (monthly)
- **Newcastle:** Royal Victoria Infirmary with Professor David Burn (three monthly)
- **Sheffield:** Hallamshire Hospital with Dr. Hadjivassiliou (three monthly)
- **Edinburgh:** New clinic with Dr Thomas Bak (hoping to start in the Autumn and then bi-monthly).

Q: How do people get referred to clinics?

A: People should ask their GP to refer them to a clinic.

Q: Do general neurology clinics formulate a plan on how to manage the individual's MSA symptoms?

A: The person with MSA may continue to see someone locally once a year, but often asks a neurologist who specialises in MSA (or Parkinson's) to review them also.

Q: Is there any reason why somebody wouldn't be referred to a specialised MSA clinic? If so, how do they get the best from their general clinic?

A: They may choose not to travel, preferring to stay local. They may be perfectly happy with the in-put from their general neurologist and not seek a specialised clinic. They can get in touch with their PNS or MSA Nurse Specialists, Samantha and Katie, to find out what questions to ask and what they should expect to receive from a clinic.

Q: Why do the Trust funded MSA Nurse Specialists attend clinics?

A: If the MSA Nurse Specialists meet people at diagnosis, they are better able to offer support throughout the course of the person's illness as well as ensuring they are getting appropriate and timely referrals to other professionals.

If you have further questions about clinics, please email the Trust at office@msatrust.org.uk, or call Lyn Shaw on 020 7940 4666.

NEWS ROUND UP

LOOKING AFTER CARERS

This month national charity, Carers UK, of which the Trust is an affiliate member, highlights the vital contribution made by carers to their families and communities.

This year's event calls for greater support for carers to help them continue in their caring role without facing ill health, stress or financial worry. It has the support of many famous celebrities with caring experience, including Dame Judi Dench, Lynda Bellingham and Dr Rob Hicks.

SERVICES COMMITTEE NEEDS HELP FROM NHS EXPERTS

Our Trustee Board has recently been reviewing the charity's infrastructure and has introduced a new committee to act as a monitoring group for the delivery of our support work.

We're looking for somebody to join our Services Committee who has senior level experience gained from working within the NHS, perhaps a PCT, or a senior policy officer from another health charity.

If you'd like to know more about this volunteer role, please call Neil Hunter, Information and Support Manager, at the Trust on 020 7940 4666 or email: neil.hunter@msatrust.org.uk.

OUR FUTURE PLANS TO HELP YOU

E-learning programmes on MSA for health professionals, piloting a home visiting scheme, developing collaborations with movement disorder clinics, increasing investment in research and tackling the isolation many people feel by having a rare disease are just some of the areas set out by the Trustee Board in its latest plans to support people affected by MSA.

The Board has also defined the Trust's Vision and Mission:

OUR VISION

A world free of MSA

OUR MISSION

Our Vision is to have a world free of MSA by finding the cause and ultimately a cure for MSA by funding and promoting research. Until a cure is found, the Trust will do all it can to ensure people whose lives are affected by MSA, including families and carers, have access to information and support to guide them and are not alone in their journey; we will strive to enable people with MSA to get the best possible care and quality of life.

We'll keep you posted on our progress through our regional support groups, in *MSA News* and on our website, www.msatrust.org.uk.

FIND OUR FUNDRAISER!

We've got a fantastic opportunity for somebody to make a real difference to the Trust's work by helping us to secure significant funding for our research and support activities. Contact Nickie Roberts, Executive Director at the office on 020 7940 4666 for details.

CARERS CORNER
EATING WELL

With the help of carers, health experts, nutritional body MEND, Bupa and Carers UK, *The Carewell Handbook* has been produced to give you helpful tips on looking after yourself. Over the next few issues, *MSA News* will feature some of the areas covered in the *Handbook*, starting with the importance of eating well.

We all know that eating a balanced diet should be second nature, but when you're busy it's sometimes easier to just eat the same things over and over again. The key to a healthy diet is variety - that way you'll get all of the essential vitamins and minerals your body needs, which will help you feel less tired and improve your overall wellbeing.

YOUR DIET SHOULD INCLUDE:

- **Plenty of fruit and vegetables** - aim for 5-a day.
- **Plenty of starchy food** - like pasta, rice and bread (always choose wholegrain where you can).
- **Some protein** - like meat, fish, eggs, beans and vegetarian options like soya and Quorn.
- **Some milk and dairy foods** - choose low-fat milk, low-fat yoghurt and reduced fat cheese.
- **A very small amount of foods high in fat or sugar** - like crisps, chocolate, pastries and pies.

KEY FOOD GROUPS TO HELP GIVE YOU ENERGY

Eating a healthy balanced diet will help to fuel you through your busy day. Including certain foods in your diet could even help to lower your stress levels and help you to experience better quality sleep.

FRUIT AND VEGETABLES FOR IMMUNITY

Getting your daily quota of fruit and vegetables is important. They're packed with essential nutrients and fibre that not only help your digestion, but can also help to keep illness at bay.

STARCH FOR LASTING ENERGY

Starchy foods provide us with loads of energy and should make up about a third of the food we eat.

When you're caring for somebody you're often constantly on the go, so think of this food group as your rocket fuel!

It's important to choose wholegrain options where possible (eg, wholemeal bread, brown rice or pasta). These foods are higher in fibre, keep you feeling fuller for longer and release energy slowly throughout the day.

PROTEIN FOR POWER

Adding protein to your meals

will also help keep you feeling fuller for longer and give you energy.

If you're caring for someone who has little appetite, or isn't able to chew properly, then it's important to ensure their diet is high in good quality protein too. Protein is essential for the growth and repair of all the tissues in the body.

FOODS IN MODERATION

Cakes, pastries, donuts, chocolates, sweets and fizzy soft drinks may be very tempting, but these types of foods and drinks contain very little nutrition and can make us overweight.

DITCH THE SUGARY FIX

There is sugar in most of the food we eat. Sugary foods might give you a quick energy fix, but this won't last long and will leave you feeling tired and irritable later on.

CUT DOWN ON FAT

We all need to include fat in our diet, but eating too much of the wrong type of fat (saturated) can make us overweight and increase our risk of heart disease.

WHERE ARE HEALTHY FATS FOUND?

Try to include more of the good fat (un-saturated) in your diet instead:

- Nuts
- Seeds
- Avocados
- Oily fish such as mackerel, salmon, sardines, fresh tuna
- Healthy oils such as rapeseed, olive and sunflower

PLANNING YOUR MEALS

If you're busy helping someone else with their food at mealtimes it can be easy to forget to eat yourself, or you might just end up picking at things. Sticking to a regular meal pattern (breakfast, lunch and dinner plus a couple of healthy snacks) is important. It will keep your energy and concentration levels high, and help you avoid snacking on unhealthy foods.

BLAST OFF WITH BREAKFAST!

Breakfast is your chance to stock up on essential nutrients, fibre, vitamins and minerals. A good, hearty breakfast will really set you up for the day and give you the energy you need to get through it.

If you start the day without eating then you're much more likely to reach for the first snack you see. This is why people who eat breakfast are less likely to be overweight.

TIPS FOR A QUICK AND HEALTHY BREAKFAST

- **Fruit bircher** - add your own favourite fruits and oats to low-fat natural yoghurt and store in the fridge overnight.
- **Cereal** - eat wholegrain cereals with semi-skimmed milk. Try weetabix, shredded wheat, muesli (no added sugar), Ready Brek (plain) or porridge oats.
- **Wholemeal, wholegrain and granary toast** - try a thin spread of peanut butter (no added sugar), mashed banana, low fat hummus, reduced-fat cheese, reduced-sugar jam, Marmite, baked beans or fresh tomatoes.
- **Porridge** - have any type you like with no added sugars. You can add fruit, cinnamon, dried fruits and seeds or nuts.
- **Eggs** - try scrambled, boiled or poached with wholegrain toasted bread.

DRINKS AND SNACKS

If you're rushing around all day, you'll most likely need a couple of snacks to keep you going until your next meal. Often the snacks that we have on the go are laden with unhealthy fats, sugars and salt. Snacks don't have to be unhealthy, especially if you plan them in advance.

HEALTHY HYDRATION

If you're busy carrying out daily tasks, something as simple as grabbing a glass of water can easily be forgotten. When our bodies don't get enough fluids, we may become dehydrated. This can sometimes lead to headaches, irritability, poor concentration, and prolonged dehydration can even cause constipation.

Now try the Eat Well Quiz on page 8 to see if you need to make any changes to your diet.

THE EAT WELL QUIZ

There may be many different factors that affect your energy, but it's much more effective to focus on making small changes in just one area at a time.

I skip meals due to being too busy, or I eat erratically whenever I can fit in a meal or a snack	A	B	C
I eat fast food or convenience meals	A	B	C
My main meals rarely include a variety of foods (eg, lean protein such as meat, starchy foods such as rice or pasta, and fruit/vegetables)	A	B	C
I struggle to eat five portions of fruit and vegetables a day	A	B	C
I find it a challenge to drink as much water as I should	A	B	C
Circle the response you gave most frequently to these statements	A	B	C

GET YOUR RESULTS

A = Never B = Sometimes C = Often

If you answered mostly As then your diet is unlikely to be affecting your energy to care and you probably don't need to focus on it.

If you answered mostly Bs then the information in this article might be helpful, and you might like further information from the Trust and/or by visiting www.carewelluk.org.

If you answered mostly Cs then this is something that is probably affecting your energy quite a lot. Hopefully this article will be helpful and further information can be gained from the Trust and/or by visiting www.carewelluk.org.

CARERS' TOP TIPS FOR PLANNING AHEAD

> *"Always keep eggs in the fridge. Scrambled egg on wholemeal toast is super quick and cheap."*

> *"A slow cooker is my trusty kitchen companion. It makes any combination of cheap cuts of meat and vegetables hearty and delicious, and it also works well with chickpeas and stews."*

> *"Always keep baked beans in your cupboard. I have them on wholegrain toast if I'm not in the mood to cook because they're easy, fast, affordable and filling."*

More tips can be found by visiting www.carewelluk.org.

Easy to digest MEALS

Swallowing can sometimes be a problem for people with MSA, so it can help to have a few tasty and easy to eat recipes in your cooking repertoire.

You may already have some favourites and this new recipe series is your opportunity to share them by emailing details to lyn.shaw@msatrust.org.uk at the Trust's office. To kick us off, here's one from the MND Association's cookbook.

STEAK UPSIDE-DOWN PIE:

- 12 oz raw minced beef
- Half pint stock
- 1 tbs oil
- Seasoning
- 2 onions
- 2-3 tomatoes
- 4 oz mushrooms

TOPPING:

- 6 oz self-raising flour
- Milk
- 2 oz cheddar cheese
- 1 egg yolk
- 2 oz fat
- Seasoning/parsley sprigs to garnish

Chop the vegetables and fry in oil until soft. Add the stock and the minced beef. Stir until a smooth, thick mixture, season well and cook for 15 minutes only in a covered pan, stirring from time to time.

Meanwhile prepare the topping. Sieve the flour with seasoning. Rub in the fat and add the grated cheese - this is an excellent way to use stale pieces. Bind with the egg yolk and milk to make rolling consistency. Form into a 7-8 inch round.

Put the meat mixture into a cake tin (one without a loose base) or oven-proof dish, top with dough. Bake in the centre of a moderate oven (180-190 degrees C, Mark 4-5) for about 50 minutes.

Invert onto a hot dish so that the pastry is underneath which will soften and absorb the pie filling. Garnish with parsley sprigs and serve with creamed carrots and potatoes. **MSA**

WORLD CONGRESS GENERATES IDEAS FOR **MSA RESEARCH**

Over 90 delegates took part in the fourth MSA international congress held in Toulouse, France this March bringing together international basic and clinical neuroscientists to generate ideas for future research.

The event's organisers, the French Reference Centre for MSA, said "Numerous discoveries have been made in MSA research (since earlier meetings) and this congress provided a unique opportunity to update and share knowledge in this field."

Trust funded researcher, Dr Janice Holton from the Queen Square Brain Bank in London, attended the conference and reports for *MSA News*:

The programme provided varied sessions on the pathogenesis of MSA, clinical presentation and natural history, imaging and biomarkers with a session devoted to the treatment of MSA patients.

A session covering the pathogenesis of MSA began with a summary of the neuropathology of MSA, providing an update on the formation of glial cytoplasmic inclusions in oligodendrocytes.

A fascinating talk about the protein a-synuclein, which has a key role in both Parkinson's disease and MSA, was given by Dr Angot from Lund in Sweden. Dr Angot discussed the hypothesis that abnormal a-synuclein can be passed from one cell to another and the implication of this for both Parkinson's disease and MSA.

Professor Gasser from Tubingen in Germany reported on the latest genetic studies in MSA. Results from animal models of MSA were presented by Drs Stefanova and Fernagut representing research groups in Austria and France respectively.

As patients with MSA may sometimes show clinical overlap with other forms of cerebellar ataxia, Dr Klockgether from the University of Bonn discussed the clinical and imaging criteria which may help to distinguish between these conditions. We were also provided with an interesting update on recent progress towards developing biomarkers for MSA by Dr Meissner from Bordeaux.

The final session of the meeting was devoted to the management of different aspects of MSA including cardiovascular, sleep and respiratory problems. Current and future MSA clinical trials were also discussed.

There are a number of cohorts of patients with MSA being studied around the world, and these studies were compared with the French, Japanese and European MSA study cohorts. In these studies, patients undergo regular clinical assessment and detailed clinical information about the disease is recorded enabling improved understanding of how the disease progresses. The previous observation that Japanese patients are more likely to have problems predominantly attributable to cerebellar degeneration than Parkinsonion symptoms while the reverse is true in Europeans, has been confirmed.

Dr Holton says, “Delegates and speakers were able to renew acquaintance, discuss their current work and develop contacts to facilitate future collaborative research in this field.” **MSA**

If you’d like more details on the congress and MSA research, please contact the Trust’s office on 020 7940 4666 or email office@msatrust.org.uk.

TRUST FUNDED RESEARCH

Dr Janice Holton has been working on a Trust funded research project entitled “The central role of oligodendroglia in the pathogenesis of MSA” . A copy of her full report can be found on the Trust’s website, www.msatrust.org.uk, or obtained from Lyn Shaw at the Trust’s office (020 7940 4666). We asked Dr Holton about her project:

Q: WHAT’S THE MAIN FOCUS OF THE PROJECT?

A: The investigation of which cells in the brain make the protein a-synuclein which accumulate in oligodendrocytes in MSA. We are developing the technique of in situ hybridisation to do this. A method called quantitative real time polymerase chain reaction will be used to determine the amount of a-synuclein expression in different brain regions in MSA, and whether there are any variations in the a-synuclein molecules produced in different brain regions. MSA cases will be compared with appropriate controls, and there may be changes in the MSA brains which are specific for this disease. This will help us to understand why certain regions of the brain are affected and others are not.

We are continuing our study of different clinical groups of MSA and are particularly interested in investigating patients who have developed memory problems with those who have not.

Q: WILL THE PROJECT IMPACT ON THE DIAGNOSIS OF MSA?

A: The on-going studies looking at the amount of a-synuclein in oligodendrocytes and in regions affected in MSA have the potential to identify biomarkers that could be used to make a more accurate clinical diagnosis of MSA.

Q: HAS THE PROJECT CONTRIBUTED TO THE TREATMENT OF MSA?

A: If the amount of a-synuclein is increased in cells that are specifically targeted in MSA and in regions that are preferentially affected, this work may provide information which could contribute to the development of drugs that aim to reduce the amount of a-synuclein as a potential for the treatment of MSA.

BED & SLEEPING SUPPORT

HELPING YOU TO GET A GOOD NIGHT'S REST

There are many pieces of equipment and aids available to help people with MSA, including those designed to help you get a good night's rest.

Bed rails (or bed levers) slide under the mattress and provide a hand rail to help with turning and getting up and out of bed. They also provide an element of safety during restless nights.

A bed cradle also slides under the mattress to keep it securely in place, but is designed so that bed sheets/clothes are rested on top of it promoting circulation and preventing overheating in the night.

If overheating in the night is a problem, then you might consider cool gel bed pads. Various items designed to help keep you cool, including cool pad toppers for pillows and cooling head bands, can be found at www.personalcooling.co.uk.

Sitting or lying in one position for any length of time can build up pressure which may result in a pressure sore or pressure ulcer (sometimes known as a bed sore). One way to combat these sores is to use a pressure relieving mattress which come in various designs.

A simple example is a mattress topper with a rippled or bubble effect that helps spread the pressure throughout the body. Advanced options are foam or air inflated mattresses, or a combination of both.

An example is a profiling bed which is an electronic bed with back rest elevation, mid-bed and foot position changes. The whole bed platform raises and lowers for ease of access. These beds can help to maintain independence and are good for gradual sitting to standing in the mornings for people with postural hypotension difficulties.

If postural hypotension is an issue, then you could consider an electronic bed recliner with speed control. These allow a gentle increase from a lying to a sitting position reducing the risk of dizziness.

It's important that you discuss your posture and mobility needs with your physiotherapist or occupational therapist before you purchase any item, as many need to be the right size to be safe and effective. These health professionals can advise you, and will also know what items might be available to you free of charge through local services. **MSA**

If you would like further information on posture and mobility, the Trust has a new factsheet which looks at aids and equipment. Please contact Lyn Shaw at the office on 020 7940 4666 or email office@msatrust.org.uk.

IDEAS FROM THE MSA TRUST FUNDRAISING CALENDAR

We often get asked for ideas for fundraising activities, so we've put together a varied and exciting MSA Trust fundraising year - there's something for everyone!

JULY

ORANGE CAKE & BAKE PARTIES

If you enjoy baking why not hold a cake and bake party? They are a great way of raising funds for the Trust in your own home and at a time which suits you. We're collecting recipes to share, including ones from well-known chefs Nigel Slater, Jane Asher and Annabel Karmel. As well as being a delicious and sociable way to raise funds for our work, the "orange" theme can help raise awareness of the Trust as orange is the colour of our logo. Mike Coffey at the Trust can let you have a template of our logo if you're feeling up to the challenge of the icing bag!

AUGUST

The Great Swim Series - Strathclyde, Scotland, Saturday 25th.
The Canterbury Half Marathon - Merton Farm, Canterbury, Kent, Monday 27th.

THE OLYMPIC CHALLENGE

How about taking on your own Olympian challenge by selecting a sport from the Olympics and setting your own personal challenge? It might be to walk 10 miles, swim 1500k or cycle the equivalent of a marathon. The challenge is entirely up to you. Let us know what you are doing and once you've successfully completed it, we'll send you one of our Olympic Challenge Certificates!

SEPTEMBER

London Stadia Trekathon - Saturday 1st
Glasgow Half Marathon - Sunday 2nd
Half Ben Nevis Triathlon - Saturday 15th
Paris to Versailles (road race) - Sunday 30th
Berlin Marathon - Sunday 30th

OCTOBER

Windsor Half Marathon - Sunday 7th
Run to the Beat - London, Sunday 21st
BUPA Great South Run - Portsmouth, Sunday 28th

NOVEMBER

A WINTER'S TALE

Choose a book to read amongst you and your friends. Set a date to read the book and invite your friends around to your house to chat about it. This can be as informal or formal as you like. Perhaps you could also share your own MSA tale? Another great way to raise funds and awareness - perhaps your local paper could follow the tale? Mike can offer suggestions on how to get A Winter's Tale into diaries.

The ING New York City Marathon - Sunday 4th

DECEMBER

The GRIM Challenge - Aldershot, Saturday 1st and Sunday 2nd

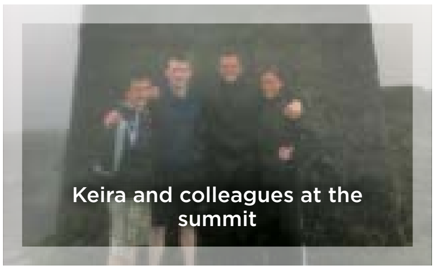
For further information on these, and other fundraising activities, please contact Mike Coffey at the Trust. Email mike.coffey@msatrust.org.uk or telephone 020 7940 4666.

FUNDRAISING

MEMBERS IN ACTION

Slieve Donard Climb

On a very wet and windy day, Keira Davidson from Belfast, along with her colleagues from Ulster Bank, took part in an organised climb of the Slieve Donard, Newcastle, Co. Down in September 2011. Thanks to Keira and her team of climbers, a total of £730 was raised for the Trust's work. The climb continued Keira's fundraising, as in May 2011 she had taken part in the Belfast Half Marathon.



Keira and colleagues at the summit

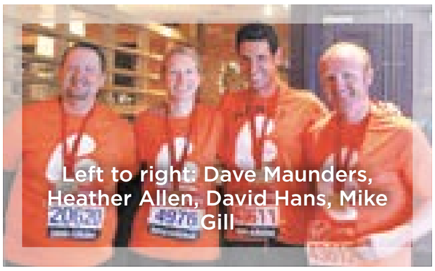
50th Birthday Party

Dorothy Callaghan from Co. Down in Northern Ireland, donated £520 from her 50th birthday party to the Trust. Dorothy's brother, Malcolm, has MSA and was at the party along with Dorothy's family and friends. Dorothy was thrilled to see how happy her brother was and said, "To see my brother smile as he attempted a dance was priceless!"

London Marathon

Nine runners took part in the London Marathon to raise funds for the Trust, more than usual as this year some people were successful in obtaining places through the Open Ballot. A big thank you goes to: Emma Coulter from Chelmsford, David Hans from Stockport, Mike Gill from Cambridge, Heather Allen from Cornwall, Linsey Connor from Kent, Karl Nutt from Essex, Thomas Phillips from Essex, Michael Samuelian from New York and Dave Maunders from Surrey.

All our runners put in hours of training to get ready for the event. Sadly in February, shortly before the event, Emma lost her mother, Angela, to MSA. Emma said, "Losing my mother made me more determined to complete the marathon". Shortly after the run, Emma's boyfriend, Mike, proposed: a wonderful ending to a memorable day.



Left to right: Dave Maunders, Heather Allen, David Hans, Mike Gill

Left to right: Emma Coulter, Innis Coulter, Emma's fiancé, Mike, and his mum

The West Highland Way

Anne Troy from Dunblane, wanted a new challenge in memory of her mother, Molly. Her sister Clare and cousin John agreed to join her in walking 96 miles in seven days. The walk itself was marked by great weather and beautiful scenery and although the trio found the going tough at times, they successfully covered the full distance and raised a total of £575 for the Trust.

Left to right: Anne, Clare and John

Many thanks to *all* the amazing people who raise funds for our work!

Sharing EXPERIENCES

Joe Mountain lives in the Algarve with his wife Erika and three daughters. Joe's 58 year old step-mum, Sara, has MSA. The family Skype to stay in touch, not letting the communication problems MSA may bring to get in the way.

My name is Gemma Mountain and I'm 12 years old. I have two younger sisters, Lara and Maia. Three years ago my Nana Sara was diagnosed with MSA. When we lived in England we saw Nana all the time, but then we moved to Portugal in August 2008. As we were in Portugal and she was in England, it was hard for us to communicate until we started using Skype. Skype is a free application that you can use to talk to other people through your computer. With a webcam we can see each other as well! Me, Maia and Lara take it in turns to read to Nana almost every day. So far we have read about 50 books to her, including Cookie and Hetty Feather by Jacqueline Wilson and George's Marvellous Medicine by Roald Dahl. Also, we play games of You Be The Judge, which Nana Sara is great at. Nana Sara has been an amazing part of our lives, she's so inspirational. She will always be in our hearts, wherever we are.

Gemma's dad, Joe, says: Sara is, and always has been, wonderful to me, my brother, our wives and her collective granddaughters. Since she entered our lives when I was six she's been nothing short of an amazing mother and inspiration, shaping the lives of Dan and I and our families.

Considering the circumstances Sara is holding up very well, but it's tough to watch. Unable to communicate effectively or leave her flat, she needs two carers to get her up in the morning and then full time help.

My girls are very aware of the situation and are fantastic. They were Skyping every night to talk with Sara but, as she can't really talk now, they read to her. Lara's and Maia's reading levels have jumped in the last year. They now also play a game with Sara called "You be the judge". It's about strange criminal cases dating back over the centuries. One of the girls will read the story/case, and Sara and the other girls decide if the jury finds them guilty or not guilty using thumbs up or down!

Setting up Skype on our respective computers has meant we can still be with Sara in a way that physical distance and MSA would have made very difficult. It's easy to set up and use and we feel has been a real help to staying close to Sara.

If you'd like to share your experiences of living with MSA, tips and ideas, please email nickie.roberts@msatrust.org.uk.

MSA SUPPORT GROUP DIRECTORY

Local support groups are a great way to meet other people who understand life with MSA. Please contact the group leader or speak to Lyn Shaw at the Trust's office on 020 7940 4666 for more details.

REGION	GROUP LEADER / CO-ORDINATORS	EMAIL	PHONE	NEXT MEETING IN 2012	VENUE
Cornwall	Jane Handy Jan Pearce	moonbeams@ymail.com	01726 747 01726 861 361	No meetings currently scheduled	TBC
Cumbria	Katie Rigg	katie.msa@cybermoor.org.uk	01434 381 932	Mon, 2nd July 1.30 – 3.30pm	Eden Valley Hospice, Durdar Road, Carlisle, CA2 4SD
Derbyshire	Karen White Kulwant Sehmbi	karen@karenwhite7.wanadoo.co.uk	01283 735 847	Thur, 14th June 2.00 - 4.00pm	Doveside Social Club, Hatton, Derby, DE65 5DT
Devon	Dennis Westrip	denniswestrip@btinternet.com	01271 378 273	Fri, 6th July 2.00 – 4.00pm	Baptist Church, High Street, Cullompton, Devon, EX15 1AJ
East Midlands	Elizabeth Brackenbury	holmepierrepont@aol.com	01159 333 083	TBC	Holme Pierrepont Hall, Holme Pierrepont, NG12 2LD
Essex	Lady Laurelie Laurie & Sir Bay Laurie	Baylaurie331@btinternet.com	01206 210 410	Mon, 29th Oct 2.00 – 4.00pm	Great Tey Village Hall, Great Tey, Essex, CO6 1JQ
Fife	Kim Carr	office@msatrust.org.uk	020 7940 4666	TBC	Burnside Hall, Balmullo, Fife, KY16 0AW
Inverurie	Gill Campbell	office@msatrust.org.uk	020 7940 4666	TBC	St Mary's Church, Inverurie, Aberdeenshire, AB51 3NW
Kent	Linda Nicolaides	marlin.michris@virgin.net	020 7940 4666	Thur, 19th July 2.00 – 4.00pm	Medway Campus, University of Greenwich, Central Avenue, Chatham Maritime, Kent, ME4 4TB
London (North)	Penny Stokes	pennystokes@hotmail.co.uk	020 7940 4666	Mon, 9th July 2.00 – 4.00pm	Southgate Hockey Centre, Snakes Lane, Oakwood, London, EN4 0PS
Greater Manchester	Katie Rigg	katie.msa@cybermoor.org.uk	01434 381 932	On hold	Mayo Building, Salford Royal Hospital, Manchester, M6 8HD
Northern Ireland	Rosemary Arbuthnott	roseyart@gmail.com	028 377 88386	Autumn TBC	TBC
Northumberland	Aileen Tuff	office@msatrust.org.uk	020 7940 4666	Wed, 27th June 1.30 – 3.30pm	Blyth Library, Bridge Street, Blyth, NE24 2DJ
Shropshire	Cathy Hopkins	cch64@myway.com	020 7940 4666	Wed, 13th June 1.30 – 3.30pm	The Lantern, Meadow Farm Drive, Shrewsbury, SY1 4NG
Southern Ireland	George Hunter	george@georgehunter.biz	00353 872 525252	Autumn TBC	The Royal Marine Hotel, Dun Laoghaire, Dublin
Southport	Jo Hans Fraser Gordon	hansjj@talktalk.net	01253 821 693	TBC	St. James Church Hall, Lulworth Road, Southport, PR8 2BQ
Surrey	Peter Turvey	peterturvey@waitrose.com	01483 827 395	Wed, 30th Aug From 1.00pm	Shalford Village Hall, Kings Road, Shalford, Guildford, GU4 8JU
Warrington	Linda Moss	linda.moss@warrington-pct.nhs.uk	01925 867 710	Thur, 9th Aug 2.00 – 4.00pm	Fairfield & Howley Neighbourhood Project, Fairfield Street, Warrington WA1 3AJ
West Midlands	Vanisha Rana	office@msatrust.org.uk	020 7940 4666	TBC	TBC
West Sussex	Gwen Yates Amanda Woodhall	office@msatrust.org.uk	020 7940 4666	Tue, 17th July 2.00 – 4.00pm	Field Place, The Boulevard, Worthing, BN13 1NP

EQUIPMENT GUIDE
HELP WITH POSTURE & MOBILITY

Daily life with MSA can present mobility and posture problems, but there are many different types of equipment available to support your body and to help you with walking or moving about.

POSTURE

SITTING & RISING

Riser recliner chairs can be helpful if you're having difficulty getting from a sitting to a standing position. They also help you change position independently without standing.

A seat riser can be used if you feel you can safely stand unassisted, but have trouble doing so from a seated position. A perch stool can be used to reduce the fatigue of standing to do tasks like ironing and washing.

BODY SUPPORT

A range of equipment can be used to help support your body, including splints for weakened limbs, inverted prism glasses to assist with visual ability when unable to look up because of head drop, as well as collars, also to help with head drop.

WALKING & MOVING ABOUT

A tripod walking stick is a simple aid that helps improve stability and balance. For slightly more control and increased stability, a walking frame may be more suitable. A rollator walker requires less effort than a static frame and has brakes to control movement. They also often include a seat so that you can stop to rest.

A wheelchair increases freedom to get out and


A rollator walker in action

about when mobility becomes more difficult. A company called TGA offer a wide range of new, ex-demo and second-hand wheelchairs, visit www.tga-electric.com or call 01787 882244.

Electric wheelchairs are also another option. Although you don't need to have a driving licence to use one, if you think you'll use the wheelchair on the road then you'll need to register it with the DVLA and display a nil duty tax disc. Electric wheelchairs allow greater independence, and the tilt-in-space variety offers increased comfort through adjustment of seat and backrests. JGP, www.just-good-prices.co.uk (0845 8674918), has a good range of power assisted chairs and mobility options.

Any type of chair can be made more comfortable by the addition of lap cushions and arm supports. They also provide greater support and aid co-ordination. A selection of attachments for chairs is available from American based AliMed, visit www.alimed.com for more details. **MSA**

MOBILITY & POSTURE HEALTHCARE PROFESSIONALS

The two professionals you are likely to meet are:

THE OCCUPATIONAL THERAPIST

An occupational therapist (OT) is one of the members of your multi-disciplinary team and can suggest equipment to help you with your day-to-day living. An OT is trained to assess and treat physical conditions to manage disability and promote independence.

They carry out an assessment of a person's needs, find the best coping strategies and recommend appropriate equipment for daily living. They can also visit you in your home to determine "environmental" adaptations that may help.

You can see an OT through the NHS by speaking to one of your medical team or to your GP for a referral. You can also access an OT through your local council's social care services.

THE PHYSIOTHERAPIST

A physiotherapist (PT) treats people with physical problems, often caused by illness. They see physical movement as central to a person's health and well-being and are trained to maximise your movement potential by health promotion, treatment and rehabilitation.

You can ask your GP to refer you to a PT, although it's also possible to find private and independent physiotherapists.

If you'd like more information on posture and mobility, please email office@msatrust.org.uk or call Lyn Shaw on 020 7940 4666.

STAND OUT
FROM THE CROWD

To help spread awareness of MSA we're collecting photos of people wearing our T-shirts. The more unusual and far-flung the better!

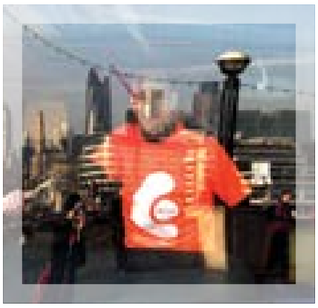
From the Manchester shipping canal to the Grand Canyon or from the North Pole to the Sydney Opera House, be seen in your MSA Trust T-shirt! Send your photo to us and we'll add it to our website.

All photos, please, to office@msatrust.org.uk.


The Nightrider event, London


Golden Temple, Amristar, India


Saint Mark's Basilica, Piazza San Marco, Venice


The London skyline, London

IN MEMORY

Nicola Bach
Angela Coulter
Melvyn Bradshaw
Richard Brown
Ronnie Brown
Roger Williamson
Loraine Ackerley
Patricia Oakley
Brian Low
Cynthia Sanderson
Albert Patrick
Brian Neal
Sylvia Thomas
Sandra Price
Alan Marie
Peter Coombe
Diana Healey
Stewart Taylor
Gary Smith
Declan Bowers
Brian Gant
Stephen Simmons
Simon Roodhouse
Fred Davies
Julie Roberts
Pauline Mortimer
Linda Pilsworth
Katherine (Kay) Daniels
Robert Walker
Stuart Robertson
Moira Tumblety
David Hodson
Graeme Smith
Tony Westwood
Ann Owen
Barbara Paterson
Ruth McCartney
Roger Crane

THE **MSA SHOP**

Our new “shop” is open for business and we have a growing range of items from badges to clothing, all of which have been designed to help raise awareness of MSA as well as funds for our work.

£2^{50}

Striking in appearance, our badges are ideal for wearing with formal or casual clothing. Wear your badge with pride and help spread awareness about MSA and the Trust.

£2

Our new MSA Trust branded wristbands are a great and inexpensive way to show your support and raise awareness.

£12

Our new polo shirts are light and stylish making them ideal for the summer. They come in a range of sizes.

£10

MSA Trust T-shirts are so bright, you’ll be noticed wherever you go! They also come in a range of sizes.

MULTIPLE SYSTEM ATROPHY TRUST ORDER FORM:

Name:..

Address:..

Postcode:.. Telephone:..

Email address:..

Badge (Qty):..................... Wristband (Qty):.................... Polo shirt (qty): S........... M............ L........... XL..........

T-shirt (qty): S........... M............ L.......... XL.........

Total payment enclosed (Postage & packing for one T-shirt or Polo Shirt £2.75. For each additional shirt add another 75p. The price of wristbands and badges includes p&p): £..

Please make cheques payable to: Multiple System Atrophy Trust and send to:
Multiple System Atrophy Trust, Southbank House, Black Prince Road, London, SE1 7SJ
For more information contact Mike Coffey on 020 7940 4666 or email at mike.coffey@msatrust.org.uk.

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