

# MSA

NEWS

ISSUE 31, 2011 | WWW.MSATRUST.ORG.UK



## ANNOUNCING OUR MAJOR FUNDRAISING APPEAL

**£1 million** needed for MSA research  
...and the launch of our first Research Strategy

*Holiday time* is HERE!

Follow our guide for tips on what to take  
and where to go

## PLANNING AHEAD

MSA specialist nurse, Katie Rigg, explains  
how to set out your treatment wishes and  
advance decisions

## PLUS!

**REGIONAL SUPPORT GROUPS AND ONLINE  
COMMUNITIES, FUNDRAISING & MORE...**



Follow us on Twitter & Facebook and help raise awareness of MSA. See our website, [www.msatrust.org.uk](http://www.msatrust.org.uk)

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Professor CJ Mathias DPhil DSc FRCP

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Michael Evans  
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**MEMBERSHIP AT MAY 2011**

Current MSA members	814
Other patient members	33
Relatives and carers	571
Professionals	1331
Others	190
<b>Total</b>	<b>2939</b>

# 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.



### INTRODUCING OUR NEW MAGAZINE!

*Welcome to your new magazine*

03

### OUR WEBSITE IN ACTION

*Three Trust members describe their experience of the Forum*

03

### DRIVING & MSA

*We look at the legal aspect of driving with MSA*

04

### TIME TO BE THINKING OF GOING ON HOLIDAY

*Read our practical guide to help plan an enjoyable break*

06

### REGIONAL SUPPORT GROUPS - MAP

08

### RAISING FUNDS FOR MSA RESEARCH

*We announce our 2012 Appeal to raise funds for MSA research, and look at how you can get involved*

10

### GUIDE: ADVANCE CARE PLANNING

*MSA specialist nurse, Katie Rigg, explains how to set out your care and treatment plans*

14

### IN MEMORY

16

### FUNDRAISING REPORTS

*Sharing the amazing efforts of our members*

17

### GOODBYE FROM OUR CHAIR

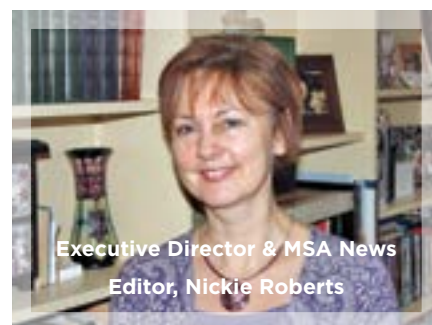
*Eileen Lady Strathnaver steps down after 10 years in the Chair*

19

## Introducing **OUR NEW MAGAZINE!**

Surprise, we've given the Magazine a makeover! Its new look has, of course, been about updating the magazine's general design to give it a more modern and fresh style. But we also want to develop the magazine's editorial, and the new layout provides us with much

more flexibility to do this. On the theme of content, I'm delighted to report too that we've increased the magazine's pages from 16 to 20, so more space to cover news and feature articles. Happy reading! **MSA**

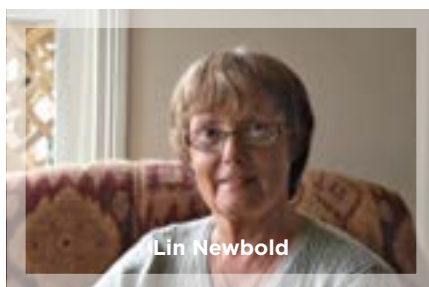


## OUR WEBSITE IN ACTION

We recently added new features to our website including an online support community.

Trust members Lin, George and Eric share their thoughts on our website Forum as a platform for sharing information, experiences and support.

Hi everyone. I'm Lin Newbold and I was told just over a year ago that I have probable MSA. I'm nearly 65 and lucky to have the support of my family, Pete my husband and Martin and Emma, our children. We also have two grandsons Lewis and Corey, and a manic Collie named Kassie. I knew nothing about MSA when I was diagnosed, so was relieved to find loads of information on this wonderful website. The addition of the Forum provides a chance to reach out to others who have the same diagnosis. It has been great to share info on things like symptoms, and I look forward to "chatting" for



a long time to come.

George Carfoot (goes by the name of "Weedy" on the Forum) says: I'm 64, married to Jennifer and have two daughters – Catharine and Bryony and I live in Theydon Bois, a little village on the edge of Epping Forest. I was diagnosed about five and a half years ago with Parkinson's Disease and decided to learn all I could, so I joined the Society and two local support groups. At one of these in September 2009 I discovered that I might have MSA. I think the Trust's Fo-

rum is a brilliant concept and that more people should use it.

My name is Eric Armitage and I live in Chadderton, Oldham with my wife Angela. I am 57 years old. I was very interested in the Forum as soon as I saw it on the Trust's website. It has provided the opportunity for me to share my experiences and hear those of other people. Unfortunately I have recently been in hospital and not been on the website. However, I intend to continue using the Forum. I have found it very helpful to hear other people's views and methods of coping, and it enables me to keep informed of developments and research.

Read Eric, Lin and Weedy's "chat" by visiting [www.msatrust.org.uk](http://www.msatrust.org.uk). You might be tempted to register too! **MSA**

# DRIVING & MSA



Driving and MSA has been a subject that's caught the attention of some of our Forum users recently. MSA specialist nurse, Samantha Pavey answers some commonly asked questions.

**Q: DO I HAVE TO INFORM THE DVLA THAT I HAVE MSA?**

**A:** Yes. You are obliged to tell the DVLA. If you fail to inform the DVLA of a health problem you are committing a criminal offence under the Road Traffic Act 1988. Having MSA does not automatically mean that your licence will be revoked, although you may be required to have a medical (which will

be carried out by a doctor specially chosen by the DVLA) or take a driving test. Medicals and driving tests under these circumstances are free and you would be given priority at a driving test centre, although travel costs incurred may be your responsibility. *The DVLA does make every effort to ensure that people with health problems or disabilities stay as mobile as possible.*

**Q: WHAT HAPPENS NEXT?**

**A:** You will be asked to complete Form PK1, 'Medical in Confidence', giving details of your GP and specialist or Parkinson's Nurse Specialist (which is a legal requirement) and details of recent hospital/clinic visits. In most cases the DVLA will contact your specialist for further information about your fitness to drive.

They will then decide if a driving test or medical is required. Following this they will reach a decision:

- To give a licence without any restriction
- To give a licence for one, two or three years. This decision is reviewed when the licence runs out
- To refuse or withdraw the licence
- To restrict the licence to particular vehicles with adaptations

The DVLA aim to make a decision within 90 working days. If the DVLA decides you cannot have a licence, it will return any fee you sent with the application form.

#### **Q: WHAT ABOUT INSURANCE?**

**A:** You should also inform your insurance company of any change in your health that may affect your ability to drive. It is an offence under the Road Traffic Act to make a false statement or withhold information for the purposes of obtaining a certificate of motor insurance, and it may also invalidate your policy. You should also inform your insurers about any adaptations made to the insured vehicle.

#### **Q: CAN I CHALLENGE THE DVLA'S DECISION?**

**A:** If you are not happy with any decision made by the DVLA, you can challenge the decision by:

- Asking the DVLA to reconsider its decision



- Appealing against the decision in the magistrate's court (sheriff court in Scotland)

In the first instance you should write to the DVLA explaining why you feel the decision is wrong. The DVLA will generally reconsider the decision, but will expect the request to be supported by fresh medical evidence.

You may need to ask your GP to refer you to a specialist who can provide this, and you might have to pay for the letter that the specialist writes.

If the DVLA does not change its decision, you can appeal to the magistrate's/sheriff court. The appeal must be lodged with the magistrate's court within six months (21 days to the sheriff court) of the revocation/refusal of the licence.

In our experience most people living with MSA will come to a decision about their own ability to drive. Slower reaction times, side effects of some medication which can cause drowsiness, episodes of fainting or blackouts with postural hypotension can all be very concerning. Whilst we appreci-

ate the difficulties losing one's independence can cause, safety of the driver, passengers and other road users must be paramount.

#### **MORE INFORMATION CAN BE FOUND AT:**

[www.direct.gov.uk/en/Motoring/DriverLicensing/MedicalRules-ForDrivers/index.htm](http://www.direct.gov.uk/en/Motoring/DriverLicensing/MedicalRules-ForDrivers/index.htm)

Drivers Medical Group  
DVLA, Swansea, SA99 1TU

#### **AND REMEMBER...**

If you are in receipt of the higher rate of the mobility component of the Disability Living Allowance then you may be entitled to a free tax disc. If you don't drive but someone drives for you, they can apply for exemption providing the vehicle is used solely for your purposes.

More information can be found at:

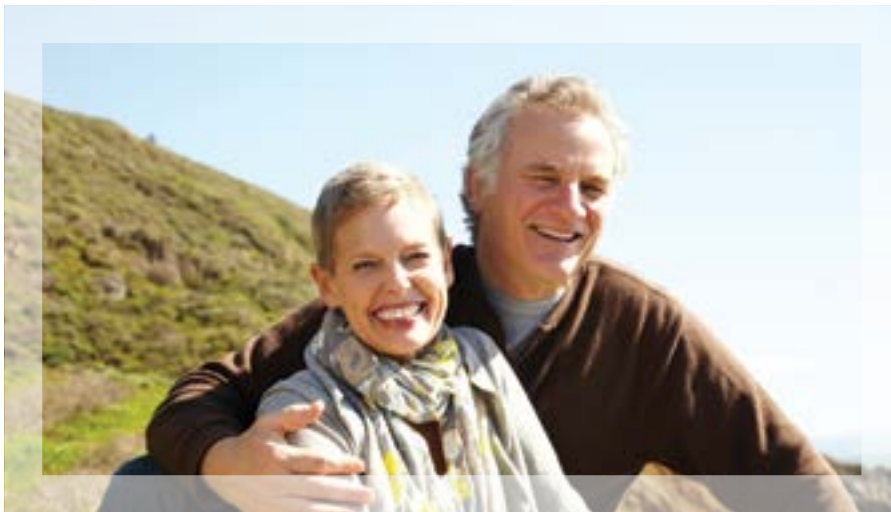
[www.direct.gov.uk/en/Disabled-People/MotoringAndTransport/Yourvehicleandlicence/DG\\_10028003](http://www.direct.gov.uk/en/Disabled-People/MotoringAndTransport/Yourvehicleandlicence/DG_10028003). **MSA**

## *Calling* **ALL iPad USERS**

If you have experience of using an iPad to help you with MSA, Neil Hunter at the Trust would love to hear how they help you. Please email your thoughts to [neil.hunter@msa-trust.org.uk](mailto:neil.hunter@msa-trust.org.uk) or call him on 020 7940 4664. **MSA**

# Time to be thinking OF GOING ON HOLIDAY

Many people at this time of year are planning, or have booked, their holidays. It is good for us all to have a change from our daily routines; and even more so when coping with the challenges of living with MSA.



It is all too easy to put-off going away because of the worry about how you might manage your daily needs in different surroundings.

Unfortunately MSA will not go away, so it may be best to make the most of “now” and be proactive about doing the things you have always wanted to if at all possible.

So how can you plan and ensure you have a positive and enjoyable holiday?

Here are a few thoughts that may help:

- Ensure you have appropriate travel and health insurance.
- Take a letter from the consultant/GP of your current situation and medicines – keep one copy with you in English for getting through airport control with medicines and one copy translated into the appropriate language for the destination.
- Take at least one week **extra** to what will be needed of any medications.
- Take the contact telephone numbers for the consultant and MSA nurse specialist so you have access to advice whilst away, and for any medical team that might need advice.
- Take your copy of the Trust’s *Guide to Multiple System Atrophy* to aid any professional you may need to be in contact with, but who may have no experience of MSA.
- Ensure if flying or cruising that the company are aware of your level of mobility nearer to the time of travelling, and whether you will need to take a wheelchair.
- Also if flying, ask for an aisle seat and with good leg room, ideally as close to the toilet as possible, and wear flight stockings.
- If you use a Convene/catheter ensure you have spares with you; and you may find using a leg bag for the journey reduces the need to find and access toilets.
- If you have a disabled toi-

let/RADAR key, have it in your hand luggage.

### AND HERE'S A FEW THOUGHTS TO HELP YOU ONCE YOU'VE ARRIVED

If staying in a hotel, contact them in advance to ensure bedroom and bathroom facilities are accessible, eg, over bath shower may be difficult; is there a stool that can be used in the shower so you can sit down whilst showering? Ideally get a disabled room as this will have more space, but still ask exactly what the bathroom facilities consist of.

Do you need other equipment such as a hoist system? Portable hoists can be loaned and delivered to hotels.

Check the accessibility of the bedroom from the rest of the hotel facilities and the street – are the lifts reliable and able to take wheelchairs?

Remember to pack adapted cutlery if you use these at home, or think about adapting cutlery provided, eg, foam grips to fit over standard cutlery are a good idea, particularly as you won't be able to take a knife on a plane in hand luggage.

If you're planning to hire a car whilst abroad, consider booking a more spacious one that is easier to get in and out of. It may help to pack a 'turntable' seat and a slide sheet in the main luggage.

It may be a good idea to get a reassessment from the physiotherapist, occupational therapist, speech therapist and continence nurse within a month of going away. They

might have tips about things they anticipate could need planning for, and ways to manage any 'hurdles' they think may occur.

If the holiday is booked through a tour operator they should be able to assist with getting many of these things addressed, but you need to make them aware of possible needs.

An element of MSA can be episodes of sudden low blood pressure. It's important to be careful not to get overheated in showers and baths or by sitting in direct sun, and take particular care if visiting a hot country. Remember to take extra fluids and salt tablets with you.

And last but not least, have a great time!

### CONTACTS:

Please note these have not been tested by the Trust, but we hope you will find them useful.

### ACCESSIBLE FACILITIES

[www.directenquiries.com](http://www.directenquiries.com) - eg, locating disabled access toilets.  
[www.dlf.org.uk](http://www.dlf.org.uk) - booklet called *Flying High* - a practical guide to air travel for people with disabilities.

### INSURANCE

[www.able2travel.com](http://www.able2travel.com)  
0845 839 9345.  
Medici Travel - 0845 880 0168.  
CK Travel Insurance - 0800 917 2274.

### ACCOMMODATION

[www.ableize.com/Holiday-Accommodation](http://www.ableize.com/Holiday-Accommodation).

[www.accessibleguide.co.uk](http://www.accessibleguide.co.uk)  
0800 953 7070 for a *Guide to Accessible Britain*.

[www.disabledholidaydirectory.co.uk](http://www.disabledholidaydirectory.co.uk)

0800 993 0796 for a range of UK and overseas holidays.

### ASSISTED HOLIDAYS

3H Fund - [www.3hfund.org.uk](http://www.3hfund.org.uk)  
or 01892 860 207 for volunteer helpers to enable family carers have a break whilst on holiday too.

Break - [www.break-charity.org](http://www.break-charity.org)  
provide holiday respite care.

Handicapped Aid Trust - 01253 796441 provide grants towards cost of holidays for the carers of disabled people, so this could go towards paying for a carer to accompany you.

Holiday Care - eg, information on accommodation, respite care, reservations, financial support.  
[www.holidaycare.org.uk](http://www.holidaycare.org.uk)  
08451 249971.

### EQUIPMENT

Travel John (pack of 3 costs around £12) order online at [www.westons.com](http://www.westons.com) reference code PR52160. These hold up to 800 ml of urine and turns it into a gel that can be disposed of complete in standard waste.

The local Red Cross in the area may supply wheelchairs/com-modes or the local occupational therapist may be able to loan these for holiday purposes or put you in touch with a local hoist company representative. **MSA**

# REGIONAL SUPPORT GROUPS - MAP

Please contact either the relevant MSA support group leader or our office (020 7940 4666) if you would like to attend a meeting.

Support groups are open to people with MSA, their carers and family members and provide an opportunity to share experiences in an informal setting with like-minded people. They are also a great way to find out about local resources.

Once you have registered your interest, you are welcome to attend whenever you can and whenever you are feeling up to it. Our volunteer group leader will keep you informed of forthcoming meetings and local information. **MSA**

The lists shown here give the name of the leader and contact details and, where known, information on planned meetings. Contact the leader or the Trust office for updates.

## BLACKPOOL

Jo Hans  
[hansjj@talktalk.net](mailto:hansjj@talktalk.net)  
01253 821693  
Date & Venue TBC

## CORNWALL

Jane Hardy / Jan Pearce  
[moonbeams@ymail.com](mailto:moonbeams@ymail.com)  
01726 74792 / 01726 861361  
No meetings currently  
scheduled for 2011

## DERBYSHIRE

Karen White / Kulwant Sehmbi  
[karenwhite7@wanadoo.co.uk](mailto:karenwhite7@wanadoo.co.uk)  
01283 735847  
02/06/11 (2 - 4pm)  
Dovenside Social Club, Hatton,  
Derby, DE65 5DT

## DEVON

Dennis Westrip  
[denniswestrip@btinternet.com](mailto:denniswestrip@btinternet.com)  
01271 378273  
01/07/11 (2 - 4pm)  
Baptist Church, High St,  
Cullompton, Devon, EX15 1AJ







### **EAST MIDLANDS**

Elizabeth Brackenbury  
Ian Jones  
[holmepierrepoint@aol.com](mailto:holmepierrepoint@aol.com)  
[i.jones5@ntlworld.com](mailto:i.jones5@ntlworld.com)  
0115 9333083 / 0115 9199294  
05/10/11 (2 - 4pm)  
Holme Pierrepont Hall, Holme  
Pierrepont, NG12 2LD

### **ESSEX**

Lady Laurelie Laurie  
Sir Bay Laurie  
[baylaurie331@btinternet.com](mailto:baylaurie331@btinternet.com)  
01206 210410  
24/10/11 (from 12.30pm)  
Great Tey Village Hall, Great Tey,  
Essex

### **GLOUCESTER**

Janice Davies  
[janicedavies147@hotmail.com](mailto:janicedavies147@hotmail.com)  
01242 224617  
Date & Time TBC  
Venue TBC

### **GREATER MANCHESTER**

Katie Rigg  
[nurses@msatrust.org.uk](mailto:nurses@msatrust.org.uk)  
01434 382931  
14/10/11 (1 - 3pm)  
Mayo Building, Salford Royal  
Hospital, Manchester, M6 8HD

### **NORTHERN IRELAND**

Rosemary Arbuthnott  
[roseyart@gmail.com](mailto:roseyart@gmail.com)  
June 2011 (time TBC)  
Venue TBC

### **NORTH LONDON**

Leader/Coordinators TBC  
Date & Time TBC  
Venue TBC

### **SCOTLAND - FIFE**

Kim Carr (contact via the Trust)  
16/09/11 (1 - 3pm)  
Venue TBC

### **SCOTLAND - INVERURIE**

Gill Campbell (contact via the  
Trust)  
15/09/11 (time TBC)  
Venue TBC

### **SOUTHERN IRELAND**

George Hunter  
[george@georgehunter.biz](mailto:george@georgehunter.biz)  
00353 872525252  
Date & Time TBC  
Venue TBC

### **SOUTHPORT**

Fraser Gordon  
[frasergordon@live.co.uk](mailto:frasergordon@live.co.uk)  
01704 894129  
01/09/11 & 01/12/11  
St James' Church Hall,  
Southport

### **SURREY**

Peter Turvey  
[peterturvey@waitrose.com](mailto:peterturvey@waitrose.com)  
01483 827395  
01/09/11 & 01/12/11  
Shalford Village Hall, Kings  
Road, Shalford, Guildford, GU4  
8JU

### **WARRINGTON**

Linda Moss  
[linda.moss@warrington-pct.nhs.uk](mailto:linda.moss@warrington-pct.nhs.uk)  
01925 867710  
Date & Time TBC  
Venue TBC

### **YORKSHIRE & HUMBER**

Karen Walker  
[karenwalker@bh-cc.co.uk](mailto:karenwalker@bh-cc.co.uk)  
07710 312552  
Date & Time TBC  
Venue TBC

# Celebrating our birthday *by* RAISING FUNDS *for* MSA RESEARCH



Next year is our 15th anniversary and we're going to celebrate by making it a year to remember. We want to raise **£1 million** to put MSA research firmly on the map. An ambitious target? **Yes, absolutely.** Are we aiming too high? **No!**

**F**or the people whose lives are already affected by MSA, and the many thousands yet to be diagnosed, we want to give hope of one day finding the cause and hopefully a cure to MSA, and of beating this devastating disease.

To do this we **must** raise significant funds for our research programme.

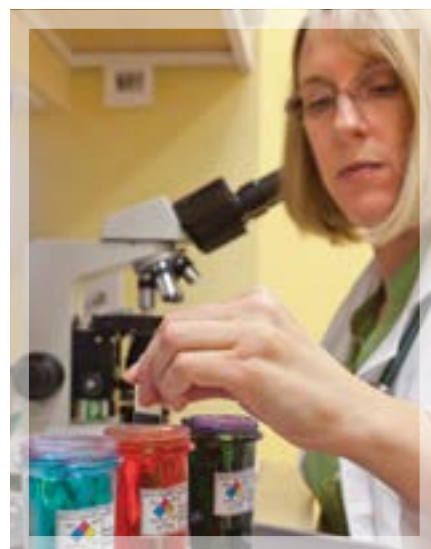
The difficult balance will be to continue funding our essential services such as our nurses, our literature, our website,

educating health professionals and trying to influence the NHS policy agenda.

But if we can raise **additional** funds we can do both - continue to fund our information and support services and make a truly serious investment in research.

Research was listed as one of your top priorities in last year's membership survey - many of you share our dream.

We'd love to hear how you can help us to realize it.



# *Want to get involved?* **HERE'S HOW...**

We're working now to build an exciting year of fundraising activities to be held throughout 2012, and if you'd like to get involved in helping us to raise £1m to make a **significant** difference to our ability to fund MSA research, then read on!



We will be organising runs, cycle rides and swimathons for those of you who like a physical challenge. We'll also be primed and ready with ideas and materials to help you carry out your own fundraising activities if you prefer something less energetic!

## **MEDALS FOR MSA**



Inspired by the Olympic year, we are holding a nationwide Medals for MSA challenge across three disciplines: cycling, running and swimming.

Runners, swimmers and cyclists will try to beat records to be set for this event by leading athletes in each discipline. We'll get them to run, swim and ride and will then text you the re-

cord you have to beat - and to everybody else around the UK taking part! Sound your sort of challenge, or perhaps you know somebody who loves to beat the clock, then let Mike Coffey at the Trust know and he'll register your interest and keep you posted.

We know there will be people champing at the bit to take part - but perhaps it's been a

while since you ran, swam or cycled... don't despair! We're keen that everybody has a chance to do their bit for MSA research and, of course, win a Medal for MSA. If you'd like to take part by setting your own personal best, then let Mike know and he'll make sure you're registered and kept up-to-date on the Medals for MSA challenge.

# MSA FOUR COUNTRY RIDE



We want to spread the word about MSA and, of course, our fundraising net as widely as we can so we're organising four cycle rides - one in England, Wales, Scotland and Ireland. Each will be over a distance of about 50 miles and will start and finish at the same place - four big loops!

The Trust is supported by a fantastic UK-wide band of volunteer Support Groups who hold informative, social meetings for people affected by MSA - so you could find yourself riding through a crowd of cheering supporters!

Does the thought of riding through the UK's beautiful

countryside as a way of raising funds for the £1m MSA research appeal sound exciting? Perhaps you could think about doing this with family and friends. Mike Coffey at the Trust can register your interest and keep you up-to-date with news on the event.

## Challenge AMBASSADORS

To meet our £1m appeal target we must generate massive interest in these challenges. This means we have to reach people who may not know about MSA.

We need to motivate **hundreds** of people to take part because they love a challenge, because they're excited by beating records - theirs or somebody else's - and because the events are so great they'll be ready and willing to support the cause by getting sponsored to take part!

Finding these people and persuading them to take part will be a challenge too.

It will need local knowledge, networks, contacts and a little bit of salesman patter!

In short, it will take a Challenge Ambassador, and we're looking for people to join us

in making these events a success by becoming just that - an ambassador for the cause. If you'd like more information, or would just like a chat about the Challenge Ambassador role in the Appeal, then please contact Mike.

### **...AND HERE'S ANOTHER CHALLENGE!**

Could you help us raise £250,000 - a quarter of our target - by raising £5,000?

OK, the maths doesn't add up when we put it like that - but it does if 50 people all raised £5,000!

We can help you with fundraising ideas, Appeal materials and lots of encouragement, so please register your interest with Mike and he'll be in touch to help get you started and guide you on your way.



If we are going to make a real difference to the lives of people with MSA, we have to undertake more research; as part of this, we aim to fund the UK's first MSA Senior Research Fellow. Our new **Research Strategy**, launched this month, is available on our website at [www.msatrust.org.uk](http://www.msatrust.org.uk) or from the Trust office on 020 7940 4666.

# THE APPEAL CLUB



Our fundraising isn't all about challenges, it's also about the Appeal club. To help us reach our target of £1 million, we've formed the Remember MSA 2012 Club. The club is open to everyone to join and by becoming a member you are directly supporting the Appeal and moving us ever closer to the magical £1 million. Club members receive a member's badge, updates on Appeal progress and information about Appeal events. Membership is..... £20.12! Please complete the form and return to Mike Coffey: Multiple System Atrophy Trust, Southbank House, Black Prince Road, London SE1 7SJ. Thank you!

## REMEMBER MSA 2012 CLUB MEMBERSHIP FORM

Name:.....

Address:.....

..... Postcode:.....

Email:..... Telephone:.....

**STANDING ORDER MANDATE:** To The Manager:..... Bank/Building Society

Address of your Bank or Building Society:.....

Branch sort code: -- Account Number:

Starting on: ..... I would like to set up a standing order, to be paid monthly/  
annually (please delete as appropriate), of £..... to the account below:

**Bank:** CAF Bank Charitable banking | **Account Name:** Multiple System Atrophy Trust

**Sort Code:** 40-52-40 | **Account Number:** 00096281

**Address:** 25 Kings Hill Avenue, Kings Hill, West Malling, Kent, ME19 4JQ

**Are you a UK taxpayer?** If you pay tax on UK wages, savings or pensions, you can make your gift worth 25% more by signing a Gift Aid declaration. Would you like to Gift Aid your donation? Yes

Signed:..... Date:.....

The Multiple System Atrophy Trust is registered in England as charity number 1137652 and registered as company number 7302036.

If you'd like to support our call to raise funds for MSA research and register your interest in any of our activities, please email Mike Coffey at [mike.coffey@msatrust.org.uk](mailto:mike.coffey@msatrust.org.uk) or call him on 020 7940 4666. MSA

# Guide: ADVANCE CARE PLANNING

BY KATIE RIGG

Advance care planning consists of two concepts, advance statements and advance decisions. MSA specialist nurse, Katie Rigg, explains what they are and how they're used.

An Advance Statement of Wishes describes how someone would wish to be looked after if they can no longer manage their own care.

This may include things like their preferred routine, what they like to eat and drink, things they enjoy doing, times of day they like to relax, where they wish to be cared for and preferences about any potential treatment.

It's important where people may be at risk of losing communication capacity that opportunities are taken to explore their understanding of their condition, the potential treatments that may be required in the future, the options available and their anxieties and perceptions about these.

These wishes should always be taken into consideration and wherever practicable and safe may be implemented - but this is not legally binding.

An Advance Decision identifies a specific aspect of poten-

tial care intervention that may in the future be required by someone, but that the person would not wish to have done.

If formulated correctly this is legally binding.

Whilst an Advance Decision does not *have* to be written, it could be made verbally, a written decision means it will be carried out effectively.

## WHY WRITE AN ADVANCE DECISION?

The purpose of completing an Advance Decision is so people who fear they may lose "Mental Capacity" in the future are able to have their decision upheld if the treatment they had specified they did not want was felt necessary at that time.

For people with health conditions where their capacity of speech and expression is likely to deteriorate, every effort should be made to enable them to consent to, or refuse, treatment. Communication difficulties do not constitute mental

incapacity.

However, people in this situation often choose to complete Advance Decisions about an aspect of care they feel strongly about – perhaps around treatment they would not wish to have in the future - in case they also lose Mental Capacity as well as their communication ability.

Thinking and planning ahead can help people to think about these choices, express and explore anxieties about a particular treatment (these should be recorded as part of their Statement of Wishes described earlier) and then, if they still feel strongly, to complete an Advance Decision.

Whilst they still have Mental Capacity they will be consulted about the treatment at the time but may, with very limited communication, be unable to indicate whether their wishes are consistent or not with the Advance Decision they have made.

## WHO CAN WRITE AN ADVANCE DECISION?

An Advance Decision is written by the person who wishes to refuse a treatment (or under their direction) and in the presence of a witness. Any clinician involved in the management of the health condition the person has can support the person in writing the Decision and witnessing it.

Some people use a solicitor and make their Advance Decision at the same time as sorting out their Lasting Power of Attorney, but it does not need to be done by a solicitor.

tion or procedure, and may relate to specific circumstances which should be clearly identified.

- It should be clearly stated that the person is aware that, by refusing an identified treatment, this may be detrimental to their overall health and ultimately may affect their survival. The Decision should therefore expressly record within the statement, “Even if life is at risk”.
- The statement is signed and dated by the individual and their witness.

It only comes into effect if the treatment and circumstances are those that are specifically identified in the Advance Decision.

At the time a treatment is required where there is an Advance Decision documented for that treatment, the refusal of the treatment is legally binding if the person no longer has Mental Capacity, even if they have an appointed Lasting Power of Attorney for Welfare Issues.

The appointed Lasting Power of Attorney for Welfare Issues can only make a decision



## WHAT MUST BE INCLUDED TO MAKE IT LEGALLY VALID?

- At the time of making the Decision the person should be over the age of 18 years with the Mental Capacity to do so.
- The Decision can only relate to refusing a treatment.
- The Decision relates to a specific treatment interven-

## WHEN TO IMPLEMENT

The Advance Decision is only activated if and when the person loses Mental Capacity. So should a treatment intervention be required whilst the person still has Mental Capacity, even if they have a relevant Advance Decision in place, the person's consent or refusal of that treatment would still be sought at the time.

about care and treatment on behalf of the person when they no longer have Mental Capacity, and if there is no relevant Advance Decision in place.

## WHO NEEDS TO HAVE A COPY?

Once an Advance Decision has been made it is the person's choice who receives a copy. As it is a document that should

be reviewed and, if necessary updated or withdrawn if the person wishes, it may be wise to keep the distribution to key people only.

However to ensure its instructions are carried out, should it be required, it may be worth considering that a copy be held:

- By the person
- By the Lasting Power of Attorney, if there is one
- In GP notes
- In hospital notes, and that
- Its whereabouts are known by next of kin

If it relates to any element of resuscitation then a copy to the local ambulance service is helpful.

Keeping a record of who has a copy is essential to ensure any changes or updates to the decision are circulated accordingly.

### WHEN IT WOULD NOT BE IMPLEMENTED

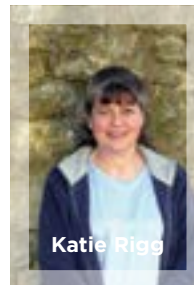
Whilst the person who made the Advance Decision still has Mental Capacity to make the decision about a treatment intervention at the time it is required.

There may be circumstances when specific treatment intervention is required but, eg, the person is unconscious or does not have Mental Capacity and the documented Advance Decision is not available.

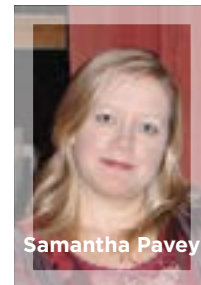
If this occurs then, where possible, health professionals will consult with the Lasting Power of Attorney and/or family members to ascertain wishes. However, they will have to act in the best interests as can be ascertained at the time, which may result in the particular treatment intervention being provided.

Please get in touch with our

MSA specialist nurses if you have any queries on this subject.



Katie Rigg



Samantha Pavey

Katie and Samantha are always happy to help answer any questions you may have about MSA and they can be contacted by email or by telephone.

MSA

**Katie Rigg:**

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01434 381932

**Samantha Pavey:**

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0203 371 0003.

## IN MEMORY

Members passed away during 2010/11

- |                              |                      |                    |                     |
|------------------------------|----------------------|--------------------|---------------------|
| • Beryl Hunt                 | • Graham Barber      | • Nancy Black      | • Jill Yeo          |
| • David Tomkins              | • Jacqueline Oake    | • Mick Gale        | • John Duncan       |
| • Peter Crozier              | • Jeanette Bottomley | • Margaret Liptrot | • Margaret Shepherd |
| • John Heath                 | • Martin Dowling     |                    |                     |
| • Alan Hogarth               | • Philip Robinson    |                    |                     |
| • Paul Halsey                | • Graham Shaw        |                    |                     |
| • Annette Wayth              | • Michael Millington |                    |                     |
| • Philip Sims                | • Barbara Hopkins    |                    |                     |
| • Elizabeth (Liz) Baverstock | • Roy Hallett        |                    |                     |
| • Tim Foote                  | • Victor Talbot      |                    |                     |
| • Tony Steen                 | • Jacqueline Dolby   |                    |                     |
| • Tony Wolfe                 | • Moira Campbell     |                    |                     |
|                              | • Kevin French       |                    |                     |



[www.muchloved.com](http://www.muchloved.com) is a website dedicated to offering personalised website tributes in memory of a loved one. MuchLoved is a UK registered charity set up to help with grieving and healing.



# FUNDRAISING

## OUR INCREDIBLE MEMBERS

### IN ACTION

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#### Jazz Night 2011

A well-attended jazz night was held in March at The Artillery Arms in London which raised £105 in support of Graham Shaw who had MSA. Music was provided by the evening's organiser, Sam Braysher ([www.sambraysher.com](http://www.sambraysher.com)) and his Quartet along with the Will Rixon Quintet. All are students and graduates of the Guildhall School in London. Sam (pictured) says there was a great atmosphere on the night and he very much hopes to organise another fundraising gig in support of the Trust.

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#### Nelson Golf Club

Captained by John Stoney, Higham, East Lancashire, whose wife Pat has MSA, the members of Nelson Golf Club staged a variety of fundraising activities throughout the year to raise £5,469.65 for the Trust and Parkinson's UK. The Club's efforts were supported by England cricketer, James Anderson, Yes Golf Southport and Thwaites Brewery. Photo reproduced with the permission of Barry Greenwood.

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#### Bridge Drive 2011

The Brierfield Bridge Club organised a bridge drive in March which raised over £1,100 for the Trust. Club member Pat Stoney (yes, the same Pat as above!) and her husband John devote a lot of time to raising awareness of the condition. Commenting on the bridge drive, John said, "It's absolutely tremendous that the money was raised, and thanks go to the hard work by the people who organised it."

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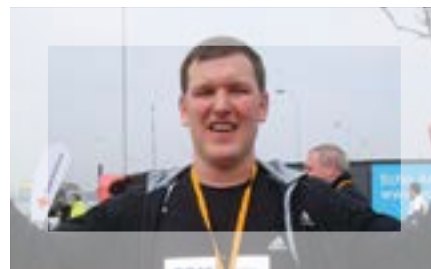
#### The Beverley & District Pipe Band 2011

On Saturday, 19th March, the Beverley and District Pipe Band performed in Beverley Town Centre, East Yorkshire, raising £412 for the Trust. The band was performing in memory of James Wood Thirsk who passed away from MSA in 1999. Blessed with fine weather, the band was able to perform two sessions to keep shoppers entertained who gave generously to the cause.



## Liverpool Half Marathon 2011

James Gill completed the Liverpool Half Marathon in memory of his partner Paula's father, Ron Dobson, who had MSA. The picture shows a delighted James with his medal. Through his efforts James raised £450 for the Trust, a sum that his employers, Shop Direct Group, have agreed to match.



## Loch Ness Marathon 2010

Billy Dunbar and two colleagues, brothers Dale and Jade Gray, completed the Loch Ness Marathon raising £2,500 for the Trust. Billy's wife Vanessa and sons Flynn and Matthew William, along with his mother Rose and sister Wendy and her family, were present to urge the trio on who were taking part in memory of Billy's father, William, who passed away from MSA in June 2010.



## Cake and book sale

Nathan "Donald" Mackenzie MacInnes raised £42.69 in memory of his Grandad, Donald MacInnes, by holding a cake and book sale in the local park after school. Nathan's mum, Janice, said that it was Nathan's own idea to raise funds for "Grandad's charity to help others".

## 100 miles plus

In addition, Iain McMillian raised £1,200 in memory of Donald MacInnes by running over 100 miles last year. Among the events Iain took part in were the Edinburgh marathon, a kilomathon, three half marathons and four 10k runs. This year he is running another marathon, half marathon and kilomathon for the Trust.

## Bagshaws & Uttoxeter Rotary Club

Bagshaws, Uttoxeter West Midlands, rural surveyors, auctioneers and valuers raised £3,000 for the Trust. The company's Jilly Gidding's husband, Geoff, has MSA. Among the fundraising activities staff members took part in were a swimathon and BBQ. A further £800 was raised for the Trust by the Uttoxeter Rotary Club. Members of the club joined Bagshaws staff and friends to hand over a cheque for £3,800 to Trust nurse Katie Rigg, at Bagshaws' Uttoxeter office.



Mike Coffey, our new Events Fundraiser, says he is bowled over by the commitment of Trust members, their families and friends. He says, "A big thank you to everyone - please let me know if I can help!" **MSA**

# Goodbye FROM OUR CHAIR

BY EILEEN LADY STRATHNAVER OBE

Like many of us, I had never heard of MSA until a consultant announced his diagnosis. In my case that diagnosis was of a wonderful friend, Sarah Matheson.

As was her way, Sarah researched what she wanted to know about the condition; to her concern she discovered there was no organisation dedicated to supporting MSA sufferers. There was clearly a crying need for one and with the encouragement of the medical profession and friends, the Trust was born.

The early meetings were in Sarah's sitting room in Vauxhall, London. They were informal; we were feeling our way. Then, through the generosity of Professor Christopher Mathias and St Mary's, Paddington, we were given space in the hospital for a proper office and the chance to work alongside the specialist unit treating MSA patients. A very experienced nurse specialist, Catherine Best, joined us part-time, plus an office administrator and we were on our way!

***That was 14 years ago.***

The need for our services has been palpable. We keep growing! Two years ago we realised we were outgrowing St Mary's,

and took the major decision to go independent. We now have our own external office – back in Vauxhall where it all began – with an office staff of four and two nurse specialists. And all the time our supporters have been overwhelming with a steady flow of contributions to our work. So much so that we have been able to fund a regular and substantial programme of grants for research.

For the past 10 years I have been privileged to act as Chairman of the Trust. It has been an exciting, challenging and rewarding experience. We have a terrific Board of Trustees with a dedication and array of talent which has made the Chairman's job much easier. I owe them all a great debt of thanks.

I owe an equal debt to the stalwart team in the office: those in the past and now, and to our two wonderful nurses. Without such devoted staff, the Trust couldn't and wouldn't exist. They daily handle, with skill and devotion, the avalanche of requests

for information and help, at the same time working hard to prepare the groundwork and advance planning strategy for the Trust's growth.

***Because we want to grow.***

We want to expand substantially our investment in research and to offer ever greater services to our members. For all that we will need funds, and we are now poised to launch our first-ever, major fundraising campaign. This is clearly the right way to go.

It also seemed the right time for me to step back and hand over the reins to a new (and younger!) chairman. I am happy to announce that Mike Evans, who has been a Trustee for seven years, has agreed to take on the job. He will be writing a piece for a forthcoming edition of the magazine to tell you about our future plans. In the meantime, I am delighted to be handing over the Chair, on the brink of this new phase in the Trust's history, to such a safe pair of hands!

***We want to make a difference. MSA***



**Multiple System Atrophy Trust**

Founded by Sarah Matheson

# WAYS TO SUPPORT THE TRUST & HELP IT GROW

## BECOME A FUNDRAISER

Events such as coffee mornings, car boot sales and a wide variety of sponsorship opportunities bring the Trust valuable income every year. New ideas are always welcome! Email [mike.coffey@msatrust.org.uk](mailto:mike.coffey@msatrust.org.uk) or call 020 7940 4666.

## USE OUR ONLINE FUNDRAISING/ DONATION FACILITY

We have the facility for you to use an online fundraising package on [www.justgiving.com](http://www.justgiving.com). This facility can be used for anything from a personal occasion to an *in memorium* for a person's life.

## MAKING A REGULAR DONATION

If you would like to make a regular donation to support our work, please complete the form below and send to the Trust office. If you are a UK taxpayer we can increase the value of your donation by 25% by reclaiming the tax as Gift Aid. Regardless of size, all donations help us to maintain and improve our services.

## CONTRIBUTE TO MSA NEWS

Sharing your experiences and tips with other members helps keep it *your* magazine. Email [nickie.roberts@msatrust.org.uk](mailto:nickie.roberts@msatrust.org.uk) or call 020 7940 4666.

## FORM A LOCAL SUPPORT GROUP

We can offer guidance and encouragement to run a group to provide local support for people affected by MSA. Email [neil.hunter@msatrust.org.uk](mailto:neil.hunter@msatrust.org.uk) or call 020 7940 4666.

## RAISE AWARENESS ABOUT MSA

Share our information with family, friends and the health professionals you meet. Follow us on Twitter and Facebook by visiting [www.msatrust.org.uk](http://www.msatrust.org.uk).

**Thank you for your support.**

Name:.....

Address:.....

..... Postcode:.....

Signed:..... Date:.....

I would like to make a regular donation. Please send me a form.

I would like to make a donation of £..... and enclose a cheque.

I am a UK taxpayer and wish all gifts of money that I have made in the past six years and all future gifts of money that I make from the date of this declaration, until I notify you otherwise, to be treated as Gift Aid donations.

**PLEASE MAKE ALL CHEQUES PAYABLE TO 'MULTIPLE SYSTEM ATROPHY TRUST'**