msa *news*

MSA Trust Members Magazine | issue 54 | February 2019

Access *all* areas

Making your home fit for you

Navigating the Benefits maze

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Welcome to issue 54

A very warm welcome to MSA News edition 54. In this issue, in addition to our regular features, you will find articles on Eye Health and Housing Adaptations.

We also have an interesting piece following a day in the life of our MSA Research Fellow - finding out what she does working at the Institute for Neurology. There's also an overview of the Trust's policy and campaigning work and what we're focusing on at the moment in this area.

Support Groups remain a core area of our work and we know that they are a great source of information, inspiration and support to our members. However going along for the first time can be daunting. On page 18 you can read about a couple's experience of their first meeting in Cornwall.

*The Neurological Alliance are still running their Patient Experience Survey until the end of March and would like to hear about your experiences of health and care services in England. You can take part by following this link - **www.tinyurl.com/neuro01**. While we don't want to bog you down with surveys we are pleased to be launching our **own specific MSA Needs Survey** which we hope you can all help with. You can find out more about this exciting project on page 5. Best wishes, Emma and Andy.*

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My Special Activity book

We're now very pleased to say that following a lot of hard graft and consultations, our Activity Book is now published and available to members.

Over the past year Katie Rigg, MSA Nurse Specialist and Emma Rushton, Information and Services Manager have been developing an activity book for children aged 4-11. This was a direct result of enquiries received from members wanting something they could use with their children or grandchildren to help them understand MSA. MSA is a complex disease with different symptoms that children may have noticed in a loved one and which may have also caused changes within the household.

'**M**y **S**pecial **A**ctivity book' aims to describe what MSA is, in child-friendly ways. It looks at the different symptoms people with MSA might experience - for instance difficulties with walking, needing the toilet and communicating. It also explores which healthcare professionals might be involved in a person with MSA's care and contains a section addressing how the child is feeling, exploring their own emotions and how to deal with these.

The book is interactive and engaging with activities for children to complete on every page. Some of these can be completed by the child independently but others need family members and friends involvement. There are also stickers that go with the book, as we know how much children love these! We have provided guidance notes to help adults who are supporting the child to use the book.

We have made sure the publication has gone through a thorough testing process where teachers and children themselves have reviewed it and we have taken on board their feedback. We feel this has really shaped the resource into something that children want to read and complete. Thank you to all the families affected by MSA that helped us create something that we hope will be fun and support many children in years to come.

The book will be available in hard copy and will be free of charge to all members who think it will be of use to their families. You can complete the form on our website here – **www.msatrust.org.uk/activity-book** or email **support@msatrust.org.uk** to request a copy. We very much welcome your feedback.

Moving forwards we will be focusing on providing a new resource for young people aged 11-17 years old. We're still open to ideas about what this might be and would especially like to hear from children in this age bracket, or young people who are slightly older but have experience of a loved one with MSA.

If you have any questions about **M**y **S**pecial **A**ctivity Book or suggestions for a resource for 11-17 year olds, please email **support@msatrust.org.uk** or call 0333 323 4591 to talk to Emma or Katie.

Our new Advocacy Officer

My name is Jane and I am the Advocacy Officer at the MSA Trust. My role is new and was set up to support people (mostly by phone or email) with a range of issues including:

- Providing information about benefits and how to claim them, supporting people in completing forms and advising on challenging benefit decisions. If you would like to check that you are in receipt of the correct benefits please do get in touch
- Supporting people with NHS Continuing Health Care (known as CHC) applications and appeals. CHC funding meets the care costs of people whose needs are primarily health related
- Providing information about care services, equipment provision, home adaptations and many other things which are not medically related
- Administering our small grants budget and working with people to identify ways of meeting needs that are not met by a statutory service.

Although I cannot visit people at home I do try to attend Support Groups on an occasional basis so hope to meet some of you at these.

Please email me at jane.stein@msatrust.org.uk or call 0333 323 4591.

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CARERS ALLOWANCE (CA)

What is it? CA is a benefit paid to people who provide a substantial amount of regular care to a disabled person living at home.

Who can claim it? CA can be claimed by people over 16 (including partners, family members and friends) who provide care for at least 35 hours a week to a disabled person who receives a relevant benefit. Relevant benefits include Attendance Allowance, Personal Independence Payment (with a daily living component) and Disability Living Allowance (with a middle or high rate care component). The carer must not earn in excess of £120 a week after deductions for tax and certain expenses. CA is taxable and cannot be claimed in addition to certain other benefits (for example, carers in receipt of a state pension can have their pension increased to the CA level but if their pension is over CA level they will not be paid CA). A claim for CA may also affect the benefits of the person with MSA. CA can be back dated by 3 months.

Are there different regional rules? Yes. This information applies to people in England and Wales. The rules are the same for people in Scotland but carers in Scotland are also entitled to a twice yearly Carers Supplement. There are some differences to CA in Northern Ireland. The benefits system is different in the Republic of Ireland.

How do I claim? If you live in England, Wales or Scotland you can claim online at: **www.gov.uk/carers-allowance/how-to-claim**. Northern Ireland: **www.nidirect.gov.uk/services/apply-carers-allowance-online**. Ireland: **www.citizensinformation.ie/en/social_welfare/social_welfare_payments/carers/carers_allowance.html**. You can also call the Helplines: 0800 587 0912 or in Northern Ireland 0800 731 0297.

If you need further advice about CA or about an 'underlying entitlement' to CA or Carers Credit please call or email me on the co. msa news

NEWS ROUNDUP

WANTED

Your experiences of living with Multiple System Atrophy – A study

We know that there are a significant number of issues that come with a diagnosis of MSA, including the practical and emotional impacts of living with the condition. We believe both awareness of MSA and its impact are poorly understood and recognised by the Government and those heading up the health and care professions. As such, we want to find out from you all the key issues you feel are important to address when living with MSA. We are calling this our 'MSA Needs Survey'.

Our objectives will be:

- To identify the impact on individuals diagnosed and living with MSA and those who care for them.
- To find your main needs regarding the provision of quality care and wider support for people living with MSA and their carers
- To ensure the services we provide are representative of the views and needs of people living with MSA
- To use the results to influence policymakers and others to ensure people with MSA and carers are offered better choices and care.

The survey is due to be sent out in April 2019 by email and post. Please do look out for it, every single response will be important. If you think your current contact details are incorrect or you want to give an email address if we don't have one for you, this will enable us to send you a link to complete it easily online. Contact us at **support@msatrust.org.uk**. msa *news*

Pension Credit Rule Change - will it affect you?

Pension Credit is a means tested benefit in the UK. It is currently available to single people of pension age and to couples where the older person has reached pension age even though their partner hasn't.

But the rules for couples are changing on 15th May and if you don't act now you could lose out. From this date, if you're in a couple you'll only be eligible to start getting Pension Credit if either:

- ***you and your partner have both reached Pension Credit qualifying age***
- ***one of you has reached Pension Credit qualifying age and is claiming Housing Benefit (for you as a couple).***

If, as a couple, you already get Pension Credit this will continue after 15 May 2019. However, if your entitlement stops for any reason (this can happen if your circumstances change), you will not be able to start getting it again until you are eligible under the new rules. Single people may be affected if they start living, as a couple, with a younger partner.

If you think you may be entitled to a means tested benefit and one of you is of pension age please act now and apply for Pension Credit. Please see **www.gov.uk/pension-credit/eligibility** for more information or contact Jane Stein, here details are on page 4. msa *news*

Looking after your *eyes*

This article gives an overview of some of the information that is in our 'Eye Health and MSA' factsheet. Please do contact your MSA Nurse Specialist if you have any further questions about this topic…

Multiple System Atrophy doesn't cause sight loss but there can be several symptoms that might arise as a consequence of having MSA.

It is recommended that everybody has a sight test at least every two years. In the UK everybody over 60 can get a free sight test as well as some other groups (free in Scotland and free in Ireland under the Treatment Benefit Scheme). These can pick up common issues but if you feel that your eyes are giving you problems, or you notice some of the issues outlined below, do make sure you tell your consultant or GP.

Some people with MSA may experience problems with eye movement, most commonly with the ability to focus both eyes together. This may result in blurred or double vision. Your specialist will refer you to other professionals who can test eye movement and suggest appropriate action.

In MSA, people blink less often, which can lead to eyes becoming drier than usual. If it is left untreated, the eyelid can scratch the surface of the eye, which can lead to ulceration. This is painful and can affect vision. People with MSA may also produce fewer tears, known as dry eye syndrome.

Dry eye syndrome is a condition where the tears produced are insufficient to moisten and nourish the eyes. This causes symptoms such as dryness, irritation and sometimes infection.

There are a range of treatments that may be brought into play to help. These include regular lid cleansing and gland expression, over the counter or prescription eye drops, sprays or speciality contact lenses.

In terms of self-help if you have sore, dry or sticky eyes you should bathe them twice a day in the following way:

1. ***Wash your hands***
2. ***Put one teaspoon of baby shampoo in a cup of water***
3. ***Gently dip some cotton wool in the diluted solution***
4. ***Gently clean the lids and eyelashes from the nose side outwards***
5. ***Wash your hands again***
6. ***Use new cotton wool for the other eye. Remember to never put the solution directly into your eyes.***

Low blood pressure, a feature of MSA, can affect the pressure within your eyes and cause blurred vision. If your low blood pressure can be corrected the blurring of vision should lessen. Please see our factsheet on blood pressure and postural hypotension for support with this - **www.msatrust.org.uk/support-for-you/factsheets**.

Nystagmus is a condition which causes constant movement of the eyes which a person cannot control. It is not painful and does not lead to loss of vision. It is caused by a problem with the way in which the eye sends messages back to the brain or by how parts of the brain which deal with eye movement actually make sense of the information. It can make you feel as if the world is moving side to side in time with the movement of the eyes. Whilst Nystagmus is not specific to MSA it is common in people with MSA or cerebellar disorders. A Low Vision assessment by an optician or ophthalmologist will explore which glasses, contact lenses or aids can be provided to make the most of your vision.

Another symptom that can impact on sight for people with MSA, although not directly related to the eyes themselves, is antecollis, where the head and neck falls forward to one side. This can affect a person's ability to see the person in front of them and can thus affect communication. Prism glasses, which use an angled mirror in the glasses, can allow people to see ahead of them without lifting their eyes. Thanks to the generosity of a good friend of the Trust we have these available for people to use so please talk to your MSA Nurse Specialist or call the office if you think they would be useful.

Finally, if you have difficulty in reading there is support available from many different organisations and through equipment and aids that can help. A good place to start is RNIB's website which looks at aids which might help as well as a range of publications and books which are accessible to people with sight problems - **www.rnib.org.uk/services-we-offer/reading-choices**. Another organisation is Calibre and again they do not require people to be blind or partially sighted to access their services - **www.calibre.org.uk**.

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So to reiterate the message at the start, if you are having worries or problems with your eyes or sight make sure you raise these with your GP, Specialist or your MSA Nurse Specialist. Do make sure that, in common with everybody else you have your sight tested at least every two years. You can find out who your MSA Nurse Specialist is, and their contact details, by visiting our website – **www.msatrust.org.uk**.

In Memory

Kenneth Conner
John Sears
Donald Ross
Doreen Dowling
Carol Hollis
John Stewart
Ian North
Sean Whelan
William Edwards
Carole Abery
Anne Bowen
John Jacobs
Paula Langford
Maree Littlewood
Michael Fea
Diana Hunter
Michael Smith
Julie Limbuvala
Anna Russell
Richard May
Mavis Blakey
Nicola Smith
Yvonne Wright
Alison Anderson
Graham Prior
Annie Aitken
Allan Wiseman
John O'Connor
Linda Collins
David Gough
Douglas Ledger
Elizabeth Gibbs
Rory Flannery
James Aitken
Jean Kidd
John Maundrell
Graham Heafford
John Edwards
Sandra Madley
Lynne Kirwan
Barbara Coxon
Anne Chester
Stuart Tyler
Ingebjorg Hopson
Andrew Holmes
Karen Harper
Desmond Maries

MSA *tribute* fund

No matter what the circumstances of a death, losing a loved one is always difficult. We know that it can take a long time for people who have been bereaved to adjust to life without the person they have loved. Our Nurse Specialists can offer support and the Trust will always try to signpost people to sources of help.

In the longer term, fundraising for the Trust is seen by some families to be a meaningful way to create a lasting tribute, whilst ensuring that vital funds are raised to support others. People do this by different means, perhaps by gently requesting donations in lieu of flowers at a Funeral or memorial service, opening an online MSA Tribute Fund (**www.everydayhero.co.uk/event/msatributefund**) or when people feel ready, arranging a fundraising event in their memory.

The Trust can help with any of these. If families choose to ask for donations at the Funeral in lieu of flowers we can send donation envelopes with the option for donors to Gift Aid their donations and collection boxes for cash donations. These can be sent directly to the Funeral Directors or sent to a family member if the Funeral Directors does not offer a collection service. Email **fundraising@msatrust.org.uk** for help with these arrangements.

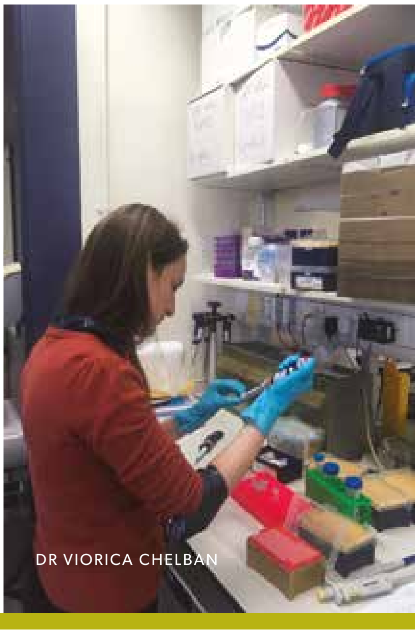
Some supporters also organise events in their community in memory of their loved ones. Kim Whittaker lost her husband Ian and with the help of family and friends raised more than £4,200 through the Ian Whittaker Memorial Ball held in Brentwood, Essex.

We are exceptionally grateful to Kim and everyone who thought of the Trust during these challenging times. msa *news*

ARTICLE BY EMMA RUSHTON

A day in the life of our MSA Research Fellow

On a wet, windy and dreary day this winter I went to visit Dr Viorica Chelban, our MSA Research Fellow at the Institute of Neurology in London. Her post is funded by us in partnership with the Association of British Neurologists.


DR VIORICA CHELBAN

The first thing I learnt was that research is only part of her work. Viorica also undertakes clinical work meaning she gets to know the main issues affecting people with MSA. She currently supports the MSA clinics alongside Professor Henry Houlden and our MSA Nurse Specialist, Samantha Pavey. This involves examining patients, providing advice and directing their treatment and care.

Viorica is currently working on a research study which is looking at identifying biomarkers for early disease diagnosis. In combination with long-term clinical and imaging analysis the aim is to improve diagnosis, monitor disease progression and treatment response and ultimately encourage further research into MSA specific treatments.

On the day that I visited the morning started off with the coordination of appointments for the Prospect-M research study, another research study Viorica is focusing on. This study comprises seven specialist centres across the UK but all people with MSA in the UK can be involved by completing questionnaires and giving blood samples. There's a lot involved with the Prospect-M one year follow-up appointments including coordinating MRI scans, blood tests, a neurological examination and a review of any concerns or changes since the last visit.

When not doing clinical work, Viorica spends her time in the laboratory. When I visited she was analysing DNA, to see if there was a 'spelling mistake' in a set of 20 letters in a DNA sequence. She then compared this to controls to see if there's a genetic difference in people with movements disorders that were initially believed to be MSA. Differentiating MSA from other diseases is often one of the most difficult stages in the diagnosis but essential in providing the correct care.

You'll find Viorica in the lab in the evenings and weekends too as this is the only time researchers have access to certain machines. If cells are being grown they need to be fed and watered like a baby, so missing a day isn't an option!

Another important element of her role that I witnessed is the management of students who stay for 6-12 months and support with research projects. It's especially important to spark their interest in MSA in the hope that these bright young minds will continue to explore MSA and make new discoveries.

Viorica's day doesn't end at 5pm, in the evenings you'll often find her writing research papers, looking at lab work findings and chasing appointments for patients. Her journey home on the Thames Boat is spent reading other research into MSA and responding to requests for collaborations from colleagues around the world. In London they have collected one of the largest biobank and clinical data resources of its kind, so Viorica and the team are very excited about encouraging and supporting international initiatives in MSA research. Our thanks go to Viorica for her amazing commitment and expertise.

You can contact Viorica for more information about taking part in the Prospect-M research study by emailing her at **v.chelban@ucl.ac.uk**. msa *news*

Home sweet *Accessible* Home

As we all know, MSA affects people in different ways and to varying degrees. Due to its effects on movement, balance and mobility, it may be appropriate to make changes to your home to support safety and accessibility. Jane Stein, Advocacy Officer and Emma Saunders, MSA Nurse Specialist, look at some potential options…

First and foremost, we would always urge that any major changes to your home are considered in good time. Building extensions or making adaptations to a property are lengthy processes so it is important to think about the issues before the need arises.

When considering any changes the first step is to seek the advice of your Occupational Therapist (OT). An OT can visit you at home, assess your home environment and individual needs, both current and future and advise on adaptations accordingly. We have produced a Guide to Multiple System Atrophy for Occupational Therapists which is available on our website.

Adaptations can be costly. Your Local Authority OT can advise you on the process for a financial assessment when considering adaptations to your current property or the possibility of moving to a different, more suitable, property. Financial help and grants may be available and it is important that you enquire about this before incurring any costs or instructing architects and builders. Jane Stein, our Advocacy Officer, is available to offer information and support regarding the funding of adaptations.

Things to consider may include:

- *Access in and out of the property – Pathways into the home need to be wide enough to accommodate a wheelchair and should have a smooth surface (as walking or manoeuvring a wheelchair across shingle or an uneven surface is difficult). Access needs to be step-free and if a vehicle is used, thought needs to be given to accessing it when parked and how you will get in and out when using mobility aids.*

- *Access inside the property – Ideally, your home should be step-free and wheelchair accessible with spacious doorways and passages that are wide enough for a wheelchair or other equipment to be manoeuvred and turned. If you need to make changes to your property to accommodate a disability, then you may be eligible for a reduction in your council tax banding. Contact your local council tax office for more information.*

- *Single-floor living – For many people with more advanced MSA single-floor living can be the easiest option. Stair lifts are not usually a good long-term option as transferring on and off the stair lift becomes more difficult as the condition progresses. A through-floor lift (a level-access lift that goes through the ceiling to the floor above) may be an option if your home is spacious enough to accommodate it and the upstairs rooms are large enough to move around in a wheelchair.*

- *Bathroom - Ideally this should be a level-access wetroom with a non-slip floor and room to manoeuvre any equipment needed. Thought should also be given to how doors open, as often doors opening outwards are easier and safer for bathrooms. Equipment like grab rails and shower seats can be installed. The height of a toilet can be adjusted and toilets with built in hygiene and drying facilities are also an option.*

There is a lot to consider and it is worth thinking, talking about and considering the complex factors involved in adapting your home environment in good time to allow for planning and carrying out any necessary work.

- *Kitchen - Think about how you currently use the kitchen and what adaptations may be needed. Taps can be changed to help with dexterity issues, counter tops and cookers can be made height adjustable, cupboards can be made more accessible. Do changes need to be made to the area where meals are eaten?*

- *Bedroom - With advancing MSA a profiling (adjustable) bed may be needed and this may require more space than a regular bed. There may also need to be room for a hoist (either a mobile or ceiling track version) to help with transfers from bed to a chair.*

- *Lounge - Many people with MSA find a rise and recline or tilt-in-space chair comfortable, so room for the chair and transfers may be needed.*

- *General - Good, even flooring, lighting, heating and a sufficient supply of electric sockets are also important. Extra storage for equipment may be needed and some electrical equipment may need charging. Space may be needed for a carer to sleep.*

Some building works (and essential equipment) are tax exempt. Please see: www.gov.uk/guidance/vat-relief-on-certain-building-work-if-you-have-a-disability for more information.

Many areas have showrooms where you can trial specialist equipment (for example, bathroom and kitchen equipment) and view a range of layouts. Your OT will be able to advise on your nearest centre. msa *news*

Any health and care professionals you engage with are welcome to contact us at the MSA Trust at any time if they need specific advice or have any questions. Your local Support Group is also a good place to ask questions and get advice and recommendations in your local area.

SECOND MSA STUDY DAY

Our MSA Study Day in Newcastle

In autumn 2018 we continued our mission to increase awareness of MSA amongst health and care professionals with our second MSA Study Day in Newcastle. Following last year's success, we organised a day of talks and provided a space where around a hundred health and care professionals could network, share their knowledge and learn more about MSA.

It was our aim to organise a programme with a diverse range of professionals who could present a full picture of MSA. We were once again very lucky to have experts from different fields able to speak on the day. We started with contributions from two Consultant Neurologists: Professor of Movement Disorders, David Burn, who gave an overview of MSA; and Dr Naomi Warren who spoke about the importance of accurate diagnosis. Professor Nicola Pavese and his colleague Laura Best discussed current research developments and how these will be able to assist in earlier diagnosis and future treatment research for MSA.

Rebekah Traynor, Speech and Language Therapist, spoke about communication and swallowing difficulties encountered by people with MSA and reminded us all of the many nonverbal ways in which we can communicate with people. Research Physiotherapist, Heather Hunter, highlighted the importance of accessing physiotherapy services early and of maintaining physical activity to prevent falls.

One of the Trust's MSA Nurse Specialists, Emma Saunders, gave an overview of the work they do and how they can support health and care professionals as well as people affected by MSA. Rachel Quibell, consultant in palliative care, emphasised the benefits of involving and coordinating a range of healthcare professionals in promoting quality of life in palliative care. We also considered the importance of Advance Care planning and how health and care professionals can play a part in supporting people with this, brought to life through Claire Morris's presentation.

We recognised the importance of ensuring that attendees heard the experiences of those who we work to support – people affected by MSA. Will Norman's moving film and his heartfelt and beautifully crafted monologue about his father's experience of MSA captured the many challenges of MSA but also the binding thread of the love and support families who experience it share. As we had hoped, feedback from attendees reflected that Will's film will help them in their work.

Despite the wide variety of health and care professionals attending the day, we were pleased that, in a similar fashion to last year, 100% of attendees felt the presentations were relevant to their roles and would enable them to better help people with MSA.

> ***"Excellent speakers and presentations, covering every aspect of condition, research, care and living with it"***
>
> ***"I have taken away a lot which I feel will better inform my practice and will pass on to colleagues"***

We will continue our mission to bring awareness about MSA in our third study day which we are planning in the West Midlands in October 2019. msa *news*

If you are a Health and Care Professional, we would love to hear from you with any suggestions of topics you would like us to cover at this next event.

ARTICLE BY ANDY BARRICK

Speaking Truth to Power

The Trust's core work will always be around offering support to people affected by MSA and reducing the isolation that so many experience. However, when we hear from our members that they are experiencing difficulties, we feel it is important we raise these issues with the people and organisations who have the power to make decisions which can make things better.

Living with MSA can mean increased expenditure on many things such as travel, diet, housing adaptations, carers and special equipment. There are benefits to meet these extra costs yet many people are unaware of their entitlements and often the people who assess benefits are unaware of MSA and its impact upon daily life.

Our new Advocacy Officer, Jane Stein can now advise on benefits. We have contacted the three main organisations that assess disability benefits and provided their assessors with information about MSA and how it affects people. We are also members of the Disability Benefits Consortium and this means our voice is part of a bigger and respected lobbying group of other national charities.

We are staunch supporters of the NHS and its staff and often hear how people have received services that are over and above what would be expected. However, we also hear of difficulties that people have in the co-ordination of their care. We regularly respond to NICE (National Institute of Clinical Excellence) consultations where we feel that it is of benefit to people affected by MSA. Recently, we have also been involved with developing a care pathway for NHS England regarding progressive neurological conditions which incorporates MSA in the guidance. Our membership of the Neurological Alliance again amplifies our voice and gives us a way in to those in powerful positions within the NHS.

Continuing Health Care, where people can get funding for their healthcare needs, can be a real issue for people with very advanced MSA. Again, our Advocacy Officer can give basic advice on this but we are members of the Continuing Healthcare Alliance whose sole aim is to improve the way the system works to make it more responsive to those who need support.

Social care is another major issue, and by the time you read this the Government may have published its Green Paper on how this might look, and be funded, in the future. (This has been subject to continual delay). Many people are unaware of what support they can expect from Social Services, yet good assessments and provision of carers, adaptations and equipment can make all the difference in making sure everybody affected by MSA can live a better life. Our involvement in the Care and Support Alliance means that we get to find out how the latest developments will affect those we serve as well as giving us the opportunity to raise awareness of MSA.

This is just a very brief flavour of our policy work, if you feel we should be tackling any other issues please let me know by emailing **support@msatrust.org.uk**. msa *news*

FUNDRAISING STARS

A ROUND UP OF YOUR LATEST FUNDRAISING STORIES

IN THE COMMUNITY

Valerie Wilkin *and her family and friends organised a Barbeque night at Rockcorry School in County Monaghan, Ireland. Along with various sports activities the children put on a musical show. This was followed by a cheque presentation in the Church where the Rockcorry and Dartrey parishioners gave us a cheque for €1,600. Well done everyone!*

Joe Cannon *was back with his third MSA Charity Ball in loving memory of his mother, Sharon Cannon. They had music and entertainment, a raffle and an auction, managing to raise £18,247 on the night. 2018 sadly marked the 5th Anniversary of Sharon's passing and in addition to the Charity Ball, Joe organised a MSA Charity Skydive, raising more than £10,000! We are so grateful to Joe, his friends and the Cannon family who have now raised close to £93,000 over the years – fantastic effort!*

Hilary Spoun *organised a sponsored Scottish Country Dance to support her childhood friend, Marilyn who has MSA. 20 dancers attended, raised £323 and evidently had a great ceilidh!*

Sean Ockwell*, right, raised over £700 at his birthday fundraising party. Overall, our annual* ***M****ilk* ***S****ugar* ***A****nd* ***T****ea Party campaign was a huge success, with over £8,000 raised in 2018 for our MSA Nurse Specialist service.*

Please get in touch at ***fundraising@msatrust.org.uk*** *if you can host one in 2019.*

RUNNING YOUR SOCKS OFF

Tim Thorowgood *ran the Melbourne Marathon last year in memory of his grandmother. Brilliantly supported by his family and friends, he raised over one thousand pounds.*

Craig Martin ran the Belfast Marathon and was able to raise £1,037 in his father's memory.

***Paul Bibby** ran the Worksop Half Marathon in support of one of our members, Eileen Shaw. He completed his personal best for the race in less than one and three quarter hours and raised a fantastic £230.*

***Ben Lawson** and girlfriend, **Sophie Collinson**, successfully completed the Leeds Abbey Dash 10k run in November. Ben's father has MSA and they supported the Trust by raising over £320.*

CYCLING CHALLENGES TAKEN ON

***Peter Latos** did a three-cycle challenge for us, taking on the incredibly tough Ötztal Cycle Marathon in Austria. Peter has said:*

"It was pretty gruelling and the weather didn't help; pouring rain at the top of the three mountain peaks and down to 1 degree in the slippery descents! Anyway, reminding myself of why I was doing it spurred me on to the finish!"

***Mark Fidler** and his daughter Phoebe did a 5km tandem cycle ride following Mark's diagnosis. At the time of writing they have raised close to £1,550. Ride on!*

*If you have your own place for the **2019 Virgin Money London Marathon**, please do join our Team – it will give us a bigger presence and raise greater awareness at this fantastic event.*

Virgin money LONDON MARATHON 2019

We still have spaces for both Ride London 46 and 100 mile races, so please email fundraising@msatrust.org.uk if you'd like to take part.

PRUDENTIAL RIDELONDON

EMMA RUSHTON PRESENTS HER REGULAR ROUNDUP OF YOUR TOP SUPPORT GROUP TIPS

Supporting & Helping Each Other

With the help of our Support Group Leaders we ran 130 meetings last year throughout the UK and Ireland. Even old hands can learn a thing or two at these Groups and as usual Emma Rushton gives a few examples of shared wisdom below.

Following the communication article in our last MSA News magazine this became a hot topic at our Support Groups. At the Cumbria meeting a member shared their experience of using the Lee Silverman Voice Treatment Program which focuses on increasing vocal loudness as a way of emphasising voice quality and articulation. If, following a voice and speech evaluation, a speech therapist recommends that you sign up for the training program, you will need to have an ear, nose and throat (ENT) consultation prior to starting. You would need to commit to attending four sessions per week, each around an hour long, for four weeks. To find out more about the technique visit - **www.lsvtglobal.com**.

The Newcastle Support Group also discussed communication needs and a member shared information about the Model Talker System which is a speech synthesis software package developed to benefit people who are losing or who have already lost their ability to speak. It allows people who use a Speech Generating Device (SGD) to communicate with a unique personal synthetic voice that is representative of their own voice. The software has to be setup and used on a PC but can then be transferred to an app such as Predictable to use on an iPad. Do discuss this with your speech and language therapist and visit **www.modeltalker.org** for more information.

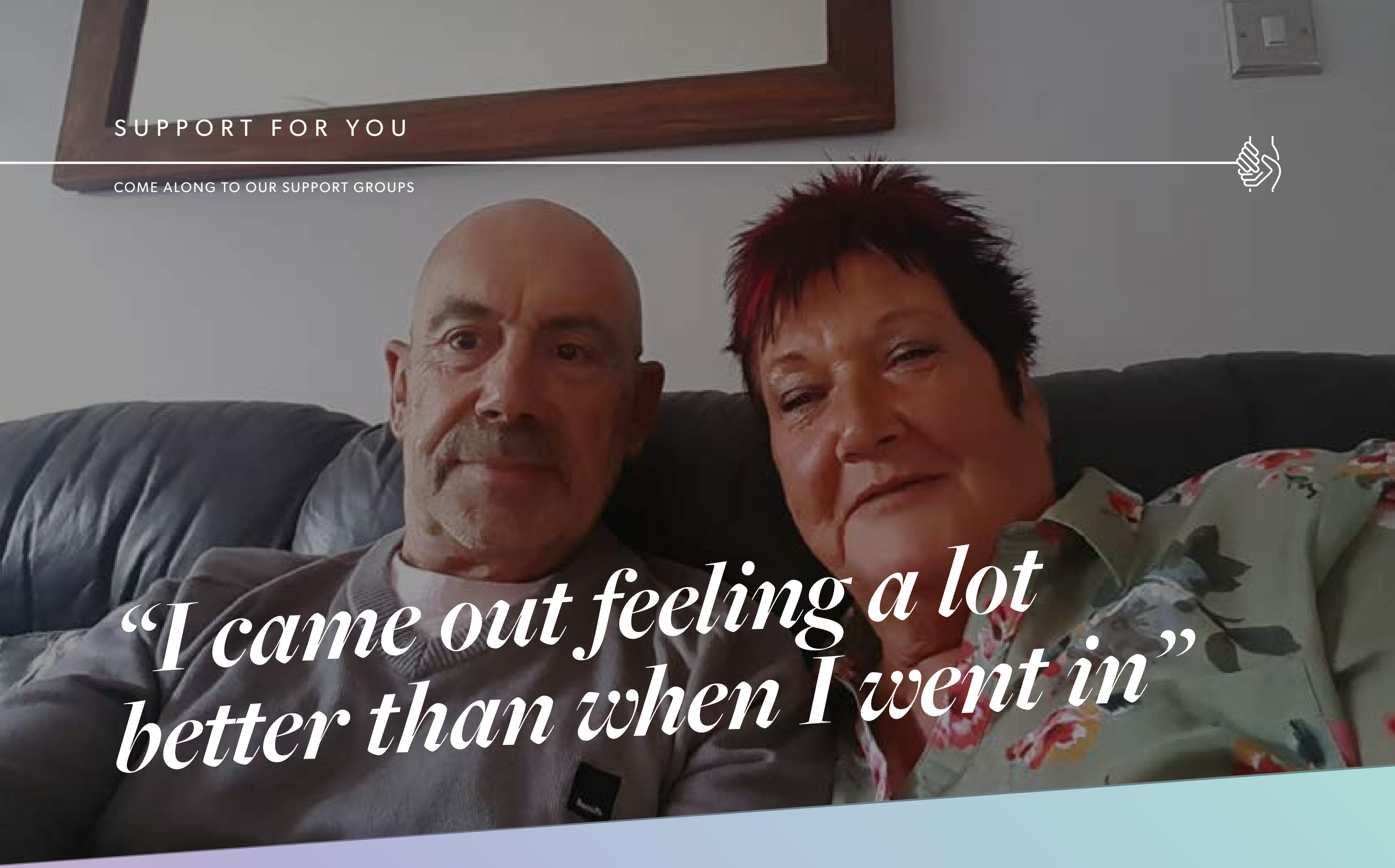
Unfortunately falls can be commonplace for many people with MSA due to mobility difficulties and coordination challenges. A member at the last North London Support Group suggested that inflatable lifting cushions can be helpful if someone has fallen. These can be slid underneath someone and then inflated to get them to a sitting position. Most designs can be used both indoors and outdoors, up to a maximum of 50 stone. They are available from a range of websites but can be very expensive so do speak to your Occupational Therapist about availability through the NHS before you buy.

The East Yorkshire Support Group discussed the usefulness and importance of Lasting Powers Of Attorney (There are two versions – Property & Finance and Health & Wellbeing). A carer at the meeting identified the value of applying for Lasting Power Of Attorney. This enables conversations to be had about your wishes and advance planning for the future. Forms and guidance for both versions are available online at **www.gov.uk/government/publications/make-a-lasting-power-of-attorney**. The forms do not need to be completed by a solicitor but some people may prefer having their professional guidance. Do also contact our Advocacy Officer, Jane Stein, who can support you with this. Her contact information is on page 4. msa *news*

If you have any questions about anything included in this article please contact your MSA Nurse Specialist at **support@msatrust.org.uk**.

Support Groups are a great way to meet other people affected by MSA, listen to presentations from healthcare professionals who can support you and meet our MSA Nurse Specialists. Please contact the Trust's office on 0333 323 4591 or email support@msatrust.org.uk for more details. These groups are subject to change, so please check the Trust's website or ring the office for up-to-date information.

GROUP	VENUE	DATE & TIME
Belfast	Marie Curie Hospice, 1A Kensington Road, Belfast BT5 6NF	Tue, 19 Feb - 2.30pm
Dublin	Education Centre, St. Francis Hospice, Blanchardstown, Dublin	Wed, 20 Feb - 1.30pm
South Yorkshire	St. Peter and St. Paul Church Hall, Todwick, Sheffield S26 1HN	Wed, 20 Feb - 1.30pm
Devon	Baptist Church, High Street, Cullompton EX15 1AA	Wed, 20 Feb - 2pm
West Sussex	Worthing Quaker Meeting House, 34 Mill Road, Worthing, BN11 5DR	Thur, 21 Feb - 2pm
County Kerry	Great Southern Hotel, East Avenue Road, Town Centre, Killarney, County Kerry V93 R866	Thur, 21 Feb - 1.30pm
County Tyrone	Please contact the Trust's office on 0333 323 4591 or support@msatrust.org.uk for more details	Tue, 26 Feb - 12pm
County Sligo	Therapy Room, St. John's Community Hospital, 8 Ballytivnan Road, Sligo	Wed, 27 Feb - 1.30pm
Bristol	The West of England MS Therapy Centre, Bradbury House Clinic, Wheatfield Drive, Bristol BS32 9DB	Thur, 28 Feb - 1pm
Shropshire	The Lantern, Meadow Farm Drive, Shrewsbury SY1 4NG	Mon, 4 Mar - 1.30pm
Cornwall	Echo Centre, Barras Place, Liskeard PL14 6AY	Mon, 4 Mar - 1.00pm
Tyne & Wear	St. John's Church Community Hall, West Lane, Killingworth, Tyne and Wear NE12 6BL	Mon, 4 Mar - 11am
East Yorkshire	Etton Village Hall, 37 Main Street, Beverley HU17 7PG	Wed, 6 Mar - 1.30pm
West Yorkshire	Small Hall, Kirkgate Centre, 39a Kirkgate, Shipley, West Yorkshire BD18 3JH	Fri, 8 Mar - 1.30pm
North London	Southgate Hockey Centre, Snakes Lane, London EN4 0PS	Mon, 11 Mar - 2pm
Leicestershire	Village Hall, Main Street, Swannington, Coalville LE67 8QL	Tue, 12 Mar - 11am
South London	St. James Church Bermondsey, Thurland Rd, Bermondsey, London SE16 4AA	Tue, 12 Mar - 1.30pm
Dorset	The Grove Hotel, 2 Grove Road, East Cliff, Bournemouth BH1 3AU	Mon, 18 Mar - 11am
Surrey	Shalford Village Hall, Kings Road, Guildford GU4 8JU	Tues, 19 Mar - 2pm
Greater Manchester	St. Andrews Church, Hope Centre, 27 Tattersall Avenue, Bolton BL1 5TE	Wed, 20 Mar - 1.30pm
Cambridgeshire	Cherry Hinton Village Centre, Colville Rd, Cambridge CB1 9EJ	Thur, 21 Mar - 2pm
Cumbria	Burton Memorial Hall, Main Street, Burton in Kendal, Carnforth LA6 1NA	Fri, 22 Mar - 1.30pm
West London	St. Paul's Centre, Queen Caroline Street, London W6 9PJ	Fri, 22 Mar - 2pm
North Yorkshire	St. Columba's Church, 119 Dean Road, Scarborough YO12 7JH	Thur, 4 Apr - 1.30pm
Essex	Great Tey Village Hall, Great Tey CO6 1JQ	Mon, 8 Apr - 2pm
Norfolk/Suffolk	Roydon Village Hall, High Road, Roydon IP22 5RB	Wed, 10 Apr - 2pm
Southport	St. James's Church Hall, 26 Lulworth Road, Birkdale, Southport PR2 2BQ	Thur, 11 Apr - 2pm
Kent	Room B028 Blake Building, Medway Campus, University of Greenwich, Central Avenue, Chatham Maritime ME4 4TB	Thur, 11 Apr - 2pm
Cardiff	City Hospice, Whitchurch Hospital Grounds, Whitchurch, Cardiff CF14 7BF	Wed, 17 Apr - 11am
Tayside	Coupar Angus Town Hall, Union Street, Coupar Angus PH13 9AE	Thur, 18 Apr - 1.30pm
Lincolnshire	Tesco Superstore, 186 Wragby Road, Lincoln LN2 4QQ	Tue, 23 Apr - 2pm
Gloucestershire	Boy's Brigade Community Centre, Canterbury Leys, Newtown, Tewkesbury GL20 8BP	Tue, 23 Apr - 1.30pm
Hertfordshire	Hospice of St. Francis, Spring Garden Lane, Off Shootersway, Berkhamsted HP4 3GW	Fri, 26 Apr - 2pm
West Midlands	Bournville Gardens, 49 Bristol Road South, Birmingham B31 2FR	Mon, 13 May - 2pm
Staffordshire	Katharine House Hospice, Weston Road, Stafford ST16 3SB	Wed, 15 May - 10am



“I came out feeling a lot better than when I went in”

We hold Support Groups across the country but going along for the first time, especially when everything is new to you, can feel quite daunting. Chris Campion was diagnosed with MSA fairly recently. He and his wife, Rose kindly agreed to share their experiences of attending the Cornwall group for the first time. This Support Group is run by one of our amazing volunteers, Jan Pearce and Jill Lyons (MSA Nurse Specialist). Jane Stein (Advocacy Officer) was also attending Chris and Rose’s first meeting.

Chris says “It helped to go along and engage with people. It was well worth it. We enjoyed being there, it felt like a family where you were embraced and felt warm and comfortable.”

Chris was concerned that Rose was in denial about his diagnosis and Rose agrees that she was, and perhaps still is. “I’m not sure if I want it to sink in but the meeting was an eye opener. You do feel isolated when people don’t understand but going along to this meeting helped me to realise I am not alone, there is support and people are very nice. I came out feeling a lot better than when I went in”.

Chris tells us that he likes the structure of the meetings, with time for group discussion then one to one time with other members, the group leader and MSA Trust staff. “Everyone’s friendly and willing to help. Information is freely given and shared. I thought it was lovely. I came away feeling buoyed up and so did Rose”.

Rose found the meeting very friendly and relaxed. “it was interesting and full of information. It was so nice to talk to others there.”

Group leader Jan added “Chris and Rose came to another recent meeting and I was pleased to hear that they had met up with another couple who they had met at our group earlier in the year. People who come to our meetings are so pleased to find out they’re not alone and are in company where they don’t have to explain the challenges that MSA presents. Everyone who attends a meeting has something to contribute, whether it be a tip on dealing with an everyday task or information that can signpost others to alternative sources of support. Our group was set up so anyone who had been touched by MSA could meet others in Cornwall who were in the same situation”.

Chris and Rose both agree they no longer feel so alone. They feel reassured that people who know about MSA are there and will be looking out for them, practically and emotionally. As Chris says “It is scary having something like MSA. It’s important to learn where this rocky road takes you. Having information really helps”. msa *news*

You can find a list of our upcoming Support Group dates on page 17 but do call us on 0333 323 4591 or email **support@msatrust.org.uk** to find out more about a Support Group near you.

Jamie completes Ride Across Britain

Jamie Mitchell remembered his mother by completing one of the most difficult cycling events in the country, taking on 980 long miles on his bike, from Land's End all the way to John O'Groats.

"It was an amazing experience, I've been cycling for many years and it's been by far the best riding I've ever done. Not just the stunning scenery but the daily challenges of massive climbs and super-fast descents. It's been ten years since my mum passed away after years of battling MSA. I've got three young kids myself, so life's been busy. This ride gave me some time to reflect on what little time I'd spent thinking of her. Having the Trust there as an anchor point was helpful to focus my attention."

If Jamie has inspired you but you aren't quite ready for the full 980 miles, try the Ride London-Surrey 46 or 100 miles on 4th August. It's an event with an incredible atmosphere and the Trust has guaranteed places waiting for you. msa *news*

Team Shaw smashes the South Coast Challenge!

Jenny Coles, Kirsten Hayward, Helen Curley, Peter Meier, Jez Allman, Pete Tweedie and Julie Tweedie all took on the scenic South Coast Challenge – a walking challenge from Eastbourne to Arundel. Jenny, who did it in support of her sister Eileen who has MSA, had this to say:

> ***"We started at 9am and finished at 10.30pm; a huge effort from the whole group over the 55km! We met so many people and I genuinely can't remember how many people we spoke to about MSA, the Trust and what it is; people like me who had never heard of it until recently."***

We have spaces in the South Coast Challenge (31st Aug – 1st Sept) and Thames Path Challenge (7th - 8th Sept) in 2019. These events all have 25km, 50km, and 100km distances to take on and can be taken at any pace you wish. They are some of the most accessible and enjoyable events in the UK and they are waiting for you. msa *news*

COMMUNITY GROUP FUNDRAISING

One of the best ways you can support us is by promoting the Trust to your local community groups. If you are a member of a Rotary club, a golf club, the Women's Institute, or any other local group that meet regularly, please suggest they support us as a charity.

Our supporter Tim Tierney did exactly this in support of his dear friend Doug who has sadly since passed away. His Mason's Lodge held a Duck Race Family event in aid of the trust:

"The race night was a huge success, we had over 50 people arrive on the night and we raised over a thousand pounds! I'm ecstatic with that result, and we even video called Doug on the night so he could see how well it was attended."

If you attend a group that may be willing to support us, please give our fundraising team a call on 0333 323 4591 for any advice or information. msa *news*

March is *MSA Awareness Month*

How will you raise awareness of multiple system atrophy? We have a few suggestions…

- ***Buy, wear and use our Trust merchandise***
- ***For just £10, get the Awareness Pack – A new tote bag containing a MSA ribbon, notelet, pen, wristband, car sticker and leaflets with information on multiple system atrophy. Order using the form below or online at: www.msatrust.org.uk/product/awareness-pack***
- ***Have a Bucket Collection and distribute our Orange MSA Ribbon.***

We have two dates in London at various tube stations, and we are encouraging you to hold your own collection locally as well. Spread the word by giving a MSA Ribbon in exchange for a donation.

So, if you have a circle of friends and family who can join you in rattling a bucket for a good cause, get in touch and we will help you arrange your permit and your materials!

If you would like to join us in London for a collection, you're more than welcome, for as long or as little as you would like. msa *news*

Awareness Pack

£10

+ £2.50 P&P

Please either fill out the form below and send it back to us or visit our website at: www.msatrust.org.uk/collections

○ ***I would like to hold a collection locally and need materials or help with permits***

I can help at the following locations and dates:

○ 02/03/2019 at Dalston Junction
○ 02/03/2019 at Embankment
○ 02/03/2019 at Hoxton
○ 02/03/2019 at Leicester Square
○ 08/03/2019 at Canada Water
○ 08/03/2019 at High Street Kensington
○ 08/03/2019 at Southwark

○ ***I would like to purchase the Awareness Pack and enclose a payment of:***...

You can also call the office on 0333 323 4591 to make the payment and order over the phone.

Name:..

Address:..

....

Postcode:.................................... Telephone:...

Due to changes in regulations, you need to let us know how you want us to keep in touch for fundraising news and events. Please fill out your contact preferences below.

○ Telephone ○ Post ○ Email.. ○ I prefer no contact

Please make all cheques payable to 'MSA Trust' & return slip to MSA Trust, 51 St. Olav's Court, Lower Road, London SE16 2XB