



msa news

MSA Trust Members Magazine | Issue 56 | October 2019



Keep on Moving



Welcome to Issue 56

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A warm welcome to your latest edition of MSA News. As well as our regular features you will find articles written by our MSA Nurse Specialists, Social Welfare Specialist and one by an expert Physiotherapist, looking at the benefits of keeping active.

At the time of writing we are still unsure about what is happening with Brexit, but we know people are concerned about availability of medicines. Updated information is given on the NHS website in the country of the UK in which you live. If you have any questions or concerns regarding your medicine, including if you're able to obtain it, you can discuss this with your GP, consultant, pharmacist or MSA Nurse Specialist. People in Ireland should be unaffected.

Our next edition will have a summary of the results from our survey looking at the needs of people with MSA, which many of you completed over the summer (see the News Roundup for more on this).

Enjoy reading and, as ever, please let us know if you have any suggestions or ideas for future articles. Best wishes, Andy and Emma. msa.news

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NEWS ROUNDUP

Messages received loud and clear

We would like to say a huge thank you to those members who were able to complete the MSA Needs Survey. We had an overwhelming response and will now be taking the time to thoroughly analyse the results. Your responses have formed the largest ever survey of people affected by MSA. Finding out about your needs will ensure we can seek to improve the services and support we, and other organisations, provide. Thank you again for your help and support for your MSA community. We will be providing a fuller report in the next edition of MSA News. [msa news](#)

DrugStars

We are now registered with DrugStars – An app you can download on your phone to track your daily medication. You collect stars every time you use the app, which DrugStars will convert into donations. You will need to choose 'MSA Trust' as your nominated charity when you download the app. An easy way to raise funds for us, whilst also helping you to remember to take your medication. Download the app from www.drugstars.com. [msa news](#)


DRUGSTARS®
 Giving by taking

Milk Sugar And Tea parties 2019

Support our amazing Nurses by hosting your own Milk Sugar And Tea party!

Follow in the footsteps of hundreds of other wonderful Trust supporters and invite your friends and family over, ply them with delicious cake, far too much tea, good cheer and simply ask them for a donation in return.

The money you raise will go directly to support our MSA Nurse Specialists. The Nurses provide telephone and email support services to people affected by MSA. They also attend our Support Groups around the UK and Ireland and offer training and support to health and care professionals.

So go ahead and host a Tea Party this year and you will enable us to continue to provide this vital service. We really couldn't do it without you!

Contact Henry at fundraising@msatrust.org.uk to receive your Tea Party pack containing all the materials you will need, including a complimentary collection of premium teabags, courtesy of Reginald Ames Tea Merchant. [msa news](#)





Research Round Up

MSA TRUST CALL FOR RESEARCH PAPERS

As the main funder in the UK of research into MSA, we are committed to funding the best scientific research to help us get closer to discovering the cause and cure for MSA.

The Trust has recently launched our 2019 Research Grant Round, inviting applications for new and innovative MSA research projects.

Applications will close on 30th November 2019. All applications are reviewed by our Scientific Advisory Panel, led by Dr Chris Kobylecki. Interested researchers can find out more information from our website - www.msatrust.org.uk/cause-and-cure/current-research-opportunities-2 or contact Karen Walker or Emma Saunders at support@msatrust.org.uk.

RESEARCH FELLOWSHIP

We are proud to announce the launch of our Roger Bannister Research Fellowship, in partnership with the Association of British Neurologists.

The Fellowship provides an exciting and prestigious research opportunity for a neurologist to undertake research into MSA. Sir Roger Bannister, who was the first person to run a sub four minute mile, was also an eminent neurologist. He was the first Chair of our research committee and a tireless advocate for research in neurodegenerative conditions. Further details are available on our website: www.msatrust.org.uk/cause-and-cure www.theabn.org/page/news#.

PROSPECT-M

Recruitment is continuing to the MSA Trust's patient registry to support our continued research into MSA.

The PROgressive Supranuclear Palsy CorTico-Basal Syndrome Multiple System Atrophy Longitudinal Study UK (PROSPECT-M) study recruits people with MSA to a long-term study of the condition. We have a new contact for the project and her name is Alkyoni. For further details and to find out how you can get involved, email Alkyoni at alkyoni.athanasioufragkouli@nhs.net. Alkyoni works alongside our current Research Fellow, Viorica and Professor Houlden to recruit people with MSA to the Prospect database.

NEW GENETIC CAUSE OF LATE-ONSET ATAXIA IDENTIFIED

Sometimes people with MSA are initially diagnosed with a condition called Ataxia before receiving a diagnosis of MSA.

New research, partly funded by the MSA Trust, has identified a genetic defect as a common cause of late-onset ataxia meaning many patients can receive a definite diagnosis of RCF1 associated ataxia. It is not a test for MSA but a test for another condition, which if confirmed can help prevent further investigation into possible MSA.

Professor Henry Houlden said of the study ***"Many patients are considered to have possible MSA because they have the symptoms and signs of late onset ataxia. This genetic test will allow early testing to obtain an exact diagnosis of RCF1 associated ataxia, and not MSA, and also exclude the need for extensive additional tests before a diagnosis can be given"***. Further information about the research can be found here www.bit.ly/32dIPAG. [msa news](#)

A time of generosity, for a time of need

At the Trust we have a small grants scheme which we use to help our members struggling with the financial implications of living with MSA.

These small grants provide a varied range of support, from help towards purchasing mobility equipment, to respite care and counselling. We are usually able to help very quickly – often providing support the same day – and we make it as easy as possible to apply.

However, each Christmas we find that the demand for support rises significantly, as our members understandably wish to travel to see their families, communicate via a Lightwriter, or make their homes more accessible and comfortable in the winter months. However, we can only afford to provide a very limited number of grants each year.

This Christmas, we want to assist more people struggling with the financial pressures of MSA.

**Will you please help us?
Whatever you can afford will
make a difference be it £10, £20
or even more.**

Our grants have helped when people have really been up against it, so anything you can give would be much appreciated.

“Thank you so much for the grant for a new battery pack for his mobility scooter. It’s made an enormous difference to us. Who would have thought that after being stuck indoors for a few months that Tesco’s would be a great place to be...” – wife of someone living with MSA



“Thank you for your Lightwriter gizmo...I couldn’t stop her “talking” yesterday afternoon!” – husband of a person with MSA.

“At last Mr X has purchased his flooring. Many thanks once again for getting the grant for him, think he would have been floorless for ever without your assistance on this!” - previously had concrete flooring and had several falls.

To donate you can visit our campaign page www.justgiving.com/campaign/MSATrustChristmas, call 0333 323 4591 to pay over the phone or send a cheque payable to ‘MSA Trust’. You can also set up a regular donation that you can specify be allocated to the grant scheme. Please email Tanya tanya.mitra@msatrust.org.uk for a Standing Order form.

Christmas can be a tough time of year when you are affected by MSA but with your support we can help those who need help the most. Thank you so much.

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Physiotherapy, exercise and MSA

Due to the complexity of MSA, it is important that people are able to get help from a Physiotherapist for advice and support in managing their condition. Fiona Lindop, Specialist Physiotherapist, looks at what support you can expect and suggests some exercises you could try at home...

People diagnosed with MSA-P have symptoms similar to Parkinson's - stiffness, slowness of movement and balance problems. Those with MSA-C ('cerebellar') have problems with coordination and especially walking ('ataxic' gait). Both groups can be at high risk of falling (especially backwards) as well as autonomic problems resulting in low blood pressure and urinary issues.

A Neuro-Physiotherapist should have an understanding of MSA and will be able to carry out an expert assessment to identify specific problems. Together with the person, a suitable management and exercise plan can be agreed. Activity should be encouraged whilst minimising the risk of falling. Exercise should include stretching/flexibility, balance and aerobic training. It is also important to identify any issues with posture such as, chin poking forward or dropping towards the chest. Assessment of respiratory function and advice on reducing the risk of chest infections will also be part of the assessment.

Some people may experience 'freezing of gait' where feet feel like they have glued to the floor and they can't take the next step. Physiotherapists can teach cues and strategies to overcome this, perhaps by counting or using a metronome (or music) to initiate the step. It is important to ensure muscle strength is maintained for as long as possible and the Physiotherapist will be able to identify any weakness and provide specific strengthening programmes. Pelvic floor exercises are also recommended as these can help with continence issues.

Although there are currently very few trials of therapy in people with MSA, one case study in 2008 had

significant results. An individual with MSA carried out a 22 week programme of twice weekly physiotherapy, and a home exercise programme which included stretches, sit to stand practice, balance, transfers, reaching, tandem walking (one foot directly in front of the other) and riding a static bike. At the end of the study walking speed improved by six seconds, they could reach further forward (by four inches) and were able to stand on one leg for ten seconds having been unable to do so at the beginning of the trial. This study highlights that it is vital to access advice and therapy early in order to maintain and improve function.

People with MSA can have difficulty sweating and regulating their temperature and may experience a drop in blood pressure at certain times of the day or during specific activities. To avoid problems, the best time of day to exercise is late morning or in the early evening, in a cool room. If motivation is a problem, and/or fatigue, it will help if the activity or exercise can be incorporated into the daily routine and wherever possible - it should be fun!

If balance is a particular problem, risk of falling needs to be minimised. This may involve provision of specific, individualised exercises but also consideration of an appropriate walking aid. The Physiotherapist will be able to advise on the correct aid, such as the use of reverse-braking walkers. Your GP or consultant should be able to make the referral for you to the local service.

Here are four seated exercises to try at home, some of which require a rubber exercise band (ensure you obtain a latex-free band if you have a latex allergy):



#1



When sitting in a chair (can be carried out when in a comfy arm chair e.g. watching TV): Sit with feet on the floor then pulling your foot and toes towards you, straighten one leg. When the knee is straight, hold that position for a few seconds then return to the starting position. Repeat with the other leg. Repeat 10 times on each leg, 3 times a day.

#2



Sit up tall with your feet flat on the floor. Put the exercise band around your knees and hold onto the band at the side of your thigh. Keeping your feet on the floor, slowly take your knees apart and hold this position for a few seconds then slowly bring your knees back together. Repeat 5-10 times.

#3



Place the exercise band under the ball of one foot and hold the ends of the band in each hand. Sit tall and lift the knee a few centimetres, keeping the knee bent, then pull your hands towards your hips and hold this position. Then push your foot firmly against the band to straighten your knee. Hold for a few seconds then bend your knee and slowly relax your arms (keeping hold of the band). Repeat 5-10 times.

#4



This exercise is a little more difficult and should only be attempted if you can sit in a chair independently without falling sideways: Sit on a dining room chair with your bottom at the back, feet on the floor and hands on the arms or on the sides of the seat. Try to walk your hips forward one at a time towards the front of the chair. You should try to lift each hip alternately and hitch it forward. When you arrive at the front of the chair, reverse the move to walk your bottom back again. When you can achieve this, try doing it with your arms folded across your body. Repeat 5 times.



In Memory

Robert Dick
John Halliday
Adrian Fairhead
Jenny Richardson
Anne Tighe
Everton Carter
Sylvia Woodhead
Robert Tonks
William Shewan
Shirley Finnegan
John Dickinson
John Dunne
Gregory Wilsdon
Patricia Dickens

Caroline Gibbs
John Johnson
Anthony Hewitt
Graham Moores
Seamus Coyle
Derek Shearson
Grace Parkin
Brian Winter
Christine Williams
Gary Buchanan
Gordon Pegg
Stephen Bilton
Margaret Latham
Rob Breathnach

Sheila Cobley
Paul MacCallum
John Yeoman
Margaret Devine
Nirmala Rajasubeshan
Tom Patterson
Mary Foley
Pat Butler
Susan Davies
Janet McGrory
Alison Bradley
Gillian Hiscutt
Peter Tan
Linda Harrison

Ian Morrison
Christopher Barrow
Sandra Parker
Llewellyn Davies
Thelma Handley
Alan Ostler
Sandra Williams
Michelle Hutchinson
Neville Raymond Fry
Alan Taylor
Barry Smith
Marie Turner
Raymond Learoyd
Henry (Harry) Pattullo

FINDING A WAY TO HELP

Last year we were really touched to receive a letter from one of our supporters. 89 year old 'Mrs I' wrote to us about her son who is living with MSA in Grimsby, and the challenge of visiting him from Burton on Trent where she lives - a round trip of 210 miles. As she said, "My son is 64 years old, has two sons and two grandchildren, the little ones adore him". She had to take expensive taxi rides to visit him, refraining from holidays to afford it. As she put it, she "found it all worthwhile if it meant seeing her only son". We offered her a grant for travel but she did not want to use our funds.

Inevitably over the years the trips became infrequent, but her thoughts kept going back to her son and the need to do something to help. She started knitting again and within eighteen months had knitted 475 squares, 147 scarves and a few woolly hats. She then sent it to us to sell on her behalf. She thought the best way to support her son was to help the Trust raise vital funds to be used to "... help find a cure for this distressing condition".

To this end we decided to make Mrs I's knitting available for you to buy this Christmas. Options are:

- **Small readymade scarves (available in Red, Green, Blue, Beige, Pink, Black and Yellow) for £10.**
- **Good quality knitted squares (6" X 6"), sold in bundles of nine to stitch a scarf longer than the readymade ones (£13), 24 squares to stitch a small blanket or knee rug (£25), or you can buy 36 squares to stitch a larger blanket (£35).**

Unfortunately we are unable to guarantee particular colours for the knitting squares.

Purchase online at www.msatrust.org.uk/product-category/christmas, via phone on 0333 323 4591 or by sending us a cheque payable to 'MSA Trust'. Please support the Trust to provide hope for people like Mrs I, her son and others in the MSA Community. [msa news](#)





Innovation through collaboration

A North East Hospice, with help from the MSA Trust, has piloted a specialist six week course for people living with MSA and their carers.



Working collaboratively, St Oswald's Hospice, based in Newcastle upon Tyne, has set up a therapeutic group providing support and information to people in the earlier stages of MSA and Progressive Supranuclear Palsy (PSP).

Jill Lisle, Deputy Day Services Manager at the Hospice, said:

"This group allowed for care and support to be bespoke to this group of people. It provided the opportunity for peer support, a safe space to explore the impact of diagnosis and managing change, as well as access to practical information to help manage day to day challenges."

Tommy Smith attended the group with his wife Christine who was diagnosed with MSA two years ago. He said:

"The course was very informative. It has been good to meet other people and find out that we're not alone, there's other people who are living with MSA. As well as peer support, we have benefitted from practical advice, such as demonstrations about how I can lift Christine in a way that is safe for both of us."

"In the sessions there was time out for carers while our partners took part in arts and crafts. It's not something Christine has done before but now she has signed up to a card making class at the Hospice next month."

This group is one of a range of therapeutic groups and short courses offered at St Oswald's. To find out more visit www.stoswaldsuk.org. Find out if your local hospice runs something similar by visiting - www.hospiceuk.org. [msa news](#)

Our Policy Work

We have been busy over the last few months with a number of issues we know are important to people affected by MSA. We met with the Commissioning Lead for NHS England's Continuing Healthcare Strategic Improvement Programme to discuss the problems that we are currently hearing regarding people with MSA getting consistent and fair access to support. We are following this up with attendance at an event enabling better training on rare conditions for assessors of NHS Continuing Healthcare. We also met with staff from one of the assessors of Personal Independent Payment (PIP) that the DWP use. This will help our Advocacy Officer, Jane Stein, to explain what evidence is most useful for people when making claims.

NICE have launched a further consultation on Guidelines for how GP's should deal with suspected neurological conditions and we will be submitting another response to this.

Finally, we were successful in getting MSA included in the NHS Rightcare Toolkit for Progressive Neurological Conditions. This has now been launched and aims to reduce delays in diagnosis and treatment, lead to better coordination between professionals, enable more neurospecialist support and improve psychological and social support.

We hope our policy work will be significantly enhanced by the evidence we are gathering through our recent survey of people living with MSA, so watch this space. [msa news](#)



Wheelchair *Accessible Vehicles*

Many people with MSA consider getting a wheelchair accessible vehicle (WAV). This is definitely worth considering if you are thinking about changing your car and you are already using a wheelchair for outdoor access or likely to need to shortly.



The positive aspects to travelling in your wheelchair are that you can get in and out of the vehicle quickly and easily, remain in a comfortable supported seating position and it is less effortful for your carer.

The key considerations when looking at a WAV are ease of access, position once in and secure fixing of the chair.

Accessing a WAV

Portable, removable ramps can be used for access but these can be heavy, need stowing out of the way and need positioning correctly for safe use. Much more preferable and easier to use are ramps that fold away – these are integral to and fixed to the vehicle.

It is best to have a one piece ramp rather than two strips. Also, you need to consider that there is no room to turn around in the vehicle so you have to exit in a reverse position coming down the ramp, which may be



difficult for some people. In this situation a lift system may be preferable. This is also true if you are a particularly large person in a large power wheelchair.

Any ramp or lift needs to be easy to operate (whether manually or under power) and have sufficient weight capacity for you and your wheelchair. For most domestic use WAVs a ramp serves very well.

Wheelchair position in WAV

A side entry electronic ramp from the front passenger door, a rear passenger door sliding/folding ramp or a back tailgate ramp will all enable you to get into the front passenger position in your wheelchair.

For wheelchair travel in the rear of the vehicle, an integral side ramp sliding or folding out from floor of the vehicle through a sliding back passenger door is one option. More commonly, and often the less expensive option, is to have a vehicle with a tailgate at the back and an integral ramp that either electronically or manually lowers from the back of the vehicle. These ramps either fold up on themselves and stow in a floor recess or lock in a vertical, upright position behind the wheelchair once in the vehicle. The latter does restrict rear-view vision.

The length of ramp and height of vehicle will impact on the gradient to access the vehicle. It is very helpful to have an electrically operated hook and strap system that attaches to the wheelchair at the bottom of the ramp and assists you getting into the vehicle.

For wheelchair travel in the rear of the vehicle you will need to have enough space for anyone assisting you to get either side of the wheelchair.

These factors will determine the size of the vehicle you consider, along with the length and width of the wheelchair and your head clearance getting in and out of the vehicle. A vehicle with a lowered chassis or added head box may be required if you are tall. For the most comfortable ride you need to be sitting in your wheelchair in front of the back axle, this makes for a less bumpy ride and is also easier to speak with the driver or other passengers.

If you regularly have to travel on anything other than highway maintained roads or live in an area with lots of

speed bumps, make sure your WAV can clear the ground without scraping.

Once in the vehicle, your wheelchair this needs to be securely fixed to the floor, usually achieved by either fixed docking bolt points or tie down inertia straps. You will still need to wear a seat belt as well as your wheelchair waist belt.

Once you are secured in position the door/tailgate may open and close more slowly than you expect if automatic. If manually operated, the height the tailgate opens to may be higher than average so your carer needs to be able to reach this to close the door.

Purchasing your WAV

There are a number of dealers that have second hand and ex-Motability WAVs so this may be worth exploring. Some will bring a vehicle to your home to allow you to look at it and try the access and positioning etc. There are also companies that provide WAVs on long and short-term rental which may be worth considering if you are uncertain of your requirements.

Leasing a WAV

If you live in the UK and receive the 'Enhanced Rate' mobility component of Personal Independence Payment (PIP), valid for at least another 12 months, then you may qualify for the Motability scheme.

The Motability scheme (0800 694 9000 - www.motability.co.uk) allows you to exchange your mobility component to lease car, scooter or powered wheelchair. You do not have to be the driver, two named drivers can be insured for your Motability lease vehicle.

This scheme allows you to lease a WAV for five years or three years in the case of nearly new vehicles. The lease takes care of all the cost and hassle of running the WAV for example the servicing, insurance and tax etc. However, there may need to be an Advance Payment if accessing via Motability. Jane, our Social Welfare Specialist, can advise on financial implications. You can find out more on these websites:

www.ridc.org.uk/content/choosing-wav

www.motability.co.uk/cars-scooters-and-powerchairs/wheelchair-accessible-vehicles.

www.motability.co.uk/cars-scooters-and-powerchairs/wheelchair-accessible-vehicles. *msa news*



Our thanks to Geoff and Diane Ball for the pictures used in this article.



Making the most of your *General Practitioner* (GP)

Being affected by MSA may mean that having a good relationship with your GP becomes extra important for you and your family. Here Samantha Pavey, MSA Nurse Specialist, looks at what services and support your GP may be able to provide.

Although your GP doesn't need to be your first point of contact if you're feeling unwell, everyone should be registered with a GP.

Your GP can give you medical advice, treatment and prescribe medication. They can also refer you to other healthcare professionals to diagnose or treat specific aspects of your condition. For example, they may refer you to a Neurologist or to a Speech and Language Therapist

who will provide support outside of the GP practice.

When you register, your GP practice must allocate you a named, accountable GP. This GP will oversee your care and take responsibility for evaluating your current physical and psychological needs. This doesn't mean the named GP is the only doctor at your practice who will provide care, but it is very helpful to have a GP that knows you and your condition.





What services should I look for in a GP practice?

Even if you have been with your GP a while you might still want to ask about the availability of services that are important to you, such as:

- **how the appointment system works (is there an online booking system?)**
- **can they offer priority booking given you are affected by MSA**
- **how far in advance you can book a non-urgent appointment**
- **extended opening hours**
- **support for carers**
- **availability of male and female GPs and Nurses**
- **wheelchair access**
- **staff who speak languages other than English.**

Some practices offer a 24-hour online service, through which you can book appointments with a GP of your choice or cancel appointments, order repeat prescriptions and view your summary care record. Speak to the receptionist to find out what online services your GP practice is offering and how to register for this.

The electronic prescription service (EPS) is an NHS service which allows your GP to send your prescription to your chemist, without the need to visit the GP for a prescription.

Depending on your situation you may want to ask about access to your GP's Palliative Care Register which has benefits in terms of care co-ordination and can trigger specific support.

If you are a carer for somebody with MSA you can register with your GP as a 'carer'. This allows you to get a priority appointment if you are unwell.

What if I'm too ill to visit my GP?

If you're unable to visit your GP surgery for medical reasons, you can ask your GP to make a home visit. Your GP may be able to give you advice through a telephone consultation. If possible, try to call your GP in the morning if you think you'll need a visit the same day.

You can still phone your GP practice outside normal surgery hours, but you'll usually be directed to an out of hours service if there is one. Alternatively, you can call NHS 111 if you urgently need medical advice but it's not a life-threatening situation.

As ever, dial 999 for emergency help.

What if I'm not registered with a GP or I'm away from home?

You should always be able to see a GP if you need urgent attention. If you're away from home or have not registered with a GP and fall ill, you should contact the nearest surgery and ask them to see you.

If you'll be living away from your usual address for up to three months, you can register as a temporary patient at a local practice.

What support can I get if I have MSA?

We know that many health professionals are not aware of MSA. We are able to send your GP an information pack that can help them support you effectively, please contact us at the Office if you would like one sent out. Your GP should help you understand and support you in managing your own care. This may include drawing up a care plan to help you manage your condition on a day-to-day basis and recognise symptoms that you should report to them. It may also include creating an 'information prescription' with the help of the NHS website - www.nhs.uk, which helps you find reliable sources of information about your condition.

You have the right to change practices if you wish to, without having to give a reason. However, you may wish to discuss this with your MSA Nurse Specialist prior to making a decision as there are pros and cons to changing your GP.

Specialist referrals

To be referred to a specialist, such as a Neurologist, you should see the GP you are registered with as all your medical records will be held by that practice. Your GP will also have better knowledge of your health history and treatments which will give evidence for a specialist referral.

A specialist will only see you with a letter of referral from your GP.

If you want to see a private specialist, you are still advised to get a letter of referral from your GP. However, it is worth noting that, either way, your GP is not obliged to accept the specialist's recommendations.

Other services you may access through your GP

You can look for services in your area via the NHS service directories www.nhs.uk/service-search. *msa news*



REACHING GREAT HEIGHTS...



Tanya Dunne raised £611 (and counting) during her incredible overnight trek to the summit of Mount Snowdon. The **Mixpanel Team** (above) took on a different challenge but along the same lines - Snowdon, Ben Nevis and Scafell Pike all ascended within 24 hours, raising £8,650 for the Trust. Mixpanel employee, Ali Maundrell, sadly lost her father to MSA.

Megan Horsham raised £1,553 in honour of her mum Esme at the extremely hilly Welsh Marathon.



Hannah, Alison, and Alex Ward ran the Great Midlands Fun Run and raised £665 in memory of Jim Ward. Well done Team Jimmy!



Jonny Simons reached an astonishing £5,281 in memory of his dad, John, completing the extreme Staffordshire Ironman.

RIDING 100 MILES FOR THE TRUST

Our Ride London-Surrey 100 Team smashed their fundraising targets and raised nearly £10,000 for us! Our huge thanks to **Peter Latos, Mark O'Connor, Ben Ewing, Graham Moorcroft, Mhairi Cameron, Trevor Thorley, Ioan Smith** and Dixon's Travel employees **Ben Williams and Damon Murphy**.

We have places in our 2020 team in both the 100 mile and the 46 mile races. Please get in touch with our fundraising team at fundraising@msatrust.org.uk for your place.



Nellie Rogers had previously raised more than £1,200 organising a fundraising event with her sister-in-law Danielle, during MSA Awareness Month. She then ran the ASICS London 10K in a really good time and raised a further £550 in support of her mum who is living with MSA.





IN THE COMMUNITY



Michael Sparrow with his work colleagues at the RBS Edinburgh branch had a bake sale and fundraising day in memory of Michael's mum, Joy.

Tim Tierney, Master of Towan Freemason Lodge kindly nominated the Trust as their Charity of the Year. This was to support his dear friend, Doug who has since sadly passed away. Cornwall Support Group leader, Jan Pearce accepted the cheque on our behalf.



Suzanne Black (pictured with father, Eddie) got her Pocklington netball team together for a charity match. This was followed by a raffle with prizes donated from local businesses. The fundraising was done in memory of Suzanne's mother, June who was always a keen supporter of Suzanne's netball matches.

Ian Pickford along with wife **Jackie**, who has MSA, run our Three Counties Support Group. They got their local Club, The Inner Wheel Club of Pershore, involved with fundraising. The Club held a number of events including a fashion show and a coffee morning to raise a fantastic £2,500. Well done!

Andrea and Andy Chudley (Andy's pictured here with two umpires) raised £3,000 through a charity cricket match attended by more than 300 people!





Supporting & Helping Each Other

So far in 2019 we have run nearly 100 Support Group meetings. While varying in location and size, they all have the same supportive, informative and welcoming environment you would expect from a Trust Support Group. Here's a summary of some of the important information and tips raised at meetings in recent months.

A simple, yet effective, tip comes from one of our members of the Leicestershire Support Group. Saying multiple system atrophy in full, rather than stating MSA, can help to avoid confusion with other conditions. The member had found it particularly helpful with health and care professionals who work with lots of people with varying conditions every day, and saying the name in full can catch their attention (you'll notice that we do this too when you call our office number).

Useful information regarding housing adaptations came from our Tyne and Wear Group. One member spoke about having steps outside their front door with no way to support a platform wheelchair lift or stair lift. They had 'Flex Step' installed which is freestanding and can lift a wheelchair user up to a maximum of five steps. With the press of a button the steps convert to a platform which elevates the person up the steps. To find out more visit their website - www.liftup.dk/en/products/flexstep.

Another useful tip for getting around your home came from our County Durham Group. People found smaller, four wheel rollators more manageable and stable than a two wheeled version. This is because they often have all-round brakes which are much safer. They are also much more manoeuvrable, have grip release brakes, so the rollator only moves when you are gripping the brake handles, and are compact for using inside your home. A Physiotherapist will be able to assess and recommend the best walking aid for you.

Both our County Durham and West Yorkshire Groups discussed preparation in case of an emergency. One included letting your utility suppliers (Electricity, Gas and Water) know that there is someone with a long-term medical condition living in the home and that they could be vulnerable. This is

so that in the case of a power or gas failure or a water issue, the suppliers know where you are and can prioritise you. At the West Yorkshire meeting they discussed the 'message in a bottle' scheme. This is where a bottle is placed in the fridge with a list of all your medications and who to contact in an emergency. A green cross sticker (widely available online) is then placed on the inside of your front door and on the outside of the fridge. This indicates to emergency services, if they need to attend, that all key information is in a bottle in the fridge. The bottle is often available from GP surgeries or pharmacies. For more information see www.carers.org/article/message-bottle.

The Solihull Support Group (which is run by staff at the Marie Curie Hospice) were talking about hobbies they enjoyed and in particular continuing to read as much as possible. RNIB, a sight-loss charity, have a digital library called Overdrive. This is where anyone experiencing sight issues can download audiobooks, e-books, films and more for free. For more information please visit their website - www.rnib.org.uk/talking-books-digital-download.

Finally, one of our MSA Nurse Specialists, Emma Saunders, suggested people contact their local council or leisure centre to ask about 'swim and gym' sessions. We are aware of some local councils that offer these free of charge for people with neurological conditions. Exercise can be hugely beneficial to people with MSA so do contact them and find out more.

[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.

We aim to send out Support Group invitations four weeks in advance. If you are not currently receiving them or would like to receive them in a different format, please contact the Trust's office on 0333 323 4591 or email support@msatrust.org.uk.

GROUP	VENUE	DATE & TIME
South Yorkshire	St Peter and St Paul Church Hall, Todwick, Sheffield S26 1HN	Wed, 16 Oct - 1.30pm
Edinburgh	Goodtrees Neighbourhood Centre, 5 Moredunvale Place, Edinburgh EH17 7LB	Wed, 16 Oct - 1.30pm
Cardiff	City Hospice, Whitchurch Hospital Grounds, Whitchurch, Cardiff, CF14 7BF	Wed, 16 Oct - 11am
Glasgow	Beechwood Community Centre, Shortroods Road, Paisley PA3 2NT	Thur, 17 Oct - 1.30pm
County Durham	Chester le Street Hospital, Day Room, Front Street, Chester le Street, County Durham DH3 3AT	Mon, 21 Oct - 1.30pm
Norfolk/Suffolk	Roydon Village Hall, High Road, Roydon IP22 5RB	Wed, 23 Oct - 2pm
Devon	Baptist Church, High Street, Cullompton EX15 1AA	Wed, 23 Oct - 2pm
Essex	Great Tey Village Hall, Great Tey CO6 1JQ	Mon, 28 Oct - 1pm
East Yorkshire	Etton Village Hall, 37 Main Street, Etton, Beverley HU17 7PG	Wed, 30 Oct - 1.30pm
Cumbria	Burton Memorial Hall, Main Street, Burton in Kendal, Carnforth LA6 1NA	Fri, 01 Nov - 1.30pm
West Midlands	Bournville Gardens, 49 Bristol Road South, Birmingham, West Midlands B31 2FR	Mon, 04 Nov - 2pm
North London	Southgate Hockey Centre, Snakes Lane, London EN4 0PS	Mon, 04 Nov - 2pm
Tyne and Wear	St. John's Church Community Hall, West Lane, Killingworth, Tyne and Wear NE12 6BL	Mon, 11 Nov - 11am
South London	St. James Church Bermondsey, Thurland Rd, Bermondsey, London SE16 4AA	Wed, 13 Nov, 1.30pm
West Yorkshire	Small Hall, Kirkgate Centre, 39a Kirkgate, Shipley BD18 3JH	Fri, 15 Nov - 1.30pm
Lancashire	Community Room, Tesco Extra, Clifton Retail Park, Clifton Rd, Blackpool FY4 4UJ	Fri, 15 Nov - 1.30pm
Dorset	The Grove Hotel, 2 Grove Road, East Cliff, Bournemouth, BH1 3AU	Mon, 18 Nov - 11am
Belfast	Marie Curie Hospice, 1A Kensington Road, Belfast BT5 6NF	Tue, 19 Nov - 2.30pm
County Sligo	Therapy Room, St John's Community Hospital, 8 Ballytivnan Road, Sligo	Wed, 20 Nov - 1.30pm
Merseyside	St John the Baptist Church Hall, Forest Road, Meols, Wirral CH47 0AF	Wed, 20 Nov - 2pm
West Sussex	Worthing Quaker Meeting House, 34 Mill Road, Worthing, BN11 5DR	Thu, 21 Nov - 2pm
Hertfordshire	Hospice of St Francis, Spring Garden Lane, Off Shootersway, Berkhamsted, HP4 3GW	Mon, 25 Nov - 2pm
Greater Manchester	St. Andrews Church, Hope Centre, 27 Tattersall Avenue, Bolton BL1 5TE	Mon, 25 Nov - 1.30pm
Three Counties	Boy's Brigade Community Centre, Canterbury Leys, Newtown, Tewkesbury GL20 8BP	Tue, 26 Nov - 1.30pm
Dublin	Education Centre, St. Francis Hospice, Blanchardstown, Dublin	Wed, 27 Nov - 1.30pm
County Limerick	Classroom 4, Nurses Home, Ground Floor, University Hospital, Dooradoyle, Limerick	Thu, 28 Nov - 1.30pm
Cardiff	City Hospice, Whitchurch Hospital Grounds, Whitchurch, Cardiff CF14 7BF	Mon, 15 Jan - 11am
West Midland	Bournville Gardens, 49 Bristol Road South, Birmingham B31 2FR	Mon, 03 Feb - 2pm
Devon	Baptist Church, High Street, Cullompton EX15 1AA	Wed, 19 Feb - 2pm
Three Counties	Boy's Brigade Community Centre, Canterbury Leys, Newtown, Tewkesbury GL20 8BP	Tues, 25 Feb - 1.30pm

These groups are subject to change so please check our website or ring the office for up-to-date information. Dates for meetings in 2020 will be added to our website in the coming weeks.



Arranging social care support at home

What is social care, how is it funded and how do you get an assessment - Our Social Welfare Specialist, Jane Stein, explains here...

The term 'social care' is often used to refer to the assistance given with the tasks of 'daily living'. For example, with personal care tasks such as washing, dressing, eating and managing continence needs, or with household tasks like cooking and shopping.

Social care is usually deemed to be different to 'health care'. Health care refers to care of a more complex and skilled nature that directly relates to a person's physical or mental wellbeing. In some areas health and social care are integrated services but elsewhere the services are separate with different budgets. This article explains how to access support with social care needs within your own home and how this care is funded. The financing of nursing home care is different.

First, you need to request an assessment as a good assessment is key to the successful provision of social care support. You should be central to the process and fully engaged in the discussions. You can choose to involve family members, informal carers and friends in the assessment if you wish. Social care assessments should cover a range of issues related to your wellbeing. For example, they should include assessment of your personal care needs, the requirement for equipment or adaptations, your needs for help with household tasks and your need for support with accessing your community. If your care needs are complex you may also require health care support and the assessment will identify this and, with your consent, relevant referrals will be made to health care professionals.

If you are eligible for financial help with social care you may be offered the option of a 'Direct Payment'. This enables you to purchase the services you need rather than having the services arranged by the authorities. The assessment team will be able to advise on this option.

Even if you are likely to have to fund your own care package (as may be the case, especially in England or Wales) you are entitled to a free assessment along with information and support to put the services you need in place. If you are arranging private care we can provide information including how to check the inspection reports of care agencies but we cannot recommend services.

REPUBLIC OF IRELAND

Home Support Services are the responsibility of the Health Service Executive (HSE) via your local Home Support Office. Assessments look at your needs in relation to living at home such as personal care needs. The service is designed for people aged 65+ but it is important to note that younger people with an illness or disability may also be eligible. There is usually no charge for personal care services. See: www.bit.ly/2MK3SGk and www.bit.ly/30NiilZ.





NORTHERN IRELAND

If you need assistance with personal or other types of social care, contact the social services department of your local health and social care trust. The assessment will cover a similar range of issues to elsewhere in the UK including, looking at equipment needs and healthcare needs. Charges are not normally made for support with personal care although health and social care trust's can choose to charge for domiciliary services. If they do charge they must carry out a means-test. Please see: www.bit.ly/2MMGRCF.

SCOTLAND

You can ask for your needs to be assessed by your local authority social care department. In Scotland all personal care is now free of charge regardless of your age. Charges can be made for some services including housework, laundry, shopping, meals and day centres. Please see: www.bit.ly/2UilwBJ and: www.bit.ly/2NIP9em or call Care Information Scotland on 0800 011 3200 for more information.

WALES

In Wales the system is similar to that in England. You can refer yourself to social services for a care assessment. In Wales there is a maximum weekly charge of £90 for support with personal care. Excluded from this cap are charges for meals, laundry and other tasks which do not involve personal care. If you have in excess of £24,000 in savings (excluding the value of the home you live in) then you will be charged the actual cost up to a maximum of £90 a week.

Age Wales has a fact sheet on care at home. It is relevant to adults of all ages see: www.bit.ly/2MKAQGo.

ENGLAND

You should contact the Adult Social Care team at your local social services to request a 'care assessment'.

Assistance with personal care, household tasks and with many other services is means- tested. The means test only applies to the person requiring assistance not their partner or family. Savings in excess of £23,250 (excluding the value of the home you live in) will mean that you are not eligible for financial support for social care.

For more information on social care in England (regardless of your age) see: www.bit.ly/2i1f9RI.

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Please see below for card costs, including P&P. If ordering advent calendars and/or gift wrap only, please add £1.50 to your total to cover P&P. There is no additional charge for P&P when order is combined with cards.

To order, visit:
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 call us on 0333 323 4591 or return
 the slip below with a cheque
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Advent Calendars: A - Christmas Greetings (Qty.....) B - Festive Tree (Qty.....) C - Around the Manger (Qty.....)

Gift Wrap: Santa and Reindeer - Gold (Qty.....) Animals at Christmas - Red (Qty.....)

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Please return slip to **MSA Trust, 51 St Olav's Court, Lower Road, London SE16 2XB** with payment by 6th December 2019.