MSA NEWS | ISSUE 77 | OCTOBER 2026

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MSA News



Drink up!

How to stay hydrated

SCAN TO VIEW ONLINE

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Welcome

Hello and a very warm welcome to your final edition of MSA News for this year.

As the seasons start to change, we at the Trust are also going through a period of change. In exciting news, we have had four new MSA Nurse Specialists join us over the last few months. We welcomed Elspeth and Lorraine in the last edition of MSA News and now have Eilidh Cameron-Smith (North East England) and Mandy Freitas (West Midlands) joining our incredible team. You can read more about their roles and how they can support you on page four.

You may have also seen that we are advertising for a new CEO. Our current co-CEO's, Andy and Karen, are retiring next year after over a decade with the Trust. We will keep you updated when we have someone in post to lead the MSA Trust into our next chapter.

Throughout this edition we have some interesting articles on MSA research including an overview of the MSA Research Symposium, held earlier this year in collaboration with UCL, and an update on the latest research projects we will be funding.

We would be very grateful if you would consider supporting our Christmas merchandise and cards this year. You can find out more on the back page.

As ever, we hope you enjoy reading this edition of MSA News.

Emma and Andy



NEWS

EAN Congress

Representatives from the MSA Trust attended the 12th Congress of the European Academy of Neurology (EAN), which took place in Geneva, Switzerland in June.

Alongside the scientific symposia and clinical workshops, the event provided a valuable opportunity to meet, engage and network with global neurology professionals, while promoting the work of the MSA Trust.

There was strong interest in the Trust's healthcare professional training programme, with international requests to use and translate our resources.

Discussions with professionals underlined the importance of accessible, specialist information and the valuable role the MSA Trust can play in supporting healthcare professionals and people affected by MSA worldwide.



Our 2025-2026 Impact Report

The Trust reached some significant milestones in the 2025-26 financial year. We were in contact with more people in the MSA community than ever before. This and other achievements are detailed in our Impact Report which is now available to be viewed online - **www.msatrust.org.uk/about-us/annual-review**. Collating insightful results from our 2025 Annual Impact Survey will also help shape our service development and strategy in years to come.

Please email **fundraising@msatrust.org.uk** if you would like a copy in the post.

MSA Study Day March 2027

On the 11th March 2027, we will be bringing health and care professionals together in Birmingham and online for a study day focused on improving understanding and care for people living with MSA.

Our flagship study day dedicated to healthcare professionals provides practical, focused information on MSA, covering how they can better support people with the condition and their families and the challenges they face.

If you have a professional involved in your care who may benefit, please let them know about the event. For more information visit our website – **www.msatrust.org.uk/msa-study-day**.



Clinical Trial Recruitment

The HORIZON study is testing an investigational treatment, ION464, designed to reduce levels of alpha-synuclein, a protein believed to contribute to MSA. This early-stage clinical trial will assess the treatment's safety and tolerability. The study is recruiting at centres in Salford, Southampton, London (UCL Queen Square) and Oxford. To learn more, contact the study team at **ionisHORIZONstudy@clinicaltrialmedia.com**. Find out more about the study, including eligibility criteria, at - **www.msatrust.org.uk/research/get-involved-in-research/open-msa-studies/horizon**.

The Trust's 30th Anniversary

2027 marks the MSA Trust's 30th birthday: 30 years of advocacy and support for people living with MSA and their loved ones, and 30 years of funding vital research into the causes of MSA.

We are excited to celebrate this milestone with our MSA community. Whether you have ideas for fundraising activities, events, or other ways to mark this special anniversary, we would love to hear from you.

Please contact **fundraising@msatrust.org.uk** and we will be delighted to support you.

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Our MSA Health Care Specialists

Our team of health care specialists (currently all registered Nurses) work around the UK and Ireland to support people living with MSA and their families. Our Lead MSA Nurse Specialist, Jill Lyons, gives an update on the team and explains more about their roles.

We are pleased to welcome four new Nurses to our MSA Health Care Specialist Team (one full time and three part time). The Nurses have been recruited as part of our succession planning and to increase team capacity. We were very pleased to have high-quality applicants and selected four Nurses for the following regions – West Midlands, Scotland, Ireland and Northern Ireland, South Central England and North-East England.

This means we now have a total of eight Nurses in our Team working throughout the UK and Ireland.

They all work regionally but provide cover for each other as required. This means that if you call or email the Trust, you may get a response from a different Nurse than the one you usually speak to.

Currently, our Nurses provide the following support to people living in the UK and Ireland:

- Telephone support available Monday to Thursday from 9.00am - 5.00pm and Fridays from 9.00am - 4.00pm. Should the MSA Health Care Specialists be away from their desks, they will reply to messages left on their answerphones as soon as they can. They receive enquiries about many different aspects of living with MSA, from people with the condition, from carers and family members and from other health and social care professionals. Our team are happy to answer any questions you have about MSA. If they do not immediately know the answer, they will discuss it with their colleagues and come back to you. They are also very happy to listen to you talk through any challenge you are facing related to MSA. The team have many years of specialist nursing experience between them and are always happy to help people understand about MSA.
- An email service, running the same hours as the phone line, as we know some people prefer to communicate by email.
- Liaison with your health and social care professionals. Our team can offer support and information and make suggestions based on their specialist knowledge of the condition. However, they do not case manage the care of people with MSA as they are not part of the NHS or HSE system. Our team are happy to liaise with any health and social care professionals who need specialist knowledge about MSA. Please give your medical team our contact details.
- We run MSA Support Groups, online and in-person, to discuss any MSA topics of interest to people attending the meetings and to provide updates on current thinking on treatments and research. The Nurses work closely with office staff and volunteers to facilitate these groups.
- Our team also writes and contributes to the factsheets and guides (and this magazine) specific to MSA that we produce at the Trust. We can help point you in the right direction so you know where to access these.
- The Nurses attend MSA clinics all over the UK and Ireland at the invitation of Specialist Consultants and NHS Teams. Some clinics are held in hospitals and some in hospices.

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MSA Trust Health Care Specialist Team

- We provide training for health and social care professionals who support people with MSA and their families. To find out more about this please visit our Education and Awareness website pages. You may have seen on page 3 about our next MSA Study Day so please tell your medical team about this.

The MSA Health Care Specialists are always looking for opportunities to develop new clinics, and work with NHS and HSE professionals who are aiming towards improving care for people living with MSA. They develop good working relationships with key professionals involved with the care of people living with MSA.

The Nurses do not have capacity to actively call or email our community regularly so please do contact them if you require information or support.

As an independent charity the MSA Trust does not hold or have access to NHS or HSE medical records. Any decisions about your care or treatment should always be discussed with your own healthcare team.

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Double Your Impact This Christmas with the Big Give

Christmas Challenge BigGive

We're delighted to announce that the MSA Trust will once again be taking part in the Big Give Christmas Challenge, the UK's largest match-funding campaign.

Thanks to the incredible generosity of our pledgers and Champion Funders (the Big Give's philanthropic partners), we have already secured £25,900 in matched funding for our Christmas Appeal. This means that every donation made to the MSA Trust through the Big Give campaign between 1st and 8th December will be doubled, while matched funds last.

A £10 donation becomes £20.
A £25 donation becomes £50.
Every gift has twice the impact.

This year's appeal will raise vital funds for our MSA Health Care Specialists. As you will be aware, MSA is rare and can progress rapidly. Often too many people are left to face its challenges without the expert support they need. Our Nurse Specialists are there from diagnosis through to end of life, providing practical information, supporting symptom management, attending neurology clinics, running support groups, training healthcare professionals, and helping people access essential services and research opportunities.

By donating through the Big Give Christmas Challenge, you can help us reach more people with this life-changing support.

Please look out for the launch of our campaign in the lead-up to the 1st December. We will be incredibly grateful if you are able to make a donation during the campaign week (1st - 8th December). Because every donation will be matched, your gift will go twice as far, helping more people affected by MSA to access the expert support, information and guidance they need and deserve. Please contact our Fundraising Team to register your interest.

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One donation, twice the impact



Your Stories

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Stan, a member of our MSA community, talks about the benefits he has felt after using a Continuous Positive Airway Pressure (CPAP) machine.

A CPAP machine can be used when someone has Obstructive Sleep Apnoea (OSA). This occurs when the muscles and tissue of the throat and top of the airway relax and collapse on themselves. This partially or totally blocks the passage of air temporarily. There is an increased risk of OSA in MSA due to damage caused to the autonomic nervous system. It occurs when we are asleep and initial signs may be an increase of noisy snoring.

"Hi, my name is Stan and I was diagnosed with MSA a couple of years ago. I also really struggled with sleeping and had terrible nightmares. Because of not sleeping soundly I was always very tired through the day and had no energy. This meant I was always going back to bed through the day and sleeping most of the afternoon. I mentioned this at one of my neurology appointments and was referred to the Sleep Clinic. I had to stay overnight at the Sleep Clinic where sensors were attached to my head which monitored my sleeping. The results showed that I had sleep apnoea and I was offered a Resmed CPAP machine with a mask attached which I had to wear whilst sleeping.

The results have been amazing and my sleep pattern has hugely improved and my energy levels throughout the day have improved. I would honestly recommend finding out more to anyone who is struggling with sleeping because of the impact it has. It is very easy to use and there are various types of masks that can be used."

There are a number of different CPAP machines, as well as the Resmed one that Stan describes. The machine is a small box that can sit on your bedside table. It draws in air from the environment and compresses it, passing the pressurised air through tubing from the machine to a face or nasal mask. The pressure from the machine is set by the team doing the sleep study to the correct level for each person, to improve their breathing efficiency whilst asleep.

A CPAP machine is significantly quieter than snoring, typically producing 30 decibels of sound, which is comparable to a soft whisper. If the mask is dislodged or there is a leak, it will trigger an alarm, but this shouldn't be a problem unless you move a lot in bed.

It can take a little while to get used to the CPAP, so it is suggested that you put it on when you first go to bed and initially wear it for an hour or so. Gradually build up the time until you can sleep all night with it on. Managing to do this is likely to give the best benefit and hopefully as good a response as Stan has found using his CPAP.

There is more information about breathing issues that some people with MSA may experience in our factsheet - www.msatrust.org.uk/support/living-with-msa/factsheets/breathing-and-possible-changes-in-msa.

Speak to your Specialist if you would like to discuss your sleep or any concerns with breathing and MSA.



Influencing Change for Those Living with MSA

Welfare benefits and social care have remained in the headlines throughout 2025–2026. Here our Social Welfare Specialists, Sam and Louise, highlight some of the recent policy work they have been involved in. This will ensure the views and experiences of people living with MSA are better understood by policymakers.

Review of Personal Independence Payment (PIP)

PIP is a UK non-means-tested disability benefit worth up to £10,119.20 per year. Claimants must be of working age.

In March 2025, the UK government proposed significant changes to PIP which may have led to far fewer people living with long-term health conditions or disabilities being eligible to claim this vital financial support. Following strong opposition from disability organisations and charities, including the MSA Trust, in June 2025 the government dropped the original proposals. Instead it launched a comprehensive review of PIP.

The review, known as the **Timms Review**, launched in October 2025, and is being led by Sir Stephen Timms (Minister for Social Security and Disability). Its overall aim is to ensure PIP is "fair and fit for the future – reflecting the reality of people's conditions and their goals and ambitions – taking account of changes in society since it was first devised and introduced".

Our Social Welfare Specialists had the opportunity to speak directly to Stephen Timms, when he attended a Disability Benefits Consortium meeting late last year. They asked the Minister to consider improving ways to fast-track PIP applications for those with life-limiting conditions and to scrap re-assessments for those living with health conditions which are unlikely to improve.

The Timms Review launched a wider consultation in April 2026. To ensure we captured the views of our MSA community, we conducted a survey of those who had recently applied for PIP. We asked people to share their experiences of the PIP process, and their anonymous feedback was included in the MSA Trust's overall consultation response, including some powerful quotes.

Following the publication of its interim report in July 2026, the Timms Review invited people to register their interest in attending a workshop to "discuss and refine the emerging recommendations". We shared this invitation with those who had recently applied for PIP and a number of people from our MSA community, including our Social Welfare Specialists, registered their interest. The workshops took place in-person and online in September and October 2026. Despite the limited number of overall spaces available, we are pleased to report that three people living with MSA were invited to attend workshops.

The Timms Review is expected to report to the Secretary of State for Work and Pension before the end of the year. You can read the Review's interim report here - **www.gov.uk/government/publications/timms-review-of-personal-independence-payment-interim-report**.

Adult Social Care in England

In April 2025, the UK government launched the Independent Commission on Adult Social Care, led by Baroness Louise Casey. It is known as the **Casey Commission**. Its aims are to:

- **set out a plan for a National Care Service**
- **make long-term recommendations on how to reform the Adult Social Care system in England.**

The Casey Commission was initially set to make its final report and recommendations to government in 2028. This date has now been brought forward to the summer of 2027.

The Casey Commission has been involved in talking to individuals and organisations that represent people living with long-term health conditions and disabilities. In March 2026, the Commission asked the government to act on three specific areas – safeguarding; dementia; and Motor Neurone Disease (MND).

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In May 2026, Andy Barrick our Chief Executive, and Louise, met with a member of the Casey Commission to share the experiences of people living with MSA, and their carers, in relation to social care. They highlighted that many people living with MSA have similar needs to people living with MND. We submitted experiences from our MSA community in relation to accessing social care, care packages, finding carers and respite, and housing-related matters, such as accessing grants for adaptations.

In August, the Secretary of State for Health announced that people living with MND will get faster access to care and support; recognising that people living with MND, their carers and families have to deal with, and navigate, a complex system involving health, social care and housing services. In response, the MSA Trust, together with other organisations and The Neurological Alliance, wrote to the Secretary of State for Health asking that the MND "fast track" pathway be extended to people living with other progressive neurological conditions whose health and care needs can deteriorate rapidly.

The Casey Commission launched 'The Big Conversation on Care' in July 2026, to give everyone in England a chance to have their say on the future of adult social care. It asked one main question to start - "When we are old or disabled, or have a serious illness, who should support us and how?" Respondents could give their views and comment on others' views. We promoted this to our community in England directly, inviting them to take part in The Big Conversation - **www.caseycommission.co.uk/bigconversation**.

Additional Work

Other work we have been involved in this year includes meetings alongside the charity Marie Curie with senior members of the Department for Work and Pensions (DWP). We discussed how people may be able to access welfare benefits more easily through the fast-track route. We provided information about MSA and the experiences of our community when applying for benefits, which was welcomed by the DWP, and provided a vital opportunity to raise the profile of MSA and the MSA Trust.



Sam and Louise, our Social Welfare Specialists

Following this meeting, we were invited to take part in further discussions with the DWP on how the Carer's Allowance application process could be improved. One of our suggestions was to include carer's details on disability benefit application forms, with any successful applications automatically triggering a potential claim for Carer's Allowance.

This summer, we also took part in the DWP's Carer's Allowance: Call for Evidence, which aims to modernise support for carers. The DWP was particularly interested in gathering views on potential reform options for how much carers can earn whilst claiming Carer's Allowance; the maximum is currently £204 per week (after deductions). We highlighted the need for a clear and easy to understand system. We suggested the earnings limit should be increased from the current level, based on 16 times the hourly National Living Wage, to 20 times the hourly National Living Wage. This would allow carers to earn an additional £50 per week without it affecting their Carer's Allowance.

Thank you to everyone in our community who has supported our policy work by sharing views and experiences. We will keep you updated on further developments.

Leave a Legacy of Hope

NATIONAL FREE WILLS NETWORK

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Making a will is one of the most important steps you can take to ensure your wishes are honoured. It also gives you the opportunity to leave a lasting legacy of hope to the MSA Trust.

Through our partnership with the National Free Wills Network, you can have a simple will written by a qualified local solicitor at no cost.

To request your free will pack, or to find out more, visit www.msamag.link/4hGahhP or scan the QR code above. You can also call us on 0333 323 4591 or email fundraising@msatrust.org.uk, and we will request a pack for you.

The pack contains details of participating solicitors in your area. You can choose a solicitor and arrange an appointment at a convenient time. Once your will is complete, the solicitor will submit a form so the MSA Trust can pay them directly.

What if my will is more complex?

The MSA Trust covers the cost of a simple will. If you need additional services, such as inheritance tax advice, Powers of Attorney or a discretionary trust, your solicitor may charge you separately.

Do I have to leave a gift for MSA Trust in my will?

There is no obligation at all. We are incredibly grateful if you choose to remember the MSA community, but understand if this comes after taking care of family and friends. Your gift ensures that the Trust can support people affected by MSA in years to come, and fund the research that will one day end this devastating disease.

What if I want an online appointment or home visit?

We understand the challenges that life with MSA brings, and if you cannot visit the law firm, the Network does recommend solicitors who can write your will online or over the phone. Since the scheme launched last October, many people in our community have used it successfully. Our supporter Sarah said:

"We found the whole process very easy from start to finish. Our solicitor was incredibly helpful, explaining everything and guiding us through each step. Sadly, my mum has MSA and is approaching the end of her life. It is important to us to give to a charity that has helped us so much, so it can continue supporting others in the future."

Please contact us on the details above if you need any further help or have any questions.

MSA Symposium 2026:

Bringing the Global MSA Research Community Together

In May 2026, the Trust hosted its fourth MSA Symposium in collaboration with University College London (UCL). Held in London, the symposium featured an academic programme developed by Dr Viorica Chelban of the UCL Queen Square Institute of Neurology and brought together researchers, clinicians, healthcare professionals, pharmaceutical companies and charity representatives with a shared goal: improving the lives of people affected by MSA.



This year's symposium marked an exciting milestone, as it was delivered in a hybrid format for the first time. Alongside those attending in person, delegates were able to join online from around the world. Around 150 people attended across both platforms, helping to create a truly international event and ensuring that those unable to travel could still hear about the latest advances in MSA research. The symposium also attracted interest from pharmaceutical companies and researchers working to develop new treatments, highlighting increasing momentum within the field.

Our Chair, Prof. Bhatia opened the day by introducing keynote presentations that explored both the science behind MSA and the practical realities of living with the condition. Professor Maria Grazia Spillantini from the University of Cambridge discussed alpha-synuclein, a protein which is widely believed to play a central role in MSA. Scientists are continuing to learn more about how abnormal forms of this protein contribute to the disease, and this knowledge is helping to shape new approaches to diagnosis and treatment.

Professor Alessandra Fanciulli then turned the focus towards improving care for people living with MSA. In particular, she highlighted the importance of recognising and managing pain, a symptom that can have a major impact on quality of life but is often overlooked. Her presentation was a reminder that while research into future treatments is vital, improving care and support today remains equally important.

Several speakers presented work aimed at improving our understanding of what causes MSA and how it progresses. Scientists are using increasingly sophisticated laboratory models to investigate why certain cells in the brain are particularly vulnerable and to identify potential targets for future therapies. While much of this work takes place behind the scenes, it forms an essential foundation for developing new treatments and moving promising discoveries from the laboratory into clinical trials.

One of the most encouraging themes of the day was progress towards earlier diagnosis. MSA can be difficult to diagnose, particularly in its early stages, and delays can have a significant impact on accessing support and participating in research. Dr Viorica Chelban shared updates on biomarker research, which aims to identify measurable biological changes that could help diagnose MSA more quickly and accurately. Although further research is still needed, developments in this area offer real hope for the future.

The afternoon sessions focused on issues that matter most to people living with MSA and their families. Emma Rushton, our Director of Services spoke about the importance of involving those affected by MSA more closely in research and service development. Increasingly, researchers recognise that people with lived experience have valuable insights that can help shape research priorities, improve healthcare services and ensure that future developments address the issues that matter most.

Delegates also heard about the impact of autonomic symptoms and sleep disorders, both of which can significantly affect daily life. Discussions highlighted the importance of recognising these challenges and ensuring they are managed effectively as part of a holistic approach to care. Professor David Oliver spoke about the role of palliative care in MSA, emphasising that it is not solely about end-of-life support. Instead, palliative care can help people manage symptoms, maintain quality of life and access the right support throughout their journey with MSA.

The final session focused on clinical trials and emerging therapies. Delegates received updates on the HORIZON trial from Ionis Pharmaceuticals and the ATH434 programme from Alterity Therapeutics. While these treatments are still being investigated, the presentations reflected a growing pipeline of potential therapies and an increasing level of investment in MSA research. For a condition that has historically seen limited treatment options, this activity is particularly encouraging.

The symposium concluded with valuable networking opportunities, reinforcing existing collaborations and fostering new connections. The strong progress reported across research, diagnosis, patient care and clinical trials highlighted the growing momentum within the global MSA community. While challenges remain, the success of this year's symposium reflected a shared commitment to improving the future for everyone affected by MSA.

It is likely that our next Research Symposium will be held in 2028.

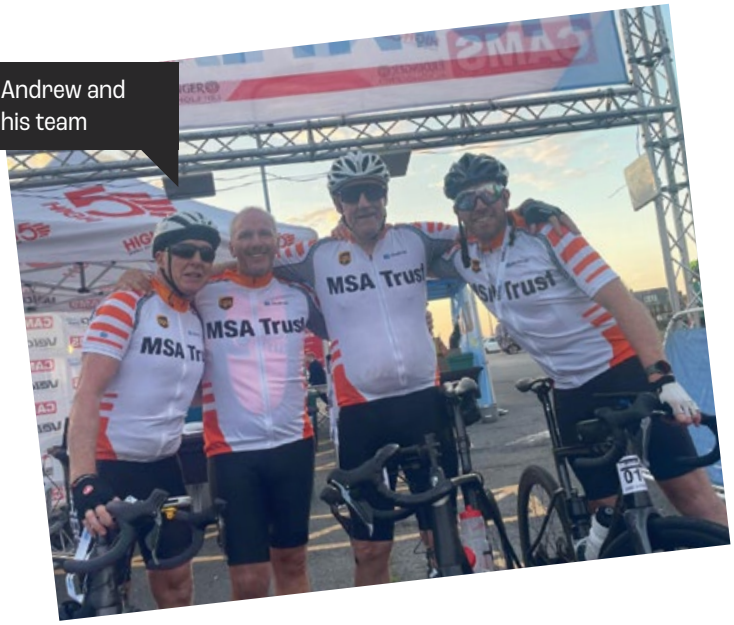
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Prof. Kailash Bhatia

Fundraising Stars

Cycling coast to coast for the MSA Trust



Andrew and his team

Thank you to Andrew and his team for completing their 153 mile cycle ride and raising an incredible **£3,632**, plus Gift Aid, for the MSA Trust.

"Well it's finally over, many months of training and preparing for this epic challenge for a dear friend and former work colleague and the MSA Trust. I won't lie, it was tough in parts but an amazing experience at the same time. I am truly overwhelmed by the generosity of people who have supported us along the way. My aches and pains will fade away but those suffering from MSA have to face challenges every day of their life".

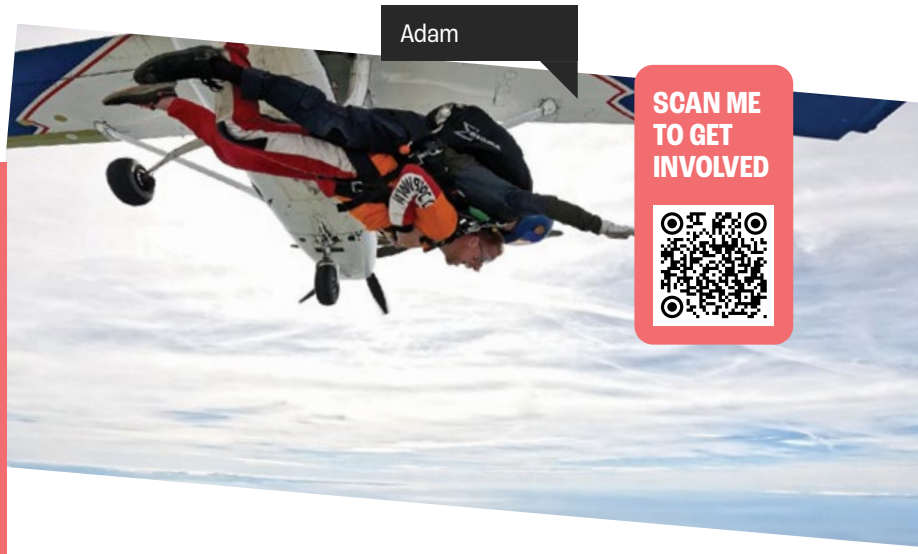
MSA Trust and Dorothy House Fundraiser



Sue, Sue and Emma

Long term friends, Sue H, Sue and Emma organised a fundraising event in support of Sue H's sister, who is living with MSA. They brought their community together and raised a fantastic **£1,750**. Thank you for your generosity, support and for helping to raise awareness of MSA.

Surprise Skydive



Adam

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"We organised a surprise skydive fundraiser for my husband, Adam, as part of his birthday celebrations. Last year, his mum, Heather, was diagnosed with MSA and since then our family has been committed to supporting the MSA Trust. Adam has raised an incredible £1,430 through his fundraising efforts, which we're immensely proud of. Together with his sister, who ran the Manchester Marathon with her partner last April, they have collectively raised over £3,200 for the MSA Trust in the past year"

Thank you so much Bethany, Adam and the rest of your family, for your amazing fundraising and continued support.

Charity Dance-a-thon



Sophie's fundraiser

Thank you to Sophie for her wonderful efforts and raising awareness of MSA.

"In memory of my dad, I organised a Charity Dance-a-thon to raise awareness of MSA and support the charities that helped my family throughout his illness. Thanks to the incredible support of our community, we raised £1,530 with the proceeds shared equally between the MSA Trust, St Michael's Hospice and Phoenix Bereavement. I'm so proud that the event not only raised vital funds but also helped shine a light on MSA and the important work of the MSA Trust"

84 miles along Hadrian's Wall

We are so grateful to friends Sarah and Susie who completed their challenge raising over £2,000.

"We had never heard of MSA until it cruelly took our best friend from us. Susie and I are raising money for the MSA Trust in memory of Kaz. Kaz, Susie and I had been best friends since we were 11 years old, and we miss her more than words can say. In Kaz's memory, we walked 84 miles along Hadrian's Wall, from Carlisle to Wallsend, Tyneside. We pushed ourselves physically and mentally but it's nothing compared to what people living with MSA face every day"



Sarah and Susie



Staying Hydrated: Why Drinking Enough Matters

Fluid helps our bodies work well. Drinking enough matters at any age, especially as we get older. Too little fluid can make you unwell and increase the risk of falls, infections, constipation, pressure sores and hospital admission. Here our MSA Nurse Specialist, Anna Kent, outlines how people living with MSA can ensure they are keeping hydrated.

Hydration is especially important if you have MSA. MSA can affect autonomic body functions, including blood pressure. Some people have a sudden drop in blood pressure when they sit or stand, called postural hypotension. This can cause dizziness, light-headedness, fainting, or pain across the shoulders and neck.

Drinking regularly can help keep blood pressure steadier, support concentration, protect skin, ease constipation and reduce urine infections. It can be easier to have small, frequent drinks rather than trying to drink large amounts at once.

Drinking enough can be harder with MSA. As we get older, thirst becomes less reliable, so you may not feel thirsty even when your body needs fluid. MSA can also make swallowing, using a cup, or getting a drink more difficult.

What is dehydration?

Dehydration happens when your body loses more fluid than it takes in. You lose fluid when you sweat, go to the toilet, breathe, are unwell or in hot weather.

Urine colour can give a rough idea of hydration. Pale yellow usually means you are drinking enough. Dark urine may mean you need more fluids. It is less reliable in older people and urine is often darker first thing in the morning. Some medicines and vitamins can also change urine colour.

When are you more likely to become dehydrated?

Dehydration is more likely when you lose extra fluid, drink too little or avoid drinking. Circumstances where this can might happen include:

- Diarrhoea, vomiting, fever or high temperature
- During hot weather or increased activity
- Difficulty swallowing, drinking or reaching fluids
- Drinking less due to toileting worries.

Signs of dehydration

Dehydration can affect how you feel, think and move. Signs include headache, tiredness, poor concentration, constipation, dizziness and urinary tract infections.

In older adults, dehydration can be harder to spot and may raise the risk of low blood pressure, falls, memory problems, infections and skin issues.

How much should you drink?

Unless you are advised to limit fluids, you should drink regularly throughout the day.

Aim for six to eight glasses or mugs daily, which is about two litres.

You may need more in hot weather or during illness.

For postural hypotension, a large glass of water before getting out of bed may help, along with extra salt if advised by your doctor.

What counts as fluid?

- Water - the best choice for hydration
- Tea and coffee but bear in mind caffeine may worsen bladder symptoms
- Milk
- Low-sugar drinks but be aware artificial sweeteners may irritate your bladder.

You can also get fluids from foods such as:

- Soup
- Yoghurt
- Custard
- Jelly
- Ice lollies and sorbets
- Fruits high in water content e.g. melon, strawberries.

If your appetite is poor, nourishing milk-based drinks can provide fluid along with extra calories.

Try to limit alcohol, as it can dehydrate you.

Practical tips to help you drink more

- Make drinking part of your daily routine
- Have a glass of fluid when taking medication
- Drink with meals and between meals (avoiding large drinks just before eating)
- Enjoy a drink socially
- Use a water bottle or jug marked with measurements to track your intake
- Keep drinks visible and within easy reach
- Add fruit or ice to make water more appealing.

If drinking a lot in one go feels difficult, try thess ideas;

- Link drinking to regular activities
- Drink small amounts more often throughout the day
- Keep drinks nearby so they are accessible and visible
- Ask for help if getting a drink is difficult and consider adapted cups, straws, lightweight bottles, or aids such as the Hydrant drinking system if grip or coordination is difficult. Speak to your medical team about this
- Set gentle reminders e.g. alarms, notes, verbal prompts
- If you are drinking less due to worries about needing the toilet more often, speak to a healthcare professional for help.

Key messages

- Drink regularly, even if you are not thirsty.
- Aim for about two litres a day, unless advised to limit fluids.
- For postural hypotension drinking water before getting up may help.
- Seek advice for coughing, choking, or swallowing problems.

If drinking or eating causes choking, coughing, a wet or gurgly voice, or worsening swallowing problems then you may be referred to a speech and language therapist for support.

SCAN ME TO LEARN MORE

Improving Palliative Care



Hospice UK is currently leading a three-year programme to improve palliative and end of life care for people affected by progressive neurological conditions, including MSA. The programme brings together hospices, healthcare professionals, researchers, charities and people with lived experience to better understand current provision and improve access to support across the UK.

The long-term aim is that people living with progressive neurological conditions receive high-quality, holistic and equitable palliative care when they need it, while families and carers feel informed and supported throughout the course of the illness.

Why is Hospice UK doing this work?

Although hospices already support many people living with neurological conditions, we know there is variation in awareness, access and experience across the UK. Hospice UK's activity data suggests that around 10,000 people with neurological conditions access hospice care each year, but there are still important questions about whether support is reaching people early enough and whether access is equitable for people with conditions other than Motor Neurone Disease or dementia.

As part of the programme, Hospice UK recently undertook research with people living with progressive neurological conditions, carers and bereaved family members to understand awareness of hospice care. One of the clearest findings was that people currently living with a condition were less likely than bereaved relatives to know about hospice services or to have discussed hospice care with a healthcare professional.

This matters because hospices can provide support much earlier than many people realise. Palliative care is not limited to the final days or weeks of life. For people living with MSA, it can help alongside active treatment and ongoing neurological care, supporting symptom management, future planning, emotional wellbeing and the needs of families and carers.

Why was the MSA Trust invited to be involved?

Partnership working is a core principle of the programme. Hospice UK recognises that improving care for people with progressive neurological conditions can only be achieved by working closely with organisations that understand the experiences and priorities of the communities they support.

The MSA Trust brings specialist knowledge of the condition and provides information, support and education for people affected by MSA and the professionals involved in their care.

By working together, Hospice UK and the MSA Trust hope to ensure that resources developed through the programme are informed by lived experience and reflect the realities of living with MSA. We also hope to strengthen links between hospices and MSA specialists, helping professionals feel more confident in supporting people with the condition.

What do we hope will change?

The programme includes a grants initiative supporting hospices to test new approaches to care, alongside the development of resources for patients, carers and healthcare professionals and the creation of a community of practice for hospice teams.

Through this work, we want to see:

- **People with progressive neurological conditions having access to appropriate palliative care when they need it.**
- **People affected by MSA feeling more informed about the support available from hospices.**
- **Hospices feeling more confident and competent in supporting people with neurological conditions and those important to them.**
- **Stronger partnership working between hospice services, neurology teams and condition-specific charities.**
- **Better support for families and carers throughout the illness and into bereavement.**

Why should people affected by MSA find out about their local hospice?

One of the strongest messages emerging from the programme is that many people do not fully understand the breadth of support that hospices can offer.

While services vary between hospices, many provide support that may be relevant at different stages of living with MSA. This can include symptom management, rehabilitation, advance care planning, emotional support, family and carer support, welfare advice, outpatient services and community-based care.

Importantly, accessing hospice services does not mean that other care comes to an end. Hospice support often works alongside care provided by neurologists, GPs, community teams and other specialists, helping to address needs that may arise as the condition progresses. Hospice services are free at the point of use, so there need not be concerns over any extra expenses.

How can people find out more?

People affected by MSA may wish to:

- **Speak with their neurologist, GP or other healthcare professional about local hospice services.**
- **Contact their local hospice directly to find out what support is available. You can find details here: www.hospiceuk.org/hospice-care-finder.**
- **Explore information about local hospices through Hospice UK and hospice websites.**

By building greater understanding of what hospices can offer, we hope more people living with MSA and their families will feel confident accessing support that can improve quality of life and help them plan for the future in a way that is right for them.

Article written by staff at Hospice UK.

SCAN ME TO LEARN MORE

Meet our New Researchers

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We are committed to funding research that brings us closer to a world without Multiple System Atrophy. This year, we are delighted to fund three projects that tackle some of MSA's biggest unanswered questions.

Why Does MSA Affect People Differently?

Dr Javier Alegre-Abarrategui, Imperial College London

One of the mysteries of MSA is why the disease progresses quickly in some people but more slowly in others. Dr Alegre-Abarrategui's research focuses on understanding why the harmful alpha-synuclein protein spreads more aggressively in some brains than in others. Using donated brain tissue, his team will study the genes and biological processes that could either encourage or protect against this spread. The project will create a map of how harmful proteins spread in MSA.

By identifying the molecular pathways linked to faster or slower disease progression, the project could reveal new targets for treatment or ways to slow the disease. It could also help researchers predict how MSA may progress in different individuals.

Understanding the Different Forms of MSA

Dr Patrick Cullinane, University College London

Although MSA is a single condition, it can affect people in very different ways. Symptoms vary, different parts of the brain can be affected and progression is not the same for everyone. We do not yet know whether this is because the alpha-synuclein protein itself exists in different forms. Dr Cullinane's research will investigate whether alpha-synuclein can fold into distinct "strains" or shapes that behave differently in the brain. Using donated brain tissue and detailed clinical information, he will examine whether particular protein strains are linked to different symptoms, rates of progression, or patterns of brain damage. The findings could improve understanding of why MSA varies so much between people, support the development of more accurate diagnostic tests, and help pave the way for more personalised treatments in the future.

Could Changes in DNA Hold the Key?

Professor Christos Proukakis, University College London

The cause of MSA remains unknown, and understanding what triggers the disease is essential if we are to develop effective treatments. Although MSA is not inherited, scientists are increasingly interested in changes that can occur in DNA during a person's lifetime. DNA acts as the body's instruction manual and small changes that develop with age may contribute to disease. Professor Proukakis will examine tissue and fluid samples to look for these changes. The research will focus on genes linked to alpha-synuclein as well as those involved in the immune system and inflammation. This research could uncover clues about what causes MSA and identify promising targets for future treatments.

Much of our funded research is made possible through gifts left in Wills. By remembering the MSA Trust in your Will, you can help drive future breakthroughs in diagnosis, treatment and care for people affected by MSA. To find out more about our Free Will Writing service, please see page 11.

Personal Experience:

SCAN ME TO LEARN MORE

One Physiotherapist's journey supporting people with MSA

My name is Nigel Kimpton, and I have been a physiotherapist for nearly 40 years, with an interest in neuro-physiotherapy for 20 years. I have had the privilege of working with patients with MSA for over 15 years during which time my clinic has delivered over 4,000 hours of pro-bono treatment to MSA patients in Essex and Suffolk.



Like most physiotherapists and medical professionals, I didn't know what MSA was until approximately 15 years ago when a friend of mine, Andrew Hulkes, developed MSA. Andrew wanted to explore physiotherapy equipment that would aid MSA symptoms such as stiffness, poor coordination and poor movement. Andrew raised sufficient funds to purchase a Giger MD rehabilitation device. After lots of research we agreed that this would be the most beneficial use of the funds. The Giger MD is a rehabilitation device where the patient lays on their back, their hands and feet are secured and supported and then the machine is lowered so the patient can see the pc screen above their head. All movement is then detected and summarised continuously and gives the patient feedback in the form of a graph. In addition to the Giger, we also use other pieces of equipment and carry out regular conservative physiotherapy rehab.

Unfortunately, most physiotherapists will not have access to a Giger MD so I would advise seeking a neuro physiotherapist who has experience of working with Parkinsons patients, as symptoms can be similar. Please ask your MSA Nurse Specialist to liaise between yourself and the physiotherapist to ascertain if they have experience of working with MSA patients.

All patients with MSA have different symptoms. We mainly see people with poor and un-coordinated movement accompanied by stiffness, difficulty moving, blood pressure issues (postural hypotension), difficulties in sitting to standing and with transferring.

When a patient comes for private physiotherapy, they can expect us to offer support and to explain the symptoms and how to best manage them throughout their journey. Dealing with blood pressure issues, where symptoms can range from dizziness and light-headedness to losing consciousness, can be difficult. In our Physio clinic we always closely monitor the patient for these symptoms whether they are walking with an aid or frame or in a wheelchair. Safety is paramount with all movement and close monitoring is extremely important. For example, the movement of rolling in bed can be complex because of the sequence of movements involved. We encourage breaking this down into a singular movement accompanied with a clear, short prompt and a tactile approach. We also try to encourage an exercise or movement programme for every patient that can be done daily and, of course, is tailored to the patients' individual needs.



I would encourage you all to regularly contact your Parkinson's Nurse or MSA Nurse Specialist for their support and information. I would also encourage families to attend the regular MSA support group meetings as discussing with other families' their issues and problems can be extremely beneficial.

Article by Nigel Kimpton of Benfleet Physiotherapy, covering Essex and Suffolk. www.benfleetphysiotherapy.co.uk.

It may be worth seeing if either of these exercise programmes may be beneficial for you. Do discuss this with a Physiotherapist first and then get in touch for further information:

Love to Move – www.britishgymnasticsfoundation.org/how-we-can-help/lovetomove
NeuroHeroes – www.neuroheroes.co.uk

Fundraising at Work

Corporate fundraising is a great way to raise vital funds and awareness for the MSA Trust. Whatever the size of your workplace, there are plenty of ways colleagues can come together to support people living with MSA and those who care for them.

Matched Giving can help your fundraising go even further. Many employers will match some or all of the money raised by employees. This increases the impact of their support while demonstrating a commitment to their staff and community. Visit our website for helpful resources, including a matched giving template to help you approach your employer.

Payroll Giving is a simple way to support the MSA Trust through your workplace. Donations are deducted directly from your salary before Income Tax is applied, meaning more of your gift goes to us. While Payroll Giving is tax-free for Income Tax, it does not reduce your National Insurance (NI) contributions. Check with your HR or payroll team to see if your employer offers this scheme.

Choosing the MSA Trust as your **Charity of the Year** enables your organisation to make a lasting difference. Fundraising activities such as team challenges, charity football matches, cake sales, or taking part in the 3,300 Mile Challenge during MSA Awareness Month, can raise both funds and awareness while bringing colleagues together.

Whatever way you choose to get involved, workplace fundraising helps build team spirit and strengthen connections while making a real difference to people affected by MSA.

Every pound raised helps us provide specialist support, trusted information, fund vital research and raise awareness of MSA.

For more information and fundraising resources, please visit our website – www.msatrust.org.uk/fundraise-at-work.

IN MEMORY

Our tribute to those loved ones recently lost to MSA.

Barbara White
William Kershaw
Nick Yarsley
Frankie Sweeney
Patricia Scutt
Brian Reynolds
Patricia Crewdson
Iain Morrison
Jane O'Connor
Tony Ellis
Bob Greensmith
Lucy Hamilton
Caroline Downie
Jayne Hyde
John McLernon
Joanna Daniel
Hilary Doxford
Pauline McCombe
Ian Frost
Elizabeth Jones
Alice McMullan
Alfreda Fairley
Mark Eccles
Fiona Murray
Imelda McCann
Susan Pugh
Elizabeth Carlisle
Margaret Sullivan
Donald Ellington
Christopher Moore
Susan Champion
Margaret Fuller
Lesley Urunsak
Adrian Driscoll
Kathryn Byrne
Keith Johnson
Philip Brammer
Margaret Haynes
Craig Donaldson
Edna Beetlestone
Christopher Hooker
Damian Wren
Jackie Taylor
Edward Richards
Gary Whitney
Wullie McTigue
Joy Robinson
Norma Lambert
Patricia Thorpe
Alan Davidson
Kenneth Wotton
Geraldine Teggart
Norma Dunning
Pamela Goldstone
Judy Bridge
Jonathan Metcalfe

MERRY Christmas

from the MSA Trust

Welcome to our Christmas Shop. Every purchase helps fund our support services and essential research into MSA. In our online shop you will also find 2027 MSA Trust Diaries (£6), notelets, pin badges, tote bags and much more, perfect as Christmas gifts or for yourself.

Cards

£5

Each pack has 10 cards with envelopes.



A: Snowy Robin – With Best Wishes for Christmas and the New Year

B: Festive Home – Happy Christmas and a Happy New Year

C: By the Manger – Happy Christmas and a Happy New Year

D: North Pole – Happy Christmas

Gift Wrap

£3

Each pack comes with 4 sheets (2 of each design) and matching sticker tags. Flat size 50 x 69cm.



Nutcracker Wrap



Robin Friends Wrap

How to Order

msatrust OFFICIAL SHOP

Scan the QR code to shop online or visit the link below:

www.msatrust.org.uk/christmas

Prefer to order by phone or pay by cheque?

Call us on **0333 323 4591** or email **fundraising@msatrust.org.uk** and we will be happy to help. We can confirm item availability, let you know the postage cost and send your order once your cheque is received. Please get in touch with the Fundraising Team if you are ordering more than 10 items or when ordering from outside the UK.

Please note we send our merchandise using Royal Mail 2nd class post. During the busy festive season it may take up to five days for your goods to arrive.

We have taken every care to ensure the accuracy of the information contained in this publication. However, the information should not be used as a substitute for the advice from your doctor or appropriate qualified professionals. Please note that personal views and opinions expressed are not necessarily endorsed by the Trust.

FUNDRAISING REGULATOR