

MSA News

**Our
Summer
Edition**

Symptom Help,
Symposium and
Social Care

SCAN
TO VIEW
ONLINE



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Welcome

Hello and a warm summer welcome to your new, refreshed and now even bigger MSA News magazine. We have spent some time redesigning our magazine to make sure it reaches all parts of our MSA Community and have increased its length to fit even more important topics in. We really hope you like it - if you have any comments please do get in touch.

You will still find your magazine jam-packed with interesting and informative articles. This time we have plenty from our MSA Health Care Specialists including an article about REMAP and the equipment adaptation services they provide (page 3), information on antecollis which can be a painful symptom of MSA (page 6) and support with monitoring your blood pressure (page 16).

Social care can be a confusing and complex area for many so do read our Social Welfare Specialists article for an introduction into social care and NHS Continuing Healthcare on page 8.

Finally, we wanted to highlight that we have a great range of useful information for you to access (see page 19). This year we have celebrated being the first organisation in the UK to have held the PIF Tick accreditation for five years - showing our information is evidence based and up to date.

We hope you enjoy reading this edition.

Emma and Andy



Custom-Made Help:

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How REMAP Supports People Living with MSA

Living with Multiple System Atrophy (MSA) can mean facing daily challenges that others might never think about. While no one solution fits all, there is an excellent charity that might be able to help if you're facing a problem that standard equipment doesn't solve.

REMAP is a charity providing custom-made equipment for disabled people across the UK. Their aim is to improve the quality of life of people experiencing disability, by making or adapting equipment to meet the unique needs of each individual.

Whether you need help with mobility, personal care, eating and drinking, or even a way to enjoy your favourite hobby or sport again, REMAP can work with you to find a solution. They have created all sorts of clever gadgets in the past, including carer-controlled wheelchair brakes, non-spill cup holders, bespoke computer tables, an umbrella holder for a wheelchair and even a voice-operated page turner.

They will only make a piece of equipment if the need cannot be met by existing sources. Each project starts with understanding your needs. Then skilled

volunteers - many of them engineers - put their heads together to come up with something tailor-made. They will consult your health professionals for advice when necessary and they also work with volunteer Occupational Therapists, to ensure the safety and quality of each adaptation or piece of equipment.

"The support we provide at Remap isn't just about providing a solution, it's about the wider effect on wellbeing."
- Kelly, volunteer maker.

REMAP complete 3,500 projects every year, helping disabled people to become more independent. **Their services are completely free of charge.**

How to get their help

If you think REMAP could help you or someone you care for, you can complete a simple online referral form. You can refer yourself or ask a health professional to help: www.remap.org.uk/referral-form.

There are 65 volunteer led branches across the UK. To find your nearest branch, you can enter your postcode on their website: www.remap.org.uk/about-us/find-your-nearest-remap-branch. You can look at past REMAP projects here - www.remap.org.uk/solutions.

If you have any questions you can contact their central office team by telephone on 01732 760209 or email at data@remap.org.uk. Do contact your MSA Health Care Specialist for further support.

NEWS

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Welsh Senedd Awareness Raising



On the 18th March 2025 the MSA Trust were invited to attend the Welsh Parliament to meet Members of the Senedd at the ‘Senedd at Y Farchnad’ event. Karen Walker, CEO and Jill Lyons, MSA Trust Nurse Specialist, were pleased to attend and talk to Members who came to visit our stand.

The picture shows Jill Lyons, MSA Nurse Specialist with Mabon ap Gwynfor AS at the Senedd who kindly invited us. Mabon is Plaid Cymru’s Health, Social Care and Housing Spokesperson.

MSA Candlelight Event – Edinburgh

The Trust’s regular memorial event, MSA Candlelight, was held in May and for the first time in Scotland. It is always a wonderful way to bring families remembering loved ones together. There were poems read by families with song and instrumental performances from a choir

based in Aberdour. Dr Lou Wiblin, a member of the Trust’s Scientific Advisory Panel (SAP), provided a fantastic overview of the latest MSA research projects and took questions from the attendees.

We are so grateful to all those who donated towards this event which helped to raise close to £3,800 for our research work.



MSA Study Day in London



In March we hosted our annual MSA Study Day for Health and Care Professionals. There were over 70 people in attendance, with another 100 participating live online. Our panel of experts spoke in-depth about living with MSA and practical ways in which people can be best supported. Feedback from attendees was overwhelmingly positive.

One attendee said “This has been the best, most informative course I have ever attended. I arrived with so little knowledge but am feeling empowered and well informed”. Another said, “My patient was so happy I was doing this and is looking forward to me giving her an update”.

Welcome to our new Nurse, Anna

In May we said a sad farewell to our MSA Nurse Specialist, Debra, who retired after 45 years in nursing. We are proud that she chose to spend her final working years at the Trust, supporting people with MSA and giving them the very best help possible. We wish Debra well on her retirement adventures.

In turn, we welcome our new MSA Nurse Specialist, Anna Kent. Anna will be covering South London and the South-East region. Anna is a highly experienced registered nurse, with over 25 years’ experience working with rare neurological conditions. Find out more about Anna via the QR code on your left.



Team MSAT



Goes the Distance at the 2025 London Marathon

Our fundraiser Eleanor & Harry



Jonathan



Tom & family



Jo



Loz & Andy



The 2025 London Marathon was our most successful marathon fundraiser to date. A huge thank you to Loz, Jonathan, Joanna, Stacy, Tom, Nia and Harry – our incredible Team MSAT runners. From tough winter training to race day, they raised an amazing **£33,800** and helped spread vital awareness of MSA throughout their journey and on the Marathon course itself.

We were also joined by over 25 family members, friends and volunteers across our two cheer stations – brightly dressed in MSAT orange – who gave their all to support our runners and raise much-needed awareness of MSA.

Our 3,300-Mile Challenge

We want to thank every single person who joined our annual 3,300-mile challenge, during MSA Awareness Month in March.

This challenge aimed to collectively walk 3,300 miles – one mile for each individual living with MSA in the UK and Ireland.

With the help of 56 walkers and 173 donors, we raised an incredible **£5,180** and covered a total distance of **2,684.9 miles**.

Whether you walked one mile a week or several miles a day, or donated directly to our month-long walking challenge, thank you for your support.

Antecollis in MSA

Some people with MSA can develop a symptom called antecollis. It is usually an advanced symptom of MSA and not everyone with MSA will develop it. Our MSA Nurse Specialist, Samantha Pavey, explains more.

Antecollis (or anterocollis), also called dropped head, is characterised by disproportionate flexion of the head over the trunk. It can result from either muscle weakness or muscle hyperactivity in cases of dystonia (an increase in muscle contraction).

This can be further described as twisting (torticollis), being pulled forwards (antecollis), or sideways (laterocollis).

Parkinson's and associated conditions can lead to camptocormia, antecollis, Pisa syndrome and scoliosis. Camptocormia is a forward flexion of the spine in the

upright position, which disappears when lying down. Pisa syndrome is described as a reversible lateral bending of the trunk with a tendency to lean to one side. Scoliosis is where the spine twists and curves to the side. This differs from your body's natural front-to-back curve.

People describe antecollis as a "pulling" or "drawing" in the neck, or involuntary twisting or jerking of the head. As things progress, people may have more difficulty stretching their neck voluntarily, with slow-motion head movements or the inability to move the neck.

The head is heavy - on average a human head weighs 11lbs or 5kgs. There are only seven vertebrae in the neck supported by around 20 muscles, responsible for moving your head around and keeping that weight in place, so trying to hold it up can be painful and tiring.

Having the neck in this forward position can impact on speech and swallowing. It can also make vision difficult. If someone can't see the person in front of them when talking, prism glasses can be helpful. They have mirrors in them which reflect the vision upwards.

Contact us at the MSA Trust if you would like to know more about prism glasses - support@msatrust.org.uk.

Management of antecollis

Your physiotherapist can assess your head and neck. They can suggest some exercises that may help with the stiffness and try to improve your range of movement. For example, trunk strength training can reduce the risk of falling.

If you are using a wheelchair regularly you should speak to your physiotherapist or wheelchair services to ask about head and neck support being added to your wheelchair.

Your neurologist may prescribe muscle relaxant medication if you are experiencing pain and the antecollis is caused by an increase in muscle tone, rather than a weakness.

Your GP can refer you to an orthotics department in your local hospital who can assess you and make a personalised collar, or other support that might be helpful.

Levodopa medications may be helpful for some people with antecollis as they can help with muscle rigidity and stiffness. Do discuss this with your neurologist.

Neck support and collars

Most people with antecollis will benefit from wearing some sort of neck support. It can be difficult to find something comfortable. People report that soft collars aren't supportive enough and hard collars are too restricting or dig into the chin or neck. Physiotherapists often say it isn't good to wear the support for too long a period at any one time, as the muscles may become weaker. But

really it is all about comfort for you, as this symptom can't be corrected.

Soft collars are made from foam that is bendable and sits around the neck covered with stretchy fabric. Your Occupational Therapist (OT) or Physiotherapist can supply this for you. They come in a few different sizes and are closed with Velcro in most cases.

A hard collar is usually made from metal and hard plastic and is very rigid. Most people can't tolerate them for long periods, but they can ease the pain by taking the weight off your head and neck. Again, these can be supplied by the OT or Physiotherapist. They can advise how long you should wear the collar for. You may want to gradually build up the time you can tolerate it. It can be helpful to get your head in a good position for mealtimes and when you want to talk to visitors.

Many people find that travel neck cushions are comfortable, in particular the softer ones with bean bag fillings. They can ease the weight of the neck without being too restrictive. There are many options available in shops or online. Speak to your OT or Physiotherapist before buying one.

Treatments

Botulinum toxin (Botox) can sometimes be helpful for antecollis, particularly if it is caused by dystonia (increased muscle tone). It is a neurotoxin that stops abnormal signals from the brain reaching the muscles. It is injected into your body to stop muscles from spasming. It begins working within two weeks, with the best results seen at six weeks. This treatment will need to be repeated at regular intervals because its effect wears off after three to six months. Treatment may not be offered for particular muscles, as this could increase swallowing problems for some people. Your neurologist can refer you to a Botox clinic that specialises in this type of symptom to see if it would be suitable for you.

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If you have any questions about antecollis do contact the MSA Health Care Specialist for your area by scanning the QR code above.

Please note that this article is not intended in any way to replace the advice of your doctor or health care professional. Specific advice should be sought from a properly qualified health worker.

Accessing and paying for care at home

People living with MSA may need extra help and support to manage tasks like washing, toileting, dressing, preparing a meal, shopping or meeting up with friends. Here, Sam Fitzgerald, our Social Welfare Specialist, outlines how you might go about accessing and paying for such help.

Accessing Social Care

If you live at home and are finding it increasingly difficult to look after yourself or need help with daily living tasks or social activities, talk to your local authority Adult Social Care team and request a care needs assessment. Everyone has a right to an assessment, free of charge. A family member, friend or carer can request one on your behalf and can be with you for support during the assessment. Given the current pressures on the social care system, we suggest requesting an assessment early, rather than waiting until care needs become more urgent, as accessing social care can take time.

Care needs assessments don't just look at the help you need with personal tasks such as washing, dressing, toilet needs, eating and drinking. The assessor should also ask you how you want to live your life and whether there are certain aims or goals you'd like to achieve and discuss the help you may need to make them a reality. The assessment may also identify the need for support from other services such as an Occupational Therapist, to access equipment or adaptations to aid your independence.

Following the assessment, you should receive a written care plan. It should outline your assessed needs and suggest appropriate solutions to address these.

Paying for Care

(this differs depending on where you live):

England

Once you have an agreed care plan, your local authority must do a financial assessment. Most people have to contribute something towards the cost of their care. Income, including benefits and pensions, as well as savings are considered. This is only for the person needing care – your partner's income and savings cannot be considered. If you have joint savings, the local authority will assume you each own half of the total amount (unless you can show evidence to the contrary). If care is being provided at home, the value of your home is disregarded.

The table below explains how savings affect the contribution you may be asked to make in England:

Savings over £23,250	You would be expected to pay for your care as a 'self-funder'
Savings between £14,250 and £23,250	You would pay a contribution from your income plus a 'tariff income' based on your savings. Tariff income = assumed income of £1 for every £250 (or part of)
Savings below £14,250	Savings below £14,250 are disregarded. You may still pay a contribution from your income.

Wales

Following a care needs assessment, the local authority must do a financial assessment. In Wales there is a maximum weekly charge of £100 for homecare services. Income, including benefits and pensions, as well as savings are considered, but only for the person needing care. If you have joint savings, the local authority will assume you each own half of the total amount (unless you can show evidence to the contrary). Some types of income may be fully or partially disregarded e.g. income from employment (including self-employment). For homecare services, the value of your home is disregarded.

In Wales, the savings threshold is £24,000 and any savings below this are fully disregarded. If you have savings in excess of £24,000, the local authority can charge the full homecare cost – up to a maximum of £100 per week.

Scotland

In Scotland, following a care needs assessment, personal care and nursing care should be provided free of charge. There may be a charge for domestic support such as shopping, laundry or housework and charges vary depending on your local authority.

Northern Ireland

You should contact your local Health and Social Care Trust to request a community care assessment. Care arranged by Trusts is not usually free and so there will be a financial assessment once you have an agreed care plan. For more information visit – www.msamag.link/4mLJBh6.

Republic of Ireland

The Health Service Executive (HSE) Home Support Service aims to help you remain at home for as long as possible. Services can include additional home help hours, nursing services, therapy services, and other services which might be needed due to illness or disability – or after a stay in hospital or nursing home. Any support received will be based on your assessed care needs. The Home Support Service is free and available to people aged 65 or over who may need support to continue living at home or to return home following a hospital stay. Some exceptions may be made for those under 65 who are living with a disability. You can find more information and download an application form here – www.msamag.link/3SzPiRG.



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NHS Continuing Healthcare (CHC)

In England and Wales, if you have complex care needs you may be eligible for NHS funded care known as NHS Continuing Healthcare (CHC).

CHC is a package of care paid for by the NHS for adults who are not in hospital but who have complex, ongoing healthcare needs. To be eligible a person must show they have a 'primary health need'. This is different to having social care needs, which are those related to daily living activities and do not require special skills or training to manage.

Primary Health Need

Having a diagnosis of MSA (or any other condition) does not guarantee that you will meet the criteria for CHC funding. Eligibility is based on having a 'primary health need' and not a person's diagnosis. It's not easy to distinguish between a primary health need and a social care need. If you find that you are having, for example, frequent falls, have significant swallowing difficulties (or have a PEG or other alternative method of feeding fitted), or are struggling to communicate then do ask about having a CHC assessment. These factors alone will not make a person eligible but could be an indication that a person may have a high level of support needs.

Applying for CHC

Applying for CHC is usually a two-stage process. First, a CHC checklist needs to be completed by a health or social care professional. The checklist is simply to determine whether a full CHC assessment should be done. If the outcome of the checklist shows there is a need to complete a full assessment, then this will be done by a multidisciplinary team of health and social care professionals. You will be invited to take part in the assessment and can be accompanied by a carer or family member for support. If you feel you may be eligible for CHC, you should speak to your GP, District Nurse, Social Worker or other health or social care professional. Please see our CHC factsheet for more information:

www.msamag.link/3ZD0VeD.

Scotland, Northern Ireland and Republic of Ireland

In Scotland CHC funding has been replaced by Hospital Based Complex Clinical Care. You can find more information by visiting:

www.msamag.link/3HJaWau. In Northern Ireland there is no national guidance on CHC funding and no evidence of people receiving CHC. Different arrangements operate in the Republic of Ireland and CHC funding does not exist.

Our Social Welfare Specialists will be hosting an online information and support group focusing on social care and CHC on Tuesday 8th July at 2pm. Email support@msatrust.org.uk to RVSP.

Improving Access to Services – A Study

ImproveAPS is a study to understand how everyone could have the same opportunities to get the services they need. Senior Research Fellow, Dr Annalisa Casarin, explains more.

A new research study has started, funded by the National Institute for Health and Care research, looking into the difficulties people face navigating the health and care system in England. Dr Casarin (University of Hertfordshire) and Dr Ghosh (Southampton NHS) are leading the study to understand what services people with Atypical Parkinsonian Disorders (APS) receive and which services are most useful. APS include Multiple System Atrophy (MSA) Cortico Basal Degeneration (CBD) and Progressive Supranuclear Palsy (PSP).

During a small group discussion, carers of people living with APS shared their experiences of engaging with health and social care services.

They told the researchers that the support provided was different depending on where they lived. There were good services with some not so good. The team wants to look at what works well and where, and also what barriers to good support there might be in order to find solutions to overcome them.

The study started on the 1st March 2025. It will run for two years. Researchers will look into guidance and policies currently available. They will then compare the findings with the care received by people who live in areas far from main centres of care and those living near them. They will interview people with the conditions and their carers to understand their experiences and will ask health and social care professionals about what they do to support them.

The team will then draw a map of the services in several areas in England to understand how people who provide care work together and how people navigate the system. This will help the team understand why people don't get what they need and how to make this better. After discussing these results with people affected by the conditions and care professionals, the researchers will design potential solutions and provide recommendations to commissioners of services to promote efficiency of the health and care system. The aim is to improve the quality of life for people with APS and their carers.

Dr Casarin and Dr Ghosh have already involved people affected by MSA, PSP and CBD who helped design the study. They now aim to recruit 24 participants in the first instance, 8 people and carers affected by MSA, 8 by CBD and 8 by PSP.

If you are interested in taking part in the project, please email Dr Casarin at annalisa.casarin@nih.ac.uk.

The Future of MSA Research

In April 2025, we hosted our third MSA Symposium, bringing together nearly 150 attendees from around the globe, including researchers, clinicians and industry experts. This event, a collaboration between UCL (led by Dr. Viorica Chelban) and the MSA Trust, was principally sponsored by Theravance Biopharma, IONIS and Alterity Therapeutics. The symposium showcased the latest advancements in early stage MSA research and created a space for networking and future collaboration.

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The Symposium was opened by Prof. Kailash Bhatia who is the Professor of Clinical Neurology at the Institute of Neurology, UCL and Chair of the MSA Trust. The first of our keynote speakers, Prof. Andrew Singleton discussed the Global Parkinson's Genetics Program (GP2) and the importance of enabling global genetics research. GP2 is an ambitious initiative aimed at understanding the genetics of Parkinson's disease and atypical parkinsonian disorders, such as MSA, by genotyping over 250,000 volunteers worldwide. Genotyping involves examining DNA and identifying variations, which can provide insights into an individual's susceptibility to certain diseases, their response to medications and other genetic traits. Prof. Wassilios Meissner from University Hospital Bordeaux, then discussed the different ways MSA may progress, and the implications this has for clinical trials.

Session #1

The keynote talks were followed by a focus on recognising MSA early. The session, chaired by Dr. Valeria Iodice, showcased presentations from Prof. Horacio Kaufmann from NYU Grossman School of Medicine, who discussed when clinicians should suspect prodromal MSA and, crucially, what steps to take. Prodromal refers to subtle symptoms, such as urinary problems or blood pressure fluctuations, that may appear before the more obvious symptoms of MSA develop. Identifying these early can help clinicians diagnose MSA sooner and potentially start treatments earlier. Prof. Jalesh Panicker from UCL discussed urinary problems in MSA and how scans have started to reveal abnormalities in the spinal cord that contribute to autonomic dysfunction, which is a hallmark of MSA.

Session #2

Session two, chaired by Prof. Henry Houlden, delved into the pathology and biomarker insights of MSA. A biomarker is a measurable indicator of a biological condition and is often used in research and clinical practice to diagnose diseases, monitor disease progression and evaluate the effectiveness of treatments. Dr. Viorica Chelban provided an overview of fluid biomarkers (usually taken from blood or spinal cord fluid) and their implications for patient care. Dr. Zane Jaunmuktane from Queen Square Brain Bank explored MSA pathology from a molecular level, while Dr. Caoimhe Morley reviewed how changes in the number of the SNCA gene relate to a protein called alpha-synuclein, which is known to clump together in the brain tissue of people with MSA. Finally, Dr. Christian Lambert discussed how advanced MRI scans can create detailed images of living tissues in the body. This technique helps clinicians and researchers see and measure specific features of tissues, like the brain, without needing to do a biopsy or surgery.

Session #3

The third session, chaired by Dr. Christopher Kobylecki, focused on improving care for MSA patients. Karen Walker, our CEO, shared strategies for shaping the MSA Trust's approach, including sharing the experiences of some of our members. Prof. Anette Schrag presented results from the MSA Survey on care needs, and Dr. Saima Sheikh reviewed how quality of life varies over the course of MSA. This session, which focused on the experience of living with MSA, was particularly well received by attendees.

Session #4

The final session, chaired by Prof. Vincenzo Libri, provided updates on MSA clinical trials. Prof. Thomas Foltynie discussed lessons learned from the Exenatide trial which explored whether a drug commonly used to treat type-2 diabetes could slow the progression of MSA. Results from this trial are expected later this year. Dr. David Stamler from Alterity Therapeutics shared findings from the ATH434 phase 2 study which looked at stabilising or reducing iron accumulation in the brain in early MSA, which is important because iron buildup may be linked to disease progression. The phase II study showed initial positive results in a small number of people with MSA. It is hoped this will go to a phase III trial to further test this experimental compound in larger numbers of people..

The Symposium concluded with a networking reception, allowing attendees to forge new connections and strengthen existing collaborations. This event marked a further milestone in the collective efforts to understand MSA. It provided valuable insights and contributed to developing our MSA research community.

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CAPTIONS

1. Professor Jalesh Panicker, Professor Henry Houlden and Professor Kailash Bhatia.

Fundraising Stars

Sandi recently took on a challenge, along with her friend Pauline, to walk the Hadrian's Wall Path. Sandi undertook this challenge in honour of her friend and former manager, Geraldine, who was diagnosed with MSA.

"The walk was 107 miles altogether and took 10 days. We received lots of kindness and support throughout. I wanted to do this walk for Geraldine, whom I've known for 35 years. She used to be a social worker – a very good one – my manager, and is a dear friend to me. Geraldine's husband, son, and carer have done an incredible job caring for her with so much love. Thank you to friends, colleagues, family, and the people we met along the way. We've raised £3,000."

Sandi



Farhana and Mahmudul recently completed a mountain climb up Pen y Fan in memory of Farhana's mother, Farben, who sadly passed away last year after a long journey with MSA. They surpassed their fundraising target, raising an impressive £3,212.

Farhana and Mahmudul



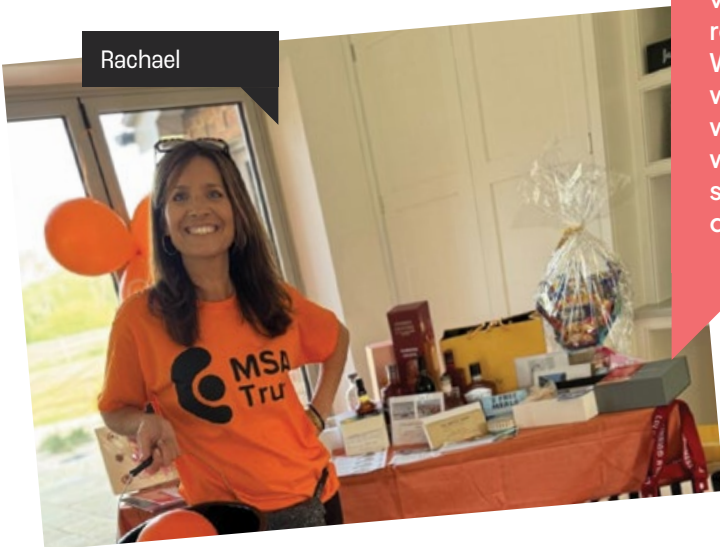
Thank you to Rachael and her family for organising a coffee morning in memory of their dad, George. The event was such a success that they are planning to make it an annual tradition.

“Our dad was diagnosed with MSA in February 2023, he died in November the same year, despite displaying symptoms for some years before. We quickly realised there is little known about this truly awful disease which is why diagnosis is so difficult. This year, on 27 April which would have been dad’s 75th birthday, we held a coffee morning and cake sale to try and raise vital funds for the MSA Trust. They really helped us when no one else did. With the help of our family and friends we raised an incredible £12,735.44 with gift aid! We hope this goes some way towards helping others who are suffering like our dad did and to one day find a cure”.

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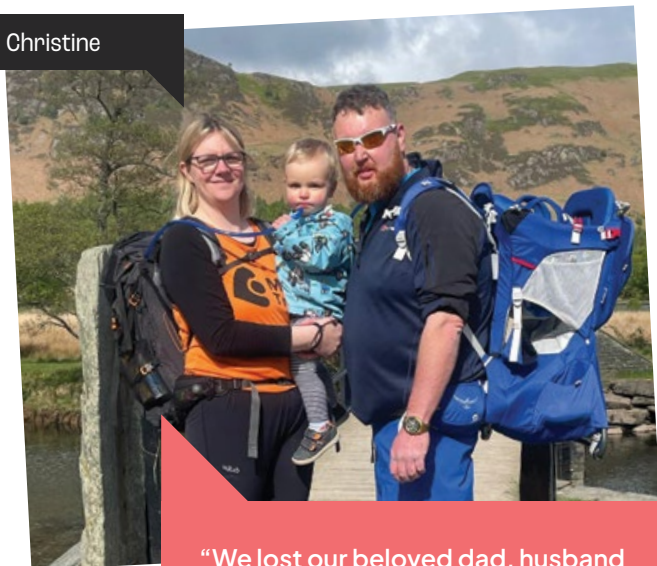
Rachael



Well done to Christine and her family, who took on a sponsored walk around Derwent Water in Keswick. Thank you for all your efforts.

A huge thank you to Nellie for taking on a skydive in support of her mum. She smashed her fundraising target and raised an amazing £900!

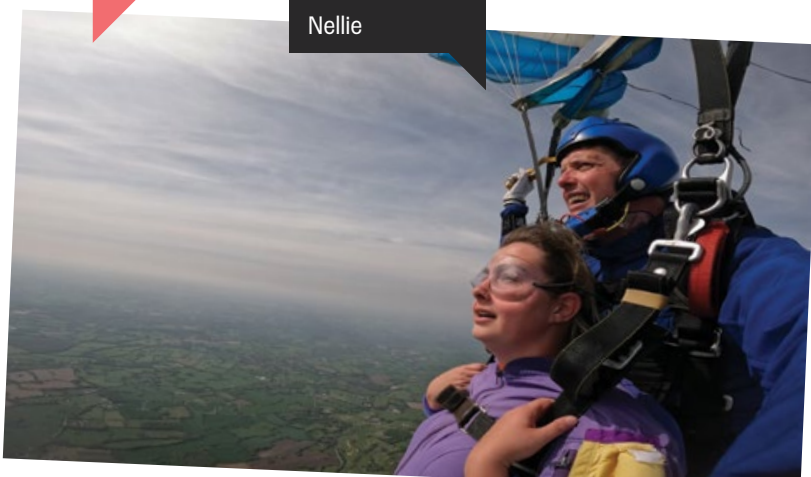
Christine



“We have grieved the woman she once was and LOVE her for the person she is today, still so selfless and powers through the day. As her daughter, I am so proud of her for facing her battle head-on!”

“We lost our beloved dad, husband and papa in October last year to MSA. Unfortunately, we didn’t get the chance to experience the help and support you offer, as things deteriorated rapidly over a short space of time. As a family, we felt we had to start raising awareness of such a rare and cruel disease. This is only the beginning of our fundraising events for MSA — and it certainly won’t be the last”.

Nellie



Monitoring Blood Pressure

Our MSA Nurse Specialist, Jill Lyons, explains more about blood pressure and how changes can affect people living with MSA.

Blood pressure changes can happen in people living with MSA. They often have blood pressure that drops when they stand up. This is called postural hypotension. They may have low blood pressure all of the time. People may also have episodes of high blood pressure.

It is a good idea to buy a blood pressure monitor to use at home. This can be helpful to give information to your health care team. It is important to buy a good quality

blood pressure monitor. You can buy them in your local chemist or online. The British and Irish Hypertension society have a list of validated machines - www.msamag.link/4jA62TW.

The monitor should have a cuff that goes round your upper arm, you should check this is the right size cuff. It will come with a medium size cuff, so you may need to order a small or large cuff depending on the size of your upper arm.

Blood pressure has two numbers.

The first number, called systolic blood pressure, measures the pressure in your blood vessels when your heart beats. The second number, called diastolic blood pressure, measures the pressure in your blood vessels when your heart rests between beats. If the measurement reads 120 systolic and 80 diastolic, this is written as 120/80 mmHg.

Some daily activities will affect the blood pressure reading, so it is best to **avoid** taking a reading if:

- you need to use the toilet
- you have just eaten a large meal
- you have drunk caffeine or been smoking within the last 30 minutes.

How to record your lying and standing blood pressure

- 1 Rest for five minutes before taking a recording.
- 2 Wear a short sleeved top or loose-fitting clothes to ensure easier access to your arm.
- 3 Use the same arm for each recording, whichever arm is easiest and most comfortable for you.
- 4 Your arm should be relaxed, not tense.
- 5 Make sure your arm is supported and is at the same level as your heart. You may need to rest your arm on a cushion.
- 6 Put the cuff around your upper arm and take a reading, write down your blood pressure and your pulse.
- 7 Stand and take another reading within the first minute.
- 8 Remain standing and take another reading at 3 minutes.

Your specialist team may want you to keep a blood pressure diary for a week at the same time of day or they may want recordings from different times of day. Do check with them exactly what they want. Make sure you note down your pulse reading as well. Also note any changes in your life in general, for example a change in your medications or if you are feeling unwell.

24-hour monitoring

Your doctor may want you to have 24-hour monitoring of your blood pressure. They will arrange for you to have a blood pressure machine fitted at your local hospital or at your GP surgery. It is a small device fitted to a belt around your body and attached to a cuff around your upper arm. You carry on with your normal daily activities and even sleep whilst the machine records your blood pressure. You will not be able to bath, shower or swim whilst the machine is in place. You will be asked to keep a diary of what you were doing throughout the day whilst the machine was taking recordings. You then remove the machine and return it to the hospital where they retrieve all the recordings and send the results to your doctor.

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TO LEARN
MORE



We have factsheets on monitoring blood pressure and a separate one on how to manage postural hypotension (blood pressure that drops on standing). You can download these from our website by scanning the QR code on the right hand side.

If you have any questions about anything you have read in this article or about blood pressure in general, please contact your MSA Health Care Specialist.

Our Policy and Campaigning Work

The MSA Trust's core services will always be information and support for people affected by MSA and research. However, we try to make sure the needs of our members are highlighted wherever this can improve provision. This involves working with a range of umbrella groups and other organisations who share a common interest with people affected by MSA.

One such organisation is the Neurological Alliance. We would like to thank all our members who completed their recent 'My Neuro Survey', which looked at a range of neurological conditions. We have now received the results specific to MSA and these will help us to identify the continuing issues that face people with MSA and how these compare with other neurological conditions. We will share these with you when we have the full picture.

Over the next few months, we will be working alongside other organisations to ensure Government proposals around disability benefit changes, and the longer-term review of social care, fully reflect the challenges our members face and want fixed. In order to make our voice heard, we will need you to share your personal experiences. Please see more in the box to your top right.

As most of you will be aware there has been significant recent activity regarding legislation connected to the provision of Assisted Dying for Terminally Ill people. The Trust has a neutral stance on this issue. We have engaged with other organisations supporting people with progressive neurological conditions as we feel that, whatever the outcome, people with MSA need to have proper options regarding their choices for the end of their lives. This includes effective palliative care, and we have submitted a response to the UK Government Palliative Care Commission to emphasise the need for improved services and resourcing.

BENEFITS ALERT

In March the UK government announced changes to disability benefits. The MSA Trust is very concerned that if implemented in the future, these may have a significant negative impact on many people living with MSA, their carers and families. We are working with other disability organisations in campaigning to stop these changes and ask for clarity on protections for those with a long-term high level of need.

We are asking our members to support our campaign by signing an Open Letter to the Work and Pensions Secretary, Liz Kendall, requesting the government to rethink their proposals.

Further details of our campaign can be found here: www.msamag.link/3Hyc2PB.

We regularly respond to NICE consultations relevant to people with MSA and always keep our eyes open for other consultations where our feedback can raise awareness of our members needs and MSA.

If you have an issue that you feel we should be addressing, please get in touch and we will be happy to discuss it with you.

Have you checked out our information materials recently?

SCAN ME FOR FACT SHEETS



We have a wealth of information materials on our website that can be easily downloaded. This includes guides, factsheets, information for children and young people and several webinars for you to browse in your own time.



In-depth Guides

www.msatrust.org.uk/guides

Guide to MSA

Introductory topics and frequently asked questions about the disease.

Carer's Guide

Tips to keep yourself healthy as you look after the person you care for.

Emotional Impact

Suggestions and ideas for looking after your emotional wellbeing.



Webinars

www.msatrust.org.uk/webinars

Introduction to MSA

For those newly diagnosed with MSA and their families.

Managing Blood Pressure

Overview of blood pressure issues, which are common in MSA. See page 16 for more.

Palliative Care in MSA

Planning for the future, with lots of very useful information about next steps for your care.



Factsheets

www.msatrust.org.uk/factsheets

We have over 30 factsheets on various topics about MSA.

We also provide information for Health and Social Care Professionals.

We are PIF accredited and have been closely involved with the PIF TICK from its inception five years ago. The PIF TICK sets standards for quality health information and is the only independently assessed quality mark for print and digital health information.



For a full list of all our publications please download our Publications List from our website here www.msatrust.org.uk/publications-list. We can post items to you if web access is a problem.

Fundraisers of the Year

We invited our members to nominate a fundraiser they felt was successful, impactful or innovative in 2024 – and the results are in!

We are so pleased to share with you our 2024 Fundraisers of the Year winners and nominees.



Lorraine Jackson

“Loz has completely changed her purpose in life to serving her husband (with MSA).”

Inspirational in instigating, supporting and participating in multiple fundraising events this year at the same time as enabling her husband Andy Jackson, who has advanced MSA, to undertake challenges that without her wouldn't be possible. Loz has used every possible avenue to fundraise. Her love and compassion for everything she touches has been the foundation for all the fundraising campaigns, which is reflected in the large sums of money raised. Lorraine raised awareness of MSA across her amazing network of colleagues, friends and family. Encouraging us to embrace life to the full and help others, at the same time as maintaining her demanding job as a surgeon in the NHS and caring for her husband Andy and her Mum.”



Joey Sheals

“Joey sadly lost his Granny when he was 6, due to MSA.”

He saw how horrible the disease was and how his Granny changed over the brief time when she was diagnosed to when she died. Joey decided that he wanted to raise money so walked 26.2 miles over the month of July to raise awareness of MSA and in memory of his Granny. We told the local press, and had an official completion ceremony at his Granny's old office. As Joey is only 7, he wanted it to be successful for his Granny, he said he didn't care if he only raised £1, he just wanted to make people aware of MSA.”



the Year

Annual Awards



Jamie & Susan McVie

“Jamie and Susan organised a charity fun day.

They got lots of local businesses from Jedburgh to donate prizes for an amazing raffle. Jamie and his work mates washed and valeted cars for money. The food truck donated half of their takings. They had a tombola and home baking for sale event including, a live band on the day with face painting and a bouncy castle for the kids. It was well attended with lots of people having never heard of MSA and again raised awareness to all these people. They managed to raise just under 2.5k, which for a small town was great.”



Deklin Gall

“He trained really hard day and night for weeks to enter into a charity boxing match.

He spread his funding page all over Facebook to family and friends far and wide and managed raised just over 2k winning him the golden glove for most raised just over the night of the boxing match. I would say the impact of his commitment and support certainly humbled his mum who has MSA and she was super proud as were all his family.”



We'd like to take this opportunity to thank everyone who nominated a fundraiser for these Awards (all quotes in this article are from the nominations received). Any funds raised by our supporters, no matter the amount, go a long way to supporting people affected by MSA every day.

The Fundraiser of the Year Awards will return in January 2026, so don't forget to nominate someone, or get involved yourself, by emailing fundraising@msatrust.org.uk to start your own fundraiser.



Supporting and Helping Each Other

Helpful tips from our MSA Community written by our Information and Services Team.

Podcasts can be an easy, free way to connect with expert information and communities.

The Movers and Shakers Podcast was suggested by a Support Group member, specifically their 'Tech Tips' episode. This looks at the technology that is available to help people with Parkinsonian conditions - www.msamag.link/4kOiyX4. The episode includes someone from Parkinson's UK Tech Guide. This is a great resource that assists people to make decisions about tech that may help them. They offer reviews based on the lived experience of people with Parkinson's and provide published scientific evidence where available - www.msamag.link/3SAfQSH.

Podcasts can be an easy, free way to connect with expert information & communities.

One podcast widely recommended in the hospice community is The Art of Dying Well - www.msamag.link/4jxyYMO. This award-winning UK podcast, supported by research from Queen Mary's University, aims to make death and dying something we can talk about openly without discomfort or fear.

If you are interested in learning more about research, The Lancet's 'Neurology In Conversation With' podcast recently featured neurologists Florian Krismer and Elizabeth Coon discussing their review paper on MSA, which was published in the Lancet in December. The discussion focused on the new diagnostic criteria for MSA and promising developments in research on biomarkers and treatments. You can listen to the episode here - www.msamag.link/4jCf5DD. If this is something that interests you, other episodes

cover a range of neurology and healthcare topics, giving you the chance for more in-depth learning.

For something a little more relaxing the BBC's Music and meditation podcast - www.msamag.link/43VNusx offers guided meditation. Their Slow Radio offers soothing immersive sounds which can be helpful when trying to sleep - www.msamag.link/45CtDQj.

At a recent Digital Support Group, the topic of the Beech Band came up. This is a wearable device that uses a tapping sensation to help with symptoms affecting speech, gait and anxiety. It shows promising signs of being able to manage some symptoms in Parkinson's disease.

The member who discovered the Band mentioned they saw it on an episode of 'The Secret life of Parkinsons' podcast www.msamag.link/43v1Obr.

The Beech Band is currently in development and therefore not proven to work with people with MSA. We will keep an eye on progress and feedback. For now, Parkinson's UK has some information on the band if you would like to learn more - www.msamag.link/4mMkEIE.

SCAN ME TO LEARN MORE



If you have a recommendation for podcasts or online resources that help you, MSA related or not, please let us know at support@msatrust.org.uk We will share your suggestions to help others in our community.

IN MEMORY

Our tribute to those loved ones recently lost to MSA.

*Carol Roper
Susan Smith
Nan Huang
Thelma Luxford
Robert Hunt
Rod Webb
Ivan Alexander
Farben Bibi
Jeffery Tobin
Janet Blair
Kelvin Webster
Mendi Kaur
Malcolm Kellet
Thomas Hair
John Bassett
Patricia Nash
David Rogers
Deborah Reynolds
Kate Macauley
Helen Younger
Bill Meer
Julie Francis
Stephen Drew
Jim Woods
Maureen Barker
Malcolm Stephenson
Brian Hodgson
James Gibson*

*Brian Dougherty
Marie Travers
Pamela Smith
Graham Wilson
Jonathan Stuart
Brian Wilson-Copp
Gaynor Matthews
Arthur Bellringer
Ruth Isaacs
Jean Schiemann
Nigel Platt
Ian Betteridge
Susan Jarrald
Joy Alcock
Patricia Eldred
Margaret Girdwood
Angela Wraight
Steven Dodgson
Robert Jones
Jasvir Singh
Anthony Walter
Aine Graham
Nigel Phizacklea
Jonathan Steel
Rosemarie Mercer
John Newman
Martin Pullan*

VOLUNTEER'S WEEK

2025

To all our volunteers, past, present and future, THANK YOU!

Every year in June, charities across the UK celebrate and thank their volunteers for the contribution they make. The MSA Trust is lucky to have a group of over 100 skilled and dedicated volunteers. It can be difficult to find time and resources to volunteer, especially for people whose lives have been impacted by MSA. We want to say a huge thank you for everything our volunteers do to build our strong, compassionate MSA Community.

We have over 100 MSA Trust volunteers including awareness raisers, advisory group members, ambassadors and Trustees.

One Office Volunteer gives 200 hours each year, producing the packs that go to members and professionals.

Every year, over 25 Event Volunteers gather to cheer on runners and make sure our events are fun and friendly.

6 User Information Reviewers – giving their time to make sure our guides and factsheets are useful and accessible.

11 Trustees donating their expertise and professional skills to grow the Trust and make sure we provide the highest quality service to people affected by MSA.

Facilitating meetings, booking venues, baking cakes, sharing lived experience – 20 Support Group Volunteers make sure our group meetings are warm and welcoming places for everyone affected by MSA.

Sarah's Wood Volunteers gather twice a year to plant trees and welcome visitors to our Summer Social, giving their all to make these days extra special.

“ I am always amazed by how generous and committed our volunteers are. Whether it's helping at Support Groups and events, reviewing our information and new initiatives, or just helping with one-offs, the support they give is vital. We simply couldn't do without them! We are lucky to have them and they have our sincere thanks. ”

Andy, Chief Executive