msa *news*

MSA Trust Members Magazine | Issue 71 | October 2024

Lighting up our Research Pathway

PLANNING AHEAD: YOUR QUESTIONS ANSWERED - PAGE 4

FUNDRAISING REGULATOR

CHIEF EXECUTIVE OFFICERS:
Karen Walker
Andy Barrick

MSA NEWS EDITORS:
Emma Rushton
Andy Barrick

ALL ENQUIRIES TO OUR NEW ADDRESS:
Multiple System Atrophy Trust
128 B Business Design Centre
52 Upper Street
London N1 0QH
Tel: 0333 323 4591
www.msatrust.org.uk

Registered Charity Number 1137652. Scottish Charity Number SC044635. Company Number 7302036.
Designed by Base Media www.base-media.co.uk. Printed by INQ Design 020 7737 5775.

Welcome to Issue 71

Hello and welcome to Issue 71 of your MSA News magazine.

First, an update on some changes in our office. Nicole Adam, our Senior Services and Volunteering Officer, is going on maternity leave in November. We wish Nicole and family well and look forward to her return later next year. In the meantime, we are pleased to welcome Kirsten Olufsen to our team who will be covering Nicole's role.

In this edition we have a featured article on page 4 from the organisation Compassion in Dying, about planning for the future and information about some new webinar sessions. We have articles from our MSA Health Care Professionals about equipment to improve sleep quality and also finding the right wheelchair, both of which are topics we get asked about a lot.

*Finally, we are happy to say that our Christmas shop is now open! You can find out what's available for purchase by going to our website (**www.msatrust.org.uk/christmas**) or looking at pages 19 and 20.*

*We hope you find this edition of your magazine useful and engaging, and as always if you have any feedback please get in touch or complete our survey here - **https://forms.office.com/e/skrE05Szq5**.*

Emma and Andy

NEWS ROUNDUP

Our New Address

We have recently moved to a new office. Please note our new address and use this for all correspondence moving forwards.

MSA Trust
128 B Business Design Centre
52 Upper Street
London
N1 0QH

Our email addresses and telephone numbers have not changed. If you need any support please contact us on 0333 323 4591 or at **support@msatrust.org.uk**.

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2023-24 Impact Report

The Trust had some significant milestones in the 2023-24 financial year; reaching more members than ever before, adding a new member to our Social Welfare Specialist Team to respond to an increased demand for financial support, launching a pilot looking at emotional support for people living with MSA and expanding the Trust's presence through several impactful events across the UK and Ireland. These, and other achievements, are detailed in our Impact Report which is available online - **www.msatrust.org.uk/about-us/annual-review**.

msa *news*

Multiple System Atrophy Trust

Welcome to our Impact Report for 2023 - 2024

The Great North Run 2024

On September 9th, 14 members of Team MSAT participated in the Great North Run, taking on the iconic half marathon to support those affected by MSA. It was a fantastic day with families and friends, along with our Fundraising Team, cheering on our runners. A big thank you to all our participants for their dedication and support, raising over £10,000 for the Trust.

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My Neuro Survey

The MSA Trust conducts our own Needs Surveys every few years which have proven invaluable in our advocacy and policy work.

The Neurological Alliance (which we are members of) is currently conducting a survey of all people affected by neurological conditions, including people living with MSA, and their carers.

We would hope that as many of our members complete these surveys as is possible, as this gives us a much better understanding of how support for people with MSA compares to other conditions and enables us to find common ground with others to improve services.

If you are in the UK please find the survey here - **https://revealingreality.welcomesyourfeedback.net/s/yl8qk**.

For those in the Republic of Ireland please find the survey here - **https://revealingreality.welcomesyourfeedback.net/s/mae0l0**.

The survey is open now and will close on 15th November 2024. It should take about 20 minutes to complete, and we very much hope all our members will take part.

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Professor Kailash Bhatia

We would like to congratulate our Chair of the Trustee Board, Professor Kailash Bhatia who has been elected as President-elect of the prestigious European Academy of Neurology at their annual Congress held in Helsinki in July. msa *news*

It's Never too Early to Plan Ahead

My name is Sarah Malik. I'm a nurse by background and I've spent the last few years leading Compassion in Dying's nurse-led information line service. Compassion in Dying is a national charity that helps people to prepare for the end of life. We want people to be in control of their end-of-life decisions because there is no-one better to make them. We support people to make informed choices, start honest conversations about death and dying with loved ones, and record and revisit their wishes whenever they want to. Whilst for many of us it's not an easy subject to think about, let alone talk about, it's incredibly important.

What I've learnt from years leading Compassion in Dying's nurse-led helpline:

Most of us would have feelings about the treatment and care we would want at the end of our lives. These may be about remaining in our own home or the treatments or care we would or would not want, such as potentially wanting to avoid cardiopulmonary resuscitation (CPR). Our experience shows that it is never too early to plan ahead and record such wishes. People tell us that doing so gives peace of mind to them and their family and friends.

We know that when these wishes are recorded and respected it can also reduce unwanted medical interventions and unnecessary hospital admissions at the end of life. For many, knowing they have some control and the ability to die as they have lived – on their own terms – enables people to live well now.

However, too often these important conversations are missed, meaning too few of us are considering these wishes and making sure what we want is documented and known about when it matters most.

> ***90% of people would want to make the final decision about medical treatment for themselves or would want a friend or family member to make those decisions. But less than 10% have recorded these wishes in advance.***
>
> ***YouGov 2024***

I speak to people every day who are facing the consequences of trying to advocate for a loved one who didn't document their wishes whilst they could. They tell me it's difficult to see a loved one receive treatment they know they wouldn't have wanted.

What can you do to plan ahead?

There are a number of ways you can plan ahead to help you and your loved ones ensure your wishes are known about. These can be followed if you become so unwell you can't say these things for yourself anymore:

- Lasting power of attorney (LPA) for health and welfare is a way to give those close to you the legal authority to step in and make decisions about your treatment and care when you no longer can
- A living will (advance decision) is a form which lets you refuse any medical treatments that you do not want to be given in the future. They would only be used if you lack mental capacity to make or communicate a decision for yourself.

You can read more about planning ahead for your treatment and care by visiting the Compassion in Dying website - **www.compassionindying.org.uk**. You can also call our nurse-led information line on 0800 999 2434 between Monday and Thursday, 11am to 3pm.

The MSA Trust also has a comprehensive resource on planning for the future which covers many elements of living with MSA. This can be accessed via the MSA Trust website here - **www.msatrust.org.uk/support-for-you/for-people-affected-by-msa/planning-for-the-future**.

Upcoming events:

To help you understand how to plan for the future I'm partnering with the team at the MSA Trust to provide some planning ahead webinars. These aim to explain your options for documenting your end of life wishes and set the record straight by dispelling some myths around what is, and isn't, needed when planning for this important time.

I'd really love for you to join me and some of the MSA Trust team on the **14th November 2024** for a more detailed discussion about:

- how decisions are made at the end of life
- why you should plan ahead for this time
- the free and legally binding documents you can complete to stay in control.

We are hoping to run these webinars twice a year for people living with MSA and their loved ones. msa *news*

If you would like to attaend this first webinar please email the MSA Trust at **support@msatrust.org.uk** or call 0333 323 4591.

Improving Sleep Quality

with Continuous Positive Airway Pressure (CPAP) Machines

Sleep apnoea is defined as frequent short episodes of stopping breathing during sleep. Alongside these episodes may be periods of ineffective shallow breathing. Our MSA Nurse Specialist, Katie Rigg, looks at sleep apnoea in MSA and how CPAP machines can help with this.

Obstructive sleep apnoea occurs when the upper airway becomes partially blocked. This may happen because of an enlarged or floppy soft palate (back of the roof of the mouth) or poor muscle tone of the tongue, allowing either or both of them to collapse into the top of the airway. This particularly happens when someone is asleep in certain positions. Changes in the nerve messaging to the muscles in the upper airway, tongue, soft palate and vocal cords can also cause sleep apnoea.

The autonomic nervous system stimulates the nerve messaging that controls our breathing and triggers the movement of the vocal cords, diaphragm and ribs that all contribute to being able to breathe well. We know the autonomic nervous system in a person with MSA does not work as well as it should, so this can make you more susceptible to developing sleep apnoea.

What signs could indicate you have sleep apnoea?

A person with sleep apnoea may not be aware of the signs that suggest their breathing is altered when asleep. It is often a partner or family member that will notice the changes such as:

- **Snoring more than you used to and more loudly and irregularly**
- **Having vivid dreams that cause you to shout and act out whilst you are asleep. This behaviour is known as Rapid Eye Movement (REM) sleep disorder**
- **More than usual daytime fatigue and morning headaches**
- **An uneven breathing pattern when asleep for example having periods of shallow breathing then pausing for a while and then a sudden deeper breath.**

What should you do if you think you have sleep apnoea?

If you are experiencing any of these symptoms discuss this with your GP or Consultant as they may refer you for a sleep study. You may be admitted overnight to monitor your sleep, breathing pattern and how well you are picking up oxygen. The sleep study team will give you an oxygen saturation monitor and show you how to use it at home overnight.

The saturation monitor has a clip that attaches to your finger. The clip lead attaches to a watch strap monitor and records your oxygen levels throughout the night. The monitor and clip is then returned to the centre for the team to interpret the results. They can determine if you would benefit from using a CPAP machine overnight.

In some areas you may be given a chest monitor, nasal monitor and finger probe, you will be shown by the centre how to attach these.

What is a CPAP machine?

A CPAP machine is a Continuous Positive Airway Pressure machine that helps keep the airway open. This encourages deeper breathing, improving the amount of oxygen you can get from the air. It can reduce daytime fatigue and headaches as well as help you get a better quality of sleep with less restlessness.

The CPAP machine will be provided by the hospital and the team there will set it up so the correct pressures for you are preprogrammed into the machine. The pressure provided by the machine helps get air from the environment past any resistance caused by the soft palate or vocal cords and creates deeper breathing.

The machine sits on your bedside table plugged into the mains electricity and switches on with an on/off press button. You will be fitted with a mask, similar to an oxygen mask, with a soft silicone seal and straps to keep it in place as securely as possible. There are a number of different masks so if the one you are given does not suit you or is not comfortable, then do ask the centre about trying a different type.

It may take you a while to get used to using the CPAP machine and the sensation of the air pressure. Initially it may be best to try it for a couple of hours each night and gradually build up your tolerance of the sensation and wearing the mask. The more of the night you are able to use it, the greater the benefit will be.

Most people do not need to use CPAP through the day as when we are awake and moving around or just sitting in different positions our ribs and diaphragm muscles are able to move more easily and assist us to breathe better. Also, if we feel a bit short of breath we will consciously make the effort to breathe more deeply when awake. msa *news*

If you have any further questions about sleep apnoea, CPAP machines or sleep issues in general, do speak to your GP, Specialist or contact our MSA Health Care Specialists.

In Memory

Andrew Cruickshank
Graham Jones
Malcolm Wightman
Heather Hunt
Deborah Lees
Sarita Sharma
Kathleen Telfer
Kieron Tatlock
Mark Hudson
Karen Guest
Sarah Humphreys
Maureen Staniforth
Robert Silcox
Peter Mottram
Dawn Dawe
Judith Philpott
Janice Smith
John Pilcher
John McGinty
Rona Elmer
Sylvia Rankin
Frederick Hattingh
Paul Charlton
Natalie Eaton
Diane McNeill
Anne Turvey
Christine Geary
Caroline Winchester
Elaine Eyres
Joe Cassidy
Susan Rowlands
David Green
Sally Hart
Amalia Michaelides
Patricia Birse
Kenneth Clarke
Simon Morgan
Stephen Bishop
Ken Bailey
Brenda Doughty
Elisabeth Pemberton
Alan Riby
Richard Knightbridge
Stephen Nixon
Salahuddin Qureshi
David Beaumont
Susan Lackie
Fred Kelly
John Day
John Pumfrey
Julie Robinson
Linda Jones
Malcolm Allan
Anthony Gaudion
Judith Wilde
Brian Coutts

Paying tribute to loved ones

Many of us will have experienced funeral attendance at some stage and we know that these events can be very difficult, especially if a loved one has been lost to MSA.

Some choose to pay tribute by supporting the Trust with donations in lieu of flowers at the service, and such generosity will always be gratefully received. We can facilitate this fundraising by sending our donation envelopes (which has a gift aid declaration for those donations that qualify for the gift aid scheme), our cardboard collection boxes or collection tins. For attendees who wish to donate online, we can provide QR codes that direct them to our website for online donations. We can also provide literature on MSA and our orange MSA ribbons that family members and friends can wear to raise awareness of this rare condition. Please contact the Fundraising Team at **fundraising@msatrust.org.uk** if you wish to request these materials.

After the service, most funeral houses offer to collate the donations and will forward them to the Trust. We are happy to liaise with the Funeral Directors directly to facilitate this. It is a good idea to discuss these arrangements before the service.

All memoriam collections, small or large, will always make a difference for those who are trying to navigate the stress, anxiety and uncertainty that comes from living with this rare and little-understood disease. Thank you in advance for your support. msa *news*

Theravance Biopharma is researching the investigational drug, ampreloxetine, a once-daily tablet in development for treating symptomatic neurogenic orthostatic hypotension (nOH) in people with multiple system atrophy (MSA).

Symptomatic nOH is common in MSA, with symptoms such as dizziness, light-headedness, and feeling faint affecting an estimated 4 out of 5 MSA patients. The research study is a Phase 3 clinical trial (CYPRESS) and is being conducted at clinical study sites worldwide, including in the United Kingdom.

Key eligibility criteria for the CYPRESS trial:

- **at least 30 years of age**
- **symptoms related to nOH**
- **a diagnosis of MSA**

Additional criteria will need to be met to qualify and a study doctor will explain these.

During CYPRESS's 20-week treatment period, all participants receive the investigational drug during the study's 12-week open-label period and then receive either placebo or the investigational drug during an 8-week double-blinded period. This initial 20-week phase is followed by an optional 2-year long-term extension in which all participants will receive the investigational drug.

The purpose of this study is to look at whether an investigational drug works and how safe it is when taken over several months to treat symptomatic neurogenic orthostatic hypotension (symptomatic nOH) in people with multiple system atrophy (MSA). The primary assessments will determine whether the investigational drug can improve the symptoms of nOH.

To learn more about the CYPRESS trial, please visit www.clinicaltrials.gov/study/NCT05696717.

Lighting up our Research Pathway

The Scientific Advisory Panel (SAP) at the MSA Trust have awarded funding for five new research projects, which will begin in Autumn 2024. Read a summary of these here...

1

Professor Nigel Hoggard, Professor of Neuroradiology at the University of Sheffield, will be using MRI scanning to try to measure mitochondrial dysfunction in the brains of people with MSA. It is known that too much of the protein alpha-synuclein accumulates in glial cells in the brains of people with MSA. This project aims to see whether changes in the mitochondria (known as 'power packs' of the cell) in the glial cells can be seen prior to the alpha synuclein accumulating. This is achieved by measuring levels of phosphorus in cells using MRI techniques, and for participants it will be like having any other MRI brain scan.

2

Professor Jalesh Panicker, Professor of Uro-Neurology at University College London will be undertaking a study to determine if MRI scans of the base of the spine can help to predict numbers of people with a condition called Pure Autonomic Failure (PAF) that will develop MSA in the future. It is hoped this may contribute to the earlier diagnosis of MSA.

3

Dr Viorica Chelban, from the Institute of Neurology at University College London is building on her previous research, to identify a biomarker for MSA. A biomarker for example, could be a blood test that definitely and objectively confirms a diagnosis of MSA. She is working with other researchers around the world to continue work on new methods such as alpha-synuclein seed amplification assay to detect misfolded proteins seen in MSA in a lab-based test. They hope to combine information already gathered and improve upon this to better understand MSA and how and why it progresses. A second stream of this project will look to further understand the genetics of MSA, using Genome Wide Association Study (GWAS) to identify why someone might get MSA and why another person may not. The aim is to combine the biomarker and genetic information gathered and use this to provide individualised treatment to people with MSA in the future.

4

Dr Maria Xilouri, Assistant Professor at the Biomedical Research Foundation in Athens, is undertaking research targeting the autophagy lysosome pathway (ALP) in MSA. The ALP is a means by which misfolded proteins are removed by the body. Professor Xilouri's research aims to determine if dysfunction of the ALP is a contributing factor to the development of MSA by investigating whether there are any differences in ALP shown in cells from people with MSA and non-MSA controls.

5

Finally, Dr Conceição Bettencourt, from UCL Queen Square Institute of Neurology, has summarised her research project in a blog we shared in early September. Here is a summary:

Understanding the role of abnormal DNA tags, iron and lipids in MSA

"Although we have known for a while that lumps of a sticky protein, called alpha-synuclein, form in MSA brains, mostly in cells called oligodendrocytes, the reasons for why this leads to death of nerve cells in the brain are not fully understood. DNA methylation is a critical chemical tag added to the DNA, which provides cells with detailed instructions on when to switch genes on and off, so that cells, such as oligodendrocytes and nerve cells, function properly and remain healthy. Building on our previous findings, our recent MSA Trust funded grant will allow us to investigate oligodendrocyte vulnerability further in MSA. For this, we will study brain tissue DNA methylation in detail as well as other molecules that are important for oligodendrocytes, including iron and lipids. We hope this may open new avenues for therapeutic development and explore whether they could provide good indicators of disease progression and help with early diagnosis in MSA". We will bring you further blogs and updates from each project over the coming months.

The MSA Trust has previously funded two clinical research fellowships. The aim of these three-year fellowships is to increase research into MSA and develop the clinicians of the future. Previous Fellows, Dr Viorica Chelban and Dr Yee Yen Goh, have undertaken both clinical and research work into MSA and have contributed to the development of new MSA knowledge. We are now advertising for a third fellowship, in conjunction with the Association of British Neurologists. **The Myra Morris MSA ABN Clinical Research Training Fellowship**, named after a member of the MSA Trust following a generous donation from her family, is currently open to applications. Following on from the success of the first and second annual MSA Research Symposium, a third symposium is being planned for February 2025. The symposium brings together MSA researchers from all over the world, giving them a chance to present their research findings to colleagues, and providing an opportunity for the MSA research community to network and collaborate.

Choosing the Right Wheelchair For You

Many people living with MSA find themselves needing to use a wheelchair as their condition progresses. While the thought of transitioning to a wheelchair can be daunting, it is important to recognise that a wheelchair can increase freedom to get out and about and improve your quality of life. Here, our MSA Health Care Specialist, Demelza Stuart, discusses some useful points for you to consider.


OUR MEMBER JONATHAN IN HIS NEW WHEELCHAIR

Starting your wheelchair assessment:

There are many different types and features of wheelchairs. Getting the right wheelchair for your individual needs is vital. In the first instance, your Occupational Therapist (OT) or GP should be able to refer you to your local Wheelchair Service. They will assess you and recommend the best type of wheelchair for you.

The procedure and timescale for accessing a wheelchair varies across the UK and Ireland. There are long waiting lists in some areas. **Therefore, it's crucial to think ahead.**

Things that will need to be considered during your initial assessment for wheelchair provision include:

- **Size of wheelchair needed. The seat depth and width will be measured to ensure a good fit for you.**
- **How will you move around in the chair? Can you manage to self-propel or will a carer be able to push you? Could you use the controls on an electric chair?**
- **Need for a recline function (often called 'tilt in space'). This design helps to redistribute pressure and can also be useful if you suffer from high or low blood pressure.**
- **How will you transfer in and out of the wheelchair?**
- **Will you need to use the wheelchair indoors and outdoors?**
- **Is your home environment suitable for wheelchair use, or will adaptations be needed?**

Funding:

Wheelchairs can be expensive. However, there are various funding options available.

In the UK, NHS Wheelchair Services will assess and provide a wheelchair. Depending on your circumstances you may need to contribute towards the cost. Some wheelchair services will give you a non-taxable voucher that you can put towards buying your own wheelchair. This can allow you more choice in the type of wheelchair provided.

Anyone getting the enhanced-rate mobility component of Personal Independence Payment (PIP) can take part in the Motability Scheme, which allows people to use their benefits to pay for an electric wheelchair.

In the Republic of Ireland, the Health Service Executive (HSE) provides wheelchairs to eligible individuals. The Irish Wheelchair Association or Enable Ireland can also potentially provide support.

Always speak to a healthcare professional to find out about funding options in your area.

Features:

No two people with MSA have exactly the same needs and that means no single wheelchair is perfect for everyone.

Manual wheelchairs can be a good option for people who still have good upper body strength. However, an electric wheelchair can provide greater independence by reducing the physical effort required for movement. It is also possible to attach a power pack to most manual wheelchairs. This can be useful if your carer has difficulty pushing a manual chair.

Wheelchairs can be customised with various features, including reclining options, adjustable footrests, specialized seating cushions and back supports. These modifications are important for people with MSA as they can help manage symptoms such as muscle rigidity, discomfort and pressure sores. If you use a communication aid, a removable arm can be added to hold this for you.

Portability and transport should also be a factor in choosing a wheelchair. Some models are lightweight and foldable, making them easier to transport in a car. Others are more robust and offer better support for long-term use. You may also need to consider whether you need a wheelchair adapted vehicle.

Home adaptations:

It is essential to think about your home environment where the wheelchair will be used. Ramps may be needed for wheelchair access and doors may need to be widened. Having a bathroom that can accommodate a wheelchair will be very important. Storage and charging points need to be considered. If your home is on more than one floor, a lift installation may also be an option. An Occupational Therapist will advise on any adaptations needed. **These adaptations will often need to be completed before an electric wheelchair can be provided, which is another reason why you should think about this as early as possible.**

Top tips:

- **Have discussions about wheelchair use early, as it may take a considerable amount of time to get you the right chair and any home adaptations**
- **Living with MSA means that your condition will change over time. Discuss long term options with your OT**
- **A manual chair may be useful in the early stages of MSA. An electric chair can provide more independence, as well as better postural support**
- **If you buy privately, you do not have to pay VAT. However, self-purchase means you are responsible for all repairs and maintenance**
- **It is always best to have an assessment with an OT, even if you wish to purchase privately, to ensure you are buying the right size and features for your individual needs.**

If you would like more information or support on your individual circumstances, contact your MSA Health Care Specialist.

Hiking for the MSA Trust

This summer, our community embraced walking, trekking and hiking to support the MSA Trust. Whether conquering Snowdon, trekking up Croagh Patrick, or tackling lesser-known routes, we are incredibly grateful to every fundraiser who completed their challenge and raised crucial funds to support people with MSA.

VICKY AND FAMILY

"We knew we wanted to raise awareness of MSA and gather vital funds to support the cause. So, when the opportunity arose to hike the highest mountain in Wales in honour of the woman who has always been my Welsh rock (she was from Cardiff), we couldn't pass it up. My 10-year-old daughter, Rosie, made us all incredibly proud, as did our Cockapoo, Boo."

Vicky and her family raised over £2,000 hiking Snowdon, and we would like to extend a huge thank you for all their support.

SHONA AND FAMILY

Shona Brady and her family recently climbed Croagh Patrick in County Mayo, in memory of Eugene Brady. They undertook this challenge to celebrate what would have been Eugene's 60th birthday, fulfilling a goal he had set for himself and honouring his memory.

"The fundraiser was a tremendous success and opened our eyes to the incredible support and generosity from so many people. We are thrilled to share that we raised a total of €5,531!"

JULIE AND PAUL WITH FAMILY AND FRIENDS

"My daughter, our family, and friends organised a walk to raise money in honour of my husband, Paul, who is fighting this horrible disease. We planned a 10k route for the more seasoned walkers and a 5k for everyone else. We were very lucky, as it was a fantastic day with sunshine from start to finish. It was a wonderful time, filled with conversation and enjoyment, and we raised an incredible £4,500."

Thank you to **Julie and Paul** for organising such a successful sponsored walk along Seaburn promenade in Sunderland, and for everything you do to support the Trust.

Tee off for the Trust

"Helen and I come from a hospitality background and were privileged to live and work together in a Sports and Social Club for many years. We were also heavily involved in the Round Table family during that time, so charity fundraising was very much in our blood.

Helen was diagnosed with breast cancer in 2013 and due to the support of Macmillan she organised a coffee morning and a tombola at the Club. This event became an annual tradition, running for 10 years and raising over £30,000. Helen was later diagnosed with MSA and sadly died in November last year. In her memory, her husband Peter decided to organise a golf day

The MSA golf day on May 15th of this year at Moseley Golf Club (pictured) was very well supported, with 20 teams of four participating in a shotgun start. I reached out to various contacts for support, and a network of friends helped ensure the smooth running of the day, including a tombola that raised £680. The auction raised £1,800, with prizes including a commissioned painting of golfer Scottie Scheffler by Mark Scorer and a meal for eight, cooked by myself and my daughter's partner, both of us trained chefs. The food for the meal was provided by local businesses. This also led to a player commissioning me to cater his larger birthday party, which raised £500 with support from his cycling group.

A grand total of over £4,000 was raised for the MSA Trust. The feedback from the day was fantastic, with many suggesting it should become an annual event. Therefore, the Helen Hunt Golf Day is already in the diary for May 14th 2025, in aid of the MSA Trust".

Thank you, Peter, for all of your efforts organising this successful golf day in memory of Helen.

msa news

Want to organise a golf day or get your club involved?

Golf days are among our most effective fundraisers, generating significant funds for the Trust. Start by securing a suitable venue - asking your local club to host is crucial for a successful event. Choose a date that avoids major events, and maximise fundraising by hosting a raffle, auction or black-tie dinner afterwards. Secure local business sponsors and promote your event through local media, golfing publications, and by distributing posters and leaflets in the area.

Every detail helps maximise the funds raised for those affected by MSA. Please contact **fundraising@msatrust.org.uk** for guidance and support to ensure your event's success. msa news

NHS Continuing Healthcare

In England and Wales, if you have complex care needs you may be eligible for NHS funded care known as NHS Continuing Healthcare (CHC). Here our Social Welfare Specialists outline what NHS CHC is and how to apply.

What is NHS CHC?

NHS 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 healthcare 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.

CHC is provided free of charge: there is no means test and no financial contribution towards the care package is made by the person receiving care, or their family. Care can be provided within different settings including your own home or a care home.

Primary Healthcare 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.

The CHC checklist and assessment focus on the following 'domains' to determine whether you have a primary healthcare need, taking into consideration the nature, intensity, complexity and unpredictability of your care needs.

CHC Assessment Domains

Breathing	**Nutrition**	**Continence**
Skin integrity	**Mobility**	**Communication**
Psychological & emotional needs	**Cognition**	**Behaviour**
Drug therapies & medication	**Altered states of consciousness**	**Other significant care needs**

The Process

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, this is 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. You should be consulted at every stage.

Preparing for a CHC Assessment

Our Continuing Healthcare factsheet includes helpful information and tips to help you prepare for your CHC assessment. You can access a copy here **www.msatrust.org.uk/support-for-you/factsheets** or call us on 0333 323 4591.

Fast Track

A 'fast track' CHC funding assessment may be appropriate if your condition is rapidly deteriorating and you may be nearing the end of your life. The fast track process can be completed by an 'appropriate clinician' - usually a doctor or nurse who sees you regularly. They will complete a form which replaces the need for a CHC checklist and assessment. An appropriate care package can be put in place as soon as possible, usually within 48 hours.

Appealing a decision

If the assessment determines that you are not eligible for CHC funding, you should be notified in writing. The letter should also tell you how to complain or appeal. Our Social Welfare Specialists are happy to talk with you about all aspects of the CHC process, however the MSA Trust does not have the expertise to support CHC appeals. You may like to contact Beacon CHC, who offer up to 90 minutes free advice, on 0345 548 0300 (**www.beaconchc.co.uk**).

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.careinfoscotland.scot/topics/how-to-get-social-care-support/hospital-based-complex-clinical-care**.

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. msa *news*

> ***"The process was very simple and empathetic. The Assessor, who came to the house was superb. She had researched MSA and ensured Jane was very much part of the process. Key learning is do your research."***
>
> Peter and Jane, Leicestershire

Frequently Asked Questions...

Does a diagnosis of MSA mean I'm entitled to CHC funding?

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 healthcare need' and the individual's specific health needs, not the diagnosis.

How do I apply?

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. Alternatively, you can contact your local CHC funding department.

How can I contact my local CHC funding department?

In England, local Integrated Care Boards (ICBs) are responsible for CHC. You can find your local ICB by visiting - **www.nhs.uk/nhs-services/find-your-local-integrated-care-board**.
In Wales, CHC funding is the responsibility of Local Health Boards (LHBs) - **www.gov.wales/nhs-wales-health-boards-and-trusts**.

Is CHC funding paid indefinitely?

A review will be carried out after the first three months, and then usually every 12 months to ensure the care plan still meets your needs. If your needs have changed, the review will also consider whether you are still eligible for CHC.

Supporting and Helping Each Other

Our wonderful members consistently share their valuable tips and insights on living with MSA. Here, Nicole Adam, Senior Services and Volunteering Officer, rounds up some tips from the last few months...

We know that, even though ideally everyone with MSA would have regular access to a Speech and Language Therapist (SALT or SLT), waitlists can mean this is not always possible. When managing MSA a SALT plays a critical role in managing the communication and swallowing challenges that can arise with MSA. There are things you can do in the comfort of your own home even without a Speech Therapist. One of our members recommended the YouTube channel Speech Therapy Practice which can be found either by searching YouTube or by clicking here - **www.youtube.com/@SpeechTherapyPractice**. They have a wide variety of exercises you can do along with the videos. **Do consult with an SLT before trying these on your own.**

Another recommendation from a member is the YourStride personal watch alarm which can be found here - **www.yourstride.com/personal-alarm-watch**. We often get asked for recommendations for personal alarms and know many of our members find them useful for peace of mind. Some personal alarms are worn around the neck. If this does not work for you, a watch alarm might be something to consider. Since a watch is typically worn all day, the alarm is always within reach. This model has an automatic fall sensor (which is available at an additional cost). It has other useful features such as medication reminders and it can also measure heart rate and blood pressure. The watch costs £59.99 initially and there is a monthly charge of £17.99 for additional features (much like with most monitored alarm systems) so you need to see if this makes financial sense for you and your family.

And finally, one of my favourite tips to come from one of our monthly online coffee mornings uses a balloon. One of our couples discussed how they used a regular blow-up balloon – the kind used at birthday parties – as a way to make chair exercises a bit more fun. Simply batting the balloon back and forth encouraged a range of movement and was so much fun even the grandchildren got involved to help out.

We are continuously impressed with the imagination and enthusiasm of our members. msa *news*

If you have attended any of our in-person or online meetings we would love it if you could share your feedback by filling out our Support Group survey - **https://forms.office.com/e/Kn1xyZWsmM**.

Our members are at the heart of everything we do and your feedback will help us further develop our Support Group services.

Let the Festive Fun Begin...

We are excited to launch our 2024 Christmas Shop, featuring Christmas cards, stocking fillers, gift wrap and pin badges to share with your family and friends this festive period.

Every purchase helps people living with MSA by enabling the Trust to fund vital services and bringing us a step closer to finding the cause and ultimately the cure for MSA.

Thank you for choosing to support the MSA Trust this Christmas. msa *news*

£5

Stocking Filler

A delightful stocking filler consisting of MSA Trust goodies – two pens, two wristbands and a pin badge.

£2.50

Pin Badge

Wear your badge with pride and help spread awareness about Multiple System Atrophy and the MSA Trust.

£3

Gift Wrap

4 Sheets (2 of each design), 8 tags (4 of each design)

Flat size: 50 x 69 cm

More items inside

A

B

£5 Christmas Cards

150mm x 150mm

Each of our packs have 10 cards with envelopes. Messages read:

Card A: *Wishing you a Merry Christmas and Happy New Year*

Cards B & C: *Season's Greetings*

Card D: *Happy Christmas*

C

D

Please include payment to cover postage costs according to the number of items ordered:

No. of items	1-2	3 - 5	6-10
Postage	£1.50	£3.50	£5.50

To order, visit: www.msatrust.org.uk/christmas, call us on 0333 323 4591 or return the slip below with a cheque payable to 'MSA Trust'.

Please get in touch with the Fundraising Team if ordering more than 10 items or when ordering from outside the UK. Email **fundraising@msatrust.org.uk** or call **0333 323 4591**. Please note we send our merchandise using Royal Mail 2nd Class post but during the busy season it can take up to five working days for items to arrive.

All orders and payment must be received by 9th December 2024.

Name:..

Address:..

Telephone:.. Email:...

Christmas Cards: A – 12 Days of Christmas (Qty)...... B – The Family Snow (Qty)......

C – Robins on the Fountain (Qty)...... D – The Journey (Qty)......

Gift Wrap: Christmas Stags (Qty)......

Stocking Filler: (Qty)...... **Pin badge:** (Qty)......

Merchandise payment £................. **Postage Payment (see above)** ○ £1.50 ○ £3.50 ○ £5.50

Additional Donation £................. **Total payment enclosed £**.................

Please let us know how you want us to keep in touch for fundraising news and events. Fill out your contact preferences below:

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

*Please return slip to **MSA Trust, 128 B Business Design Centre, 52 Upper Street, London N1 0QH** with payment by **9th December 2024**.*