



msa news

MSA Trust Members Magazine | Issue 65 | October 2022

*“Autumn is a
second spring
when every leaf
is a flower”*

— *Albert Camus*

**Making the best of our
most challenging seasons**



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COST OF LIVING - PAGE 4

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Hello and a warm welcome to your 2022 Autumn/Winter edition of MSA News.

First, a huge thank you to everyone that completed their MSA Needs Survey. Once analysed, we will publish the key findings in this magazine, which enable us to plan for your support and services over the next few years.

We know for lots of our members cost of living is at the forefront of your minds. Our Social Welfare Specialist, Sam, has written about this on page four, detailing how you can ensure you're maximising your income and receiving all entitlements. If you need further help during these challenging times, don't hesitate to get in touch with us and we will do our utmost to support you and your family.

On page 10 you will also find an outline of the four new research studies that we are funding this year.

Finally, we understand that finances are currently difficult for some, but if you feel able to give during the festive period, we are launching our appeal on page six. All proceeds go towards our MSA Health Care and Nurse Specialists.

We hope you enjoy reading this edition of MSA News. As ever please contact us with any feedback you may have.

Emma and Andy. *msa news*

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NEWS ROUNDUP

Blood Pressure Webinar

Following the success of our "Introduction to MSA" webinar, we are excited to announce the second in our series, Managing Blood Pressure in MSA. This has recently launched on our website and is aimed at anyone affected by MSA looking for more information on how blood pressure is affected by the condition. It gives a useful overview with a range of practical tips to manage the impact of low blood pressure - www.msatrust.org.uk/bloodpressure-webinar.

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New Staff at the Trust

We are very pleased to welcome a new member to our MSA Health Care Specialist Team. Debra Vincent-Scott joins us as a new MSA Nurse Specialist. She will be covering the South East of England and South London. Debra has over 40 years of nursing experience and most recently worked as a Parkinson's Nurse Specialist. We are very proud to now have six MSA Health Care Specialists, meaning we're able to offer more support to our members. To find out more about our MSA Health Care Specialist Team see here - www.msatrust.org.uk/hcps.

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Needs Survey Thank You

Thank you so much to every single person that completed our MSA Needs Surveys this year. We are delighted to say that over 450 people affected by MSA took part. We are currently analysing the results and hope to have a summary available in early Spring. These survey results help shape our strategy for the next three years, and ensure we remain constantly focused on our member's needs.

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MSA Research Symposium

On Friday 20th January 2023, we will be helping our former Research Fellow, Dr Viorica Chelban to host a research symposium at the UCL Queen Square. We are delighted to be supporting this initiative, which will include reports by some of our current researchers on the work they have been undertaking throughout the pandemic. We will make sure we bring you an event update next year. We hope it will be the start of a new series of research symposiums to highlight the excellent work being undertaken to further our understanding about MSA. *msa news*

25 Years of the MSA Trust

This year the MSA Trust has been marking our 25th anniversary. From the small beginning of our first Support Group in the sitting room of our founder Sarah's sisters home, we have now established a charity with a growing UK and Ireland wide Services Team. This includes six Health Care Specialists and a Social Welfare Specialist who are all supported by our CEO and our Fundraising and Support colleagues. Our aim throughout was, and remains, the pursuit of a cause and cure for MSA whilst making sure we provide the individual information and support that Sarah was so desperate to find when she received her diagnosis. Thank you to all of you in our MSA community who have supported, and continue to support us with so much commitment along the way.

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Maximise your Income

With winter approaching most of us are worried about the rising cost of living, particularly our energy costs. Here, Sam Fitzgerald, our Social Welfare Specialist, highlights some of the support available to help combat the increasing cost of essentials.

Maximise your Income

There is certainly no harm in checking you are getting all the financial support and welfare benefits you are entitled to. Online benefit calculators are a great way to do this. The benefits calculator at www.entitledto.co.uk is for people of any age. If you are of state pension age www.gov.uk/pension-credit-calculator can check whether you are eligible for Pension Credit, which can top up your State Pension and open the door to other benefits such as a free TV licence. Alternatively, you can contact me for support.

Priority Services Register

All energy suppliers have a **Priority Services Register** (PSR) which offer free advice and support to people who have a disability or long-term medical condition. It is particularly important to join the PSR if you rely on your energy supply for medical reasons. You can apply for the PSR by contacting your energy supplier. You should also ask them to pass on your details to your network operator so they can add you to

their register too. The support available includes priority help in an emergency – network operators can provide heating and cooking facilities in the event of a power cut. For more information, please visit www.ofgem.gov.uk.

Water companies also offer a PSR. Those registered will be given longer notice of any planned maintenance work which may disrupt your water supply. They can also provide a priority water supply connection or, if needed, bottled water will be delivered to you. To register, contact your water supplier. For more information visit www.ofwat.gov.uk. If you live in England or Wales, receive certain benefits, have a water meter and use a lot of water because of a medical condition, you may be eligible to join the 'Water Sure' scheme. Under the scheme, you can have your water bill capped at the average household water bill for your water company – some people who've been accepted onto the scheme have seen their water bills halve.

Most phone companies also offer help and support to those living with a disability or long-term condition, including a free priority fault repair scheme (for landline and broadband), which takes priority over standard faults and operates 365 days a year. Some phone



companies are also introducing 'social tariffs' which provide low-cost landline and broadband connectivity for people on certain benefits. Contact your phone company for more information.

What if I'm struggling to pay my energy bills?

It's essential to keep warm this winter. If you are struggling to pay your energy bills, you should contact your energy supplier as soon as possible. Under Ofgem (the energy regulator) rules, energy suppliers must offer a payment plan you can afford. If you have a prepayment meter you can ask for 'emergency credit' if you can't afford to top it up. Some energy suppliers are also offering additional financial support to their customers. You can find what help is available by visiting www.charisgrants.com or contact your energy supplier directly.

Additional Government Support

In addition to the Cost-of-Living Payment and £400 Energy Bills Support Scheme, from 1st October the new 'Energy Price Guarantee' caps the amount energy providers can charge per unit for gas and electric. You don't need to apply, the Energy Price Guarantee will be applied automatically when your bill is calculated.

The Government Help For Households website also gives a good overview of support available - <https://helpforhouseholds.campaign.gov.uk>.

Grants

Your local authority may operate a local welfare assistance scheme. These are discretionary payments and will be means-tested.

- If you live in England, contact your local council
- In Scotland you might be able to get help via the Scottish Welfare Fund - www.mygov.scot/scottish-welfare-fund
- In Wales you may get support from the Discretionary Assistance Fund - www.gov.wales/discretionary-assistance-fund-daf
- In Northern Ireland, you can apply to the Finance Support Service using their online application - www.nidirect.gov.uk/services/claim-discretionary-support
- Information on financial help and support available for those in the Republic of Ireland can be obtained from Citizens Information www.citizensinformation.ie or the Health Service Executive - www.hse.ie/eng/

services/list/3/carerssupport/financial.

Many charities also offer welfare grants, which don't need to be repaid, although some have specific eligibility criteria. Turn2Us has a search tool to help you find what's available www.grants-search.turn2us.org.uk.

Benevolent Funds

Depending on where you work or have worked in the past, you may find additional funding (usually for specific items) through benevolent funds. Benevolent funds are often linked to professions, trades, unions or the armed forces and there are hundreds across the UK. You can find a useful list of some of the funds available by visiting www.britainexplained.com/list-of-benevolent-funds.

Debt advice

If you are struggling with debt, it's always best to seek advice at the earliest opportunity. There are a number of organisations offering free help and advice:

- **Citizens Advice**
www.citizensadvice.org.uk
- **National Debtline**
www.nationaldebtline.org
- **Step Change Debt Charity**
www.stepchange.org
- **Debt Action NI (Northern Ireland)**
www.adviceni.net
- **Money Advice & Budgeting Service (Republic of Ireland)**
www.mabs.ie

Food Banks

Food banks can provide a lifeline to anyone struggling to afford essentials. For more information and where to find your local food bank please visit www.trusselltrust.org/get-help/find-a-foodbank.

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If you still remain in exceptional hardship, please contact the Trust and we will endeavour to find help for you, either from ourselves or through other support. The information in this article is likely to change over the coming year so please contact Sam Fitzgerald, our Social Welfare Specialist for up-to-date information.



Supporting us this Christmas

For 25 years our MSA Nurse Specialists have remained the Trust's core service and a lifeline to people affected by MSA

Please help us this Christmas to continue this vital support. We know it is a difficult time financially for everyone, but every £1 you give will really help us to continue their essential work.

"As a family we are very grateful for the help, education, facts, kindness and empathy that we have received from the MSA Nurses. Your reassurances, honesty and compassion have been so very needed and much appreciated. Simply, thank you!"

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£14

pays for a half hour welcome call from one of our Specialist Team for those newly diagnosed. This answers initial questions and reassures people they are not alone on their MSA journey.

£28

contributes towards a virtual Support Group session with one of our Specialist Team, where people affected by MSA address common concerns in a supportive environment.

£60

will pay for an hour of training by the Specialist Team to ensure NHS, social care and hospice professionals are best able to support someone living with MSA.

£120

pays for a morning's clinic attendance with a consultant by one of our MSA Health Care Specialist Team such as Debra and Samantha (above).

Please visit www.justgiving.com/campaign/ChristmasforMSAT or call us on **0333 323 4591** and we can take your donation over the phone. Alternatively enclose your cheque payable to 'MSA Trust' with the form below. Thanks to the Gift Aid scheme MSA Trust can reclaim an extra **25%** in addition to your donation at no extra cost to you.

Title:..... Full Name:..... Surname:.....

Address:.....

Telephone:..... Email:.....

Your Donation ☐ £14 ☐ £28 ☐ £60 ☐ £120 ☐ Other Amount £.....

If this donation does qualify for Gift Aid, please tick the box and complete the statement below:

☐ I want to Gift Aid my donation of £..... and any donations I make in the future or have made in the past 4 years to: **Multiple System Atrophy Trust**

giftaid it

I am a UK taxpayer and understand that if I pay less income tax and/or Capital Gains Tax in the current tax year than the amount of Gift Aid claimed on all my donations, it is my responsibility to pay any difference.

Signed..... Date.....

Carer's Story

In October 2021 it felt like bleak mid-winter as Eric was given a diagnosis of MSA-C. We grappled with prognosis and spent hours discussing issues both present and future, as we realised that as in the Star Trek saying "it was life but not as we know it"! Read more from Dorothy, Eric's wife, below...



By January all our conversations were focused on problems and the negativity had a drastic effect on the whole family. Eric had little interest in anything or anyone, while I was frazzled juggling work and home life. It was apparent the situation couldn't continue as it was, since the MSA-C was only going to progress, so somehow, we had to consciously adapt our lives around it. We stopped talking about issues beyond our control and what life would be like as Eric's MSA progressed, accepting that we would face many problems but felt it was imperative that we focused on the 'here and now', while putting solutions in place. So, with great reluctance we agreed that we would need to accept friends help.

The main issue we had was that Eric felt like he was useless due to limited capability, so our focus had to be on his interests and how he could achieve them even on a mini scale. The easiest one was his bird watching so bird feeders and water baths were purchased. The next focus was trying to make getting out into the garden easier with his walker, so old slabs were replaced with

new. Next was his gardening skills, so raised beds and upright cold frames were purchased which Eric painstakingly spent hours painting before a friend or myself helped him put them up. I won't lie there were some frustrating moments, but after a few weeks the garden looked quite different, and many seeds were planted then sold so £200 was raised for the MSA Trust.

Our summerhouse was adapted into a craft room where Eric could use his art and wood skills to decorate the many wooden projects I purchased. The aim couldn't be for perfection, but a rustic look was just fine. So, the summer has been a busy one, albeit a bit different for Eric while focusing on what he can achieve rather than the capabilities of the past.

Now as the weather changes Eric can sit crafting Christmas items in the summerhouse while listening to the birds, while I research local Christmas fairs to sell his work. Thankfully we now have professional help we can call, along with the local neurology group which Eric attends. We feel in a place where we can also do small favours for our ever dependable friends.

We know that life with MSA will never be easy due to its rapid progression and constant problems that it creates, but with as positive mindset as we can muster, while focusing on solutions along with help and advice from others (especially all at the MSA Trust) we hope to laugh and make memories that will last forever while we can. [msa news](#)

Dorothy Westland





In Memory

David Thomson
Paul Devlin
Sheila Rae
Maria Read
Christopher Tarbet
Petula Winson
Elizabeth Macnaghten
George Kalli
Robin Gill
Wendy Burchett
Joanna Wright
Debra Morgan

Gay Biggs
Clare Tromans
Mike Pinner
Andrew Hearn
Roy Crooks
Dorothy Bywalec
Ronald Jones
Edward Varndell
Heather Watson
Valerie Stainthorpe
Caitriona McMahon
Andrew Chudley

Sheila Litton
Jeremy Davies
Martina Trainer
Julia Thompson
Laura Haydock
Martha Brown
Peter Beedell
Andrew Seabrook
Joan Evans
Gary Knight
Patricia Doran
David Snape

George Paterson
Charlotte Drake
Roger Prout
Eamon Hession
Gavin Snowden
Peter Rowland
Vera Ward
David Atkinson
Andy Wells
Michael Lovatt

YOUR REGULAR SUPPORT

The very best way you can give back to the Trust

Your donations fund all our support services and research endeavors. Arranging a regular donation to the Trust is one of the most helpful things you can do for us. It lets us plan ahead, confident that your support is ongoing and also helps us keep our costs to a minimum.

Setting up a regular donation can also be a meaningful way to honour a loved one. For example, you could set-up an annual donation to mark birthdays, Mothering Sundays or Father's Days.

Setting this up online is a secure and convenient way to give. An amount of your choice is debited every month (or at whatever regular time you choose) from your payment card. Please visit our

website to set this up:

www.msatrust.org.uk/make-a-regular-donation.

You can also support us via a Standing Order mandate for your bank. You decide the frequency (monthly or yearly) as well as date of transfer. Simply complete your bank information and return our Standing Order form. To request a form, email fundraising@msatrust.org.uk or call the office on 0333 323 4591.

We understand these are difficult financial times for everyone, so are grateful for whatever amount you can give. Thank you in advance for your kindness. *msa news*



My Continuing Research Journey

MSA Trust member, Helen Davies, shares her experience of participating in a research study...

I am 65 and I have been fit, healthy and active all my life. About four and a half years ago I started having symptoms which the Doctor thought was vertigo. I have become steadily worse and now look back as far as ten years and can identify things weren't right even then.

About two years ago, I found and joined the MSA Trust. They have been a tremendous help and support to me, especially during the pandemic. During an MSA Trust online Support Group I heard about a research project that was being sponsored by Exeter University and carried out at Imperial College Hospital, London. The study is conducted by the Neurodegeneration Imaging Group, led by Professor Marios Politis. The group aims to investigate the causes of neurological diseases and identify new targets for treatments.

Dr Edoardo De Natale explained to the Support Group what the research involved. I am willing to be a guinea pig to help anyone else who may benefit from research. I believe that without research we can't discover and progress, so I put myself forward for it. The study involves four attendances at the start (baseline) and four visits after 12 months (follow-up).

My first visit was at the beginning of October 2021. The project co-ordinator organised the train tickets and reimbursed us for any taxis needed. The first session involved a blood test, urine test, ECG test and a cognitive test. The screening and clinical assessment was quite extensive and there was also necessary paperwork for myself and my husband to complete. At that stage it was emphasised that we could terminate the research at any point.

The second visit was just before Christmas 2021, when I had an MRI scan. I had to fast beforehand and have a blood test at my GPs the day before which measured my blood sugar. I let them know in London what the reading was before my scan.

My third visit was at the end of January 2022 and I had a cannula fitted in my artery for a PET scan. This was fine but it was explained to me that I would have severe bruising afterwards and was advised that I should

abstain from strenuous activity for at least 24 hours.

On the fourth attendance towards the end of March 2022 I was willing to have a lumbar puncture but after three attempts we had to abandon it as it was unsuccessful. I had an MRI scan too.

There is now a break of approximately 12 months, when I will have all the tests repeated for comparison.

The research was fine and the organisation of it all was brilliant, with the only issue being that on my fasting visit we were desperate for a cup of tea! I would urge anyone to participate in research and once I was able to organise assisted travel with the trains it was even easier. [msa news](#)



HELEN WITH HER FRIEND NETTIE



Research Roundup

John Telford, the lay advisor to our Scientific Advisory Panel, summarises four new MSA Trust-funded projects that have started this autumn.

1

Hard to Swallow

Impaired swallowing (known as dysphagia) is a feature of MSA. Aspiration pneumonia – caused by food and liquids going into the lungs instead of the stomach – can occur as dysphagia gets worse. Some people have a PEG (Percutaneous Endoscopic Gastrostomy) tube passed through the abdomen straight into the stomach for food, fluids and medications to be given.

This project aims to gather evidence for when and how PEGs should be employed and what the outcomes are likely to be in terms of effective disease management and quality of life. The ultimate aim is to formulate a Clinical Care Pathway for the best management of swallowing problems in MSA. A survey will be available for people living with MSA to take part in this study in the coming months. We will share this as soon as it becomes available.

2

Is MSA a distinct strain of alpha-synucleinopathy?

MSA and Parkinson's Disease (PD) are called synucleinopathies because they involve the mis-folding and laying down of a protein called alpha-synuclein in brain cells. In PD this occurs in cells called neurons and in MSA it occurs in a type of brain cell called glial cells. Evidence over the last few years has suggested that alpha-synuclein can misfold in more than one way and there can be various 'strains' of this misfolded and aggregated protein. This project aims to detect different strains of alpha-synuclein using specially generated antibodies. We know antibodies are proteins used by the immune system to identify and neutralise bacteria and viruses. But they can be created to recognise and stick to other entities such as misfolded protein. This project will use novel techniques to detect this in post-mortem brain tissue. These new techniques, it is hoped, will enable researchers to explore the pathological processes involved in MSA at the cellular level. They will then go on to find out whether they can detect the binding of the antibodies to the MSA-specific strain of alpha-synuclein in cerebrospinal fluid. If so, this would provide a way of confirming, ideally at an early stage, that a person definitely has MSA.



3

Speech and Communication

In MSA, voice volume drops and articulation declines, which can reduce quality of life and cause isolation. Speech and Language Therapy (SLT) is key to maintaining communication. Standard SLT usually provides time-limited one-to-one sessions with a therapist. Therapy utilises exercises and strategies aimed at having an enduring effect. This can be very beneficial but, of course, is quite expensive in terms of the use of the therapist's time and doesn't necessarily fit with the progressive nature of MSA. This project will explore a programme called ClearSpeech Together. Individual sessions with an SLT are followed up with group sessions, in which the members follow a programme of exercises together. The SLT is still actively engaged but is interacting with more people at once. Patients are involved in mutual delivery of the therapy and are drawn into active participation with the others in the group, reinforcing the communication skills and strategies that easily get lost with conditions like MSA. This project is aimed at testing the feasibility and effectiveness of this approach amongst people with MSA-C over two years. If it has a positive outcome, a larger project will be designed with a view to making it standard within the NHS.

4

The Wrong Number

Professor Chris Proukakis's team have discovered that mutated cells with duplications of the alpha-synuclein gene (known as SNCA) can be found in areas of the brain which atrophy in MSA. They want to examine whether these mutations arise over time or through ageing in people with MSA.

The project aims to initially confirm the close association of Copy Number Variations (CNVs) - as these mutations involving extra copies of the genes are called - with the presence of protein in the same cells. The second aim is to discover if CNVs cause the excess protein in the cell and therefore are drivers of the disease. The aim is then to explore this mutation as a potential cause of MSA at a cellular level.

Two new trials are expected to recruit participants in the UK over the coming months. Alterity Therapeutics are recruiting a very small number of people with early-stage MSA to a phase 2 trial of their compound ATH434. The study will examine if ATH434 has any effect of the aggregation of alpha-synuclein and iron in the brains of people living with MSA.

Theravance Biopharma's previous research into amprelosetine for the treatment of postural hypotension (blood pressure that drops when someone changes position) showed a potential benefit for people living with MSA. Theravance want to test this further in a phase 3 trial and will be seeking people living with MSA to contribute to the development of the protocol for the study.

Updates will be posted on our research pages as we

find out more information -

www.msatrust.org.uk/cause-and-cure.

The Journal of Parkinson's Disease have recently published a paper that summarises MSA research to date and is available online at -

www.tinyurl.com/msa-research. [msa news](#)

Remember to check our online Research Hub regularly for research news and opportunities. John has written blogs giving more detail on the four research studies, all of which can be read here - www.msatrust.org.uk/blog.



Safe Moving and Handling

When you are living with MSA simple daily tasks such as standing up from a chair, getting in and out of bed and walking can become difficult. If you need help with any of these tasks it is important for your family members or carers to learn safe moving and handling techniques. Here our MSA Health and Care Specialist (and Occupational Therapist), Demelza Stuart provides some tips on managing these activities safely.





Standing up from a chair or car seat

Ensure your movement is slow and controlled. Moving from sitting to standing can cause a fall in blood pressure, making you feel dizzy.

Bring your bottom forward in the chair, lean forward, nose over toes, then push up using the chair arms. With car transfers you should get your bottom in first and feet out first.

Carers should stand at your side and help by supporting your lower back. They can also help to push forwards and up into standing (they should avoid pulling you up).

Think about equipment that could help:

- Chair raisers can adjust the height of the chair, making it easier to stand up
- A slide sheet can be used to help slide your bottom forward
- Transfer belts can help provide a secure grip for carers
- A frame can provide support to push up from
- Hand grips or hanging handles can be attached to a car frame
- Swivel cushions can help you turn easily in a car seat without twisting
- Riser recliner chairs can assist you to stand. There are lots of variations in these so please seek advice before purchasing yourself.

If your mobility deteriorates further, a hoist may then be required.

Ask your Occupational Therapist (OT) if you feel you would benefit from any of these aids.

Getting out of bed

An OT can help you to break down the steps required to move from lying to sitting and can recommend if any equipment would help with this. Mattress elevators,

bed rails and profiling beds can all be provided if needed.

To stand up, your carer can sit next to you on the bed with an arm around your waist. Place the palm of your hand over the top of their hand or fist. This is safer than holding hands in the usual way, with interlocked fingers.

Place your feet flat on the floor with one foot slightly in front of the other. Agree on wording, like "ready, steady, stand". Make sure you both know to move on the word "stand".

Wait until you feel steady before starting to walk. It can take up to three minutes after standing before a drop in blood pressure occurs.

Walking

As MSA will affect your ability to walk, your Physiotherapist can recommend the best techniques for you to use and can also prescribe mobility aids such as a walking stick or walking frame.

If your vision is poor, or your posture is affected, this can make you more at risk of falling. Please seek advice from your OT or Physiotherapist and listen to prompts given by carers.

Make your home safer by decluttering, removing loose rugs, installing banisters and grab rails and having good lighting. Ensure you are wearing well-fitting footwear.

Getting up from the floor

It's important to practice this as a movement before it becomes necessary to use it in an emergency. Ask your OT or Physiotherapist to demonstrate this with you. Also make sure you are not hurt before attempting to get up if you do fall.

Try to get onto your hands and knees. Ask your carer to place a chair close to you, or crawl to a stable piece of furniture such as a sofa or bed. Hold on to the furniture with

both hands and, when you feel ready, slowly push up with your legs, and sit in the chair.

Always seek professional advice about the best and safest way to perform these tasks.

Top tips for carers

Consider factors that can impact a person's ability to carry out daily tasks effectively, such as time of day, medication, mood, symptoms including pain or fatigue and environment (temperature, access to suitable equipment or aids). Speak to a health professional if you need further advice.

Try giving verbal instructions first, so they can attempt to do the task themselves.

If your loved one falls your first reaction may be to help them up immediately, but it's important to check they are not injured first. Make them comfortable with a pillow and blanket until they feel better. You can help to keep them steady, but make sure they are doing the physical work to get up. If they are unable to get up by themselves, call an ambulance.

It's ok to ask for help when you need it. If you don't feel able to safely help with daily tasks, then you may need additional support, such as a paid carer.

You can have a carer's assessment to see what might help make your life easier. This can include training on how to lift safely. Contact adult social services to ask about this or our Social Welfare Specialist, Sam, can assist you. [msa news](#)

Do contact your MSA Health Care Specialist if you need further support. You may also find the information here helpful - www.mariecurie.org.uk/help/support/being-there/caring/supporting-person-stand-walk.



Once isn't enough for our thrill seekers...



What's scarier than completing one 160ft bungee jump? Going straight back up and completing a second jump...backwards! Thrill seeker **Christian Ford** did just that, raising an amazing £571 in memory of his Grandad, Malcolm Ford.

After completing his first skydive, in memory of his wife Sue, courageous and daring **Chris Mayers** decided that one skydive was just not enough. Chris is now planning to complete a second skydive in November while holidaying in New Zealand. He smashed his £2,000 target, raising close to £3,000 so far. A brilliant achievement, thank you Chris.



A Year to be Challenged...



HANNAH, FRIEND THEA AND BELLA THE DOG

Over the last year the incredible **Hannah Laurence** has pushed herself to the limit and embarked on the ultimate fundraising challenge. She has taken on a 10k Obstacle Run, non-stop 12 hour indoor cycle, 100m abseil off the Portsmouth Spinnaker Tower and hiked up both Snowdon and Pen Y Fan, raising a whopping £4,093.

"I am proud to have made a small positive impact on this incredible community and to have raised awareness of this awful disease."

An amazing achievement- well done Hannah!

After their mum and wife Astral (Annie) Moldram was diagnosed with MSA, the **Moldram family** decided to embark on a series of running, cycling and other fundraising challenges throughout 2022, to raise funds for the MSA Trust. Collectively they have raised £4,355 to-date, and have more events planned to hit (and hopefully exceed!) their fundraising target.

"The MSA Trust is the tiniest of charities who've provided amazing support since diagnosis, from a brilliant MSA Nurse to intervention support."



PETE AND MATT MOLDRAM



This summer **Chris Morgan** decided to run, ride and swim to raise awareness of MSA in memory of his Mum, Christine Morgan. He completed the Ride London to Essex, Southend Half Marathon and Sundried Southend Triathlon and raised an amazing £1,230. Well done on your incredible achievement Chris.



Attend our Tree Planting at Sarah's Wood: 26th November

We are delighted to invite all our members to our Tree Planting Day on the 26th November at Thoresby Park. This is an opportunity to contribute to our growing copse of oak trees at Sarah's Wood. Sarah's Wood was created to commemorate our founder, to serve as a symbol of hope and growth to all those living with MSA and to remember those we have lost. We do not name any saplings, instead we ask you to see Sarah's Wood as a place of remembrance and a lasting symbol of hope for all people affected by MSA.

When: Saturday 26th November, 2-3pm
Where: Thoresby Park, Nr Ollerton, Newark, Nottinghamshire, NG22 9EP. Parking is £3, payable at the car park.

We will meet with Thoresby Park's foresters at Sarah's Wood to plant our saplings, which will be provided to you. The site is accessible to people using a wheelchair. You will also have the chance to view our Path to a Cure,



enjoy some mince pies and mulled wine and to visit the Thoresby's annual **Winterfest Fair**.

This is a free event as we encourage all members of our MSA community to join us in growing this special place. Register before **20th November** on our website to secure your place - www.msatrust.org.uk/tree. Alternatively, call our office on 0333 323 4591 to sign up. *msa news*

Get FUNdraising this Christmas...

Liz Taylor and the amazing Do Your Thing Choir have been busy doing their thing, performing across Manchester in memory of Liz's wonderful Dad. They have collected over £400 for the Trust.

"It is one of the great privileges we have, helping others by doing what we love - singing together"

If you are inspired by this, you can get in the festive spirit and sing or organise a Christmas choir to collect for the Trust. But if singing is not your thing, don't worry. There are more ways to let the festive fun roll on. Perhaps you could...

- Participate in your local Santa Run
- Have a 'charitable' Secret Santa where the gift can be a donation to help all those affected by MSA
- A popular one for the workplace is 'wear-your-Christmas-jumper-to-work' in return for a donation to the Trust.

We can provide all the help you need – collection tins, sponsorship forms or perhaps a letter to your workplace explaining MSA and our work. Just give us a call on 0333 323 4591 or email fundraising@msatrust.org.uk today. *msa news*





Emotional Lability in MSA

MSA can change parts of the brain that regulate or control emotional behaviour and feelings. In many people this can cause emotional lability which means a rapid and exaggerated change in mood. The person may feel strong emotions and express them more dramatically than before. Here, one of our MSA Nurse Specialists Debra Vincent-Scott, looks at how to recognise this, how it may affect you and provides some management tips.

When a person is emotionally labile, emotions can be out of proportion to the situation or environment the person is in. For example, a person may cry even when they are not unhappy. They may cry in response to strong emotions or feelings, or it may happen 'out of the blue' without warning.

These emotional reactions may be appropriate to the situation, but the behaviour or expression may be stronger, louder or last longer than would be usual for that person. For example, a person may be genuinely happy but once the laughter has started, they may be unable to stop or regulate the behaviour. This could include

laughing too loudly, too much or for too long.

You may experience feelings that come out of nowhere and overwhelm you. You may, for instance, start crying for an unknown reason. Some people living with MSA tell us they have become more sensitive or may overreact to people or things





happening around them that never affected them before their diagnosis. For example, you may become more emotional when watching a sad or funny film. Some people find they may overreact to people or events around them, conversations about topics, sad or funny stories.

An individual may also lose emotional awareness and sensitivity to their own and other's emotions. Therefore, their capacity to control their emotional behaviour may also be reduced.

You may have less control over your emotions in some situations such as, listening to music, attending a quiet church, in the library etc. These behaviours can be confusing, embarrassing and difficult to understand both for you and the people around you.

It may be helpful to provide simple explanations or information to other people about emotional lability, for example, "I cry a lot since I was diagnosed with MSA ... don't worry about it" or "Sometimes when I am nervous, I get the giggles". Let people know what they can do, for example "Just ignore me and it will stop".

Coping with the Emotional Lability can be challenging for you and others you live with. However, it can be managed and below are some things that may help you cope if you experience this.

Become aware of triggers:

- Excessive fatigue or tiredness
- Stress, worry or anxiety
- High stimulation (too demanding, too noisy, too many people)
- Strong emotions or demands from others
- Very sad or funny situations (such

as jokes, films, certain stories or books)

- Discussing certain topics e.g. driving, loss of job, relationships, planning future care etc
- Speaking on the telephone or in front of a group or where a person feels under pressure.

Plan ahead:

When there is severe Emotional Lability, one-to-one, brief, and fun activities in a quiet environment will be better.

- Try to avoid being in stressful situations or environments e.g. noisy, busy, high levels of activity or that are too demanding
- Plan more demanding activities or appointments after rests or when you have the most energy.

Do something that makes you feel good:

- Relaxation and breathing exercises to reduce tension and stress
- Using distractions – thinking of something else, imagining a peaceful image or picture, counting
- Spend time with people who make you smile and feel relaxed
- Get enough sleep, eat healthily and if you can, exercise regularly.

Things that may help your family & friends:

Carers, family members and friends should, whilst acknowledging the persons difficulties, gently try to ignore the Emotional Lability as much as is possible. Try to get others to ignore it too and continue with the conversation or task.

Focussing on the lability or giving

the person too much attention when it is happening can reinforce and increase the problem.

Changing the topic or activity (redirection and distraction) may reduce stimulation or stress - particularly if the topic was a trigger.

Medication:

Antidepressant medication can be helpful for some people with Emotional Lability to help manage their labile mood. Talk to a Specialist or GP who can also check for depression and support with this.

Counselling and support:

A person living with MSA has had many losses and changes to cope with.

Feelings of sadness, grief, anger, frustration, disappointment or depression after a diagnosis are common and may be very difficult to cope with.

If there are emotional adjustment and coping issues, referral to a counsellor, Psychologist or Psychiatrist may be helpful.

Finally, don't be afraid to ask for help from family and friends who care about you. This can make a huge difference to helping you manage Emotional Lability effectively. [msa news](#)

Speak to your health care professional team to discuss your specific concerns and difficulties. We have a factsheet on Emotional Lability available on our website - www.msatrust.org.uk/support-for-you/factsheets.



Supporting and Helping Each Other

Our members continue to share their helpful tips and advice in our Digital and In-Person Support Groups. To make sure you are receiving updates for our Support Groups, do get in touch and we can check that you are getting the right invites. Here, Nicole Adam, Senior Services and Volunteering Officer, shares some of the tips from our members...

We know that keeping warm is on everyone's mind right now. While these tips are not a substitute for central heating, they may help you keep comfortable, especially if you struggle to regulate your temperature.

There are a variety of electric heating items that can help deliver targeted temperature control. The first to mention is, of course, the heated blanket. There are multiple options available at a variety of price points. Most new models have improved safety features to prevent overheating and timers, so they are only on when you need it. Over-blankets are like traditional blankets, but with a heating element, that are easy to move with you around the house. Under-blankets can go below your sheet in bed and can be efficient at keeping you warm at night. Many now have the option for two temperature zones so you and your partner can each choose a setting that is comfortable for you. Where possible we recommend buying from a reputable retailer, to make sure you can feel confident all safety standards have been met.

For more targeted warmth there are items like this heated footwarmer which can be bought online - www.stressnomore.co.uk/beurer-footwarmer-81027.html. Another option if you want to stay warm while moving around the house, or maybe doing some gardening outside, is a rechargeable heated jacket. These come with a small battery pack that you can charge and pop it in, keeping you warm while moving around.

They are available through multiple retailers including - www.regatta.com/collections/heated-jackets. If you are considering buying any device we recommend doing it sooner rather than later, as it is possible there will be a rush on demand as the weather turns.

Finally, do not ignore the low-tech classic techniques for staying warm. Multiple thinner layers are better than one large jumper. Light thermal wear can be bought from most sports shops and one of our members highly recommends the '32 Degree' brand available from Costco. Thin, fingerless gloves can be useful around the house if your hands get cold easily.

If you are having issues staying warm please do get in touch with us for further support. [msa news](#)

A reminder that we are hosting our next MSA Study Day in Cardiff on the 17th November. Our annual Health and Care Professionals Day is a chance for us to spread awareness of MSA and for professionals to share knowledge with each other. Do encourage anyone in your professional health care team to check out our website - www.msatrust.org.uk/event/2022-msa-study-day.

The countdown to the festive season has begun...

Get a head start on shopping for the festivities with our carefully chosen cards, gift wraps, Advent calendars and stocking fillers to give to your family and friends this Christmas.

Every purchase helps fund our vital support services and brings us closer to finding the cause and, ultimately, the cure for MSA.

To place an order, visit our website at www.msatrust.org.uk/christmas, call our office on 0333 323 4591 or return the slip overleaf with a cheque payable to the MSA Trust.

Thank you for choosing to support us this Christmas. *msa news*

£5

Stocking Filler

A delightful stocking filler comprising of MSA Trust goodies - two pens, two wristbands & a pin badge



£4

Advent Calendars

34 x 24 cm with postal envelope
Individually wrapped



£3

Gift Wrap

4 Sheets (2 of each design),
8 tags (4 of each design)
Flat size: 50 x 69 cm



£5

Christmas Cards

Each of our packs has 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*

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	£3.00	£5.00

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.

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'.



B & C



D



Name:.....

Address:.....

Telephone:..... Email:.....

Christmas Cards: A – 12 Days (Qty)..... B – Colourful Street (Qty).....

C – Speedy Scooter Santa (Qty)..... D – Bethlehem (Qty).....

Advent Calendars: White Christmas (Qty).....

Gift Wrap: Santa and Rudolf (Qty)..... Robin and Berries (Qty).....

Stocking Filler: (Qty).....

Merchandise payment £..... **Postage Payment (see above)** ☐ £1.50 ☐ £3.00 ☐ £5.00

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, 51 St Olav's Court, Lower Road, London SE16 2XB** with payment by **9th December 2022**.