msa news
MSA Trust Members Magazine | Issue 62 | October 2021

Building your Circle of Support

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Welcome to Issue 62

Hello and a warm welcome to your Autumn 2021 edition.

*We start off by letting you know that our Senior Fundraising Manager, **Tanya Mitra**, has gone on maternity leave and **Jennifer Ebrey** will cover until Tanya's return. We also welcome three new staff members – **James Grogan** is our new Administration Assistant and will be coordinating our Support Groups. **Antonio Torres** is our Individual Giving Officer and will be your contact for all donation enquiries. Lastly, we welcome **Sam Fitzgerald** as our new Social Welfare Specialist. Sam will be taking over from **Jane Stein**, who retires in November. I'm sure you will join us in saying goodbye and a huge thank you to Jane for all her hard work and dedication.*

As always, we have a wide variety of articles in this issue. On page 6 we feature a piece on infections and how to spot these. We also focus on what good care looks like (page 12) offering some tips on how to get this in place.

We can scarcely believe it ourselves, but once more the time has come to buy your Christmas cards and goodies - everything is available to order on pages 19 and 20.

Thanks for your support during what has been a difficult year. We are hopeful for a more settled 2022. Enjoy reading your MSA News. Emma and Andy. msa *news*

Registered Charity Number 1137652. Scottish Charity Number SC044635. Company Number 7302036
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Our New Resources

Emma Rushton, Information and Services Manager, looks at four new initiatives we have launched in the last year...

In 2019 we completed our first MSA Needs Surveys which gathered members experiences and views on life with MSA. As a result of these, we developed our new Strategy taking us from 2020 to 2023. Despite the potential for the pandemic to give us a knockback, we have continued to drive forward to provide members with the support that they told us they needed.

Emotional Support

Living with MSA brings many challenges and just as with your physical health, there may be times when you need support for your emotional and mental wellbeing. The MSA Needs Surveys highlighted a lack of information and support in this area, so we have worked with a qualified counsellor to produce our 'Living with MSA: The Emotional Impact' resource. Whether you are living with MSA, or are providing support to someone, we hope this will help you find the words to ask for support from family, friends and health professionals when you need to. This resource is available online and in hard-copy (free of charge - just call our office to order one) - **www.msatrust.org.uk/support-for-you/living-with-msa-the-emotional-impact**.

Introduction to MSA Webinar

The first in a series of webinars presented by our MSA Nurse Specialists, an Introduction to MSA Webinar, is now live on our website. It gives a 20 minute overview of MSA including, what MSA is, how it is diagnosed, the symptoms and support that is available. The webinar is primarily aimed at people who have recently been diagnosed and would like further information but is also helpful to family members, friends and health care professionals as a starting point to their learning. You can watch the webinar here - **www.msatrust.org.uk/introduction-to-msa-webinar**.

Befriending

We have recently started a volunteer befriending service for people living with MSA and carers. People are matched with one of our volunteers (often someone who has previously cared for a loved one with MSA) who holds weekly sessions lasting for six months. Befriending aims to reduce the isolation often felt by people affected by MSA. Offering dedicated time with a friendly, caring individual who understands MSA may help to ease some of loneliness felt from living with a rare condition. If you would like to get involved, as a volunteer or to take part, please contact Nicole at **support@msatrust.org.uk**.

Young Peoples Hub

We already have a Children's Activity book for 4-11 year-olds and wanted to provide something suitable for older children and young people. Young people themselves told us that an online resource would be best as it's easily accessible. The Young People's Hub aims to give answers and provide support for those aged 11-17. Topics include the symptoms of MSA, how MSA affects family life and managing feelings and emotions. It can be accessed here - **www.msatrust.org.uk/support-for-you/for-people-affected-by-msa/young-people**. We're keen to hear from any young people that use this resource so do get in touch with your feedback. msa *news*

NEWS FROM OUR NURSE SPECIALISTS

Voice Amplifiers

A voice amplifier is a device that helps amplify a quiet or strained voice so that the person using it can be heard with less effort. It consists of a small microphone that can be clipped to clothing or attached to a light-weight headset, which picks up vocal sounds, and a small speaker that projects the speech so that the affected voice can be more easily heard.

The model we have available - the Voice Aid portable voice amplifier kit - also includes an integrated pitch modulator, which means that even a soft voice or whisper can be more defined and easier to hear. It is rechargeable, with a 12-hour battery life. As well as being used for individual and group face-to-face communication, the voice amplifier can also be used alongside a phone or computer to aid remote communication. The Voice Aid amplifier was created as a result of someone with MSA experiencing speech problems. This online video shows how the voice amplifier works - **www.youtube.com/watch?v=Y3HJzPqyPh8** .

Our MSA Nurse Specialists each have a voice amplifier that they can demonstrate at upcoming Support Groups. If you would be interested in borrowing an amplifier, please contact your MSA Nurse Specialist. You can find the Nurse for your area here - **www.msatrust.org.uk/support-for-you/nurses**. msa *news*

Cognition in MSA

Cognition refers to a range of high-level brain functions including your ability to learn and remember information, organise, plan and problem-solve, focus, maintain and shift attention, understand and use language, accurately perceive the environment and perform calculations.

Several recent studies have helped us to understand more about cognition in MSA, but more research is needed to understand the extent and severity of cognitive change. A change in cognitive function is common in MSA, for most people the changes are mild and may involve one or two areas of cognitive functioning. For a few people with MSA the changes in cognitive function will be more challenging.

Areas of cognition that may be affected include:

- **Information processing** (dealing with information gathered by the five senses)
- **Attention and concentration**
- **Executive functions** (planning and prioritising)
- **Visuospatial functions** (visual perception and constructional abilities)
- **Verbal fluency** (word-finding)

For a few people memory (acquiring, retaining and retrieving information) may be affected.

Talk to a member of your health care team if you are concerned about cognitive changes. They will likely perform a short screening test and those results may lead to a referral for a more comprehensive cognitive evaluation. Careful evaluation is helpful to determine the specific cognitive functions that are affected and to sort out other possible causes of cognitive problems, such as poor sleep, medications, fatigue, depression, anxiety or stress. If you experience changes in cognitive function, strategies and tools can help you function more effectively.

If you have further questions about how cognition may be affected in people living with MSA, please contact our MSA Nurse Specialists by emailing **support@msatrust.org.uk**. msa *news*

NEWS ROUNDUP

LPA Consultation

A Lasting Power of Attorney (LPA) is a legal tool that helps people to plan for their future. It lets someone choose people they trust to support them and make decisions for them if they lose ability to make their own decisions in the future.

Many people with MSA choose to use LPA's and our Social Welfare Specialist can discuss what options might be helpful for you. In 2019/20 just under 920,000 LPA's were registered in England and Wales so it is far from unusual.

The Ministry of Justice and the Office of the Public Guardian have just held a consultation on modernising the process and we will report back on their response when it's available early next year. msa *news*

Needs and Neuro Surveys

Some early notice that the Neurological Alliance will be running another survey looking at services provided for people with neurological conditions. We will promote this nearer the time, but it is likely to launch in late October to run until mid-January 2022.

We will also be repeating our own MSA Needs Surveys next year. If you have suggestions for questions you would like us to ask to support service improvement or build evidence of where change is needed, please do let us know. msa *news*

Impact Report

The Trust has just produced our Impact Report for 2020/21 which we are delighted to share with you. It can be found on our website here - **www.msatrust.org.uk/about-us/annual-review**.

Not only does it show what we did and how we spent our resources during this time, but it also has a lovely cover picture and quote from Hayley and Colin Tamplin and our thanks go to them both. msa *news*

Multiple System Atrophy Trust

Impact Report 2020-2021

"There's nothing easy about living with MSA, but knowing the Trust is always available makes the burden so much lighter."

The Last Straw for Plastic Straws?

We all want to do what we can to reduce single-use plastic. In April 2021 the Government banned the supply and sale of single use straws by businesses to the public in England.

This has caused debate in the disability movement where some have argued that there are no suitable alternatives to plastic straws in certain circumstances. The Government exempted registered pharmacies from this ban, "so that disabled people or those with accessibility needs can still use them".

We are interested in what alternatives people with MSA have found, and do find, helpful to them. For example, one participant in a Support Group mentioned this - **www.amazon.co.uk/Conexus-Infant-Tumbler-Multi-Colour-4-Piece/dp/B01DC570C0**.

We would love to hear from our members if you recommend any other products that we can share, please email **support@msatrust.org.uk** with your suggestions. msa *news*

Recognising an Infection

Typically when we have an infection there are some key symptoms that give us good clues as to where that infection may be. For reasons not fully understood this may not be the case when someone with MSA gets an infection. Katie Rigg, MSA Nurse Specialist, looks into this further…

If we get an infection when we are fit and healthy we will be aware of feeling significantly less well and markedly different to how we normally feel. When you have MSA this initial 'not feeling well' may be less easily identified.

One of the main reactions to an infection is a rise in body temperature. Our bodily functions work best when our temperature is 36.5 to 37 degrees Celsius. Maintenance and control of body temperature is by the autonomic system. For some people with MSA their reduced movement, along with the altered autonomic control, results in having a lower than average 'normal' temperature.

A rise of one degree or more suggests something untoward is

happening. This rise in temperature is called a pyrexia and tells the doctor that the person may have an infection. If you have MSA and your 'normal' temperature is 35.5 degrees Celsius then a doctor unfamiliar with MSA may not recognise that when you have a temperature of 36.5 degrees Celsius this is a significant increase for you indicating an infection. Tracking your baseline temperature so you can demonstrate what is 'normal' for you, might be useful.

How else can you recognise an infection?

For most people, changes and deterioration in their overall MSA symptoms occur over a number of months. Subtle changes accumulate to make moving about more difficult, speech at first intermittently and then more consistently becoming less clear and more effortful, episodes of what you eat or drink going the wrong way and bladder and bowel symptoms requiring more focussed management.

Change to these overall MSA symptoms in a short time period (for example 72 hours or less) suggests that you are coping with an acute stress such as an infection. If the stressors mentioned below can be ruled out, your bowels are working normally for you and you are drinking usual amounts, then you should assume the change in your condition is due to an infection.

Other stressors that may cause unexpected change in your MSA symptoms can be a fall, extreme fatigue or anxiety due to a recent stressful event, or doing activities significantly above and beyond your usual daily routines. Recognising this and allowing yourself time to recover will usually help the situation to improve. Also, consider if you have had recent medication change that coincides with the deterioration you are experiencing and discuss this with your doctor if this is the case.

Sudden occurrence of hallucinations or reduced responsiveness may also be strong indicators of a significant infection and require prompt medical assessment.

Urine infections and chest infections are the most common and will require antibiotic treatment if it is a bacterial infection. Viral infections largely have to be cleared by the body itself.

Noticeable features of a urine infection

A urine infection may cause your urine to look more cloudy, there may be sediment in it, often darker in colour or have a definite odour to it. A urine specimen should be taken and tested for infection.

Urine should be a clear pale straw-coloured fluid. There should be no odour apparent when you pass urine. It is important to be aware how your urine looks when you are well as it is often the changes that are important. Some people have more colour to their urine for example, even though there is no infection, and they are drinking properly. The more we drink the paler our urine should be, so it is always advisable to drink as much as you can manage. This is particularly important if you do have a urine infection both to help reduce irritation to the bladder lining and to clear the infection.

When you pass urine there should be no discomfort. If it is uncomfortable to pass urine or you feel ongoing discomfort in the groin, lower abdomen or lower back then take a urine specimen to be checked for presence of infection.

Susceptibility to chest infections

Being less able to exercise vigorously and induce deep breathing can increase susceptibility to developing a chest infection. Build-up of saliva and secretions in the mouth and back of the throat, reflux symptoms and changes to efficiency of swallow can all contribute to the risk of getting a chest infection. If you get a chest infection, as described earlier all your general MSA symptoms will suddenly become worse.

Indicators of a chest infection are changes to your breathing pattern in a short time period, increasingly noisy, bubbly sounding breathing, feeling you can't get your breath or changes in your pallor for example more pale, grey or bluing around the mouth.

A chest infection may cause the secretions to be yellow or green coloured, more sticky than usual and possibly have an unpleasant smell to them. If you can cough up a specimen of these secretions for testing an antibiotic specifically effective for the identified infection can be started. It may not be possible to get a specimen but the doctor can listen to your chest and identify if you have signs of a chest infection and start treatment. msa *news*

If you have any questions about infections, how to recognise these if you are living with MSA and treatment, please contact your MSA Nurse Specialist on **support@msatrust.org.uk** or call 0333 323 4591.

In Memory

Andrea Oatley
Stephanie Pordage
Ann Lusk
Mary Kirwan
Adrian Kelly
Janice Matthews
Patricia Clifford
Amelia Reynolds
Norman Lumsden
Martin Graham
Brenda Morris
Barbara Curtis
Susan Tuck
Joan Deegan
Jim McGarry
Alan Barnes
Alan Hyde
Ann Ebbs
Alan Vivian
Yvette Jenkins
Mina Craig
Martyn Rouse
Richard Sellings
Thomas Foley
Stephen Warren
Robert Brooks
Diane Burrell
John Taylor
Michael Finbow
John Hunt
Marian May
Susan Cole
Carol Eastwood
Garry Bell
Colin Wilson
Sandra Lindsay
Christine Smith
Marian Crowe
Gordon Clarke
Susan Callaghan
Ruth Heard
Daphne Couch
Heather Fisher
Kenneth Block
Kathy Moore
Julie Lugton
Alastair Campbell
Lycia Sellars
Rick Magdzinsk
David Dolman
Caroline English
Jennifer Taylor

MEMORIAL GIVING

With the pandemic still an ongoing challenge for many, we understand the December holiday period can be hard for those mourning the loss of a loved one. This Christmas, supporting the Trust in their memory can be a lovely way to remember them and help others living with MSA. Many families choose to ask for donations to the Trust in lieu of presents, or simply make a one-off or regular contribution to the Trust themselves. You can do this online on our website at **www.msatrust.org.uk/donate**, call us on 0333 323 4591 to do this over the phone or raise a cheque payable to 'MSA Trust' and send to our office.

You can also contribute to our online memorial space, Light of Hope, a place to honour everyone sadly lost to MSA. Post a picture of your loved one with a holiday message to create a lasting memory. Visit - **www.msatrust.org.uk/msacandlelight**. Donations are optional and will be used to fund MSA research, ensuring every contribution brings us a step closer to fulfilling our vision of a world free of MSA.

If you have any questions about supporting us through any of the above, please contact Antonio at **fundraising@msatrust.org.uk** or call 0333 323 4591. msa *news*

The Big Give Christmas Challenge 2021: *One Donation, Twice the Impact*

The MSA Trust is hugely excited to be participating in this year's Christmas Challenge – a week-long opportunity to have any donations made to the Trust doubled!

From **midday on Tuesday 30th November to midday on Tuesday 7th December**, donations made to us via The Big Give platform (www.thebiggive.org.uk/s/christmas-challenge) will be matched by participating philanthropists to double the value of each donation.

This year, we will be dedicating the funds raised from the Challenge to our Welfare Grant Scheme.

In addition to offering a rare chance of doubling every penny donated to us, the popularity, prominence and prestige of The Big Give Christmas Challenge will also offer us the invaluable opportunity to raise awareness of MSA. So, if you would like to support our Challenge and help us to make the most of this extraordinary week, there are several ways you can take part:

- You could undertake your own sponsorship challenge during this week - some organised events that are already taking place can be found below
- You could organise a charity event for that week and have all the funds you raise doubled
- Like and share our social media posts to help us get the word out
- Or you could make your own donation to us via The Big Give platform.

We need the donations to be paid within this week to ensure they are doubled up.

If you would like to hear more about any of these options or how you could help support our Welfare Grants Scheme, please contact our Fundraising Team at fundraising@msatrust.org.uk. msa *news*

Challenge Runs

By taking part in one of our challenges below, from 30th November to 7th December, you'll be contributing to our Big Give campaign as all funds raised will go directly to it.

Santa in the City Run

Turn London red by gearing up in a free Santa costume to take part in the largest Santa Run in the UK. Join the festive fun and burn a few calories by running 5k with your friends and family this Christmas to help raise funds for us. You will also receive a finishers medal after the event. To take part please email us at: fundraising@msatrust.org.uk.

Where: Paternoster Square, London
When: Wed 1st and Thur 2nd Dec 2021
Time: 7pm
Registration fee: FREE
Minimum sponsorship: £150pp

Miles for MSAT

Take part in our bespoke Miles for MSAT challenge by completing 26.2miles in any activity of your choice within one week. Connect to a fitness app and log your miles as you take on your own tailored challenge during the last month of the year.

Where: Your own location
When: Tue 30th Nov to Tue 7th Dec 2021
Minimum sponsorship: Raise as much as you can!

To take part, please register here - www.givepenny.com/campaign-setup/join/marathon-for-msat.

We need any donations to be paid within the Big Give week to ensure they are doubled up. msa *news*

Research Strategy

It has been an incredibly busy summer for MSA Trust Research. The revisions to our new Research Strategy are complete and it is now available on the Research Hub on our website. Our Scientific Advisory Panel (SAP) were the major players in its development and you can access it here - **www.msatrust.org.uk/research-strategy**.


DR YEE YEN GOH

Research Grant Programme

We have recently launched the latest round of our MSA Trust Research Grant Programme, whereby scientists, researchers and clinicians are invited to apply for a research grant to further our knowledge about MSA.

This funding call incorporates a change to how we assess applications, with the introduction of a pre-proposal round, which is a direct response to the fantastic increase we have seen in the number of applications we receive for research funding. Researchers seem much more interested in studying MSA and that can only be good news for our community. However, we do not want to add to their heavy workloads by asking for long and detailed applications. By having a pre-proposal system we can seek a shorter application which, if successful, can be worked up into a full application.

We have also undergone an audit from the Association of Medical Research Charities (AMRC) with some recommendations on how we can improve our information for researchers, and these have been fully implemented. Please do head to the website to check out any new updates on the Research Hub at *www.msatrust.org.uk/cause-and-cure*.

Our latest funding round began in September and this year the themed call is 'Projects aimed at improving clinical care and management of people with MSA'. A themed call is where a particular subject or area is highlighted in order to encourage applications from researchers with an interest in that field. For this call we wanted to prioritise projects aimed at improving patient care and quality of life. The decision to add a themed call stems from the need to study and understand the best ways to support people living with MSA as they continue on their patient journey. This is in addition to our normal call for innovative translational or clinical neuroscience research projects, to improve our knowledge of the cause of MSA and support the development of a cure.

Clinical Training Research Programme

In summer, our CEO met with our Research Fellow, Viorica Chelban, Professor Henry Houlden and our new research fellow, Dr Yee Yen Goh, who will be working alongside the team at the Institute of Neurology in University College London (UCL). Dr Yee Yen Goh will be funded by the MSA Trust Research Fund from Autumn 2021.

Dr Goh is currently working at the Institute of Neurology at UCL and has already been involved in some of the work Dr Chelban has been undertaking. Dr Goh will be supported during her Fellowship by the Association of British Neurologists, and we are pleased to continue our assistance developing clinicians with a specialism in MSA.

Dr Goh's study, which will continue the work started by Prof Houlden and Dr Chelban to identify longitudinal biomarkers to inform clinical trials, was highlighted in her application:

"The advent of treatment trials for MSA has highlighted the importance of an accurate early diagnosis and the identification of biomarkers of progression, to help understand if therapies work. This includes the MSA Exenatide and alpha-synuclein-antisense-oligonucleotide (ASO) trials, starting at UCLH shortly. We are part of the PROgressive Supranuclear Palsy CorTico-Basal-Syndrome MSA UK-Wide-Study (PROSPECT-M-UK) that has collected longitudinal clinical, imaging and biosamples. This includes over 100 MSA patients where the only studied biomarker has been cross sectional neurofilament light-chain, which is raised in MSA, similar to other neurodegenerative disorders.

In this proposal, I plan to benefit from the longitudinally collected MSA biosamples from the PROSPECT-M-UK study and the Exenatide trial. I will focus on four key abnormal pathways identified from work on MSA brain tissue to investigate biomarkers in MSA blood and cerebrospinal fluid, urine and skin. These markers will be correlated with clinical features and investigations to identify biomarkers of MSA diagnosis, progression and prognosis."

It is important to note that the research Dr Goh will be undertaking directly relies on the amazing support from readers of MSA News and other people with MSA being willing to join the Prospect-M study.

New Imaging Study starts Recruitment

The Neurodegeneration Imaging Group, led by Professor Marios Politis at the University of Exeter, is recruiting for a new study called 'Synaptic loss in Multiple System Atrophy'. Participants must be diagnosed with MSA-P, aged 45-70, and be able to travel to Hammersmith in West London for study visits. Assistance can be given with transport and accommodation.

The study consists of clinical assessments, brain imaging with PET and MRI scans, blood sample collection and optional lumbar puncture. These procedures will be performed over four visits and will be repeated in another four visits after approximately one year.

The aim of the study is to help understand if synapses and glucose levels within the brain of patients with MSA are altered during the disease and what role these changes could have in relation to clinical symptoms. It is hoped that findings will provide a deeper understanding of the brain changes in MSA and help track progression over time. Additionally, the study may have the potential to help with the discovery and development of new medications aiming to delay the progression of symptoms of MSA. msa *news*

Further information about these studies and study team contact details can be found on our website – **www.msatrust.org.uk**.

What Good Care Looks Like

When someone is diagnosed with a rare and complex condition like MSA building a consistent 'circle of support' (of family, friends and professionals) is key to ensuring that the individual feels supported, that independence is maximised and personal wishes respected. Jane Stein, Social Welfare Specialist, looks to the Isle of Man for a great example of good care support…

SUE WILSON AND NIC BLAKE

Services will vary across the UK and the Republic of Ireland but one place that does offer good support is the Isle of Man. Here a dedicated team of professionals work together in close collaboration with the person living with MSA and their family. That the current type of service exists is, in large part, down to the vision of Nic Blake who cared for her husband Chris, Sue Wilson who is a long-term conditions nurse, and our own MSA Nurse Specialist, Katie Rigg who offers ongoing support and information.

KATIE RIGG

As Katie explains

"Good care is most likely to happen when one of your health professionals is prepared to be your 'go to' person and proactively help you be linked into, and engage with, all appropriate services in a timely way. Regular review of your care by all care and health professionals involved –ideally at a multi-disciplinary team meeting – enhances how the professionals all work together to address the things that are important to you."

Good care should be person-centred, sensitive, responsive and well co-ordinated. It will be supportive of everybody including the carer. The professionals involved may include the Long-term Condition Nurses, GP's, Physiotherapists, Occupational Therapists, Speech and Language Therapists, Dieticians, Continence Advisers, Specialist Consultants, a Hospice and perhaps a Neuro Psychologist.

When Nic's late husband Chris was diagnosed with MSA, Nic was keen to build relationships with the core team of professionals from an early stage and saw the value of bringing the professionals together for meetings. Sue was instrumental in these discussions and supported this approach. It helped the whole team get to know the family. It also helped to build shared knowledge which is especially important with a condition like MSA that professionals may be unfamiliar with. As Nic says

> ***"We were extremely lucky – we're a small island so it is easier to reach in and get attention and easier to get things off the ground. It is important that people are open to change and new ways of doing things. Instead of making seven or eight different calls we all came together as a team to look at the issues and plan for the future."***

Planning can help relieve anxiety and gives you and the services time to explore various options.

Nic explains that she and Chris tried to operate a 'no shocks or surprises policy' within a gentle and thoughtful framework. Nic says

> ***"Sue is the lynchpin – consistency is so important. You need someone who is familiar with your journey to date and who knows the family. Sue understands how the NHS and other agencies work and can reach in to the therapists. MSA is tough but it's the passion for patient care from health care professionals that makes the difference – together they are a powerful force."***

Others living with MSA agree. One gentleman said:

> ***"They are just there any time I want them and I get sensible, considered advice. Sue has been a big factor in my life – she is terrific and Katie likewise."*** Another, Lavinia, said: ***"Sue is always at the end of the line. If you need something, or to see someone, Sue will sort it. It's great to know someone's there."***

For a carer, being unfamiliar with MSA and unsure who does what can be a real worry. Carers on the island now have the reassurance of regular contact with Sue who acts as a key worker. Jeanne, who cares for her husband, says:

> ***"Terry has had MSA for many years. We used to feel very alone but that all changed when we met Sue. She knows the people to go to and what to say. She organises hospital appointments and transport and refers to consultants. Sue is an absolute lifesaver and having her there is incredibly reassuring to me. Before we met Sue we didn't know what we needed to know. Now all the professionals visit and we have all their contact numbers. You don't feel isolated."*** Terry himself acknowledges how good the service from all the professionals is but, stresses too how important a loved one can be saying ***"…and last but in no way least my wife of 54 years, Jeanne, whose care for me is first class. I would not be here today apart from her care."***

As Sue says "A diagnosis of MSA is life changing but it's different for everyone. We need to focus on what matters for the individual."

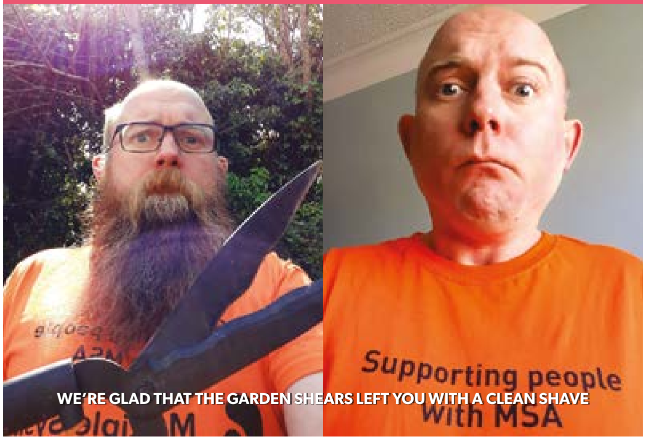
Unfortunately, the type of support available to those on the Isle of Man will not exist everywhere but doing these things may help:

- **Contact the MSA Trust Nurse Specialist for your area – they can liaise with local professionals and identify key links**
- **Ask professionals to copy clinic letters to each other and to you (keep a file of these documents and a list of contact details and take it to appointments)**
- **Suggest professionals work together, meeting as part of the team around you**
- **Pro-actively request regular reviews with key professionals**
- **Read and pass on MSA Trust information materials such as our Carers Guide and Emotional Support Booklet to healthcare professionals**
- **Family and friends can be incredibly helpful, especially if you ask them to take on specific tasks. They may also offer valuable support to your main carer**
- **Don't try to cope alone. Being open and honest about your wishes and needs will help ensure you and your carer receive appropriate support.** msa *news*

Please contact our Social Welfare Specialist at **support@msatrust.org.uk** if you'd like to discuss your care support and other non-medical issues.

Community Summer of Fun

Paul Suteez decided to complete a fundraiser during the pandemic, pledging to grow his beard out until he received his first vaccination jab. He managed to raise £745 in memory of Linda Shinton and has now received his jabs alongside a new look. Well done Paul!



WE'RE GLAD THAT THE GARDEN SHEARS LEFT YOU WITH A CLEAN SHAVE

FROM THE LEFT TO RIGHT: DONNA, TOM AND DONNA'S NIECE

Donna Grove-White put together a fantastic Coffee & Cakes event at Roamer Coffee and The Flower Pavilion in Montrose in honour of her loyal customer and friend, Tom Lochhead, who is living with MSA. Donna and her team baked and sold some delicious coffee and bakery goodies which led them to raise almost £5,500 for the Trust - what an amazing achievement.

Major Miles for MSAT

Patrick Ollerton organised a group, including his brother and a team from Ashton, to courageously complete The Three Peaks challenge in July in support of his dad. He is currently sitting close to raising an impressive £10,800, helping to make a big impact for the Trust and spread awareness of MSA. Well done for this exceptional fundraising Patrick!

Our incredible supporter **Nick Kirkwood** completed a 905 mile walk in memory of his wife, Julia Kirkwood. Walking in Yorkshire, Buckinghamshire and along The Thames Path, Nick has been blogging his progress towards his final mile at Tower Bridge and has managed to raise a marvellous total of £8,213. We so appreciate your dedication, Nick.

The Thomson Trio take on the Virtual Edinburgh Half Marathon

Our wonderful Thomson Trio supporters - Kara, Darren and Kelly completed the Virtual Edinburgh Half Marathon 2021 in support of their dad, David Thomson, who is currently living with MSA. David, who was diagnosed in October 2020, was told the exciting news about the sibling's challenge in his honour on New Year's Day.

Remotely taking on one of Scotland's most popular challenges, they hoped to raise awareness and show their appreciation to the Trust. Kara expresses:

> ***"The MSA Trust gave invaluable support to Dad, Mam and us and we will be forever indebted to them for their care, compassion and expert advice."***

Despite the run being their 'biggest challenge' and falling on one of the hottest summer days, they accomplished the 13.1 miles locally and raised an amazing total of £10,580. They were happily greeted by their community as they ran the Shetland roads and were cheered on by close family and friends up until the finish line with a BBQ waiting on standby.

David sent a heartfelt note to his children after their amazing achievement saying, "I would like to thank my bairns Kelly, Darren and Kara along with my good friend Colin Summers and my niece Alina Murray for running the half marathon for the MSA Trust. I am immensely grateful and proud of them for doing this."

Well done Team Thomson! msa *news*

Our 'Tree of Hope' Planting Days

We would like to invite our MSA community along to our next Tree Planting Sessions at Sarah's Wood. You can enjoy a family day out planting saplings into the ground, with each new tree representing a symbol of hope towards a world free of MSA. Sarah's Wood is located at Thoresby Park, Nr. Ollerton, Newark, Nottinghamshire NG22 9EP.

We currently have two dates for these events:

Saturday 27th November 2021

Saturday 26th February 2022

If you would like to join us to plant your own tree of hope, or would like someone to plant one on your behalf, then please visit our website to fill in the form - **www.msatrust.org.uk/get-involved/sarahswood**.

msa *news*

PATH LEADING TO SARAH'S TREE IN NOTTINGHAMSHIRE

NICOLE ADAM PRESENTS A REGULAR ROUNDUP OF YOUR TOP SUPPORT GROUP TIPS

Supporting & Helping Each Other

Members continue to be generous with sharing advice and recommendations at our Digital Support Groups. Nicole Adam, Services and Volunteering Officer, reviews some of the tips given over the past few months…

Different equipment and aids are a staple subject at our Support Groups. One member has found that their legs were becoming quite swollen affecting their mobility, but they also found that the lack of movement made the swelling worse. They have been using an EMS machine, specifically designed for the feet, which has proved helpful. Electric Muscle Stimulation (EMS) machines are designed to stimulate the muscles for the purpose of strengthening and rehabilitating them. This member using an EMS machine had one made by Revitive which is a premium model. There are multiple options available online if you feel this is something that you might like to try but do not wish to spend as much.

Bodydryers have also come up at a few of our Support Groups now. There are multiple models available but in essence they blast warm air to dry you off after washing. They can be installed in a bathroom or a wetroom and our members say they can make washing more enjoyable as it keeps you warm afterwards while drying you off. They obviously do need to be properly installed. We would suggest you consult your Occupational Therapist before making any dramatic changes to your home both to make sure they are suitable for you and also to get recommendations as to where is best to purchase items.

Both pieces of equipment recommended above are quite costly. If you are considering investing in some expensive equipment it is always a good idea to try and test it out for yourself if you can. If that is not possible, try and get experiences from those with similar needs to see if you feel it is worth it for yourself. You could always check out what others think on our HealthUnlocked Forum (**www.healthunlocked.com/msa-trust**). A good place to sample equipment in-person is at a Disabled Living Centre if there is one local to you. These centres allow you to try multiple pieces of equipment without pressuring you to buy. Check online to see what is in your area - **www.focusondisability.co.uk/disability-aids-and-equipment-resources/disabled-living-centres-uk-regional-index**.

It is also always worth remembering if you are purchasing an item because of disability it may be VAT free so do check this before paying.

And finally, some useful advice was shared about emergency planning. In case of any unexpected hospital admissions, we always recommend keeping information about MSA and your specific needs easily available. We have produced our Hospital Information Folder for this reason and you can order one by contacting **support@msatrust.org.uk** or calling 0333 323 4591. Along with this, a member pointed out it can be useful to also have a few days' supply of any necessary medication available, in case of any delays if you are admitted to hospital. msa *news*

If you have any questions about anything mentioned on this page, please contact our MSA Nurse Specialists. You can find the Nurse for your area by visiting here - **www.msatrust.org.uk/support-for-you/nurses**.

Update us - Join us!

We take our responsibility around appropriately recording your personal details and data very seriously, and we therefore need your consent to add you to our database.

It is really helpful for us to have information on our database about people living with MSA and their carers and families. It ensures our MSA Nurse Specialists and Social Welfare Specialist can help you get expert help. Having an accurate understanding of numbers of people living with MSA also helps us to plan services, campaign and influence for appropriate support for people affected by MSA. It is especially useful to have your date of birth and your Doctors details. If you think we may not have this information for you, you can let us know these details by returning the form included in your initial membership pack or by emailing us at support@msatrust.org. If we don't hold these details for you, we may be in touch in the coming months.

Please also encourage family members and healthcare professionals to 'Join us' here - www.msatrust.org.uk/support-for-you/join-us or phone 0333 323 4591.

The more people know and understand about MSA the better and we want to reach and support as many people affected by MSA as possible. msa *news*

Support Group Invitations

One of the benefits of keeping us up to date with your contact details is that it means we can let you know about our Digital and any In-person Support Groups in your area.

Our Digital Support Groups are arranged roughly by Nurse area. We do this so you see a familiar face and hopefully will have a chance to talk to other people in your local area. We send the information for each area by e-mail so need to ensure we have a correct email address for you.

We are also cautiously putting together dates for the revival of our In-person Support Groups for the coming months. We let you know about any in your area either by e-mail or by post depending on how you have asked to receive invites. Due to Covid-19 restrictions we need to know if you are planning on joining, so we will not be putting the full details on our website as we normally would. Please get in touch if you have questions about specific Support Group meetings.

If you have any questions about Support Groups or are not receiving information about Support Groups but would like to, please do get in touch with James or Nicole at support@msatrust.org.uk or call 0333 323 4591. msa *news*

Prevention of Falls

Falls are a common symptom in MSA and there is specialist help available. If you are having issues with poor balance, do ask your GP to refer you to a local falls clinic. Services are varied across the UK but here Samantha Pavey, MSA Nurse Specialist, looks at what might be offered to you.

Most falls clinics are run by a team of professionals including Physiotherapists, Occupational Therapists, Nurses and Support Workers. They identify why someone is falling or is at risk of falling. They provide intervention to help maintain independence and prevent hospital admissions. If someone living with MSA should sustain an injury such as a fractured hip, the enforced bedrest and resulting hospital stay often means they don't return to their previous level of mobility. Adding in the current risk of Covid-19, it's clear hospital admissions are best avoided.

Falls clinics focus on increasing confidence and reducing the risk of falling. Intervention may include activities to develop muscle strength, balance and coordination. It may also include providing equipment or adaptations to your home environment. The team can also advise on performing activities of daily living safely. They will usually offer a home visit to undertake an assessment and offer advice to the person living with MSA, their family, friends and carers. Some clinics run local exercise or balance classes with many including chair-based exercise classes and group activities. Often a series of educational talks on falls related topics is offered, allowing group discussion and support.

Points to consider:

Balance:
Whilst people with MSA are at an increased risk of falling, balance reaction times reduce as we age, as do our reflexes. This makes it harder to regain balance, particularly when moving quickly e.g. turning. Balance is vital in ensuring you stay upright when over-reaching for items or if you trip up, and this can often be improved with regular exercise.

Bones:
As we age our bones become more brittle making fractures more likely if we do fall. Weight-bearing activities are good for maintaining healthy strong bones as is a diet with sufficient calcium. Vitamin D will help you absorb calcium and can be obtained through sunlight and from foods such as:

- **Oily fish – including salmon, sardines, herring and mackerel**
- **Red meat**
- **Liver**
- **Egg yolks**
- **Fortified foods – fat spreads and breakfast cereals.**

Muscle strength and joints:
Between the age 50-70 years old, 30% of muscle strength is lost. By taking regular strengthening exercise whatever your age, you may begin to feel a little stronger and more stable. It is recommended that you exercise for 30 minutes, five times a week, if possible. You can break this down into shorter periods if you fatigue easily.

Other factors for you to consider:

- **To reduce your trip or falls risk ensure that all rugs have a non-slip underlay and replace any that are worn**
- **Cable tidies allow you to organise jumbled cables by electrical equipment**
- **Ensure that walkways are free from clutter especially in your hall, landing, stairs and doorways**
- **Companion animals have a habit of staying close to us and people do at times fall over them - consider purchasing a brightly coloured collar or a bell to alert you of their location or presence.**

Useful information:
www.fallsassistant.org.uk & **www.asksara.dlf.org.uk**

msa *news*

MSA Trust *Christmas Raffle*

To take part in our raffle, simply fill out the order form on the back page and we will send your tickets out by post. Alternatively, you can enter by visiting our website - www.msatrust.org.uk/raffle.

If you have any queries please email us at fundraising@msatrust.org.uk.

The MSA Trust is licenced and regulated in accordance with The Gambling Act 2005 & the Small Society Lotteries (Registration of Non-Commercial Societies) Regulations 2007 under Registration Certificate R391. For full Terms and Conditions, please visit our website. The Multiple System Atrophy Trust is a charity registered in England as a limited company. Company Registration No: 7302036. Registered Charity No. 1137652 (England & Wales) and SC044535 (Scotland)

PRIZE DRAW
WILL BE ANNOUNCED
11TH JAN 2022!!

MSA Trust
Christmas Raffle

TOP PRIZES INCLUDE:

A WEEKEND GETAWAY IN A LUXURY LODGE AT THE SHERWOOD HIDEAWAY AT THORESBY PARK

A SIMON ROGAN AT HOME MEAL FOR TWO AND A SIGNED COOKBOOK

A LADIES SEIKO STAINLESS STEEL BRACELET WATCH

A RUNNING VEST SIGNED BY JESSICA ENNIS-HILL

A SIGNED COPY OF AWARD-WINNING PLAYWRIGHT SIR DAVID HARE'S NEW BOOK - WE TRAVELLED: ESSAYS AND POEMS

AND MORE!

SINGLE TICKETS: £5
STRIP OF 5 TICKETS: £20

FOR FURTHER INFORMATION AND FULL TERMS AND CONDITIONS, PLEASE VISIT OUR WEBSITE:
WWW.MSATRUST.ORG.UK/GET-INVOLVED/SUPPORT-US-THIS-CHRISTMAS/RAFFLE

Support us this *Christmas*

£3

Gift Wrap

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

Flat size: 50 x 69 cm

Maximum of 2 per order

£4

Advent Calendars

19 x 19 cm with postal envelope

Individually wrapped

Maximum of 2 per order

More items inside

Support the Trust this *Christmas*

£5 Christmas Cards

Each pack 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: *On this Holy Night may your heart be illuminated with Love, Joy and Peace. Happy Christmas*

A

B & C

D

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

No. of items	1	2 - 10	11 - 12	13 - 20
Postage	£1	£3	£5.10	£8.79

Our cards from last year are currently available at sale prices, and can be purchased online: www.msatrust.org.uk/product/christmas-cards

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 5 working days for items to arrive.

Name:...

Address:..

Telephone:.. Email:..

Raffle Tickets: I would like.......... individual ticket(s) (£5 each) / I would like.......... ticket strip(s) (£20 each)

Christmas Cards: A – The Blue Pear Tree (Qty)...... B – MSA Trust Snowman Directions (Qty)......

C – In the Winter Garden (Qty)...... D – Joy to the World (Qty)......

Advent Calendars: (Max Qty - 2) (Qty)......

Gift Wrap: (Max Qty - 2) Santa and Snowman (Qty)...... Floral (Qty)......

Merchandise payment £................. **Postage Payment** ○ £1 ○ £3 ○ £5.10 ○ £8.79

Total payment enclosed (for merchandise, raffle tickets & postage) £.................

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 **10th December 2021**.*