msa news
MSA Trust Members Magazine | Issue 63 | February 2022

Supporting your Emotional Wellbeing

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Welcome to Issue 63

Hello and a warm welcome to your first edition of MSA News in 2022.

First, we want to acknowledge the retirement of our Chair of Trustees, Clare Fowler CBE, after more than ten years of service. Our heartfelt thanks from us all go to Clare for all that she has done for the MSA Trust over these years. More on this, including information about our new Chair, on page three.

As always, we hope you enjoy the wide range of articles we have in this edition of MSA News from our Information and Services, Fundraising and Research Teams.

To highlight a few of these, we have the first article from our new Social Welfare Specialist, Sam Fitzgerald, which is about Retirement Age Benefits. This will be part of a series written by Sam so do look out this year for more helpful benefits and advocacy articles from her.

We also have two pieces in this edition written by our MSA Nurse Specialists. One covers Postural Orthostatic Hypotension, a common and difficult symptom of MSA, on page four. The other, on page 18, gives information about hospital admissions and planning for these where possible.

This is just a snapshot of what is included in your Spring edition of MSA News, so we hope you enjoy reading all the way through.

Emma and Andy. msa *news*

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NEWS ROUNDUP

A momentous change for the Trust

After more than ten years of service, Professor Clare Fowler CBE is retiring from her role as Chair of our Board of Trustees. She has expertly led the Trust and helped to forge a stronger, more resilient charity that continues in its mission to find a cure for MSA. Clare wrote our first research strategy before joining the Board and we are so thankful for all she has done for the Trust.

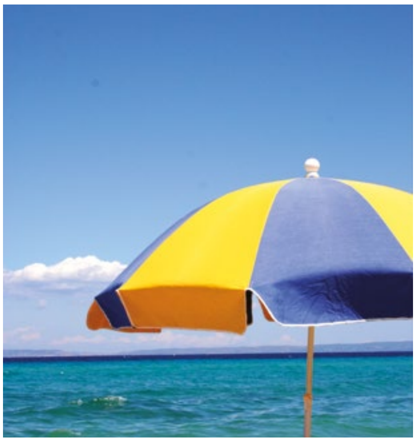

PROFESSOR CLARE FOWLER

From March 2022 we are delighted to welcome our new Chair, Professor Kailash Bhatia. He is based at UCLH and is a leading neurologist in the study and treatment of movement disorders. We look forward to the knowledge and experience Professor Bhatia will bring to the role. msa *news*


PROFESSOR KAILASH BHATIA

Travel insurance

As travel restrictions due to Covid gradually ease and the summer beckons, people will start to think of holidays. The Trust currently has a factsheet on Travelling and MSA which you can download here - **www.msatrust.org.uk/support-for-you/factsheets**.



We recognise that cover from insurance companies regarding travel has been subject to change during the pandemic. We currently include a list of possible companies who may offer travel insurance to cover medical conditions such as MSA, but we are very keen to know people's experiences of getting cover, whether these be good or inadequate.

Please do let us know whether you have been successful in getting travel cover and which companies you would recommend to others- and those you would not.

This will help us update our information so that people with MSA can continue to travel with confidence. Send your responses to **support@msatrust.org.uk**. msa *news*

A Transformational CAF Grant

We are thrilled to announce that the MSA Trust has been awarded a transformational grant from the Charities Aid Foundation (CAF) as part of their Resilience Fund initiative. The scheme was setup to help small charities like us adjust to the challenges that have been caused by the pandemic. Primarily this grant will be used to recruit two additional MSA Specialist Healthcare Professionals to our team and fully fund their roles until the Spring of 2023. Karen Walker our CEO said " We are very grateful to accept this key piece of grant funding to help us support our community as we rebuild from the pandemic. This funding is a vote of confidence in our work, our purpose and our determination to improve the lives of the people affected by MSA." msa *news*

Project Euphonia

Google are looking to improve how well speech recognition systems (like Alexa or your mobile phone voice recognition) understand people with speech problems. Taking part involves recording yourself reading lists of words and phrases at home. A professional speech and language therapist will support you with this, and they offer a £50 gift voucher. If you would like to find out more, email **project.euphonia@lsvtglobal.com** or follow this link **www.docs.google.com/forms/d/e/1FAIpQLSeWrslavjCepFh7gQcxSYFd2h59kSIMZmJDyK8Nk3fhcM51lg/viewform** and someone will get in touch with you with more information. msa *news*

Managing Postural Orthostatic Hypotension

One of the common issues people with MSA experience is controlling their low blood pressure. Our MSA Nurse Specialist, Katie Rigg, describes the management and treatment options for this, called in medical terms Postural Orthostatic Hypotension.

Our autonomic nervous system plays an important role in helping keep blood pressure (BP) at the ideal level to keep us well. In MSA we know the function of the autonomic nervous system can be impaired and 70% of people living with MSA will develop some degree of BP problems.

Postural Orthostatic Hypotension (POH) and MSA

The most common BP problems in MSA are episodes of POH – which means that the BP reading drops significantly, by 20 or more in the top number and 10 or more in the bottom number, whenever the person changes position and mostly when they stand up. These numbers relate to the pressure in the blood vessels when the heart beats and relaxes. Normally the autonomic nervous system would detect the change in position from lying to sitting and sitting to standing. The elasticity of the blood vessels and the pressure the heart has to pump at is adjusted to keep a good blood supply in the upper body and particularly to the brain so we don't pass out. In MSA, this reaction is impaired.

> **People with MSA should have their blood pressure recorded whenever they attend their clinic appointment. This reading should be taken when the person is seated and then repeated with them standing for 1 and 3 minutes, if possible. The time delay in taking readings can help determine if the low reading is due to problems with the autonomic nervous system rather than just because someone stood up too quickly.**

The pulse recording that the machine also takes is important for this purpose, as usually the heart rate would increase to compensate for the low blood pressure. If the autonomic system is not as responsive as it should be, then the heart rate may not alter even though the BP has dropped.

The Consultant may organise for further tests to be done such as a 24-hour blood pressure reading, or some basic blood tests for anaemia or thyroid function that may be increasing the problem. It is also worth having a medication review to check that any current medications are not triggering a lower BP.

Everyday triggers of POH

Symptoms usually occur at the time of position change or if someone stands in the same position for a long period of time. For some people it occurs after eating when the blood supply is drawn to the gut to assist digestion, but can also happen if there has been a prolonged period between eating. Not drinking enough is a common cause of fainting too, so if you have MSA it is important to keep well hydrated.

Straining to open the bowels can trigger episodes as can sitting for long periods in direct sunshine or hot rooms.

When someone with MSA has an infection they may be more susceptible to episodes of variable BP.

Symptoms of POH

POH can cause lightheadedness, blurred vision, confusion, nausea and weakness.

Prolonged spells of lower than ideal BP, rather than a sudden drop when you change position, may cause achy pains in the larger muscles that need a good blood supply. For example, the 'coat-hanger pain' across the neck and shoulders, low back pain or aches in the muscles at the top of your arms and legs. Having a low BP can also make you feel persistently tired and weak.

There are practical measures that can reduce or even prevent the drop in BP, but additional medication to boost BP may also be required.

The key messages are:

- **Everyone with MSA should get regular blood pressure recordings done at their neurology or movement disorder clinic**
- **A review of medications or further tests may be needed if your blood pressure reading is consistently low**
- **If you experience symptoms of low blood pressure try to identify if there are any triggers and avoid these**
- **Keep well hydrated – drinking 2 litres a day; water is quickly absorbed and beneficial**
- **Put into practice the practical measures suggested below.**

msa *news*

All the information given here is in our Postural Hypotension factsheet on the website **www.msatrust.org.uk/support-for-you/factsheets** or it can be posted to you. Contact your MSA Nurse Specialist for further support.

Practical Measures to reduce POH

- Do not lie completely flat
- Do leg exercises
- Get up slowly
- Drink plenty
- Add salt to your food if advised
- Eat small meals more often
- Avoid constipation
- Wear an abdominal binder
- Wear support stockings
- Keep cool
- Take your medicines on time

Living with MSA: *The Emotional Impact*

In response to feedback from members regarding the impact of MSA on their emotional wellbeing and mental health, we recently launched a new online and printed resource: ***Living with MSA: The Emotional Impact***. Mary Norowzian, the accredited counsellor who helped us develop this resource, gives an overview for members…


MARY NOROWZIAN

The emotional impact of MSA is considerable and brings great challenges, however little information or support for emotional wellbeing and mental health has been available to people affected by MSA. This makes it more difficult to know what support is available or to ask for help when you need it. **Living with MSA: The Emotional Impact** aims to help make that a little easier. Suggestions and ideas for looking after your emotional wellbeing are included as well as information about the kinds of support that are available and how to access help, whether you are living with the condition or supporting someone close to you.

As a wide range of information is included, the resource has been divided into six sections, making it easier to find what you need, with links between each section and to other relevant resources. You may decide to read it a little at a time, to dip in and out of the sections that are of most interest, or to revisit it as and when you need to. You may also wish to share the resource with family, friends or health and care professionals as a way of helping them understand how it can feel to live with MSA.

Being able to make sense of how you are feeling can be an important step in coping with MSA and in looking after your emotional wellbeing. The first section: **The Emotional Impact of MSA**; explores the wide range of thoughts and feelings that many people living with MSA experience from the point of diagnosis onwards, such as fears about facing an uncertain future and feelings of grief. The possible impact on mental health and wellbeing is explored, including information about anxiety, feelings of panic, worry or low mood and when it may be helpful to seek professional support.

It is not always easy to talk about the impact that MSA has on close relationships and the second section: **MSA and Relationships** aims to address this. Individual coping styles are explored, as is the impact of needing personal care. There are suggestions for ways of letting people know how MSA is affecting you, including talking to children and young people. This section also includes how it can feel to support a person with MSA, with information about specific sources of support for carers.

The link between emotional and physical wellbeing

is often overlooked even though they are closely connected. **Looking After Your Emotional Health and Wellbeing** is therefore very important and can bring great benefits. This third section suggests ways to care for your wellbeing, from simple daily activities through to planning for the future as a way of taking back some sense of control. Information about techniques such as relaxation and mindfulness are included, along with suggestions about ways of expressing feelings and maintaining communication.

The fourth section: **Building Your Support Network** suggests ways you can develop a circle of support to help you and the people closest to you. Suggestions are given to help you ask for or accept specific help from family and friends, the challenges and advantages of having paid for care are explored, and information is provided about peer support, the MSA Trust Support Groups and pilot befriending scheme.

Just as with your physical health there may be times when you need **Professional Support for your Emotional Wellbeing** and the fifth section explores this. Although psychological support is not routinely provided to people living with MSA, there are sources of support that you may be able to access and benefit from. There are suggestions about speaking to your GP and other health and care professionals, the role of medication, as well as information about self-help resources. The role of hospices in providing a range of free or low-cost emotional support or counselling is included, as is the role of complementary therapies in emotional wellbeing.

Finding a counsellor or therapist can feel daunting, therefore detailed information about counselling, talking therapies and creative arts therapies is given, with suggestions about sources of funding and ways therapy can be adapted to be accessible.

The final section of the resource is **An Index of Resources** which lists all the external resources and organisations that have been mentioned throughout.

Living with MSA: The Emotional Impact can be found at: www.msatrust.org.uk/support-for-you/for-people-affected-by-msa/living-with-msa-the-emotional-impact.

If you would prefer to receive a free printed booklet, just call the office on 0333 323 4591, email support@msatrust.org.uk or contact one of our MSA Nurse Specialists. msa *news*

Our thanks go to Mary for helping us develop this new resource, available free of charge to anyone affected by MSA.

In Memory

Martin Evans
Lilian Bowker
Trevor Venables
Maureen Wood
John Lally
Margaret Lemon
Vasilios Petsas
David Boisseau
Margaret Jellings
Paul Jones
William Eaglestone
Michael Huntley
Robert Skelton
Nicholas Lowe
Tony Jones
Alan Henderson
Raymond Amer
Hilary O'Doherty
Mark Sims
Shirley Kendall
David Kempen
Gilly Middleburgh
Kathleen Nicol
Barry Mitchinson
Susan Mayers
Paul Lister
Jenny Woolcock
Barbara Berks
Francoise Webb
Sandra Peaks
David Emery
Michael O'Loughlin
Carole Barrow
Eric Teare
Sandra Waldron
Anthony Buttle
James Moran
Mary Suzanne Myler
Martin Wildsmith
Arthur Dowell
Jon Smith
Lindsay Jones
Sharon Adams
David Gibson
Mark Graves
Donald Strathearn
Andrew Bailey
Stephen Beale
Susan Woolley
Angela Doherty
Debbie Boobier
Marie O'Sullivan

MSA Candlelight: A Time for Remembrance and Hope

The Trust's memorial event, MSA Candlelight, is an opportunity for family and friends to come together for a message of hope – the hope that with continuing research into MSA, we will find its cause and, eventually, its cure.

On the day there will be music from a local choir, poetry read by families affected by MSA and afternoon tea. All funds raised will be allocated to the pioneering research that we are conducting into MSA, and so, we will also be providing an update on what we have discovered so far. Finally there will be a dedication to those who we have sadly lost to MSA. For this, we will enter the name of your loved one into our special Book of Remembrance and light a candle in their honour.

To fund research into MSA and help cover the event's expenses, we are asking for a suggested donation of £12 per attendee with a maximum of five people per party. If you are unable to attend, we can still enter your dedication in the Book of Rememberance and have a copy sent to you after the event. Again, we would ask for a suggested donation of £12.

Date: Saturday 14th May 2022
Venue: Yatton Village Hall, The Causeway, Yatton, Bristol BS49 4HL
Time: 2.30pm - 5.00pm

To buy tickets or to send a dedication you can donate online at www.msatrust.org.uk/msacandlelight, call us on 0333 323 4591 or send a cheque payable to 'MSA Trust' to 51 St Olav's Court, City Business Centre, Lower Road, London SE16 2XB.

If you would like to attend or to have your dedication included in our Book of Remembrance, please contact us by Friday 18th March. msa *news*

MSA Awareness Week

We are all too aware that as MSA is a rare and little-understood condition, it struggles to get the attention it deserves. MSA Awareness Week is a chance to change that. From Monday 21st March 2022 to Sunday 27th March 2022, we want to highlight MSA to the world. Increasing awareness increases understanding and hopefully leads to greater resources for a cure.

So how might you help us this MSA Awareness Week?

- Follow, like and share our posts on social media to help us spread the word
- Wear one of our enamel pin badges - you can order these from our online shop
- Suggest us to businesses for their end of financial year charitable donation or for MSA Trust to be their new Charity of the Year

- If you feel able, make your own one-off or regular donation to the Trust
- Host a tea party, a quiz night, or even a karaoke contest in your local community
- Or take up a week-long sponsored challenge – whether it's running your first 5k; mastering your marathon; finishing War and Peace without skipping a bit; or completing a 10,000-piece jigsaw puzzle.

For more information or to get involved, please visit our website, email fundraising@msatrust.org.uk or call 0333 323 4591. msa *news*

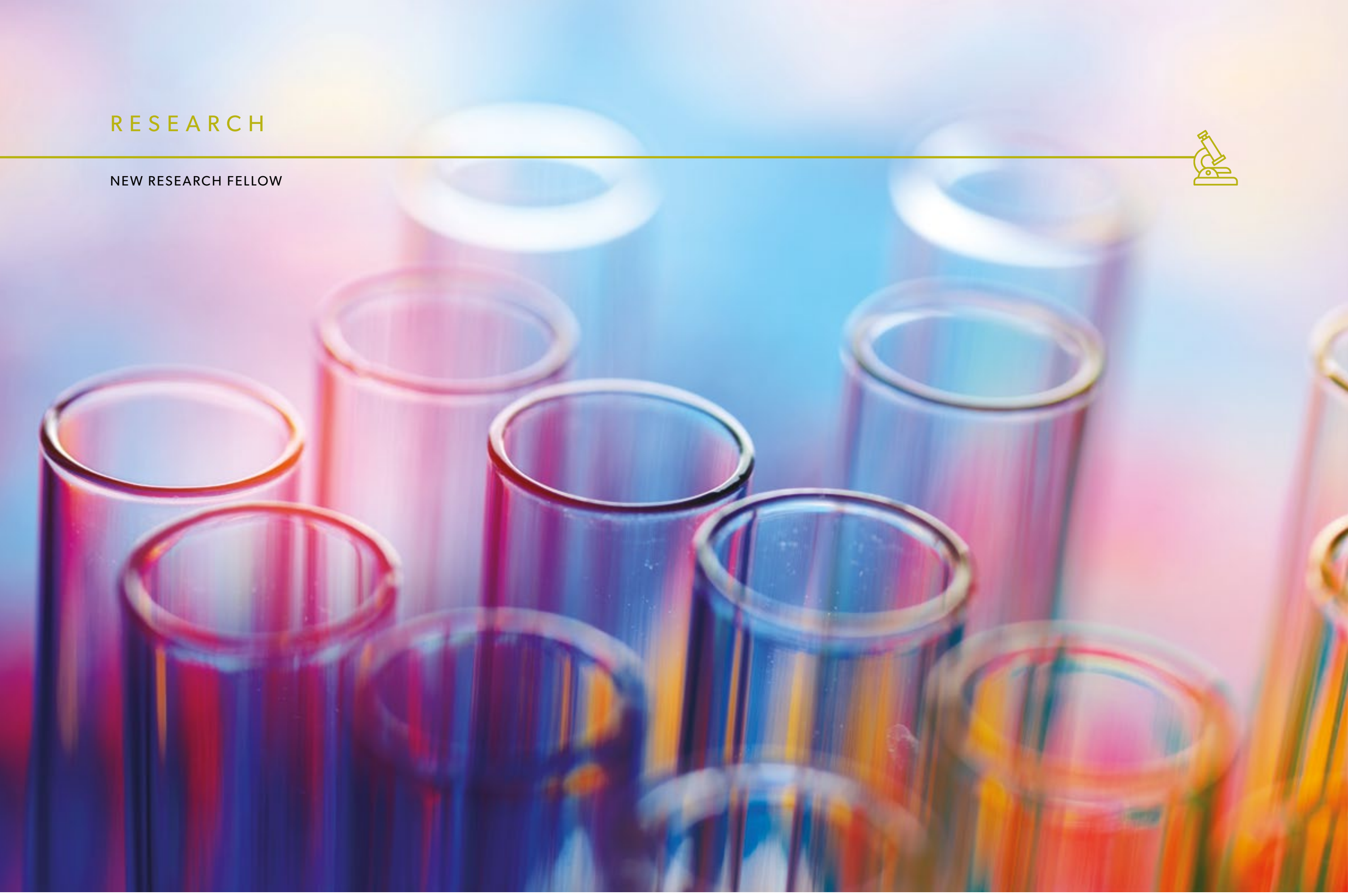
25 Years of the MSA Trust

This year, the MSA Trust will be celebrating a very special birthday as 2022 marks 25 years since we were first founded. A quarter of a century later, a great deal has changed, and we're planning lots of ways to celebrate how far the MSA community has come. So, grab a slice of cake, put on your best party hat and let's toast to 25 years of supporting each other. Here are just a few of the ways that we will be celebrating this momentous milestone:

- **25 for 25** – Later in the year, we will be recognising 25 key people or groups who have helped to shape the MSA Trust into everything it is today
- **The Summer Social** – Covid permitting, we will be transforming our traditional Summer Social at Thoresby Hall, Nottinghamshire into a special 25th Birthday Party

- **The Virtual Meadow** – In the summer, we will be bringing the MSA Community together to share in the beauty of our Virtual Meadow, where a photo collage of your homegrown flowers can be uploaded in exchange for a small donation - symbolising the growth and developments that we have made; and sharing the hope that together, we will find the cure to MSA.

Look out for exciting updates coming to our website in the spring; or email fundraising@msatrust.org.uk for more information. msa *news*



Our new Clinical Training Research Fellow, Dr Yee Yen Goh

I grew up in a small town called Kuantan on the east coast of Malaysia and went to school in Singapore. I then came to London to study medicine following in the footsteps of both my doctor parents.

My first job was in Liverpool, doing general clinical work and neurology research. I then returned to London to complete the rest of my general medical training and finish my post-graduate exams. I spent a year as a National Medical Director's Clinical Fellow to the President of the Royal College of Physicians, gaining experience in national health care policy.

More recently I have been a Neurology trainee in London and completed a rotation in movement disorders at the National Hospital for Neurology and Neurosurgery, including a movement disorder outpatient clinic, gaining experience with Parkinsonian syndromes such as MSA.

My dad always says, 'listen to your patients, they are the only people who know what's wrong'. Truer words were never said. All patients' stories are unique, with different constellation of symptoms, priorities, and challenges, more so in conditions affecting multiple body functions such as MSA. I find developing personalised treatment plans together with my patients immensely fulfilling. However, there is still much we don't know about MSA, which has prompted my involvement in research.

DR YEE YEN GOH

Since starting as the Association of British Neurologists /MSA Trust Clinical Research Fellow, I conduct an MSA outpatient clinic as well as recruit MSA patients for the PROSPECT-M trial. I've been formulating research plans with already collected data and planning future collection protocols. Due to COVID-19, I've been working on amending PROSPECT-M ethics to include remote online patient participation. I'm really looking forward to the next three years, and hope that the work I do will bring us closer to understanding and treating MSA.

Completed, current and upcoming trials – an update

Biohaven's trial of Verdiperstat in MSA failed to show any benefit in a recent phase 3 clinical trial into whether it slowed the progression of MSA. There was no significant difference found when comparing Verdiperstat to placebo. Although disappointing, Biohaven said "We are hoping that this global MSA study - the largest ever conducted - will help further research for MSA".

Theravance Biopharma also have announced that their phase 3 study of ampreloxetine for the treatment of orthostatic hypotension did not show a significant improvement when compared to placebo. Due to this, the ongoing Redwood and Sequioa studies were sadly stopped early.

Currently, there are three studies- Exenatide, Prospect-M and Synaptic loss Imaging studies which are open and recruiting participants with MSA. More details can be found on the research section of our website - **www.msatrust.org.uk/cause-and-cure**.

Alterity Therapeutics have announced that they will be starting a phase 2 trial of new candidate ATH434 in people with early-stage MSA in 2022. The study will examine if the molecule can inhibit the accumulation of protein in the brain, seen in neurodegenerative conditions.

The Trust's own Research Grant Programme's latest funding round is currently underway, with successful projects expected to begin in the Autumn of 2022.

One of our existing grant funded projects is lead by Dr Christos Proukakis at UCL. An update on the project is given below by Christos:

'Investigation of somatic DNA copy number gains of SNCA (alpha-synuclein) in different brain regions in MSA subtypes'

The cause of MSA remains unknown, although accumulation of the alpha-synuclein protein into 'clumps' may play a key role. Mutations in this and other genes are not at first glance an obvious candidate, as the condition is not inherited. However, there is increasing evidence that DNA in the brain may acquire mutations, termed 'somatic', during development or ageing. Mutations leading to extra copies of the alpha-synuclein gene could lead to increased protein levels, and eventually disease, while mutations in other genes could also compromise the cell normal function. Even a low level of cells with mutations could be detrimental, especially if excess protein could then spread to other cells.

DR CHRISTOS PROUKAKIS

We have already reported that extra copies of the alpha-synuclein gene are present in a small proportion of brain cells (less than 1 in 10) from individuals who had lived with MSA or Parkinson's disease. When we then analysed the entire genome of single brain cells in MSA as 'proof of principle' in two individuals we detected additional or missing copies of large DNA stretches in almost 1 in 3 cells.

The generous funding by the MSA Trust has allowed us to expand our investigation. We are analysing the alpha-synuclein gene in more brain regions and comparing them between people with different MSA symptoms. We can thus determine whether a higher proportion of cells with mutations in a given region corresponds to that region being more severely affected. We can also investigate this relationship at the single cell level, and our results suggest that certain cells with extra gene copies are much more likely to have protein clumps. These findings suggest that the mutations may be directly driving the disease process. We are also trying to determine whether cells known as oligodendrocytes, which are the most affected in MSA, have the highest levels of mutations.

Detecting extra or missing copies of genes does not give us all the details we need to understand the DNA changes. The technology required is advancing rapidly, and we are now aiming to combine different ways of analysis of DNA both from the brain tissue overall, which need to be sensitive enough for low levels, and from individual cells. We hope to build on this work further, as it may provide a piece of the puzzle into why MSA occurs in the first place. msa *news*

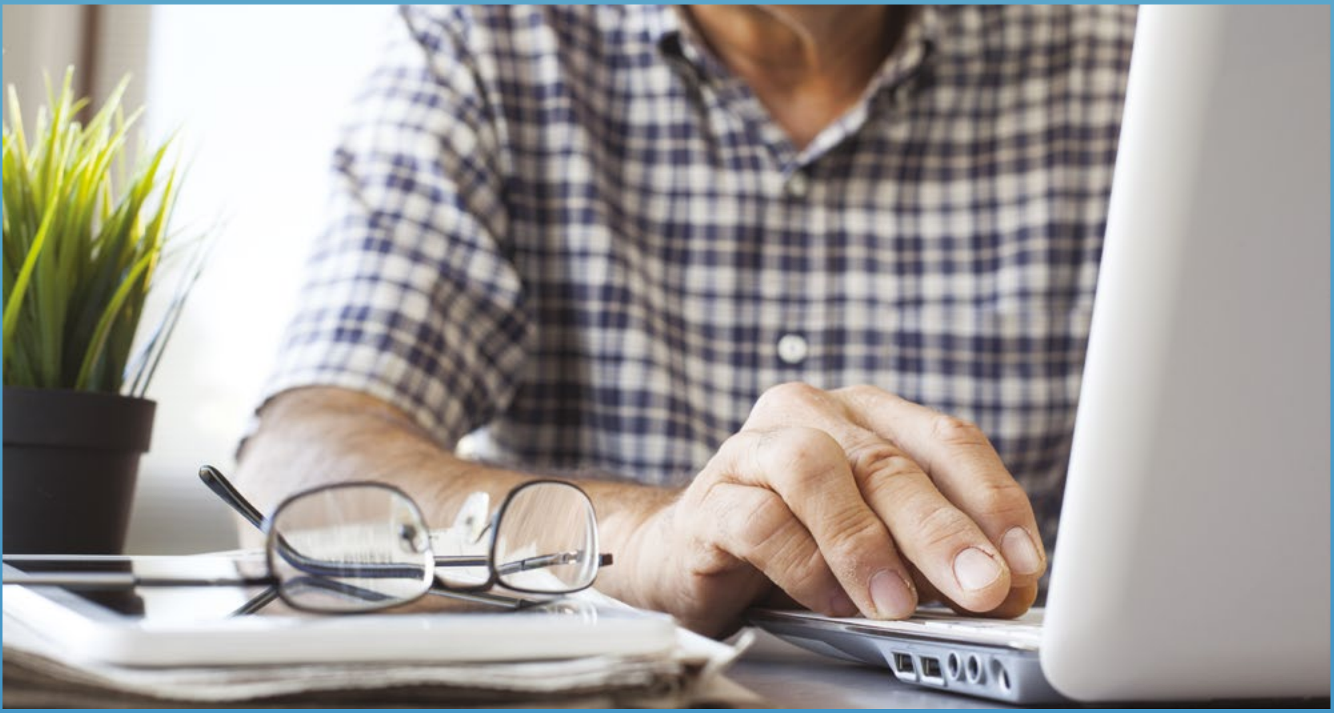
Are you over state retirement age? Please don't miss out...

The Trust aims to support anybody affected by MSA to get all the services, support and benefits they may be entitled to. Here, Sam Fitzgerald our Social Welfare Specialist, outlines some of the benefits you may be entitled to if you've reached retirement age...

Many people of retirement age may never have claimed benefits before. Often people imagine that they are not entitled to benefits, perhaps because they have savings, or a good pension, or they or their partner are in employment. They may be mistaken and could be missing out on money they are entitled to, money which may assist with additional expenses or help enhance quality of life.

Attendance Allowance (AA):

AA is a benefit that can be paid to people who are of state retirement age who require assistance with their personal care and/or supervision. You don't have to be receiving this assistance to qualify. If you live alone you can still apply.



AA is not means tested or taxed. It is paid at one of two rates and is worth up to £89.60 a week.

If you were already receiving Personal Independence Payment (PIP) or Disability Living Allowance (DLA) prior to reaching state retirement age, you will remain on this benefit instead of AA. This is usually a good thing. In this case do ensure you are on the correct rate of the mobility component before you reach state retirement age as after that it cannot be increased. There is no mobility component to AA so if you are approaching state retirement age please contact our Social Welfare Specialist if you wish to discuss applying for PIP. You cannot apply for PIP after reaching state retirement age.

Receiving AA may enhance certain other benefits and may entitle any unpaid carer you have to Carers Allowance (restrictions apply, especially note those relating to the carer's state pension – see: **www.gov.uk/carers-allowance**).

To apply for AA see: **www.gov.uk/attendance-allowance** or call the AA Helpline on 0800 731 0122. We have a factsheet on AA: **www.msatrust.org.uk/factsheets/aa**.

Pension Credit:

This is a means tested benefit that Age UK say nearly a million pensioners are entitled to but not getting.

The amount payable depends upon your circumstances. Having a disability or housing costs are two of the factors that may increase what you are eligible to receive. If you receive Pension Credit it can entitle you to other help – for example Housing Benefit, a reduction in your council tax, or help with the costs of your mortgage interest payments.

If you are a couple you can only apply for Pension Credit if both of you have reached state retirement age. That is unless one of you is currently receiving Housing Benefit for people over state pension age. Otherwise Universal Credit (or existing means tested benefits you receive including tax credits) remain relevant.

See: **www.gov.uk/pension-credit** or call the Pension Credit Helpline on 0800 99 1234 for more information.

There is a pension credit calculator at: **www.gov.uk/pension-credit-calculator**

Housing Benefit:

Housing Benefit can help pay your rent and/or some service charges. You can usually only apply for Housing Benefit if you, and any partner you have, are both over state pension age but there are exceptions (for example, if you live in sheltered or supported housing). If you receive Pension Credit you can apply via the Pension Service for help with housing costs otherwise contact your local council.

Council Tax/Rates Reductions and Support:

You may be entitled to help with your council tax or rates. Contact your local council or see their website for more information. This help may be means tested or you may be eligible on a range of other grounds. For example, you can sometimes obtain a non-means tested reduction in your council tax if your home has been adapted for a disabled person (such as, an additional room has been added or the property made wheelchair accessible) or if someone has a severe mental impairment.

General information:

Remember that it is important to tell the benefits agencies about any changes which may affect your entitlements. For example, if you start receiving Attendance Allowance, if you move home or if you start or stop living with a partner. These changes may affect your entitlements in a positive or negative way.

There are small differences across the countries of the UK. Please note that the system in the Republic of Ireland is completely different and is not covered here. Advice on entitlements for those in the Republic of Ireland can be obtained from Citizens Information **www.citizensinformation.ie/en**.

UK residents may find it helpful to use a benefits calculator such as: **www.turn2us.org.uk** or **www.entitledto.co.uk** to see what they may be eligible for.

Further information (ensure you are reading the pages relevant to the UK country you live in):

Citizens Advice: **www.citizensadvice.org.uk/benefits** or contact your local office.

Age UK: **www.ageuk.org.uk/information-advice/money-legal/benefits-entitlements** or call 0800 678 1602

In Scotland: **www.mygov.scot/benefits-support** or call their MoneyTalk Team on 0800 085 7145 msa *news*

This year in MSA News we will also be including articles covering benefits under retirement age and paying for residential or personal care. Whether you're of working age, approaching retirement or over state retirement age, if you need more information or support with benefit related issues, please get in touch with us. Our Social Welfare Specialist will be happy to help.

Manchester Marathon Family Duo

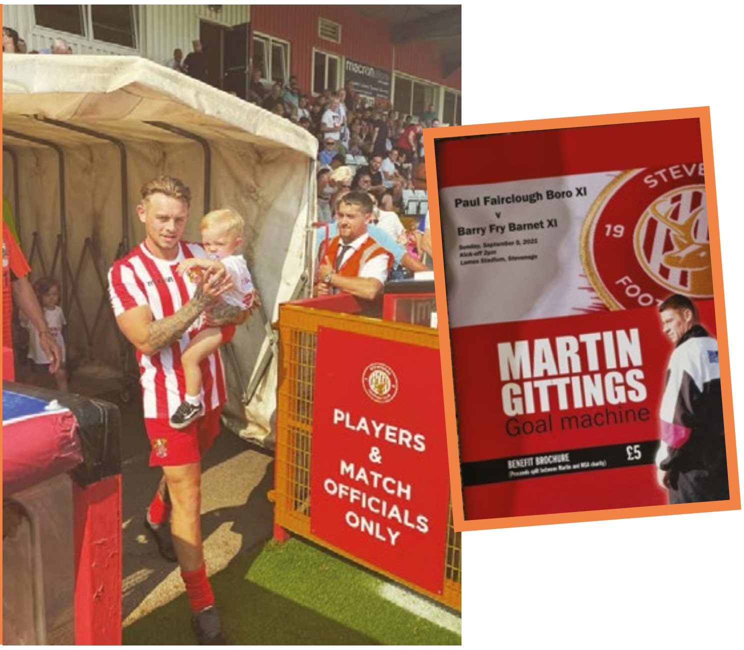
We had two inspirational families separately take part in the Manchester Marathon last year. Sisters Rachel Thilwin and Rebecca Majchrzakowski and the Swanborough combo of father, Andrew and daughter, Jasmine, ran the 26.2 miles through the heart of the city. The siblings ran in memory of their father Brian Thilwin whilst the Swanborough family ran in support of Mark Eccles which resulted in them collectively raising £2,650. What superb family achievements!

Festive Family Fun

James Darvil and his daughter Gabby took part in the celebratory 'Santa in the City' Run in London to support our Big Give Campaign. Dressed up as the wonderful Father Christmas, they completed the 5km challenge and did an amazing job raising £515 in memory of James's dad. Well done to you both!

Community Fundraise for a Community Champion

Neil Trebble, Stevenage FC and Barnet FC (and many others), organised a benefit football match to raise funds in support of Martin Gittings. The team arranged a number of events to promote the MSA Trust which included a charity football match that took place in September. Martin is a record goal scorer for Stevenage FC and is described by his community as 'touching the lives of many' with his commitment to helping disadvantaged young people through college, work and further training. His compassion and commendable gestures don't go unnoticed as his friends from different avenues joined forces to support him by helping to spread awareness of MSA, which Martin is currently living with. As a heartfelt thank you, they managed to raise an incredible £8,151 through their various fundraisers. Thank you for all your amazing efforts!



Paul Fairclough Boro XI
v
Barry Fry Barnet XI
Sunday, September 5, 2021
Kick-off 2pm
Lamex Stadium, Stevenage

MARTIN GITTINGS
Goal machine

BENEFIT BROCHURE
(Proceeds split between Martin and MSA charity)
£5

Paul's Victory Desert Trek

Amateur ultra-runner, Paul Weeks, shares his incredible experience of participating in the most infamous race on earth: the Marathon des Sables (MdS) - a gruelling six-day race of 156 miles (254 kms) in the searing heat of the Sahara Desert while carrying everything you need, including water. After training for two years, Paul entered the 35th instalment of this epic challenge in October 2021.

So, why do it?

He explains ***"My Dad, Phil, suffered with MSA from age 40 to when it finally beat him aged 63. It rendered him unable to do most physical things, which was devastating for him, but I never once heard him complain. When I reached 40, I decided to start really testing myself physically. 10 years later, I was at the MdS start line!"***

When describing the MdS, Paul uses the word "brutal", having battled through the +50°C heatwave that resulted in it being the hottest race in the event's history. He also encountered a nasty gastro bug that infected the entire camp and found the race to be "by far the hardest thing" he had ever attempted.

Despite the adversity, Paul was hugely successful – being one of only 351 people to complete the course from 673 starters - and finishing in 77th place, raising an amazing £3,900 in the process.

He concluded, ***"Compared to 23 years living with MSA, the pain was nothing and to raise the money we did for MSA Trust - that will directly help people suffering from MSA now - made it all worthwhile"***.

Thank you so much, Paul - we're thrilled to have been a part of your incredible challenge! msa *news*

Your Generous Giving This Christmas

Thanks to your stunning generosity, we smashed our target for The Big Give raising an incredible £6,025 for our Welfare Grant Scheme. This means that we now have a dedicated pot of funding available to those who are in need of it most, ensuring that the season of giving will carry on through 2022 and beyond.

We're thrilled to announce the winning numbers of our hotly anticipated 2021 Christmas Raffle in the panel on the right. Congratulations to all our lucky winners and our sincere thanks to everyone who chose to participate – helping us to raise £1,420 for the Trust which will go directly to supporting people who are affected by MSA.

We also wanted to say a huge thank you to everyone who supported our work this festive season by purchasing items from our Christmas Shop. In total, we sent out over 400 separate orders, raising over £10,000 for the Trust - an incredible gift from you to us. Thank you! Is there something we should be adding to our 2022 Christmas Shop? Email us at fundraising@msatrust.org.uk and let us know.

We are also so grateful to those of you that donated through 'Don'tSendMeACard.com' over the Christmas period. Although we would like to thank you individually, the website prevents us, but we can confirm we have received your contributions. From all of us to all of you, a massive thank you for your donations.

msa *news*

1st Prize	00317
2nd Prize	00214
3rd Prize	00241
4th Prize	00257
5th Prize	00152
6th Prize	00076
7th Prize	00050
8th Prize	00199

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

Supporting & Helping Each Other

We greatly appreciate the support and input of our members as they have continued to share their 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...

Tips for making everyday activities easier are always welcome at our Support Groups, and recently we had several positive ideas for eating and drinking. Remembering to drink enough liquids, whether that be tea, squash or water, can be challenging and constantly being reminded to drink by family members can be frustrating. An electronic reminder can be helpful in these situations. Some of our members set a regular alarm but another alternative is a device you can attach to a glass or bottle that flashes regularly. The light alerts you to take a sip, which can be a much gentler reminder than an alarm and saves any family members from having to remind you! There are different options and styles available online depending on your preference, the 'Ulla' hydration reminder can be bought on **www.amazon.co.uk** (remember to use Amazon Smile!).

A challenging aspect of mealtimes if you need to eat at a slower pace, is that your food can go cold making it less appetising. Something that can help in this situation is a heated plate. Again, like the hydration device, there are different options available. Some are electronic while others allow you to put a small amount of boiling water into the plate turning it into a thermos which helps keep your food warmer for longer. The 'Thermo Plate' can be bought from **www.completecareshop.co.uk**, alternatively talk to you Occupational Therapist as they may be able to provide other options or suggestions.

Co-enzyme Q10 is a herbal supplement that has been mentioned at several of our Support Groups. Some members have found it useful as a method of helping to alleviate fatigue. It is not available on prescription as it is a herbal remedy so has to be purchased privately, however this does mean it can be tried by either carers or people with MSA. It is generally sold as capsules though some members have tried it as a spray under the tongue and found it to be effective. As it is herbal it can be used with most other medications, though if you have any questions you should consult your GP or MSA Specialist Nurse before taking anything. The supplement can be ordered online at reputable websites such as **www.naturesbest.co.uk** or **www.healthspan.co.uk**.

Finally, a useful recommendation to try and minimise costs if you are paying for your prescriptions was shared in one of our digital groups. As prescriptions are usually charged according to each time it is filled, rather than the quantity of medication, make sure that your GP is prescribing you the maximum dosage per prescription. This should mean you refill your prescriptions less often costing you less overall and hopefully saving you time and hassle as well. It may also be worth checking if a Prescription Payment Certificate (known as a PPC) could save you money. This allows you to pay a fixed amount over three or 12 months and covers all your prescription costs in that period.

You may well be entitled to **free prescriptions** so please check with our Social Welfare Specialist. 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**.

Our Support Groups – *An Update*

As many of you will know the way we deliver our Support Groups has changed over the last couple of years.

At the start of 2020 all our Support Groups were in-person at over 40 locations throughout the UK, Northern Ireland and the Republic of Ireland. Like the rest of the world this had to change dramatically after the emergence of Covid-19 and our groups went exclusively online for over 18 months. Towards the end of last year, we cautiously started bringing back some of our in-person Support Groups on a trial basis. We were grateful for the efforts made by all those who attended to help manage the risks of our in-person Support Groups and after the meetings we were so pleased to hear from members who enjoyed attending and said they wanted to come again.

We did not take the decision to restart our meetings lightly. It continues to be difficult to balance the best interests of our members and their desires to meet in person, whilst still managing the changing risks of Covid-19. The safety of our members and volunteers is always our priority. Unfortunately, the Omicron variant forced us to adapt our Support Groups once more for the safety of our members and we had to cancel our groups again at the start of this year. We are hopeful that we may be able to start in-person meetings again in the Spring. The latest information for our Digital and In-Person Support Groups can be found on the calendar on our website - **www.msatrust.org.uk/calendar/category/support-groups**.

Our digital offering now includes regional Support Groups attended by our MSA Trust Nurses, Monthly Coffee Morning Socials and we will be launching a Monthly Carers meeting soon as well. If you are concerned you are not receiving information about any of these contact us at **support@msatrust.org.uk**.

Recruiting Support Group Leaders

One thing that has become clear as we try to re-start our Support Group network is how vital our Support Group Leader volunteers really are. Without them we would likely have held no in-person Support Groups at all in 2021.

Understandably, over the last two years some of our previous leaders have stepped down and are no longer able to support our meetings. This means there are certain locations where we are specifically looking to recruit new volunteers for in 2022. To see these areas please visit our website **www.msatrust.org.uk/get-involved/volunteering/volunteering**.

Our MSA Trust Support Group Leaders:

- Liaise with local venues on behalf of the MSA Trust to book rooms for meetings
- Attend on the day and help arrange refreshments for members
- Are prepared to host meetings when our MSA Nurse Specialists are unable to attend
- Help arrange outside speakers – such as Physiotherapists, Nutritionists etc. from your local area.

If you believe you could take on this role, please get in touch at **volunteer@msatrust.org.uk** for more information on the application process and to see which areas require support. msa *news*

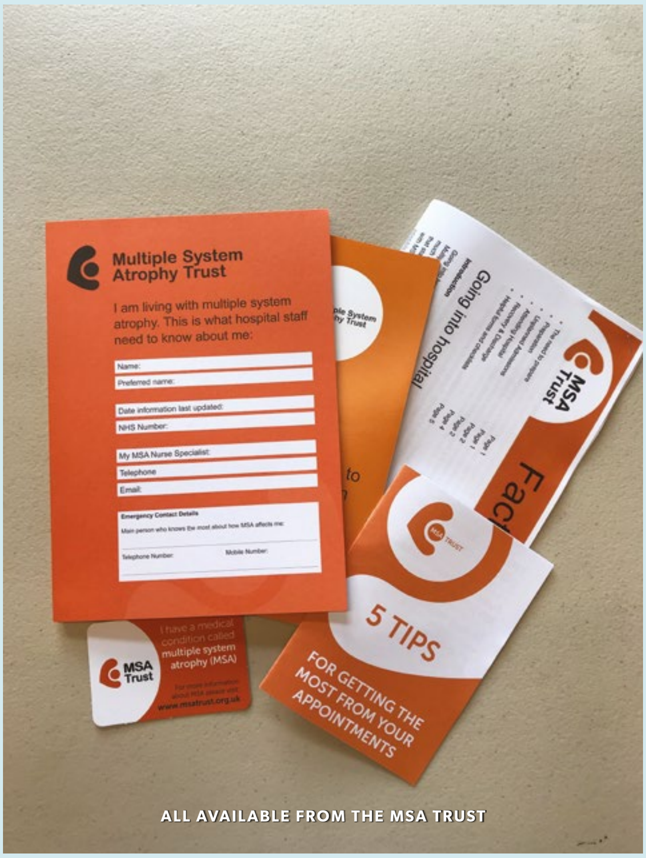
Making a Hospital Stay Easier

In this article, Samantha Pavey, MSA Nurse Specialist, looks at practical ways to prepare for an emergency or planned admission into hospital.

Any hospital stay, planned or unplanned, can be a bit of a trial. Unfortunately, many of the staff looking after you may not have much knowledge of MSA and how it might affect you. We would recommend you plan in advance for any eventuality and make sure you have to hand both equipment and medication that you use, and basic information about MSA which you can show staff. Here is a handy summary of what you might take with you:

- ***A Guide to MSA.***
- ***MSA Trust Nurse services information sheet***
- ***Our Going into Hospital factsheet -which includes sections on communication, sleeping, moving around, eating & drinking, bladder & bowels, along with any other information you wish to add. This helps staff identify what assistance you might need during your stay. There is also a contacts sheet, so you can complete names and telephone numbers of people who help you at home. Keep this in your 'Hospital Information Folder' (also available from the Trust) and ensure it is kept up to date.***
- ***A few days' supply of all your prescribed medication, correctly packaged and labelled, with a list of medication, doses and times taken. The hospital pharmacy may not stock all of your prescribed medications.***

If you are mobile prior to admission, ask for assistance in moving around if needed. Take any walking aids that you use (labelled with your name if possible). Take any communication aids that you use and be aware that if you are being treated for an infection, or if you are undergoing surgery, that this may make all of your MSA symptoms worse, including communication. You may wish to take a communication board or simple



ALL AVAILABLE FROM THE MSA TRUST

alphabet board with you for backup in case you are not able to communicate your needs. Current Covid restrictions may mean your next of kin has limited visiting opportunities and may not be able to advocate for you.

Once you are on a ward, please ask the staff for a generic ward email address that you or your family can give to the MSA Nurse Specialist for your area. This means they can then contact the ward to give them information about MSA or yourself. Often it is difficult to get through on the telephone to an individual ward.

We know from experience that ward staff are often busy so you may not get offered adequate fluids (particularly important to manage any postural hypotension) and the staff may not appreciate how important fluids are for you. Try to get a family member to bring in drinks and snacks that you enjoy. Salt may not be offered at mealtimes - if this is the case, ask family to bring some in for you to keep in your locker.

You will likely need anti-thrombosis stockings if you are on restricted bedrest (for example if you have a bone injury from a fall) and you should be offered these in hospital, but please request them if they are not. You should also have a pressure relieving mattress. If you have postural hypotension you may need to take your abdominal binder in with you. You should ask for the backrest of your bed to be raised so you are 30 degrees head up, daytime as well as night. You can request more pillows for comfort but should not be lying flat (unless the procedure that you are having dictates otherwise). If the Physiotherapist or Speech and Language Therapist visit you on the ward, please tell them we have specialist guides for them to download from our website (or we can post or email these to them).

A change of diet (to hospital food) can cause an alteration in bowel habit. Ensure your daily laxatives are prescribed as normal and if you do not have a bowel movement for three days or more, ask the Nurses for suppositories or an enema. Constipation is common in MSA and if you are not going to the toilet regularly, your prescribed medication will not be absorbed properly, so you will not be getting the benefits from them. Bowel blockages can occur if left untreated, which can be serious. Antibiotics may make stools loose for a few days. Unless medically unsafe, you should be supported to use a commode chair for toileting purposes.

If you are having a general anaesthetic while you are in hospital, the anaesthetist will meet with you beforehand. You should explain that blood pressure control can be an issue. If it is possible to have a local anaesthetic for a procedure that may be a better option - you can request some mild sedation if you are anxious. Some surgery can be carried out with a spinal (epidural) anaesthetic, so do discuss this with the anaesthetist. We don't expect to see confusion or hallucinations in MSA, but they might occur if you have an acute infection and they will subside once the infection is treated.

If you have a Parkinson's Nurse Specialist, do get someone to inform them of your admission; they may be able to visit the ward and advise staff. They can check that any new medications you may have been prescribed are not contra-indicated for you.

Whilst none of us want to be in hospital, sometimes it is necessary. If you find yourself there for any reason, please let us know so we can help to support you and make your stay safer and shorter where possible. msa *news*

SARAH'S WOOD

Established in 2017 to commemorate our founder, Sarah Matheson, Sarah's Wood is our special place for the MSA Community. Located in the stunning grounds of the Thoresby Estate in Sherwood Forest, Nottinghamshire, it is our favourite place to welcome you. Here are some of the plans we have for this year:

25th Birthday Party!

16th July 2022

Covid permitting, we are excited to welcome back our annual Summer Social in the form of the Trust's 25th Birthday Tea Party, including afternoon tea and children's activities.

*Visit: **www.msatrust.org.uk/25th** for more information.*

Path to a Cure

In the heart of Sarah's Wood is our beautiful Path to a Cure, where each stone honours someone from the MSA community. Together they form a trail that symbolises the hope and steps we are taking to eventually defeat MSA. For a suggested donation of £60, you can add your own dedicated stone for yourself or a loved one.

*Visit: **www.msatrust.org.uk/path** to find out more.*

Tree Planting

November 2022

We are delighted to host another Tree Planting session this winter, where you can plant your own oak sapling in Sarah's Wood.

*Visit: **www.msatrust.org.uk/tree** to register your interest in this free event.*

For further information about any of our forthcoming events, please email fundraising@msatrust.org.uk, call us on 0333 323 4591 or visit our website: www.msatrust.org.uk.