



# *msa news*

MSA Trust Members Magazine | Issue 68 | October 2023

*Nurturing  
wellbeing*  
through social  
prescribing





Welcome to Issue 68

HOSPITAL DISCHARGE PLANNING - PAGE 12

<b>News Roundup</b>	03
<b>Social Prescribing</b>	04
<b>Fighting Fatigue</b>	06
<b>In Memory</b>	08
<b>Pre-loved Equipment</b>	09
<b>Research Update</b>	10
<b>Hospital Discharge Planning</b>	12
<b>Fundraising Roundup</b>	14
<b>Housing Adaptations</b>	16
<b>Supporting and Helping Each Other</b>	18
<b>Support the MSA Trust this Christmas</b>	19



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**H**ello and welcome to your autumn/winter edition of MSA News.

When we heard that one of our members had found real benefit from their local social prescribing service, we wanted to highlight what is often a little-known support service. Read more about this on page four.

Our latest MSA Needs Survey showed that fatigue affects 89% of people living with MSA. One of our MSA Nurse Specialists has written an article on page six looking at fatigue and ways you can help manage this symptom. In our February edition we will include an article on fatigue in carers, which was shown as another key issue for our members.

We would also draw your attention to a piece on page 16 from one of our MSA Healthcare Specialists, who is an Occupational Therapist by background, focused on housing adaptations.

As always, we have our research roundup and amazing stories from our fantastic fundraising supporters. If you are able, please do make a purchase from our Christmas shop to support the Trust and raise awareness of MSA – find more information on the back page.

We hope you enjoy reading this edition of your magazine.

Emma and Andy

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# NEWS ROUNDUP

## Our Impact Report



We hope you will be interested in reading our 2022-2023 Impact Report, summarising our work with the MSA Community last year. It includes an update from our Chief Executive, Karen Walker, details the main findings from last year's MSA Needs Survey and also our Research Symposium in January. As always, we end the report with the Trust's income and expenditure summary for the year.

You can read the full report on our website - [www.msatrust.org.uk/about-us/annual-review](http://www.msatrust.org.uk/about-us/annual-review).  
*msa news*

## Right Information at the Right Time

We currently produce over 50 information resources for people living with MSA, carers and health and care professionals. The majority of these carry the Patient Information Forum (PIF) TICK kitemark which is an accreditation to show that our materials go through a clear production and review process. Part of this process is to ensure that we are creating the resources most needed by

people affected by MSA. We would love to hear from you with any feedback or suggestions on our information resources. If a factsheet has been helpful, you've been using one of our Guides to manage a symptom, or watching a webinar has answered some of your questions we would love to know. All resources can be accessed on our website - [www.msatrust.org.uk/support-for-you/factsheets](http://www.msatrust.org.uk/support-for-you/factsheets).  
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## Cereals Event at Sarahs Wood



In June we were delighted to be chosen as the Charity Partner for the 2023 Cereals event. Cereals is the UK's largest annual arable farming event. A heartfelt thank you to Cereals for supporting us

as their charity. This incredible fundraising opportunity, which took place within Sarah's Wood, gave us a platform to raise awareness and funds, with 50% of entrance fees being donated directly to the Trust. We are pleased to say the event raised £32,000 and supported awareness of MSA amongst the thousands who attended. *msa news*

## Share Your Story

Check out the new section of our website where we ask you, our members, to share your stories. Personal narratives are an impactful way to convey the challenges of life with MSA. These stories can help us by raising awareness of MSA and are also vital in our fundraising efforts. It is also a chance to connect with others affected by MSA and show them they are not alone in their journey. Feedback suggests members find it a positive experience. For more information on how to share yours, head to - [www.msatrust.org.uk/get-involved/volunteering/sharing-your-story](http://www.msatrust.org.uk/get-involved/volunteering/sharing-your-story).

In the meantime, check out Kenneth's story on our YouTube channel - [www.youtube.com/watch?v=XYRDMresOZw](https://www.youtube.com/watch?v=XYRDMresOZw). *msa news*





# Getting Social

Social Prescribing is a relatively new concept that is being rolled out in some areas around the UK. Clare, a local Wellbeing Advisor, explains what it is and the benefits for someone living with MSA.

**M**y name is Clare and I am a Wellbeing Advisor for our local Wellbeing Prescription Service in East Surrey. This is a free social prescribing service established a few years ago. Social Prescribing has been explained by the Kings Fund as enabling GP's, Nurses and other primary care professionals to refer people to a range of local, non-clinical services to support their health and wellbeing. To make this happen we provide support, advice, signposting and referrals.

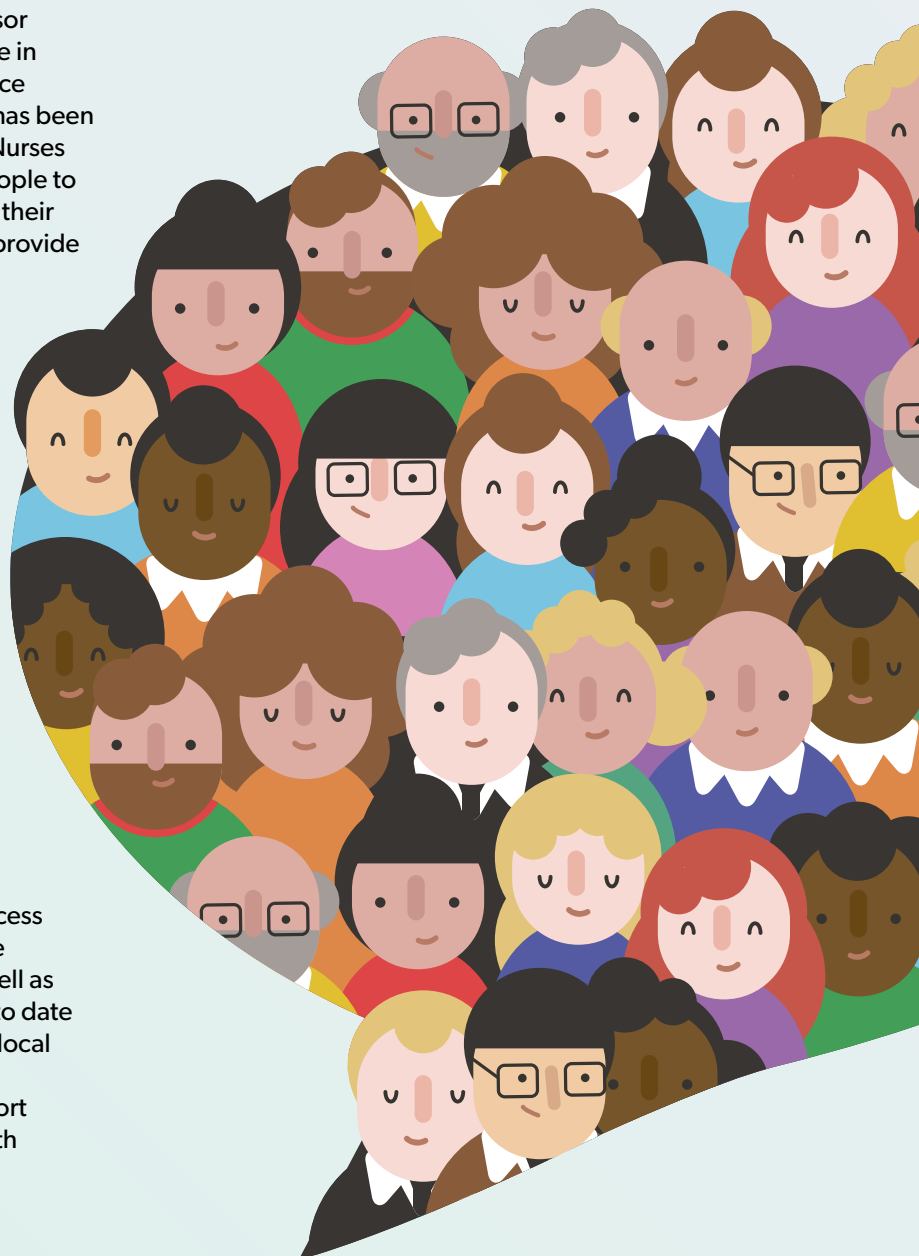
As a Wellbeing Advisor I can offer up to three appointments that can be via telephone, video or face to face in the clients' home or community settings such as their GP practice or a local community centre.

We also offer group workshops on topics including:

- **improving mental wellbeing**
- **healthy eating**
- **lowering cholesterol**
- **ageing well.**

Common reasons for referral to our service include reducing social isolation, becoming more active, supporting emotional wellbeing, carers support, maintaining independent living and healthy eating. We can also help people access financial support and frequently connect people with local community groups and activities as well as national organisations. This means we keep up to date with health, social and voluntary services in our local community.

To give you an insight into how this can support people I will share some recent engagement with







Graham (pictured with me). This I hope will show how social prescribing could be useful for people living with MSA and their families.

I first had the privilege of meeting Graham in his local GP practice in December 2022. He had been diagnosed with MSA only a few months previously. I had never worked with anyone living with MSA before, so was grateful for Graham's patience in explaining how MSA was affecting him and his family. Our first session was mainly spent building a working relationship and me trying to get some understanding of the key issues for Graham. He began by explaining that he wanted to increase his activity levels but did not know where to start. After liaising with his Occupational Therapist and Physiotherapist we organised an exercise referral which resulted in Graham being supported at his local gym. He also restarted swimming which is a sport he used to love. Both activities have helped Graham's confidence and he also feels better physically. Graham also identified in the initial session that he wanted to better manage his anxiety, so we

discussed how exercise, mindfulness apps and talking therapies might be beneficial. Another key concern Graham identified was how MSA was affecting his family. We therefore agreed a follow up session at home when his wife could be present.

Following the second session I signposted Graham's wife to 'Action for Carers' as she was unaware of the carers' support available. I also encouraged her to register as a carer at the GP practice and requested a Carers' Break Payment from the GP surgery. Graham's wife has found 'Action for Carers' a huge support and their online support meetings useful and informative.

Finances were initially also a big concern for Graham since stopping work. I did liaise with our local Disability Employment Advisor, but her input was not needed as Graham was incredibly well supported by the MSA Trust regarding his benefits and financial concerns. Graham has also been very proactive in seeking out the support of others living with MSA and has benefited

from attending both the local neurological support group as well as the MSA Trust meetings.

In subsequent sessions Graham wanted to work on re-establishing some routine which had been missing since stopping work. Having his gym and swimming in the diary helped, but we also discussed how voluntary work might help provide some sense of purpose as well as routine and hopefully enjoyment. It was also a fantastic opportunity for a local organisation to benefit from Graham's multiple skills and experience that had not disappeared just because of his MSA diagnosis. I therefore put Graham in touch with 'Voluntary Action Reigate and Banstead' and he was successful in getting a role with a local charity as well becoming a Trustee on the MSA Trust Board. This has helped both his confidence and given him back a sense of purpose.

Our sessions have now finished and I am aware that I only worked with Graham for a short period in his journey. However, it has been a pleasure to get to know Graham and his family and I wish them all the best in their future.

If you feel that you could also benefit from social prescribing, then please do contact your local GP to find out what is available in your area. Provision does vary enormously but each GP practice should now have access to social prescribing in some form. [msa news](https://www.msa-trust.org.uk/news)



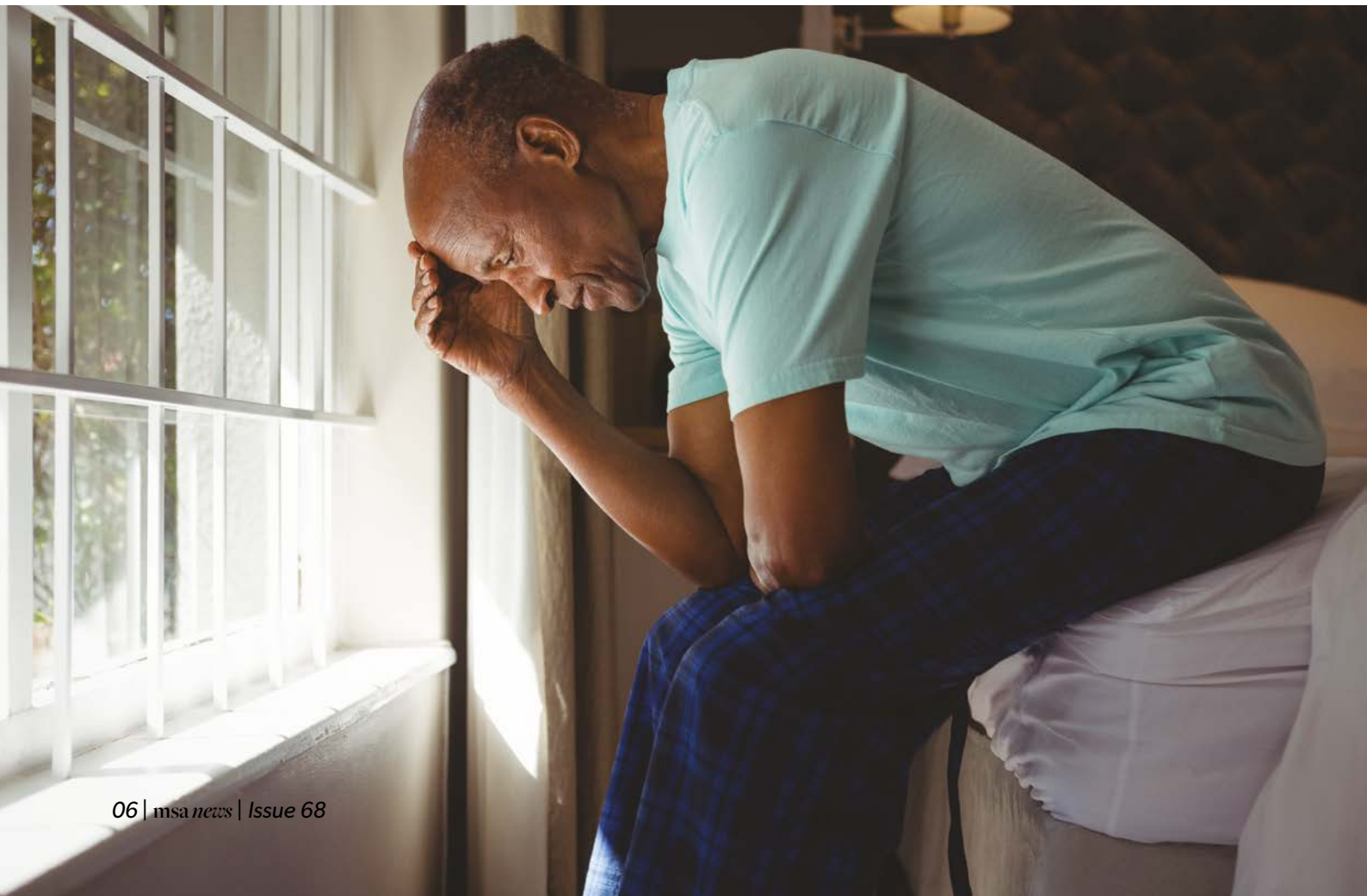
GRAHAM AND CLARE

We're keen to hear about any activities that have helped you better manage your MSA. Please get in touch with us at [support@msatrust.org.uk](mailto:support@msatrust.org.uk) to share your suggestions.



# Fatigue in MSA

Fatigue is a common symptom of MSA. In our recent Needs Survey 89% of people living with MSA indicated it was a problem for them. This article, written by Debra Vincent-Scott our MSA Nurse Specialist, aims to look at the causes of fatigue, the things which might aggravate it, along with non-medical steps you can take that may help control it.





**F**atigue is not the same thing as tiredness. Tiredness happens to everyone after certain activities or at the end of the day. Usually, a good night's sleep solves the problem. Fatigue is a daily lack of energy. It is unusual or an excessive whole-body tiredness not relieved by sleep and can occur even after a restful night's sleep. Fatigue can prevent you from functioning normally and can affect your quality of life.

MSA related fatigue tends to get worse as the day goes on, is often aggravated by heat and humidity and comes on more easily and suddenly than normal fatigue.

### What can cause Fatigue?

Unfortunately, the exact cause of MSA related fatigue is often unknown, or there may be multiple causes.

Although fatigue is a common symptom of MSA, you should mention your concerns to your doctor as there are times when fatigue may be a clue to another medical problem such as:

**Abnormal blood levels** - low Vitamin B12, Folic acid, Vitamin D or calcium levels, along with abnormal Thyroid hormone levels can all contribute to fatigue levels and can be treated.

**Infection** - Infections can make MSA symptoms worse and fatigue may increase suddenly. It is therefore important to treat any infection promptly. Please remember that the lack of a high temperature does not rule out the possibility of an infection.

### MSA symptoms that may contribute to Fatigue

The following MSA symptoms may be experienced and can contribute to your fatigue levels. They can all be managed and it is important to discuss them with your specialist team or GP when you

become aware of them.

**Postural hypotension** - This is low blood pressure when going from sitting to standing. If you are experiencing any dizziness on standing, please inform your specialist team as there are medications and techniques to help.

**Depression** - A person who is depressed can experience reduced motivation to be active and this can lead to fatigue in addition to depression. If you are diagnosed with depression there are effective treatments. These may involve a combination of medication and counselling. It is important to discuss these feelings early on with your GP or Specialist neurology team.

**Constipation** - Try not to become constipated as this can add to fatigue. Many people require a laxative to help the bowel empty fully in MSA.

**Sleep disturbances** - People living with MSA can experience problems with sleep. You may wake up often for the toilet or have difficulty turning in bed. Poor sleep does not cause fatigue but can make it worse. Identifying sleep problems and discussing them with your GP or specialist neurology team for treatment will help you feel better during the day.

### Tips which may help manage Fatigue

**Evaluate your level of energy** - Think of your personal energy stores as a bank. Deposits and withdrawals have to be made over the course of the day or the week to balance energy gained and spent. Keep a diary for a week to identify the time of day when you are either most fatigued or have the most energy.

Note what you think affects your fatigue.

**Try and conserve your energy** - Learning to pace, plan and prioritise your daily activities will help save energy. It may be helpful to balance activities with quieter rest days. Try breaking activities into smaller ones spread throughout the day.

**Prioritise** - For example, change where you store items to reduce trips or reaching and delegate tasks when needed. Prioritise the things you love doing and that make you smile whenever possible.

Equipment and adaptations can help make your daily life easier. An Occupational Therapist can provide an expert assessment and advice on this within your own home.

**Schedule rest** - Try and balance periods of rest and activity before you become fatigued. Frequent, short rests are beneficial. Aim for a nap of around 20-30 minutes. Taking this before 3pm will reduce any negative effect of your bedtime routine.

**Eat right** - Fatigue is often made worse if you don't eat enough or if you don't choose the right foods. Maintaining good nutrition can help you feel better and have more energy.

Keeping well hydrated will help with both the constipation and low blood pressure as well as the fatigue.

**Exercise** - Try to maintain any regular activity you are able to undertake safely and which you enjoy. A Neuro-physiotherapist will be able to carry out an individual assessment and recommend activities and exercises that are right for you to help maintain your fitness level. This could be as simple as a chair-based exercise or a gentle walk. [msa news](#)

The next edition of MSA News will include a related article focused on fatigue and caring. Do look out for this and contact your MSA Health Care Specialist if you need any support in the meantime.





# In Memory

Bernard Fox  
 Patricia Sharp  
 Alan Walden  
 Margaret MacLeod  
 Barbara Hayes  
 Terence Cole  
 Alison Sellar  
 Richard Shannon  
 Frederick Holliday  
 Ian Benson  
 Peter Davies  
 Sheila Shave

Sandra Symonds  
 James Jennings  
 Stephen Robinson  
 Roger Mutch  
 Elizabeth Koe  
 David Collinson  
 Rita McCormack  
 Michael Whatley  
 Peter Walker  
 Alan Rye  
 Jean Faulkner  
 Roger Matchett

Pauline Joyce  
 Susan Park  
 Peter Knight  
 William McIntyre  
 Jean Ainsworth  
 Richard Whitfield  
 Bill Brennan  
 Julia Gore  
 Jonathan Bird  
 Mark Graves  
 Hasan Deveci  
 Maureen Jones

Sharon Druce  
 Carol Goodwin  
 Brenda Frost  
 Marion Barrs  
 Maria Di Raimo  
 Martin Roe  
 Christopher Bradford  
 Mark Cleverley  
 Merry Fay

## How your personal acts of remembrance can help so many others



SIOBHAN

Many of our supporters choose to remember their loved ones in meaningful ways such as through an event or challenge. As well as being a visible symbol of remembrance these can also raise essential funds for the Trust.

Siobhan Brennan did just that, taking on the Camino trail and walking 180km in memory of her dear husband, Bill.

***“I’ve wanted to do something to remember***

***Bill, raise awareness of MSA and fundraise for the Trust for some time now. But many things got in the way including my immense grief coupled with COVID. Bill had planned on giving an interview to raise awareness but it could not happen so I’m carrying his baton.”***

Emma Todd explained why she chose to run the Manchester Half Marathon in memory of her partner’s father, Nick Bate.

***“Nick was always very generous and kind. So, when we lost him I wanted to be able to repay the favour to him and his wife, Trish, and show how much we love them both by completing a challenge in his memory.”***

Well done and thank you Siobhan and Emma, your loved ones would have been so proud.

If you wish to take part in a similar event in memory of a loved one, please email [fundraising@msatrust.org.uk](mailto:fundraising@msatrust.org.uk) or call us on 0333 323 4591. *msa news*



EMMA





# Our Second-Hand Equipment Page

Here at the MSA Trust we always encourage our members to plan ahead. One area where this can be particularly beneficial is thinking about what equipment you might need in the future.

To help with this we have three separate factsheets focusing on equipment - Eating and Drinking, Personal Hygiene and Posture and Mobility. Alongside these materials we have a Second-hand Equipment webpage for our MSA Community. Members advertise items they would like to sell, with many of the items being sold for a low price or provided for free. We know the cost of equipment can be difficult for many, so we encourage people to check this page before committing to a large purchase.

The Second-hand Equipment page has been home to many different types of equipment, from riser/recliner chairs, hoists and wheelchairs to rollators and beds. These are just some examples of items that have been advertised, but equipment is added regularly so it's worth keeping an eye on the page as you may find something you need.

Before you purchase any equipment, including items from our Second-hand Equipment page, we encourage you to consult with your Occupational Therapist. They can help make sure you are getting the most appropriate item for yourself or the person you care for. You will need to ensure anything you buy has been well maintained and is in good working order, as well as asking for any instruction manuals. It is also worth researching which type of equipment is best for you, particularly when buying a wheelchair as you will need to consider size

to ensure it is safe and appropriate. 'AskSara' is a free online tool provided by the Disabled Living Foundation which provides expert advice and information on products and equipment -

[www.asksara.livingmadeeasy.org.uk](http://www.asksara.livingmadeeasy.org.uk).

If you have equipment you no longer need and you feel could benefit others, please list it on our Second-hand Equipment page. We do not store the equipment ourselves but will advertise them on your behalf.

You can find more details here - [www.msatrust.org.uk/support-for-you/second-hand-equipment](http://www.msatrust.org.uk/support-for-you/second-hand-equipment).

If you would like to list any items on this page, please email [support@msatrust.org.uk](mailto:support@msatrust.org.uk) with the following information:

- **Item name**
- **Sale price**
- **Price at new**
- **Picture of product**
- **Delivery/Collection details**
- **How old the item is and in what condition (Very Good, Good or Average)**
- **Contact details – Name, email address and/or phone number**

We want to thank everyone who has already advertised equipment on our website and helped others with MSA in the process. [msa news](#)



# Research Roundup

## The MSA Trust Scientific Advisory Panel (SAP)

Following a meeting of our MSA Trust SAP it was agreed that a further call for high quality research projects will be made by the Trust this Autumn. The application process will be as before with pre-proposal submissions. Our panel will then decide on the proposals to be invited to a full application. Once again, we will be inviting people to submit proposals which consider both clinical management of MSA and scientific projects.

The SAP also discussed the second Research Symposium to be held at UCL in February 2024. Following the success of the Symposium last year, we are pleased so many scientists and clinicians wish to take part again to share their understanding of MSA. This will be open to all those in the field of science and medicine with the aim of developing and increasing their knowledge of MSA. Researchers and Clinicians can register for the Symposium here - [www.msatrust.org.uk/event/2024-msa-research-symposium](http://www.msatrust.org.uk/event/2024-msa-research-symposium).

## Online Research Group

This autumn we are launching our first online Research Group. Hosted by us, with input from various researchers, it will run twice a year. It gives you, our members and supporters, the opportunity to hear from researchers on their latest developments and be part of helping to set research aims for MSA. We are keen to register anyone interested in attending this online group, which will have short presentations from researchers, followed by a Q&A session.

We anticipate that over time this group will invite companies developing drug therapies to present and help to establish a good working partnership between patients and researchers.

Join us for our first session on the 7th November at 3pm. Register your interest by getting in touch at [support@msatrust.org.uk](mailto:support@msatrust.org.uk).



## Clinical Trials

We hope to have some interesting news in the next magazine about a Phase 3 trial of Amprexetine to treat blood pressure that drops in MSA. It is currently awaiting ethics approval before launch. Some of you may remember reading about the Sequoia studies that were launched just as lockdown began. Initial results were disappointing however longer-term results and more importantly, results showing good improvements in people with MSA, meant that Biopharma Theravance received agreement to proceed with a longer Phase 3 study. They are currently working with us to have some information for our readership by the next MSA News and perhaps in advance, so also keep your eyes on our social media.

We are also in contact with two other companies interested in establishing patient advocacy groups given we are well placed to help them. Patient advocacy groups are very important for drug companies as there is an expectation that if they wish to undertake a clinical study they will have been carefully thinking about the impact on people taking part. For example questions may include; how reasonable is the journey to where trials will take place, is the length of time someone must spend there reasonable, will there be adequate refreshment and support given, including necessary costs of travel or overnight accommodation etc. These questions are best answered by the people potentially taking part in a study, so we are keen to be involved and to work with these companies to make trials a success.

Keep an eye on our online Research Hub for updates on these trials - [www.msatrust.org.uk/cause-and-cure](http://www.msatrust.org.uk/cause-and-cure).

## ExPRESS

**(Early assessment, diagnosis and treatment of Parkinson's Plus Related Syndromes)**

Earlier this year, we sent a letter of funding support for Professor Huw Morris at University College London (UCL). The subsequent successful bid will build upon and develop the infrastructure to enable national network activities and representative patient recruitment to clinical trials. Working alongside other charities who support people with Parkinson's Plus syndromes such as PSPA, we had already established the ongoing Prospect-M study. The next phase is to maximise the impact of forthcoming trials by increasing the recruitment of people who are in the early stages of their diagnosis. We very much support the development of coordinated approaches to promoting new disease modifying therapies. This is being funded by the MRC and NIHR. In July the UK Research Institute said:

***"The UK Rare Disease Research Platform has been established with a £14 million investment over five years by the Medical Research Council (MRC) and the National Institute for Health and Care Research (NIHR).***

***It is made up of a central coordination and administrative hub and 11 specialist nodes based at universities across the UK.***

***The aim of the Platform is to bring together expertise from across the UK rare disease research system to foster new and innovative treatments for those directly and indirectly impacted by rare conditions."***

Professor John Iredale, MRC Executive Chair said:

***"The UK has great strengths in rare disease research. However, that very rarity means it can be difficult to bring the right people, technologies and tools together to develop effective approaches.***

***Although these diseases are diverse and have different causes, they often bring common challenges for research into disease mechanisms, diagnosis, management and treatment.***

***The platform will bring people together, link participants to resources and activities in the UK and internationally, and support projects that deliver advances in rare disease research."***



# Hospital Discharge Planning



**Leaving hospital following a planned or unplanned admission can be an anxious time. Here, Sam Fitzgerald, our Social Welfare Specialist, outlines what you can expect when it comes to hospital discharge planning.**

**A**ccording to the Department for Health and Social Care

**'people should be supported to be discharged to the right place, at the right time and with the right support that maximises their independence and leads to the best possible sustainable outcomes'.**

Hospital discharge preparations should begin as soon as you are admitted or even before if your hospital stay was planned.





The Health and Care Act 2022 places a duty on NHS hospitals to involve family carers as soon as possible in this process. During your stay your healthcare team will regularly review whether you are ready to be discharged. Once you no longer require hospital treatment and support, and it's safe and appropriate to discharge you, staff should assess any immediate needs you may have once leaving hospital. The discharge assessment may include input from your doctor, nurses, physiotherapist, occupational therapist and hospital social worker. You should not be discharged from hospital until your immediate needs have been assessed and any agreed support services or equipment is in place.

Staying in hospital longer than necessary is not good for your wellbeing and recovery. Once you are well enough you will be discharged to a more suitable setting, with any immediate support in place, where your longer-term needs can be assessed – this may be your home or a residential setting such as a community hospital or care home. After a period of recovery, community-based health or social care professionals should then assess your longer-term needs. This process is referred to as 'discharge to assess' or 'step down'.

The discharge to assess process varies depending on your immediate needs, although wherever possible you should be supported to return home for assessment of your long-term needs.

### **If you need minimal help and support at home:**

Ward staff will usually manage and arrange your discharge, which may include hospital transport to get you home. They may put you in touch with voluntary services who can offer short-term assistance with domestic tasks such as shopping, laundry or cleaning.

### **If you need some care and support to further recover at home:**

The discharge team or a case manager will arrange your discharge and any support needed to help you settle back at home. If you need a package of care and support you should receive an initial safety and welfare check on the day of discharge to make sure your care needs are met.

### **If you would benefit from short-term support in a residential setting to aid recovery:**

If your immediate needs are too great to manage at home, you may be discharged to a residential setting such as a care home or community hospital for short-term support. During your stay, a full assessment should be carried out to determine what care and support you may need at home in the longer term.

### **If short-term support is unlikely to aid recovery and you need ongoing nursing care:**

The discharge team or case manager will discuss your long-term needs with you and your family/carers. They will probably arrange discharge to a care home where a full assessment can be done to review your options, for instance moving to a care or nursing home long-term or returning home with a package of care in place if appropriate. The full assessment should include checking your eligibility for NHS funded continuing healthcare (CHC) support. Fully funded CHC support can be provided either at home or in a care home. Please see our Continuing Healthcare Factsheet for more information -

[www.msatrust.org.uk/support-for-you/factsheets](http://www.msatrust.org.uk/support-for-you/factsheets).

### **Intermediate / Reablement Care**

If ward staff feel you may benefit from extra support at home to aid recovery and help you to rebuild your confidence and live more independently, you may be offered intermediate or reablement care. This should be provided free of charge for a limited period of time (usually no more than six weeks).

### **If you live in the Republic of Ireland**

You and your family or carer will be invited to attend a discharge planning meeting to discuss any support or follow up services you may need, which may include attending day hospital, outpatients clinic or rehabilitation services.

### **A few simple tips for preparing to leave hospital:**

1. If you rely on home care services then it is advisable to avoid being discharged over a weekend.
2. If your prescription has been changed, request a week's supply of medication to take home.
3. If you need special dressings, request that you have at least one spare to take home.

#### **Useful organisations**

- The Royal Voluntary Service offers a 'Home from Hospital' service. For more information visit [www.royalvoluntaryservice.org.uk](http://www.royalvoluntaryservice.org.uk).
- The British Red Cross can help with transport home from hospital as well as providing practical support such as shopping, picking up prescription, short-term use of wheelchairs or toilet aids. Visit [www.redcross.org.uk](http://www.redcross.org.uk) or call 0808 196 3651. *msa news*



# A Summer of Fundraising for the MSA Trust

**As the days grew warmer and longer, an unprecedented number of supporters participated in challenge events and reached remarkable heights, both literally and metaphorically, in their fundraising endeavours. We want to express our heartfelt thanks to each one of you for your marvellous dedication and determination. Here are just some of the amazing fundraisers from this summer...**

## Team Yarsley Take on Snowdon

Following on from last year's successful Yorkshire 3 Peaks Challenge, **Nick and Tracey Yarsley**, alongside their incredible friends, decided to conquer Mount Snowdon. Nick, who is living with MSA, was once again overwhelmed by the support he received on the day and the amount of money raised due to people's amazing generosity. So far, they have brilliantly raised over £13,000 for the Trust.

*"I'm living with this horrible, life limiting diagnosis and it humbles me to know that I have such lovely family and friends who take time out of their busy lives. I also want to thank my wife Tracey, who despite everything she must come to terms with, can still find the time to organise this event. It was a fantastic day, and it looks like it's going to be an annual event."*

**Nick**

*"I would just add how fantastic it was that we could involve Nick in the challenge. It was brilliant for us all to meet him off the train at the summit and spend some time with him appreciating the spectacular views. We could not have asked for a more perfect day."*

**Tracey**







## Kayaking Coniston Water

**L**indsey was diagnosed with MSA in 2019 and spent the first two years of her diagnosis worried about the future, then both anger and determination kicked in. Lindsey describes her kayaking fundraising event:

*“I don’t know where I would be without Katie Rigg. Her support is invaluable. As the MSA Trust is funded by donations and relies on the kindness of people and organisations, I was determined to do something I loved where I could raise funds for the Trust at the same time. I decided to undertake a 10-mile round trip around Coniston Water in a kayak.*

*We could not have asked for a better day. The water was like glass and the sun was shining on us. In all it took us six hours to paddle around the lake, with a couple of stops to take in the day. When we finished, I felt fantastic, tired but fantastic. I had achieved, not only to raise money for the MSA Trust, but also the very feeling that, even with MSA, I can still do some of the things I love so much, and it made me feel alive. So much so that next year we plan on doing a zipline across the Tyne so watch this space”.*

Thank you, Lindsey, for raising an incredible £2,475!

## Three Peaks Challenge in 24 Hours

**C**hris Yates and friends **Adam, Dan** and **Scott** took on the ultimate walking challenge in memory of Chris’s dad David Yates, who sadly died in 2021. The challenge involved climbing the highest mountains in Scotland, England and Wales (Ben Nevis, Scafell Pike and Snowdon) in 24 hours. Chris says:

*“I promised myself that I would complete this challenge after dad’s sad passing and finally got around to doing it in the summer. Spending time outdoors with my family and a lifelong mate, who I rarely get time to see, was a real high, as was getting to go hiking in some of the most scenic parts of the UK. Enjoying a few well earned beers in the hot tub at the end of our Snowdon climb was also a bonus!”*

*“The lows were definitely the sheet rain and wind we had at the top of Scafell Pike at dawn, plus the relentless slog of the uphill - despite being the smallest of the three climbs, it definitely packed the most punch!”*

They raised an astounding £5,364. Thank you so much - your dedication and generosity are truly appreciated.



If any of these fundraising challenges have inspired you, why not sign up for your own event and raise vital funds for the MSA Trust? Contact a member of our team at [fundraising@msatrust.org.uk](mailto:fundraising@msatrust.org.uk) for more information.



# A Home To Fit Your Needs



People living with MSA often have to make changes to their home to enable them to continue living there safely. Demelza Stuart, our MSA Health Care Specialist, details what these adaptations may be and the process to get these.

## Changes to your home may include:

- widening doors and installing ramps to give access to the property
- a walk-in shower or wet room
- a through floor lift (stair lifts are not recommended for people living with MSA)
- a hoist system
- minor adaptations such as stair rails or grab rails
- major structural adaptations such as an extension or downstairs bathroom.





## Assessment and Funding Process:

The first step in deciding what adaptations are needed is to have an Occupational Therapist (OT) assess your physical needs and your home. To arrange an OT assessment, contact your local authority or local health and social care trust. Our MSA Health Care Specialists can provide information to support the OT, so it may be helpful to contact us at the beginning of the assessment process.

The OT will also help with the funding process, which is means tested. Disabled Facilities Grants (DFGs) are provided by the local authorities in England, Wales and Northern Ireland. You can find up-to-date information on DFGs at [www.gov.uk/disabled-facilities-grants](http://www.gov.uk/disabled-facilities-grants).

If you live in Scotland you can find information on funding provided through 'mandatory grants' here - [www.gov.scot/publications/funding-adaptations-home-guide-homeowners/pages/1](http://www.gov.scot/publications/funding-adaptations-home-guide-homeowners/pages/1). In the Republic of Ireland, housing adaptations grants are available - [www.citizensinformation.ie/en/housing/housing\\_grants\\_and\\_schemes](http://www.citizensinformation.ie/en/housing/housing_grants_and_schemes).

The amount of funding available and the application processes differ across the UK and Ireland, and it is important to note that it can take a long time. Ask for an assessment as soon as you start to need support. Funding will not usually be granted after the work has started so it is advisable not to commence work before your application is processed.

Some people may not be entitled to financial support to obtain the adaptations or equipment they require. In this situation, the OT can advise on what support is available and how to access it. Other options include funding the work yourself, seeking funding from charities or moving to a more accessible home. If you live in the UK, you may be eligible for VAT exemption on equipment purchased for personal use, including installation, repairs or maintenance and spare parts or accessories. Please check the Government's website for further details - [www.gov.uk/financial-help-disabled/vatrelief](http://www.gov.uk/financial-help-disabled/vatrelief).

## Typical adaptations for people living with MSA:

**Minor adaptations:** Following an assessment of need, smaller items, such as grab rails or stair rails, can be supplied by your OT. In most cases they can be fitted easily and quickly and may be supplied for free.

**Bathroom adaptations:** A level access shower or wet room is ideal for someone living with MSA. If you have problems with balance or standing, or are a wheelchair user, this adaptation will give you more space for easy access for both you and your carer.

**Through floor lift:** This will allow you to use one wheelchair for both floors of your home. There is no need to transfer in and out of your wheelchair when using the lift. Not all homes are suitable for lift installations as they need a certain amount of space.

**Ground floor living (extension):** When a lift is not suitable, you may wish to consider staying on the ground floor in your home. This often requires installation of a bathroom/bedroom, depending on space available. Extensions are costly adaptations and it is important to note that a full funding grant is usually not enough to cover the total cost.

**Wheelchair access:** This may include adaptations such as ramps to the entrance of your home or door widening inside to allow access between rooms. Access to your garden can also be considered and may be covered by a DFG.

## Important points to consider:

There is lots of equipment available that can make your home safer and easier to use. Often equipment will be provided first, before an adaptation is considered. For example, transfer benches or bath hoists can be used to help someone access their bath. However, it is important to consider the long term and changing needs of someone living with MSA. Therefore, it is recommended to discuss possible adaptations with your OT as early as possible.

Sometimes adaptations are just not possible. An architect may be involved to tell you what is feasible for your property. In this case, it is important to discuss your wishes and preferences. You may decide that re-housing is the best option. Or you may also wish to look at care home facilities. If you want to be cared for in your current home, your OT will discuss options for maximizing your safety and comfort.

An Occupational Therapist will recommend adaptations that are the most cost-effective way to meet your needs. Sometimes that can lead to a discrepancy between your preference and what is recommended.

Please speak to your MSA Nurse/Health Care Specialist for further support in this area. [msa news](#)

We are producing a more detailed factsheet on Housing Adaptations. Keep an eye on our social media channels for updates as this will be published soon.



# Supporting and Helping Each Other

*In their regular article Nicole and James, our Support Group Facilitators, pass on some of the tips shared by members at our Support Groups, both In-Person and Digital.*

Several items of equipment have been recommended by members at our recent meetings. If balance or strength is an issue and you are struggling to bend down, some members recommended 'grabbers' to help pick items up. These are available on Amazon, as well as specialist websites, and are affordable enough so that you can have several around your home. They are available to buy at [www.completecareshop.co.uk](http://www.completecareshop.co.uk).

Although a much more significant investment from both a cost and installation perspective, wash-dry toilets were highly praised during one of our online Support Groups. Wash-dry toilets combine the functions of a toilet, bidet and dryer in one. Many members said they made managing the toilet routine much easier. It was also emphasised that it could be used as standard toilet by the rest of the household (quite a few people said the whole family enjoyed the wash and dry features!). As stated in our article on pages 16-17, when it comes to expensive equipment that requires installation make sure to speak to an Occupational Therapist (OT) first to see if it is suitable for your home and needs.

We have had repeated discussion about resources for carers at several of our Support Groups. MSA affects the whole family, and it is important for carers to look after themselves as well. There are a variety of ways to look for carer's resources that work for you. The MSA Trust has a monthly Carers' Support Group that meets online – if you would like more details or to sign up for it, please contact us at [support@msatrust.org.uk](mailto:support@msatrust.org.uk).

Some of our members have found it useful to look at what local carer support is available, even if it is not specific to MSA. There are many local independent organisations that work to support carers in the community. Many have helplines that can offer further information. You can find out more about what is available to you using the search function at Carers Trust - [www.carers.org/help-and-info/carer-services-near-you](http://www.carers.org/help-and-info/carer-services-near-you). These groups can foster a space for self-care, empowering carers to sustain their own health and continue providing the best possible care for their loved ones.

There is also a wealth of information on caring available online. Carers UK covers England, Wales and Northern Ireland and is free to sign up for which can be done here - [www.carersuk.org](http://www.carersuk.org). In Ireland there is Family Carers which can be found here [www.familycarers.ie](http://www.familycarers.ie). Connecting with others can provide a wealth of resources and reassurance that you are not alone in your journey. *msa news*

If you are not currently getting invitations to our in-person or online Support Groups and would like to attend, please email [support@msatrust.org.uk](mailto:support@msatrust.org.uk) or call 0333 323 4591.



# The countdown to the festive season has begun...

We hope you will enjoy browsing our fabulous selection of Christmas cards, gift wrap, advent calendars and stocking fillers to share with your family and friends this Christmas.

Whenever you buy from our Christmas shop you are supporting our work with every purchase helping us to

fund our vital support services and bringing us closer to finding the cause and, ultimately, the cure for MSA.

To place an order, please see information on the back page.

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

**£5**

## Stocking Filler

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



**£4**

## Advent Calendars

34 x 24 cm with postal envelope  
Individually wrapped



**£3**

## Gift Wrap

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





More items inside

£5

**Christmas Cards**

150mm x 150mm

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

- Cards A & D:** Season's Greetings
- Card B:** Happy Christmas
- Card C:** Wishing you a Merry Christmas and Happy New Year



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

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

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

Please get in touch with the Fundraising Team if ordering more than 10 items or when ordering from outside the UK. Email [fundraising@msatrust.org.uk](mailto:fundraising@msatrust.org.uk) or call 0333 323 4591. Please note we send our merchandise using Royal Mail 2nd Class post but during the busy season it can take up to five working days for items to arrive. **All orders and payment must be received by 9th December 2023.**

Name:.....

Address:.....

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

**Christmas Cards:** A – Fluffy Robin with Present (Qty)..... B – Glory to the Newborn King (Qty).....  
 C – 12 Days of Christmas (Qty)..... D – Let it Snow (Qty).....

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

**Gift Wrap:** Happy Christmas Wraps (Qty)..... Festive Tree Wraps (Qty).....

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

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

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

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

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

Please return slip to **MSA Trust, 51 St Olav's Court, Lower Road, London SE16 2XB** with payment by **9th December 2023.**