



Carer's Guide

Looking after yourself
and the person you care for

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What is a carer?

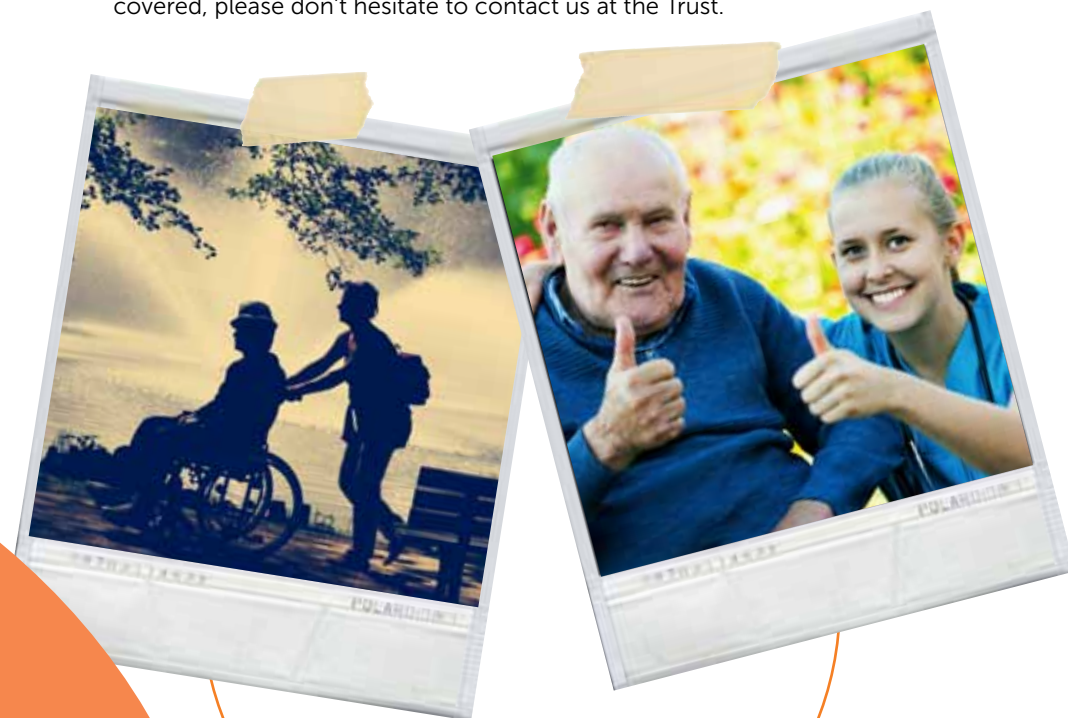
A carer is someone who looks after a partner, family member, friend or someone else who couldn't manage without their help. Carers may look after that person all of the time or just some of the time, and they aren't paid for the support they provide.

If you look after someone with multiple system atrophy (MSA), you may not see yourself as a carer or be aware of the wide range of support available. It's only natural to want to put the needs of the person with MSA first, but it's really important that you think of your own needs too. Caring is often physically and emotionally demanding, and if you don't look after yourself, you won't be able to provide the best possible care and support.

About this guide

This guide addresses some of the worries or problems you may face if you care for someone with MSA. It looks at the practical, physical and emotional aspects of being a carer.

At the back of the guide you'll find a list of useful contact details for organisations that can provide further information and support. If you have a question that isn't covered, please don't hesitate to contact us at the Trust.



A world free of MSA

Things to think about early on

If someone close to you is diagnosed with MSA, many of the ideas and plans that you had for the future will change. Thinking ahead and talking things through with the person with MSA and health and social care professionals can help you prepare for what's to come. Here are a few of the questions you may want to ask yourself.

Practical aspects

- Do you work and, if so, would you like to continue working while caring? Is flexible working an option for you?
- Can you afford to give up work? Do you have a mortgage to pay off? Do you have access to a pension or savings?
- Are you aware of your benefit entitlements, or do you need more information?
- Do you have children or other family members to care for?
- If you live with the person you care for, can you make any adjustments to your home, for example, bringing a bed or washing facilities downstairs?
- Is there any carer training available in your area that may help you?

Physical aspects

- How is your health in general? Are you physically able to care for someone?
- Are you eating properly and getting exercise?
- Are you getting enough sleep?

Emotional aspects

- How will caring for the person with MSA affect your relationship with them?
- How will your relationships with other family or friends be affected?
- Do you have family or friends to talk to about your feelings and concerns? If not, who else is there to support you?
- Is there a carers' support group in your area?
- Are you able to take a break and have time for yourself? For example, time to relax, see friends, or maybe pursue a hobby or interest.

Getting some sleep

Making sure you get a good night's sleep is extremely important. If you're having trouble sleeping, a little gentle exercise or some relaxation techniques can help. For more information, visit the Carers Direct website at www.nhs.uk/carersdirect

Where to find support

There is plenty of information and support available for carers, from a wide range of sources:

- The MSA Trust
- Carer organisations, such as Carers Trust
- Health and social care professionals
- Benefits and financial support
- Employee welfare organisations, such as Employers for Carers

The different types of support available will depend on where you live. Asking for support may seem daunting at first, but just remember that that you're entitled to ask for it. Nobody expects carers to manage on their own.

Contact details for organisations that offer further information and support can be found at the back of this guide.

"Lots of carers carry on as if it's their duty, or feel guilty if they have to ask for help. But you have a right to ask for that support."

Samantha Pavey, MSA Trust Nurse Specialist

Think ahead

MSA is an unpredictable disease and the condition of the person you're looking after may change quickly. When it comes to caring and living arrangements, try to consider what their needs might be in one or two years' time, as well as right now.



Getting help with practical things

After a diagnosis of MSA, it's important you have the right support and expertise around you. Because the symptoms of MSA vary from person to person, you should ensure there is a team of specialists involved in providing care and treatment for the person you're looking after:

- Parkinson's nurse, community matron, neurology nurse (if available in your area)
- Occupational therapist
- Speech and language therapist
- GP
- Continence adviser
- Physiotherapist
- Social worker
- Neurologist (a person with MSA is entitled to at least one appointment with a neurologist every six months)

Ensuring these specialists are involved early on will make things a lot easier for you. Besides offering expert support and advice, they will be in a good position to keep an eye on the condition of the person you're caring for and anticipate any changes or problems.

Respite care

There are a number of ways you can take a break from your caring role. These include long or short-term residential respite, where the person you care for is looked after by someone else in either residential or nursing care.

There is also domiciliary care, where someone comes into your home and takes over care for a few hours or overnight. Sitting services are similar, but do not usually provide personal care, for example, toileting. One example of a sitting service is the Crossroads Care scheme – a network of local, independent charities that support carers and the people they look after, often through the provision of flexible breaks.

You can find out more about Crossroads Care and other respite services in your area on the Carers Trust website.

Many hospices also provide short-term respite care, including day care or even home visits. To learn more about how hospices can help you and the person you care for, at any stage of their illness, see the next page.

"After dad had a fall and had to go into hospital, we prepared a folder with everything about MSA, his specific symptoms, a list of his medications and what foods to avoid. The staff were grateful as they hadn't heard of MSA before."

Suzanne

How hospices can help

It's a common misconception that hospices only exist to provide end of life care. In reality, they provide a range of free care and support that can help improve a person's quality of life, no matter what stage of a life-limiting condition they're at.

Importantly, hospices also recognise the importance of the caring unit around a person with a long-term illness, so they also offer help for carers and family members. Some even host support groups.

"As well as offering a number of week-long respite breaks, the hospice also arranged for my father to attend day care and provided transport."

Carolyn, cared for her dad

What services do they offer?

Hospice care providers offer a range of support, which may include:

- Pain and symptom control
- Psychological and social support
- Palliative rehabilitation – helping patients to stay independent
- Complementary therapies, such as massage and aromatherapy
- Spiritual care
- Practical and financial advice

Hospices may offer day care, short stays or longer term admissions. Some may even provide home visits.

Whatever the location or duration, this respite care can be incredibly beneficial both for the person with MSA and their carer. The person with MSA has access to therapies and support and an opportunity to interact with new people, while their carer gets a much needed break.

Getting referred to a hospice

You can be referred by your GP, hospital doctor or district nurse, though some hospices also accept self-referrals. Bear in mind that some professionals also make the mistake of equating hospices with end of life care. Don't be afraid to ask if you think you and the person you're looking after could benefit from hospice care now.

You can find your nearest hospice online at www.helpthehospices.org.uk or by using the MSA Trust Local Hub at www.msalocalhub.org.uk

Carer's assessment

All carers have a legal right to a carer's assessment by their local authority. This can be done by social services at the same time as the community care assessment (sometimes called a needs assessment) for the person you're looking after, or separately if the person you care for doesn't want an assessment.

The carer's assessment is your opportunity to tell social services about the things that could make life easier for you and help you balance caring with other aspects, such as work or family. You can get contact details for your local authority by calling the Carers Direct helpline on 0300 123 1053.



Working while caring

If you work, you may need to stay in employment for financial reasons. Or you may simply enjoy your job and want to continue working for your own benefit.

Under the Work and Families Act 2006, any employees who care for, or expect to care for, adults have a legal right to request flexible working. You can find out about the procedure for requesting flexible working on the Carers Trust website.

Benefits and allowances

There are a number of benefits and allowances available to carers. You may be entitled to:

- Carer's credit - a National Insurance credit that builds your entitlement to the state pension.
- Carer's premium - an amount that is included in the calculation of any means-tested benefits you get if you're also paid carer's allowance.
- Bereavement allowance - available if you're a widow, widower or surviving civil partner aged between 45 and state pension age.

These benefits were correct at the time this guide was last reviewed. For an up-to-date list and to find out whether you're eligible, check the UK Government's website at www.gov.uk or visit your local Citizens Advice bureau.

Continuing healthcare

This is free care outside of hospital that can be arranged and funded by the NHS. It can be provided in any setting, including a care home, hospice or the home of the person you look after.

To be eligible for continuing healthcare, the person you look after must be assessed as having a complex medical condition and substantial, ongoing care needs. A team of professionals will need to carry out an individual needs assessment to determine whether they are eligible.

For details, visit www.nhs.uk and search for 'Continuing healthcare'. In Scotland, visit www.careinfoscotland.co.uk



Tips on getting help with practical things

"Even just sitting down with the building society and talking to a financial adviser helped me. Don't be afraid to ask as many questions as you need to."

Linda, cared for her husband

Request a carer's assessment Social services can do this at the same time that they carry out a needs assessment for the person you look after. Contact your local authority to arrange an assessment and always request that it is carried out in person, not over the phone.

Register as a carer with your GP Most practices offer priority appointments for carers.

Seek out respite care

This might involve getting a sitter in for a few hours a week, day care at a nearby hospice (see page 7) or something more long term. Try to build relationships with care providers so that you can get a break every now and again.

Offload everyday tasks If you aren't keen on the idea of getting someone else in to provide care, think about which everyday tasks you could pay someone else to do – such as the housework, gardening or DIY.

If you work, speak to your employer Explore whether flexible working is an option for you. Even if it isn't, it's good to let your employer know about your situation so they are aware of the additional strain you're under.

Talk to your bank and a financial adviser It's a good idea to do this as soon as possible after a diagnosis of MSA. That way you can get everything in order and hopefully put your mind, and that of the person with MSA, at ease.

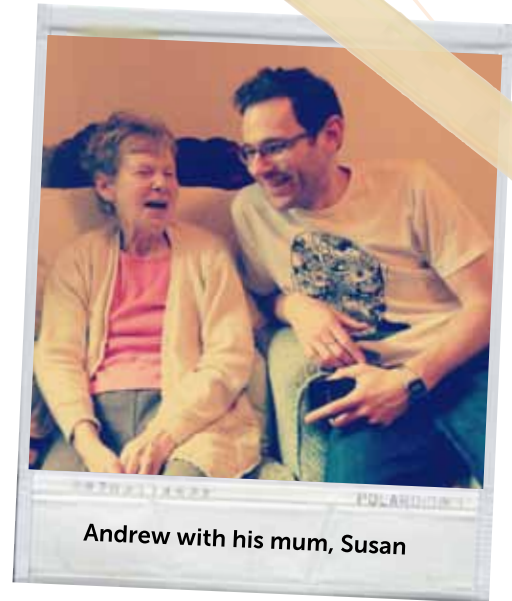


Andrew's story

"Within just a few years of being diagnosed with MSA, our dear mum was almost completely disabled and unable to do almost anything for herself. Mum lives in Sheffield, while I'm in Brighton. And my sister Becca has small children of her own to look after. So mum's now in a care home where she can get 24/7 support and medical care.

"Becca took power of attorney for our mother and dealt with the tough practical issues that come up when your loved one can no longer look after themselves. In the early days, we weren't as united as we needed to be. It's hard, especially with me living so far from home. Now, though, we're dealing with this together as a family unit – and that is really important. I try to visit as regularly as I can.

"Our journey of looking after mum has brought guilt, anger and despair at times. Equally, though, spending time with our mum is now more precious than ever, and the best advice we can give you is just to cherish it as much as possible."



Andrew with his mum, Susan

Don't be afraid to ask for help

Family, friends and neighbours often want to help but don't know how. Give them specific things you need doing – like picking up some milk or walking the dog. You'll probably find they'll be pleased to be asked.



Caring from a distance

There are a number of reasons you might end up living away from your family and those you care about. And if someone you care about has a condition like MSA, it can make the distance feel even further. If you're not the primary carer, it's not unusual to feel helpless or guilty. Here are a few tips to help you cope with the situation.

Lend an ear Offering a friendly, listening ear can help someone offload. Try to speak regularly with both the person with MSA and their carer. Maybe you could arrange a weekly call or use video calling, such as Skype.

Be informed Find out everything you can about MSA and the type of care and support the person with MSA will need. It will make a big difference to the carer if they know that you understand what's involved.

Stay in the loop Buy a diary and keep track of appointments and follow-up visits, and call to find out how appointments went. It will be an enormous comfort to the person with MSA and their carer, and will help you feel more involved too.

Plan your visits Try to arrange visits in advance so you can make maximum use of your time there. If you can, spend some individual time with both the person with MSA and their carer. Scheduling visits in advance will also give you and them something to look forward to.

Run errands If you live close enough, remember that small gestures can make a big difference. Maybe you can pick up the monthly prescriptions, or do the weekly shop? If your offer of help isn't accepted, don't be afraid to offer again another time.

Learn about technology The carer may not have the time to explore how certain gadgets, equipment and other aids may help them and the person with MSA. Why not volunteer to find out?

While you're visiting

Think about ways you can enjoy some quality time with the person with MSA while providing respite for the carer – especially if you can visit regularly or extend your visits to a few days. It might be something as simple as taking the person with MSA out for a drive or a cup of tea.

Other ways to show you care

In most cases your offers of help will be welcomed by the person with MSA and their carer. But if for some reason they don't want your help, or if it's not practical for you to help them directly, why not channel your energy into running a support group or fundraising? These are excellent ways to show you care and make a positive difference.

Offer financial support Technology and equipment can be expensive. If you're not in a position to help financially, maybe you can offer to find out about any grants and benefits the person with MSA, or their carer, may be entitled to.

Plan a break You may want to research holidays for the person with MSA and their carer (see the Trust's 'Travelling and MSA' leaflet). You could even offer to go with them and spend some quality time together.

Be nice to yourself Don't get so caught up worrying about your loved ones that you end up neglecting your own health. You need all your strength and wits about you, so a good diet and plenty of exercise are essential. Keep your own doctors' appointments and don't put any concerns about your own health on the back burner.



Staying healthy and stress-free

Looking after someone close to you when they need care can be very rewarding, but it can also be incredibly stressful and exhausting at times. If you don't look after yourself too, caring can take a serious toll on your own health.

Managing stress Lots of people suffer from stress for different reasons, but being a carer can mean that you're placed under a considerable amount of stress for sustained periods. Regular breaks and exercise can help you manage your stress levels effectively.

Eating a healthy, balanced diet This will help fuel you through your busy days. Including certain foods in your diet, such as fresh fruits and vegetables, could even help you reduce your stress levels and get a better night's sleep.

Doing regular exercise Even doing some gentle exercise a few times a week will make you feel refreshed and energised, and may even help you sleep better.

Getting a good night's sleep If the person you look after needs care during the night, you may want to consider asking for some respite care on occasion so you can get some uninterrupted sleep.

The Carewell website has been put together by Bupa and Carers UK, with the help of carers. Its 'Energy to Care' section offers information and advice on how to reduce stress, eat well, stay active and ensure you get a good night's sleep. This information is also available as a PDF booklet. Visit www.carewelluk.org



Tips on staying healthy and stress-free

Eat breakfast A good breakfast is essential to set you up for the day and give you the energy you need to get through it. It'll also mean you're less tempted to snack later on.

Do regular exercise Exercise helps us sleep better, de-stress and stay healthy, so it's extremely important for carers. If you feel like you don't have the time to exercise, try incorporating it into your routine, for example, by walking to the shops instead of driving.

Keep your stress levels in check If you notice that you're starting to feel more stressed, or that you are stressed almost all the time, talk to someone about it. Your GP may be able to refer you to counselling or other methods of support.

Make sure you get enough sleep If the person you care for has sleep apnoea, a common symptom in MSA, it can be distressing and interrupt your sleep. But sleep apnoea can be managed using a piece of equipment called CPAP (Continuous Positive Airway Pressure).

Accept the situation Sometimes it isn't possible for things to be better or easier so it's important to recognise how well you are coping in a very difficult situation. Just acknowledging this may help you feel better.

Don't forget to drink
Dehydration can lead to headaches and irritability, but it's easy to forget to have a drink when you're busy looking after someone else. Try to drink eight glasses of water a day.



Looking after yourself

It's natural to go through a wide range of emotions when caring for someone with MSA. As the condition progresses, and your relationship with the person you're caring for changes, so will your feelings.

You may feel you don't have the time to worry about your own emotional wellbeing, or you may think it selfish to do so – but this isn't the case. Looking after the way you feel is just as important as looking after your physical health.

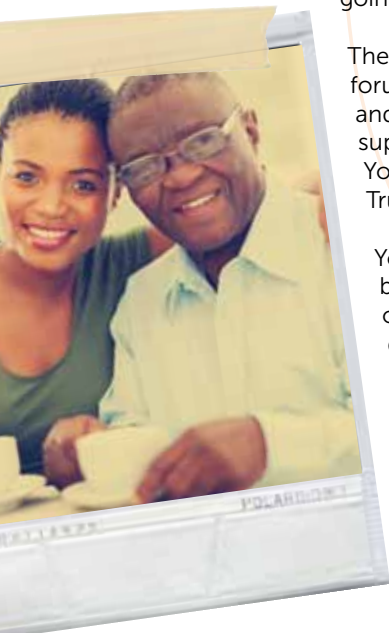
Support groups

Lots of carers find it useful to get to know other carers of people with MSA through a support group. Sharing your ideas and experiences can really make a difference, especially if you don't feel you can talk to family or friends about what you're going through.

The MSA Trust offers two types of support group: our online forum, which is moderated by MSA Trust specialist nurses and can be accessed through our website, and physical support groups in different locations across the country. You can find your nearest support group using the MSA Trust Local Hub.

You can also visit your local carers' service. As well as being a great source of information and advice, these often hold events such as coffee mornings and massage days. Visit the Carers Trust website for details of carers' services in your area.

You may need to arrange respite care in order to be able to attend support groups or carers' events. See the section on 'Getting help with practical things' for more information about this.



Tips on looking after yourself

Find some time for you Even taking a short break from caring can make a huge difference to how you feel and your energy levels. You can get details of respite opportunities from the Carers Trust. Alternatively, ask your GP or social worker.

Talk to someone about how you're feeling Don't keep your emotions bottled up as this could make you feel depressed, angry or resentful in the long term. If you can't talk to family or friends, try to attend a local support group and chat to other carers.

Access support online If it's not practical for you to attend a support group in person, join the Trust's online forum. You can also use Skype to chat to other carers you've met, or stay in touch with family and friends.

Keep doing something you enjoy This might be going to work, or something as simple as reading, gardening or walking. Do anything that makes you happy, even if it's just for a few hours a week.

"I carried on working throughout Marino's illness. It paid the bills, but more importantly I enjoyed my work and it helped me keep some sense of normality."

Linda, cared for her husband



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020 7940 4666
www.msatrust.org.uk

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samantha.pavey@msatrust.org.uk

Jill Lyons (Wales and the West of England)
01934 316 119
jill.lyons@msatrust.org.uk

Katie Rigg (Scotland, Ireland and the North of England)
01434 381 932
katie.rigg@msatrust.org.uk

MSA Trust Forum
www.msatrust.org.uk/our-forum

MSA Trust Local Hub
www.msalocalhub.org.uk

Carers' organisations

Carers Trust
www.carers.org
support@carers.org

Carers UK
0808 808 7777
www.carersuk.org

Carers Direct
0300 123 1053
www.nhs.uk/carersdirect

Working Families (helps working parents and carers achieve a work-life balance)
0300 012 0312
www.workingfamilies.org.uk
advice@workingfamilies.org.uk

Useful contacts

(For Scotland residents)
Care Information Scotland
08456 001 001
www.careinfoscotland.co.uk

Other organisations

Citizens Advice Bureau
www.citizensadvice.org.uk
Or visit your local bureau
(see the website for locations)

Help the hospices
020 7520 8200
www.helpthehospices.org.uk
info@helpthehospices.org.uk

NHS
www.nhs.co.uk

UK Government (benefits information)
www.gov.uk/browse/benefits



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Your feedback helps us ensure we are delivering information to the highest standard. If you have any comments or suggestions please complete a short survey by following the links from our website: www.msatrust.org.uk or by contacting us at office@msatrust.org.uk.



Multiple System Atrophy Trust
Information, support, education and research

Free services for people with MSA, carers, family, and health and social care professionals

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