



**Multiple System
Atrophy Trust**

Carer's Guide

Looking after yourself
and the person you care for

If you do just six things do these:

Create a network of support - People who can support you and help you offload when you need to.

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 are under.

Get a full benefits check - 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.

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 are looking 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 and some offer other services such as Support Groups.

Seek out respite care - This might involve someone coming in for a few hours a week, day care at a nearby hospice (see page 8) or something more long-term. Try to build relationships with care providers so that you can get a break every now and again.

About this Guide

This guide addresses some of the worries or problems you may face if you care for someone living with MSA. It looks at the practical, physical, financial 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 MSA Trust.

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 some of the time, and they aren't paid for the support they provide.

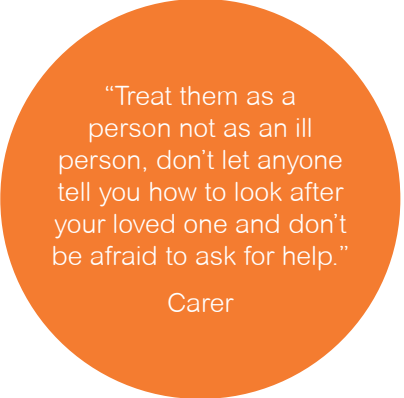
If you look after someone with multiple system atrophy (MSA), you may not see yourself as a carer or be aware of the wide range of support available. It's only natural to want to put the needs of the person with MSA first, but your needs are important too. Caring is often physically and emotionally demanding,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

Things to think about early on

If someone close to you has been diagnosed with MSA you may need to reconsider some of the plans and ideas you had for the future. Thinking ahead and talking things through with the person with MSA, and with 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 think about:

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?
- Have you had a carers assessment and is there any carer training available in your area that may help you?
- Is it possible to get a named health care professional to support you in coordinating care?



“Treat them as a person not as an ill person, don't let anyone tell you how to look after your loved one and don't be afraid to ask for help.”

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Physical aspects

- How is your own health in general?
- Are you physically able to care for someone?
- Are you eating properly?
- Are you managing to 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, pursue a hobby or interest.

You will find more helpful information to think about early on in our 'Things I Wish I Knew A Year Ago' factsheets, which are available on our website.



Where to find support

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

- The MSA Trust
- Carer organisations, such as the Carers Trust or Carers UK
- Health and social care professionals
- Benefits and financial support (contact our Social Welfare Specialists)

The different types of support available will depend on where you live. Asking for support may seem daunting at first, but just remember 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.

Thinking Ahead

MSA is an unpredictable condition and the needs 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.



“Do your research and know what you are dealing with. Make sure the team you work with are all aware of the condition and how to support properly.”

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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. This may include the following:

- Neurologist (a person with MSA should see their Neurologist every six months).
- Parkinson's Nurse Specialist or Neurology Nurse, Community Matron, District Nurse
- Occupational Therapist
- Speech and Language Therapist
- GP
- Bladder and Bowel Specialist
- Physiotherapist
- Social Worker
- Counsellor

"Get as many physical aids as you can. Allowing your loved one to retain as much independence and dignity for as long as possible is one of the best things you can do."

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Ensuring these specialists are involved early on will make things 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 with MSA and anticipate any changes or problems. You can access all of these professionals through a referral by the GP.



Respite care

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

There is also domiciliary care, where someone comes into your home and takes over the caring role 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. It is 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 - details are at the back of this Guide.

Many hospices also provide short-term respite care, including day care or even home visits.



How hospices can help

It is a common misunderstanding 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 are at.

Hospice staff also recognise the importance of the caring unit around a person with a long-term illness. They often offer help for carers and family members. Some host support groups, run activities such as exercise classes or relaxation sessions and offer complementary therapies.

What services can they offer?

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

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

“Don't let anyone tell you how to look after a loved one, no one knows them better than you.”

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All Hospices vary in terms of the services they provide. Hospices may offer day care, short stays or longer-term admissions.

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 carers can get a much-needed break or access support of their own.

Getting referred to a hospice

You can be referred by your GP, hospital doctor or District Nurse, though some hospices also accept self-referrals. 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.hospiceuk.org.



“MSA Trust were of invaluable help in the early days. In the last 6 months, having the support of our local hospice palliative care nurses made a huge positive difference.”

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Carer's assessment

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

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 of your life, 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.

Flexible working arrangements might help. You can find out about the procedure for requesting flexible working on the Carers Trust website or speak directly to your employer.

Benefits and allowances

There are a number of benefits and allowances available to carers. At the time this Guide was reviewed you may be entitled to:

- Carer's Allowance or Carer Support Payment - a taxable benefit available to help look after someone with substantial care needs.

- 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 also receive Carer's Allowance.
- Bereavement Support Payment - available if you are under state pension age and you're a widow, widower or surviving civil partner, or lived with a partner and had dependant children.
- Other benefits based on your income and savings.

It is worthwhile finding out about all the benefits and entitlements you could claim. Our Social Welfare Specialists can discuss these with you but you can also go to www.turn2us.co.uk or www.entitledto.co.uk for a full, confidential, benefits check.

NHS Continuing Healthcare funding

This is free medical 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. This currently only applies to England and Wales. There are other funding models available in Scotland, Northern Ireland and Republic of Ireland.

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

A health or social care professional who is trained as an assessor is able to complete an initial assessment to see if the person with MSA might qualify. For further details talk to our Social Welfare Specialists, download the factsheet from our website or visit www.nhs.uk and search for 'Continuing Healthcare'. In Scotland, visit www.careinfoscotland.co.uk.

Colin's Story



My wife, Hayley, was diagnosed with MSA in 2016 at the age of 53. In 2017 I took early retirement, so at the time of writing I am into my ninth year as her full-time carer. Hayley is now significantly disabled, with speech and mobility most profoundly affected.

Thankfully, her mind remains clear but she is dependent on myself, carers and District Nurses for all her daily needs.

Nothing prepared me for life as a carer! I know I have failed on countless occasions, but as I look back there are a few things I've learned that I think have helped me survive, and perhaps even thrive at times.

The first is acceptance. It didn't take me long to realise how much Hayley's diagnosis would affect me, and how much my future would also have to change. But I knew that if I allowed resentment to creep in that future really would be bleak. I am thankful that from early on I was able to accept my situation for what it was, and not what I had hoped it would be.

Second is humility. I realise now how proud I was at the beginning and how confident I was that I could manage on my own. I still struggle with this in some ways, but I'm thankful for the degree to which I have learned the lesson and become willing to accept help when I need it.

Third is self-care. The advice I received early on was to make sure I did not entirely neglect my own physical, mental and social needs. As Hayley's needs have grown my attention to myself has had to be reshaped, but I am thankful for the advice and know it has been invaluable in getting me this far.

Fourth is my faith. Both Hayley and I have a strong Christian faith and we have learned to press into that increasingly as Hayley's MSA has progressed. Not everyone has a religious faith, but in our case it has proved to be the rock on which everything else has been built.

Finally, is thankfulness. MSA gives you a lot to complain about, but I have become increasingly aware of many reasons for gratitude. Both our families have been wonderful, and our wider circle of friends has never let us down. Medical professionals, the MSA Trust and many others have served us so well. We would never have fully appreciated any of this had MSA not entered our lives.

If you are not the 'main' carer

In many instances its simply not possible to be a 'main' carer. In this situation there are still many things that you can do to help, such as:

Lending an ear

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

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. Attending one of our Support Groups can help with finding out about how people manage everyday lives, as can joining our online HealthUnlocked community.

Stay in the loop

Keep track of appointments and follow-up visits and call to find out how the 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 living 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 main 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?

Financial support

Technology and equipment can be expensive. If you are not in a position to help financially, maybe you can offer to find out about any grants or 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' factsheet). You could even offer to go with them and spend some quality time together.

Just do what you can

Don't get so caught up worrying about your loved ones that you end up neglecting your own health. You need all your strength 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 resilient

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

Managing stress

People suffer from stress for different reasons but being a carer can mean that you are placed under a considerable amount of stress for sustained periods. Regular breaks and exercise can help you manage your stress levels effectively. Your GP may be able to refer you to a counsellor or other support if you would like this.

Eating a healthy, balanced diet

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

Doing regular exercise

Doing some gentle exercise a few times a week, especially with other people, 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, or has sleep apnoea, you may want to consider asking for some respite care occasionally so you can get some uninterrupted sleep. Sleep apnoea, a common symptom of MSA, can often be

managed by a piece of equipment called a CPAP machine. The symptoms of sleep apnoea may include loud snoring, noisy and laboured breathing and repeated short periods where breathing is interrupted by gasping or snorting. Discuss this with the GP or Nurse Specialist if this is an issue.



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.

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

A useful read is 'The Selfish Pig's Guide to Caring' by Hugh Marriott, available in most libraries and bookstores.

Support Groups

Lots of carers find it useful to get to know other carers of people living 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.

We run in-person Support Groups in different locations across the UK and Ireland. We also offer Digital Support Groups, which you will receive invitations for after registering with us. We have a specific Carers Online Group which meets monthly.

You can find all Support Group information on our website, www.msatrust.org.uk or email support@msatrust.org.uk

We also have a HealthUnlocked community, which is moderated by MSA Trust staff and can be accessed here - www.healthunlocked.com/msa-trust.

You may want to 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 information days. Visit the Carers Trust website for details of carers' services in your area.

"Learn to take one day at a time. Know your limits as caring for someone with MSA is not easy but is possible."

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Useful Contacts

We have MSA Health Care Specialists that support people affected by MSA in the UK and Ireland. If you would like to find the MSA Health Care Specialist for your area, contact us on the details below or use the interactive map on our website - www.msatrust.org.uk/hcps.

We also have a Social Welfare Service which supports with benefits, care and welfare enquiries.

The Multiple System Atrophy Trust
0333 323 4591
support@msatrust.org.uk
www.msatrust.org.uk

MSA HealthUnlocked Community
www.healthunlocked.com/msa-trust

Carers Organisations

Carers Trust
0333 772 9600
info@carers.org.uk
www.carers.org

Carers UK
0207 378 4999
www.carersuk.org

Carers Direct
0203 904 4520
info@carersdirect.org
www.carersdirect.org

For Scotland Residents
Care Information Scotland
0800 011 3200
www.careinfoscotland.scot

For Ireland Residents
www.hse.ie
Family Carers Ireland
1800 240 724
Familycarers.ie

Other Organisations

Crossroads
www.crossroadscaringforcarers.org
0121 553 6483

Citizens Advice
www.citizensadvice.org.uk

Hospice UK
www.hospiceuk.org

NHS
www.nhs.uk

Benefits Information
www.turn2us.org.uk
www.entitledto.co.uk



Patient Information Forum



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Our vision is a world free of MSA

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