



**Multiple System
Atrophy Trust**

Carer's Guide

Looking after yourself
and the person you care for

Six Things...

If you do just six things do these...

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 someone coming 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.

Create a network of helpers - 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're under.

Talk to your bank and a financial adviser and 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.

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 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 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.

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?



"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 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.



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 or Carers UK
- 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 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:

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

"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 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 with MSA 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 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 - 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 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's 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're at.


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

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

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



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

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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.

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.hospiceuk.org.uk or by using the MSA Trust Local Hub on our website.



"Getting a sippy cup that allows them to choose to drink when they want is invaluable."

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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, or 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 - a taxable benefit available to help look after someone with substantial caring 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'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.
- Other benefits based on your income and savings.

It is worthwhile finding out about all the benefits and entitlements you could claim. For further details, and to get a full, confidential, benefits check go to www.turn2us.co.uk.

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.

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.

District Nurses are able to complete an initial assessment to see if the person with MSA might qualify. For further details visit www.nhs.uk and search for 'Continuing Healthcare'. In Scotland, visit www.careinfoscotland.co.uk.

Bev's Story

In October 2014 my husband John was diagnosed with MSA and so began my journey to becoming his carer. As a wife I would have always loved and cared for him but now the caring is taking over. I have learned that I need to share that care with others and this has been one of the hardest things I have ever done. I wanted to do it all but that is impossible and to acknowledge this is the first, biggest step you take. My biggest help and inspiration is John as he is so positive and this inspires and encourages me - he is my hero.



With MSA change comes slowly so we work together to put in place things to help with these changes. It is also vital to tell people about your problems. All the health care providers have been fabulous so never be afraid to ask for help. Friends and family have also been wonderful and with their help we still have a great social life, going dancing (for chats only now) football as season ticket holders, family meals and occasions, and lots of holidays. As a carer it has been my lifeline to carry on doing all the things I love. It is so important to look after yourself and find some 'me' time.

We do everything together. There have been tears but we laugh a lot, have made some mistakes (often hilarious) but have got a lot right. The future is unknown but we face it with humour and patience. Never turn down an offer of help, people are wonderful and need to feel they can help, so let them. You never need to feel alone as there will always be someone there to help. Enjoy as much as possible the time you have together but most of all look after yourself as this will make you a better carer.

If you can't be the 'main' carer

In many instances it's 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, 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. Attending one of the MSA Trust's Support Groups can help with finding out about how people manage everyday lives, as can joining our online Forums.

Stay in the loop

Buy a diary and 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 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?

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 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 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 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

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. Also 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

Even 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.



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.

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 Nurse Specialists and can be accessed through our website, and physical Support Groups in different locations across the country.

You can find your nearest Support Group on the event calendar on our website www.msatrust.org.uk.

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 information 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 page 6 for more information about this.

"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

Nurses, carer's organisations and other organisations

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

MSA Trust Nurse Specialists
Samantha Pavey (South and East of England)
0203 371 0003
samantha.pavey@msatrust.org.uk

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

Katie Rigg (Scotland, Ireland and North of England)
01434 381 932

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

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

For Scotland residents
Care Information Scotland
www.careinfoscotland.co.uk

For Ireland residents
www.hse.ie

Other Organisations

Citizens Advice
www.citizensadvice.org.uk

Hospice UK
020 7520 8200
www.hospiceuk.org

NHS
www.nhs.uk

Benefits information

UK
www.turn2us.org.uk

Ireland
www.turn2us.ie

and finally...

"You're doing a brilliant job, so go to bed each night knowing that and find the humour in each day and cherish your time together."

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Join the MSA Trust

Information, support, education and research

Services for people with MSA, carers, family,
health and social care professionals.

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Email **support@msatrust.org.uk**

www.msatrust.org.uk
www.healthunlocked.com/msa-trust



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Our vision is a world free of MSA