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I wish I'd known that a year ago – Scotland

If you have been diagnosed with MSA fairly recently there are a number of things that it is important you know, even if they are not relevant to you at this moment. This factsheet aims to provide basic information along with links to more detailed guidance. We are here to offer information and support so please don't hesitate to contact us if you need more information, have questions or are worried about anything related to your diagnosis.

Getting Out and About

If your mobility is limited you may be eligible for a blue badge which can help with car parking. Visit www.mygov.scot/apply-blue-badge/ or contact your local council to apply. It is possible for you to obtain a blue badge (if you meet the criteria) even if you do not own a car. Friends and relatives can then use this to enable easier parking when you are travelling with them. The badge cannot be used to park in a disabled parking bay if the person with the badge is not getting in or out of the car. If you don't have access to a car there may be a community transport scheme near you. Your local council or library will have details or you can search for providers via this link <https://cta.uk/>.

Most larger towns and cities have a Shop Mobility scheme which allows people to borrow a powered wheelchair or scooter for the day.

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Always check in advance that what you require is available and that you are eligible for their scheme. It is also possible to hire manual wheelchairs (ones without a battery) from the British Red Cross.

Further information can be found here - www.redcross.org.uk/get-help/borrow-a-wheelchair.

Taking holidays, in the UK or abroad, can be important and we have a specific factsheet about this including details of companies who may offer travel insurance to people diagnosed with MSA. It also lists specialist travel agents and advice services. You can download it on our website here - <https://www.msatrust.org.uk/wp-content/uploads/2015/11/FS403-V2.4-Travelling-and-MSA-1.pdf>. If you have concerns about toilets when you are out, there are keys (sometimes known as Radar keys) which unlock disabled toilets in many public places around Scotland. They are available from local councils or from www.disabilityrightsuk.org/shop/official-and-only-genuine-radar-key.

'Just can't wait' cards are available via www.bladderandbowel.org/helpinformation/just-cant-wait-card/. These can be used discreetly when you urgently need to use a toilet when out and about. There is also a phone app which can be downloaded and used to locate the nearest toilet facilities.

Driving

It is a legal requirement to let the DVLA know of any medical condition which may affect your ability to drive – this includes a diagnosis of MSA even though it is not listed in DVLA literature. It is also essential to tell your insurance company as not doing so may invalidate your policy. Telling the DVLA will not automatically lead to you losing your licence but further investigations into your ability to continue driving may need to be made. You can contact the DVLA on 0333 790 6806.

People in receipt of the enhanced mobility rate of Personal Independence Payment (PIP) or Adult Disability Payment (ADP) may be able to obtain a vehicle through the Motability scheme. See the section below for more information. You do not have to be a driver yourself to use this scheme. People in receipt of Disability Living Allowance (DLA), PIP or ADP may be entitled to help with road tax -

https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/645097/ins216-how-to-apply-for-free-disabled-tax.pdf. We also have a factsheet on driving which you can read on our website here - <https://www.msatrust.org.uk/wp-content/uploads/2015/11/FS401-V1.4-Driving-and-MSA.pdf>.

The Motability Scheme

The Motability scheme is available to people in receipt of DLA with the higher rate mobility component, PIP or ADP with the enhanced mobility component. Please note, no new claims can be made for DLA and only people under state pension age can apply for ADP. Under the Motability scheme people can use their mobility component to help fund a vehicle, a powered wheelchair or a scooter. See www.motability.co.uk for more information or call Motability customer services on 0300 456 4566.

Employment

If you are in employment but need support, you should talk to your employer about 'reasonable adjustments'. This covers things like a change in your hours or to your work location.

If you require specialist equipment to enable you to continue in your job you may get help via the government's Access to Work scheme. This applies even if you are already in a job or are self-employed. Access to Work can also provide help from another person where needed, for example through a taxi to work and for workplace adaptations. More information is available via your local Job Centre Plus or see the Government website here - www.gov.uk/access-to-work.

Employers can read more about this at www.gov.uk/government/publications/access-to-work-guide-for-employers/access-to-work-factsheet-for-employers.

If you are seeking work you may be eligible for benefits support, there's more information on this in the section below.

Work coaches at your local Job Centre Plus should offer assistance with finding employment and advising on any employer's responsibilities and the Access to Work scheme. Please see here for more information - www.gov.uk/looking-for-work-if-disabled.

If you feel your MSA prevents you from working, please see the benefits section below.

Benefits

Not all benefits are means-tested. Some benefits are paid to assist with additional care or mobility needs, some to help replace lost income and some to assist carers. You can read more about benefits at www.gov.uk/browse/benefits, see www.cas.org.uk/ or visit your local Citizens Advice Office. Older people can also contact an Age Scotland centre (0800 470 80 90) for further information and support or they can ring the Money Talk Team on 0800 085 7145. Over time an increasing number of benefits will be administered by the Scottish Government and this may alter some of the eligibility criteria.

Up to date information can be found at www.mygov.scot/benefits/ or contact our Social Welfare Specialists via the main office on 0333 323 4591.

Non means-tested, non-contributory benefits which will be especially relevant to people diagnosed with MSA include:

- Attendance Allowance (AA) - If you are over state pension age and require help with personal care or need supervision with some activities consider applying for AA. See www.gov.uk/attendance-allowance for more information or download our factsheet about AA on our website here - <https://www.msatrust.org.uk/wp-content/uploads/2015/11/FS405-Attendance-Allowance-V1.0.pdf>.
- Adult Disability Payment (ADP) - If you are under state pension age and require assistance with tasks of daily living or with mobility, consider applying for ADP (which has replaced Personal Independence Payment (PIP) in Scotland). See www.mygov.scot/adult-disability-payment for further information and support.

If you are almost state pension age it is very important to ensure that you are in receipt of ADP (if you are entitled to it) and that you are receiving the correct rate of the mobility component. This is because after you reach state pension age you cannot claim ADP but will need to claim AA and this has no mobility component to it. People already in receipt of ADP usually remain on it but the rate of the ADP mobility component cannot be increased after you reach state pension age. If you are currently receiving PIP, Social Security Scotland will move your benefit to ADP without you having to do anything.

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- Carers Allowance / Carer's Support Payment – In Scotland, Carer's Allowance is being replaced by the Carer's Support Payment from spring 2024. You should visit postcodecheck.socialsecurity.gov.scot to see whether the Carer's Support Payment has been rolled out in your area. If not, you will need to claim Carer's Allowance.

Carer's Allowance / Carer's Support Payment is payable to carers who support someone receiving AA, ADP or PIP for 35 hours or more a week. Although not means-tested, it cannot be paid to a carer who earns over £151 per week (after deductions). The carer may be your partner, a family member or a friend. It is a benefit which overlaps state pension so some pensioners may not receive it. See here for further details - www.gov.uk/carers-allowance.

Carers in Scotland may also receive a Carers Allowance Supplement, see www.mygov.scot/carers-allowance-supplement/.

Non means-tested, contributory benefits especially relevant to people diagnosed with MSA include:

- *New Style Employment and Support Allowance (new style ESA)* – This is paid to those who have limited capability to work because of a health condition or disability and have paid enough National Insurance contributions in the past 2 years. This is a non means-tested benefit and any savings are disregarded. Some permitted work may still be possible whilst claiming new-style ESA. You can find more information on new-style ESA here - [New Style Employment and Support Allowance - GOV.UK \(www.gov.uk\)](https://www.gov.uk/new-style-employment-and-support-allowance)
- *New Style Job Seekers Allowance (new style JSA)* – Similar to new style ESA above but for those seeking employment. Your local Job Centre Plus can advise you further on new style JSA or see here for more information - [Jobseeker's Allowance \(JSA\) - GOV.UK \(www.gov.uk\)](https://www.gov.uk/jobseekers-allowance)

Means-tested benefits especially relevant to people diagnosed with MSA include:

- Pension Credit – For people over state pension age. See www.gov.uk/pension-credit or call the Claim Line on 0800 99 1234.
- *Universal Credit* – This is a benefit for those under state pension age. It is replacing Child Tax Credits, Working Tax Credits, Housing Benefit, Income Support, Income Based Employment and Support Allowance and Income-Based Job Seekers Allowance. See www.gov.uk/universal-credit or call the Helpline on 0800 328 5644 for further assistance. Transitional protection may exist for those people who are moved on to Universal Credit but whose circumstances have not changed. A change in circumstances (for example, you get married) will affect your benefits and you must notify the Department of Work and Pensions about this change. Please seek independent advice before choosing to switch from your current benefits to Universal Credit. Even an unsuccessful application for Universal Credit will result in the immediate loss of the benefits Universal Credit replaces and it will not be possible to reclaim those lost benefits.

You can check your entitlement to benefits at www.turn2us.org.uk or www.entitledto.co.uk, or contact our Social Welfare Specialists via the main office on 0333 323 4591.

Age Scotland produce a range of helpful factsheets - www.ageuk.org.uk/globalassets/age-scotland/documents/ia---factsheets/general/gen-1-publications-list-jun-19.pdf. Citizens Advice also has good online resources which can be accessed here - [hwww.citizensadvice.org.uk/benefits/](https://www.citizensadvice.org.uk/benefits/).

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Prescriptions are free in Scotland but there are entitlements to help with other health related costs (travel to appointments, dental and optical charges etc.) and to schemes such as the Winter Fuel Allowance. Sometimes people not in receipt of benefits but on a low income can be entitled to these. Our Social Welfare Specialists can give further information on these.

Council Tax Reductions

These schemes are operated by local councils and you should contact your local council directly, but reductions are usually available if:

- You live alone or the other person/people you live with are 'disregarded' (for example they are severely mentally impaired, a child or a full-time student. Some carers may be disregarded)
- You are severely mentally impaired
- You have had your home adapted for disability related needs (this depends on what adaptations have been made but examples include having an adapted bathroom or a ramped access into the property).
- Your home is unoccupied as you are staying elsewhere.

Please see [/www.mygov.scot/council-tax/discounts-exemptions-and-reductions/](http://www.mygov.scot/council-tax/discounts-exemptions-and-reductions/).

There are other benefits available so do seek further advice where possible. It is a good idea to review the benefits you receive annually and at times of change.

Energy Suppliers

Many gas and electricity suppliers have discount schemes for people on low incomes or who are disabled. Try to ensure you are on the lowest tariff. If you are using essential electrical equipment because of your disability you should advise your energy supplier so that they can consider arrangements to cover power cuts.

Managing Financial and Other Affairs

Everyone diagnosed with MSA should consider having Powers of Attorney in place. A Power of Attorney is a legal document that allows you to appoint either one person, or more than one person, as your 'attorney' in respect of the management of your property and finances (a continuing power of attorney) or your health (a welfare power of attorney) or both (a combined welfare and continuing power of attorney). These are a little different to the powers of attorney documents used in England.

Many people mistakenly believe that their partner or next of kin will have the automatic right to make decisions for them if they are unable to do so, but this is not the case even if you are married. It is extremely important to appoint people you trust and to be specific about the scope of their powers.

Attorneys can be in a position to make significant decisions if you lose the capacity to make your own decisions, for example about how your money is spent, about selling your property or about where you should live. The usual choice is to appoint close family members or a solicitor. Powers of Attorney can only be made by people who 'have capacity'. Capacity relates to the making of specific decisions. This means that powers of attorney can only be made by people who are able to understand the issues, weigh them up and make an informed choice. They must also be able to communicate that choice (verbally, in writing or in some other way). The making of what others may consider an unwise choice does not

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mean a person lacks capacity to make that decision. Please see www.mygov.scot/power-of-attorney/further-information/.

Many people choose to use a solicitor to make a power of attorney although it is not essential to do so and you may choose to complete the paperwork online yourself. A continuing power of attorney (for property and finances) can be registered and used before a person loses capacity if the donor (the person making the power of attorney) wishes this. With a combined power of attorney only the part relating to finances can be used before a person loses capacity.

If no continuing power of attorney is in place, it may be possible to arrange with the Social Security Scotland and/or the Department for Work and Pensions (DWP) to appoint someone to manage your benefits for you. Please see www.mygov.scot/acting-on-behalf-of-someone-claiming-benefits/.

Help with Care at Home

If you live at home and require help with tasks of daily living (for example, washing, dressing, preparing a meal, shopping) talk to the social care team at your local Council and request a 'community care assessment'.

This looks at your care needs and how they are (or can be) met. It will cover tasks of daily living, social activities, equipment needs and the need for support from other services, for example, from a District Nurse. You can refer yourself for this assessment.

In Scotland, following assessment, identified nursing and personal care needs are met free of charge without means testing. Nursing needs are met via your GP surgery but other needs may be met in a variety of ways including through self-directed support where you may choose to hold the allocated budget and use it in the way which best meets your agreed needs.

Charges may be made for assistance with home care (laundry, cleaning shopping) subject to a financial assessment of ability to pay.

You can read more about care support at home at: www.careinfoscotland.scot/ or call Care Information Scotland on 0800 011 3200.

Non-Statutory Services

In every area there will be a range of services provided by voluntary organisations or by private providers. A care assessment may help identify these. Examples would include day centres, lunch clubs, befriending schemes and the home library service. Many hospices have a range of services offering ongoing support to people with progressive neurological conditions. Hospice support is not only for end of life care but is about improving quality of life.

Each hospice is different but many offer day hospice support, regular home visits by trained volunteers and access to specialist advice. Your GP can refer you and some hospices do take self-referrals.

Obtaining equipment

Equipment that enables a person to be as independent or safe as possible, or which assists their carer, can be obtained and funded in a variety of ways. Medical or nursing equipment will be arranged via your GP surgery. Wheelchairs can be provided by the NHS – request a referral via your therapist or GP at an early stage.

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To ask about equipment speak to your Local Authority's Social Work/Social Care Department. Discussions around equipment needs should be included as part of your care needs assessment. Equipment to assist a carer can be part of a carers assessment. Occupational Therapists take a lead in this. Do not wait until your need is acute as waiting lists for assessment can be lengthy.

Always seek advice before buying expensive equipment privately. Some areas have an Independent Living Centre where you can view equipment and obtain impartial advice. See www.focusondisability.org.uk/dlc-3.html for a list or speak to your Occupational Therapist (OT).

There is general advice at www.mygov.scot/care-equipment-adaptations/.

The Scottish Fire and Rescue Service offer free home fire safety visits and free smoke alarms.

Many people living with MSA notice that their voice becomes softer or quieter over time making speaking difficult and their speech possibly unintelligible. This can cause frustration, both for the person living with MSA and their family. Because of this, the MSA Trust has entered into a contract with a company who support voice banking. Through voice banking a version of your voice can be banked whilst it is still reasonably clear and used with various devices to aid communication in the future.

It is important that this is considered at an early stage and that you discuss it with your Speech and Language Therapist. Where the therapist recommends it we can provide the service free of charge. Please see: <https://www.msatrust.org.uk/support-for-you/for-people-affected-by-msa/voicebanking/>.

Help to Adapt a Home or to Move

If your home needs adapting, or you think you may need to move, it is important to arrange an appointment with an OT from your Local Authority. Do this before arranging for any work to be done. You can refer yourself via the local Social Work Department. Advice on what may be required and the help available to finance adaptations is part of the role of the OT and their approval will be required if funding is to be obtained from a statutory source.

There is helpful advice online at: <https://www.mygov.scot/care-equipment-adaptations/>. If you own your own home and your Local Authority (usually following detailed assessment with one of their OT) agrees that the adaptations are essential they must offer you a grant. This will, in all cases, cover 80% of the cost of the work. For people on some means tested benefits the grant will cover the whole cost.

Please see www.mygov.scot/funding-adaptations-homeowners/. For tenants in privately rented accommodation similar rules apply – please see www.mygov.scot/funding-adaptations-private-tenants/. If you rent from a local authority you should read www.mygov.scot/funding-adaptations-local-authority/ and if you rent from a housing association please see www.mygov.scot/funding-adaptations-housing-association/.

Care Information Scotland can give information on obtaining home adaptations. The number is 0800 011 3200.

Services for Carers

Carers need support and many carers leave it a long time before asking for help. It is a good idea to request help at an early stage so the risk of a crisis developing is lessened.

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Every Social Services department will be able to provide information on the support they offer to carers. It is important to ask them to carry out a 'Carers Assessment' which looks at your needs as a carer and may lead to additional services being offered, for example, a sitting service or respite care. You can refer yourself for a Carers Assessment. Be honest about what support you feel able to offer and about your need for things like regular respite care breaks. Carers Assessments do not have to be carried out with the person you are caring for present and you can request a Carers Assessment even if the person you care for has refused a Needs Assessment. Social Services should help carers to put in place an emergency care plan outlining what to do in the event that the carer is ill or injured. Carers may carry a Carers Emergency Card.

Carers need to look after their own health. Advise your GP and the surgery of your role as a carer.

Carers are usually entitled to a free flu jab and many surgeries offer other support to carers. Carers (or the person they care for) may be entitled to discounts at visitor attractions or on public transport. Check your eligibility for Carer's Allowance/Carer' Support Payment – please see the benefits section for further information on this. Many areas have carers centres and Social Services will be able to tell you about these. Carers centres often arrange meetings so you can share experiences with other carers and some have advice workers.

There are also two national voluntary organisations for carers – Carers UK and The Carers Trust and both of their websites are here www.carersuk.org and www.carers.org.

Many carers find the online forum HealthUnlocked a convenient and helpful way of asking questions of other carers and people living with MSA. You can access this by going to www.healthunlocked.com/msa-trust. Our Support Groups are also a helpful and supportive way for carers to get together. You can read more about this at <https://www.msatrust.org.uk/>.

Six Things... If you do just six things do these...

1. Get a benefits check
2. Have a care needs assessment (and ensure your carer has a carers assessment) and accept care support if needed
3. Look into arranging Powers of Attorney (for financial affairs and for health)
4. Plan ahead with respect to housing and adaptation needs
5. Maintain your network of family and friends and accept their help
6. Do things you enjoy.

The MSA Trust's Contact Details:

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 here – <https://www.msatrust.org.uk/support-for-you/hcps/>.

T: 0333 323 4591 | E: support@msatrust.org.uk | W: www.msatrust.org.uk

If you have any questions about anything you have read in this factsheet, then please contact your MSA Health Care Specialist or our Social Welfare Specialist.

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Disclaimer:

We have taken every care to ensure the accuracy of the information contained in this publication. However, the information should not be used as a substitute for the advice from appropriately qualified professionals. Speak to your doctor, qualified health care professional or legal professional before taking any action. Please note that personal views and opinions expressed are not necessarily endorsed by the Trust. The resource is produced independently, is not influenced by sponsors and is free from endorsement.

References for this information sheet are available by contacting support@msatrust.org.uk.

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Patient Information Forum

