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I wish I'd known that a year ago... (England and Wales version)

If you have been diagnosed with MSA fairly recently there are a number of things that it is important you know about, even if they are not relevant at the 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 parking. Visit <https://www.gov.uk/apply-blue-badge> or contact your local council to apply for a blue badge. 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://ctauk.org/>.

Most larger towns and cities have a Shop Mobility scheme which allows people to borrow a powered wheelchair or scooter for the day. Always check in advance that what you require is available and that you are eligible for their scheme.

It is also possible to borrow manual wheelchairs (ones with no battery) from the British Red Cross. Further information can be found here - <https://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 here <https://www.msatrust.org.uk/wp-content/uploads/2015/11/FS403-V2.1-Travelling-and-MSA.pdf>.

There are keys (sometimes known as Radar keys) which unlock disabled toilets in many public places around England and Wales. They are available from local councils or from <https://www.disabilityrightsuk.org/shop/official-and-only-genuine-radar-key>.

'Just can't wait' cards are available via <https://www.bladderandbowel.org/help-information/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 or visit this website for more information - <https://www.gov.uk/browse/driving/disability-health-condition>.

People in receipt of the enhanced mobility rate of Personal Independence Payment (PIP) 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) or PIP 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 have a factsheet on driving which you can read here <https://www.msatrust.org.uk/wp-content/uploads/2015/11/FS401-V1.3-Driving-and-MSA.pdf>.

The Motability Scheme

The Motability scheme is available to people in receipt of DLA with the high rate mobility component or PIP 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 PIP. Under the Motability scheme people can use their mobility component to help fund a vehicle, a powered wheelchair or a scooter. See <https://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 work place adaptations. More information is available via your local Job Centre Plus or see the Government website here - <https://www.gov.uk/access-to-work>.

Employers can read more about this at <https://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 - <https://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 <https://www.gov.uk/browse/benefits> or you can visit your local Citizens Advice Centre or Age UK centre where they can give you further information. You can also contact our Social Welfare Specialist 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 - <https://www.msatrust.org.uk/wp-content/uploads/2015/11/FS405-Attendance-Allowance-V1.0.pdf>
- *Personal Independence Payment (PIP)* - If you are under state pension age and require assistance with tasks of daily living or with mobility, consider applying for PIP. See www.gov.uk/pip for further information and support. If you are almost state pension age it is very important to ensure that you are in receipt of PIP (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 PIP but will need to claim AA and this has no mobility component to it. People already in receipt of PIP usually remain on it but the rate of the PIP mobility component cannot be increased after you reach state pension age. We have a fact sheet about PIP which can be downloaded on our website - <https://www.msatrust.org.uk/wp-content/uploads/2015/11/Personal-Independence-Payment-V1.0.pdf>
- *Carers Allowance (CA)* – This is payable to carers who support someone receiving AA or PIP for 35 hours or more a week. Although not means-tested CA cannot be paid to a carer who earns over £123 (2019/20 rate) a 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.

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.

Both Pension Credit and Universal Credit can include amounts to help cover housing costs. Housing Benefit and help with Council Tax may also be available.

You can check your entitlement to benefits at www.turn2us.org.uk or www.entitledto.co.uk.

Age UK produce a range of helpful factsheets - https://www.ageuk.org.uk/globalassets/age-uk/documents/information-guides/inf_guide_index.pdf.

Citizens Advice also has good online resources which can be accessed here - <https://www.citizensadvice.org.uk/benefits/>.

Remember there are also entitlements to help with health related costs (prescriptions, travel to appointments, dental and optical charges etc.) and to schemes such as the Winter Fuel Payment. People not in receipt of benefits may be entitled to these. Our Social Welfare Specialist can give further information on these.

Council Tax Reductions

These schemes are operated by local councils 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 (depends on what adaptations have been made)
- Your home is unoccupied as you are staying elsewhere.

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 Lasting Powers of Attorney (LPA's) in place. A Lasting 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 LPA for property and financial affairs) and/or your health and welfare (a LPA for health and welfare).

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. Lasting Powers of Attorney can only be made by people who 'have capacity'. Capacity relates to the making of specific decisions. This means LPA's 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 mean a person lacks capacity to make that decision. Please see <https://www.gov.uk/power-of-attorney> for more information.

Many people choose to use a solicitor to make a LPA although it is not essential to do so and you may choose to complete the paperwork online yourself. A LPA for property and finances can be registered and used before a person loses capacity if the person making the LPA wishes this.

If no LPA for financial affairs is in place, it is possible to arrange with the Department of Work and Pensions (DWP) to appoint someone to manage your benefits for you. Please see <https://www.gov.uk/become-appointee-for-someone-claiming-benefits>.

Help with Personal Care Needs

If you live at home and require help with tasks of daily living (for example, washing, dressing, preparing a meal, using the toilet) talk to the Adult Social Care team at your local Social Services and request a 'care assessment'. This looks at your social care needs and how they are (or can be) met. It will cover tasks of daily living, social activities and the need for support from other services, for example, from an Occupational Therapist for equipment to aid your independence. You can refer yourself for this assessment.

Social Services may charge for services they agree to provide or arrange, subject to assessing a person's financial situation.

In England people who have in excess of £23,250 (2019/20 level) will be expected to 'self-fund' their care in most cases. If you have joint savings half will be assumed to be yours unless you can show otherwise. See here for more details -

https://www.ageuk.org.uk/globalassets/age-uk/documents/factsheets/fs46_paying_for_care_and_support_at_home_fcs.pdf.

In Wales there is also a means-test, though different to the one in England. In Wales there is a maximum weekly charge of £90 (2019/20 level) regardless of how much support is provided, though you cannot be charged more than the actual cost of the support received (for example, if you have a service that costs the authority £20 a week you cannot be charged more than £20). See here for further explanation -

<https://www.ageuk.org.uk/globalassets/age-cymru/documents/information-guides-and-factsheets/fs46w.pdf>.

Instead of accepting the services arranged by Social Services you can choose to have a 'Direct Payment' instead. This is a budget that you hold to organise your own care support. Every area has an independent agency that can advise on and assist with the administration of Direct Payments for a small fee. Your social services can provide the contact details for your area.

People who self-fund the services they receive are still entitled to information and advice from Social Services free of charge. If a person requires help to arrange the care services they need, this too should be provided (but the authority can charge for this).

People who fund their own care support may choose private carers or may use a care agency. All care agencies are inspected by the Care Quality Commission (www.cqc.org.uk) and their inspection reports can be read online. If using a private carer check if they operate in a self-employed capacity, check references and request a Disclosure and Barring Service check (DBS). See <https://www.gov.uk/dbs-check-applicant-criminal-record> for more information about this.

Anyone who has been in hospital may be offered a short period of 'intermediate care' free of charge to help them settle back home safely. Intermediate care is care based in your own home.

There are many reasons why it is advisable to get care support in early. These include:

- maintaining your safety and energy (especially if you live alone, it may be better to save your energy for more enjoyable activities)
- giving a break to your partner/relative who normally assists you
- ensuring others are familiar with your routines should you need them to help in an emergency.

It is important to know that people who have complex health care needs may be, or may become, eligible for NHS funded care known as Continuing Health Care (CHC). This can be provided in your home or in a nursing home. It is free of charge to all who meet the criteria and should fully cover the cost of your assessed care needs in your own home or nursing home. The amount of care needed and the home chosen is the responsibility of the NHS in consultation with you. See www.Beaconchc.co.uk for more details or talk to our Social Welfare Specialist.

Non Statutory Services That May Help

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

Many people spend a lot of money on things which they later discover could have been funded by the NHS or Social Services, or are not suitable for their needs. Purchasing equipment privately often means that no professional advice has been obtained on the suitability of the equipment for your needs. Do look at our range of factsheets on mobility and communication aids that may be helpful and discuss further with your Therapists, Specialist Nurse or GP. Should you wish, or need, to purchase equipment privately try to obtain advice from a relevant professional (typically an Occupational Therapist, Physiotherapist or Nurse). In many areas there are Independent Living Centres (sometimes known as Disabled Living Centres) which allow you to try equipment without the pressure of a sale and where you can usually book an appointment with an Occupational Therapist. Please see <http://www.goingforindependence.org/ILCs> for a list of centres. The Disabled Living Foundation also has a useful website <https://www.dlf.org.uk/>.

Equipment that aids your independence at home, or which assists your carer, can often be obtained free of charge via your Occupational Therapist or Community Nurse.

Continence aids are usually supplied via nursing services.

Manual wheelchairs and, in certain circumstances, powered wheelchairs, are available free of charge via NHS Wheelchair Services. You will need your GP, Occupational Therapist or Physiotherapist to refer you. It is very important that your wheelchair is right for your needs.

Some items are not funded by a statutory source, a powered scooter would be an example of this. In some areas equipment which is funded in another part of England or Wales may not be funded in your area for example, riser recliner chairs.

If you require help with obtaining the equipment you need please contact our Social Welfare Specialist.

We do have a very small grants budget – please contact us if you would like to apply for a grant. Help can also be given to apply to other organisations that provide grants.

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 you live in a rented property speak to your Occupational Therapist, there are schemes to assist with adaptations or to help people to move. For owner occupiers, help with the cost of essential adaptations (or with moving costs) may be available via a means-tested Disabled Facilities Grant (known as a DFG) from your local council. Councils work with Occupational Therapists from Social Services to establish which needs can be grant aided so you must involve them. Help is never given retrospectively and the process can be lengthy so advance planning is important. In England the maximum DFG is £30,000 and in Wales the maximum DFG is £36,000. You can read more about DFG's at <https://www.gov.uk/disabled-facilities-grants>.

If you are funding the adaptation yourself you can check on products and services that could be tax-free, here - <https://www.gov.uk/vat-builders/disabled-people>.

Minor adaptations, for example grab rails or extra bannister rails, may be arranged by your Occupational Therapist. In England this is usually free of charge. In Wales a modest charge may be made.

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. 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 Carers Allowance – 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.

I Wish I'd Known That a Year Ago

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 <https://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/support-for-you/local-support/support-groups/>.

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 Lasting 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.

Further information

The MSA Trust offers information and support in a number of ways.

Our main office support line is available Mondays to Fridays 9am-5pm. Please call 0333 323 4591 or email support@msatrust.org.

If you have questions relating to your diagnosis or your care needs you can contact one of our MSA Nurse Specialists. Please see overleaf for their details.

If you have questions about benefits, grants, CHC applications or advocacy related issues please contact our Social Welfare Specialist via our main office on 0333 323 4591 or email support@msatrust.org.uk.

You can visit our website at www.msatrust.org.uk.



Samantha Pavey 0203 371 0003
samantha.pavey@msatrust.org.uk

Katie Rigg 01434 381 932
katie.rigg@msatrust.org.uk

Jill Lyons 01934 316 119
jill.lyons@msatrust.org.uk

Emma Saunders 0330 221 1030
emma.saunders@msatrust.org.uk

Social Welfare Specialist:

Sam Fitzgerald
0203 404 6673
sam.fitzgerald@msatrust.org.uk

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