MSA Trust

Factsheet

I wish I'd known that a year ago – Northern Ireland

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.

Once you have been diagnosed it may be helpful to contact the Neurological care advice service that supports people across Northern Ireland - they offer a 'one-stop' link to ensure you are receiving the local support available.

Telephone: 028 9504 2270 and Email: neurocareadvice@belfasttrust.hscni.net

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.nidirect.gov.uk/services/apply-or-renew-blue-badge-online 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://www.nidirect.gov.uk/articles/community-transport-and-shopmobility-schemes

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. See https://www.shopmobilityni.org/ for more details. 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 in the UK and Europe. They are available from local councils (sometimes free of charge) or from https://shop.disabilityrightsuk.org/products/radar-key. 'Just can't wait' cards are available from https://www.bladderandbowel.org/help-information/just-cant-wait-card/. These cards can be used discreetly when you urgently need to use a toilet when out and about. There is also a phone app (Wheelmate) 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.nidirect.gov.uk/articles/how-tell-dva-about-medical-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. See https://www.gov.uk/financial-help-disabled/vehicles-and-transport.

We have a factsheet on driving. Please see 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 or, if required, a taxi to work. More information is available via your local Job Centre Plus or see the Government website https://www.nidirect.gov.uk/articles/employment-support-information. Employers can read more about this at https://www.gov.uk/government/publications/access-to-work-guide-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 others to assist carers. You can read more about benefits at https://www.nidirect.gov.uk/information-and-services/benefits-and-financial-support/disability and https://www.nidirect.gov.uk/information-and-services/benefits-and-financial-support/low-income or you can visit your local Citizens Advice Centre or Age NI 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 https://www.nidirect.gov.uk/articles/attendance-allowance for more information or download our factsheet 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 https://www.nidirect.gov.uk/articles/personal-independence-payment-pip for further information. 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 from 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 £139 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: https://www.nidirect.gov.uk/articles/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 - https://www.nidirect.gov.uk/services/claim-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 - https://www.nidirect.gov.uk/services/claim-new-style-jobseekers-allowance

Both ESA and JSA have means-tested versions too which now form part of Universal Credit. It is the new style versions of ESA or JSA you need to apply for if you have been paying National Insurance contributions in recent years.

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

- *Pension Credit* – For people over state pension age or for couples, where both of you are over state pension age. See https://www.nidirect.gov.uk/information-and-services/state-pension/pension-credit or call the Claim Line on 0808 100 2658
- *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 https://www.nidirect.gov.uk/campaigns/universal-credit or call the Helpline on 0800 012 1331 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 NI has helpful information on their website: https://www.ageuk.org.uk/northern-ireland/information-advice/.

Remember there are also entitlements to help with health-related costs. Please see https://www.nidirect.gov.uk/articles/help-health-costs and for schemes such as the Winter Fuel Allowance, see https://www.nidirect.gov.uk/articles/winter-fuel-payment for more information.

Rate Reductions

Please see https://www.nidirect.gov.uk/information-and-services/guide-rates/help-paying-your-rates. There is a 25% discount available if a person has a disability and their home has been adapted to suit their needs. This is not means-tested. See https://www.nidirect.gov.uk/disabled-persons-allowance for more information.

Utilities

Northern Ireland Water has a customer care register for vulnerable customers. To join call Waterline on 03457 440088.

You may be entitled to help with heating costs. Talk to your energy supplier. For details of the warm home discount scheme see: https://www.gov.uk/the-warm-home-discount-scheme.

Managing Financial and Other Affairs

Everyone diagnosed with MSA should consider making an Enduring Power of Attorney. An Enduring 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. 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 or about selling your property. With your consent an Enduring Power of Attorney can be used whilst you have capacity and this can be useful if you physically struggle to manage your financial affairs. You can specify in the document the extent of the powers your attorneys will have. The usual choice is to appoint close family members or a solicitor. An Enduring Power of Attorney can only be made by people who 'have capacity'. Capacity relates to the making of specific decisions. This means Enduring 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 mean a person lacks capacity to make that decision. There is more guidance here. https://www.nidirect.gov.uk/articles/managing-your-affairs-and-enduring-power-attorney.

Unlike elsewhere in the UK there is no Power of Attorney in respect of health and welfare in Northern Ireland.

Help with Personal Care Needs

If you require support with daily living (for example with your personal care or with accessing facilities), you should ask your local Health and Social Care Trust to carry out a Community Care assessment. This is a detailed assessment that usually results in an agreed care plan being created. The care plan should detail your needs and how these needs will be met. Please see https://www.nidirect.gov.uk/articles/support-stay-your-own-home for more information. A means test may be carried out to determine whether you will need to contribute although Health and Social Care Trust's can choose not to charge for domiciliary care. The means test will exclude the value of your home (assuming you are living in it) and will only be applied to the person needing care support, not their partner. If it is agreed that services should be provided you will be given information on options for service delivery. For example, a person may choose to have a 'Direct Payment' (a sum of money) which allows them to purchase the services they need instead of having the service arranged by the Health and Social Care Trust. Standard charges apply to some services such as Meals on Wheels.

If you have health care needs these should be discussed with your GP.

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.

Obtaining equipment

Many people spend a lot of money on things which they later discover are not suited to their needs or which could have been funded by their Health and Social Care Trust. Please see https://www.nidirect.gov.uk/articles/equipment-people-disabilities for information on equipment that can be funded by a statutory agency. 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). The Disabled Living Foundation 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 and equipment which is funded in some areas 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/.

How to Adapt a Home or to Move

Disabled Facilities Grants (DFG's) are available to some people who need to adapt their home. DFG's are available to owner occupiers, landlords and to people who live in private rented accommodation. DFG's are the responsibility of the Northern Ireland Housing Executive.

The person applying for the DFG must be either the owner or tenant and the person with the disability must plan to live in the property for the 'grant period' (usually five years).

DFG's are means-tested grants. The means test looks at household income and at household savings over £6,000. DFG's cover things like the fitting of ramps, adding ground floor bedroom and bathroom facilities, adapting a kitchen and installing a through floor lift. To find out more about applying for a DFG speak to your Occupational Therapist as only works that meet the criteria and 'assessed need' can be considered. You cannot apply directly to the Housing Executive yourself. The maximum DFG in Northern Ireland is usually £25,000.

To obtain more information contact The Northern Ireland Housing Executive on 03448 920900 or see https://www.nihe.gov.uk/Housing-Help/Grants/Types-of-grants-available/Disabled-Facilities-Grant. For information on other types of housing grants see https://www.nihe.gov.uk/Housing-Help/Grants.

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 Health and Social Care Trust will be able to provide information on the support they offer to carers. You can read more about this support here https://www.nidirect.gov.uk/articles/assessments-carers.

It is important to ask your Health and Social Care Trust 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.

Health and Social Care Trust's 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 your Health and Social Care Trust 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.

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/

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 Enduring Powers of Attorney

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.

If you have questions relating to your diagnosis or your care needs you can contact one of our MSA Health Care Specialists, via our main office on 0333 323 4591 or email support@msatrust.org.uk.

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.

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/.

PO Box 80803, LONDON, SE16 9JA

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

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