

• Introduction	Page 1
• Living with a long-term illness of disability	Page 1
• Support for daily living and mobility needs	Page 1
• Carers Allowance	Page 2
• Other Benefits	Page 3
• Health costs	Page 4
• Care Support	Page 4
• Useful contacts	Page 4

Basic Benefits and Entitlements

Introduction

If you have MSA or you are a carer, there are a range of benefits, entitlements, grants and financial support you may be able to claim.

Millions of pounds worth of entitlements go unclaimed each year, yet people affected by MSA will usually have a range of needs that lead to significant extra costs, such as travel, equipment, heating and laundry. Claiming the right benefits can make a real difference in managing your finances and giving you more control.

The following information outlines the main benefits you are likely to be able to claim depending on your circumstances and how living with MSA is affecting you. Due to the complexity of the benefits system this is guidance only and is based on UK benefits. If you live in Ireland you may wish to look at our dedicated webpage [Benefits if you live in the Republic of Ireland – Multiple System Atrophy Trust \(msatrust.org.uk\)](#) or visit www.citizensinformationboard.ie.

You may also like to check what you may be entitled to by using the confidential online benefits calculator at Turn2uscalculator (www.turn2us.org.uk).

Living with a long-term illness or disability

Given that MSA is a progressive condition it is very likely that people with MSA will qualify for benefits based on needs around daily living and mobility. The amount paid will vary depending upon how MSA affects you individually. You can request a review for higher rates if your condition progresses, meaning you need additional help.

Support for daily living and mobility needs

Personal Independence Payment or Adult Disability Payment (Scotland only)

For people who are under state pension age when a claim is made and who need support, a benefit called Personal Independence Payment (PIP), or Adult Disability Payment (ADP) for those living in Scotland, can help. It is for people who need help with everyday activities or who find it difficult to get around. It is tax free, is not means tested, not based on National Insurance contributions and is almost always paid in full in addition to other social security benefits.

Basic Benefits & Entitlements

It has two components:

The daily living component - which looks at things like dressing and undressing, preparing food, eating and drinking, washing, bathing, managing toilet needs and communicating. This also includes your ability to do these activities safely, repeatedly, to an acceptable standard and within a reasonable time period.

The mobility component – which looks at the difficulties people have in walking and moving around. Again, the guidance suggests that assessment must include the ability to walk any distance safely, repeatedly and in a reasonable time period. This means that falls or risk of falls can also be taken into account as can difficulties walking on different surfaces or terrain.

For both elements you will need to have been experiencing problems throughout the three months prior to any claim. Both components are paid at either a standard rate or an enhanced (higher) rate. If somebody's condition gets worse they can go from the standard to the enhanced rate but the mobility rate cannot be increased once a person reaches state pension age. If you live in England, Wales or Northern Ireland, claims for PIP can be made by calling 0800 917 2222 (or 0800 012 1573 in Northern Ireland) and the date of claim will be from the date of the call. Always have your National Insurance number handy when you call. If you live in Scotland, you can apply for ADP online by visiting www.mygov.scot/adult-disability-payment/how-to-apply, alternatively you can call 0800 182 2222.

Attendance Allowance (AA)

For people over state pension age, Attendance Allowance can be payable for help with personal care or supervision to remain safe. There is no mobility component to AA. Again, if eligible, the benefit is not means tested, not taxable and normally paid in addition to other benefits. The qualifying conditions mean that you must have needed care for six months before you make a claim. Again, if you are eligible there are two rates, the lower rate and the higher and to claim you will need to call 0800 731 0122 (0800 587 0912 in Northern Ireland). It is highly likely that at some stage people with MSA will be entitled to this benefit if they are over state pension age.

You cannot claim both PIP/ADP and AA at the same time. If you are in receipt of PIP/ADP when you reach state pension age this is the benefit you remain on.

The highest rates of the daily living /care components of PIP/ADP or AA can be paid immediately if a claim is made under 'Special Rules'. Special Rules apply when a person has a life expectancy of less than twelve months.

Carer's Allowance

Carer's Allowance is a benefit for people who spend at least 35 hours a week caring for a severely disabled person. This includes somebody who is getting PIP/ADP daily living component or Attendance Allowance. You do not have to be related to, or live with, the disabled person. It isn't means tested and entitlement can give the carer Class 1 National Insurance contribution credits. Net earnings of less than £151.00 per week do not affect Carer's Allowance.

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.

Basic Benefits & Entitlements

The rules about entitlement and how it relates to other benefits are a bit more complicated than PIP/ADP or Attendance Allowance so if you are unsure it is best to get advice. You can contact our Social Welfare Specialists on 0203 404 6673 or call the Carers UK Adviceline on 0808 808 7777.

Other Benefits

If you are on a low income you may be able to claim Universal Credit (if you or a partner are under state pension age) or Pension Credit (if you and your partner are both over state pension age) and entitlement to any of the benefits mentioned earlier may increase these benefits. 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 may also be able to get help means-tested help with your housing costs and Council Tax.

If you have limited capability to work because of your MSA and have paid enough National Insurance contributions in the past two years you may be eligible for new-style Employment and Support Allowance (new-style ESA). This is a non means-tested benefit and any savings are disregarded. A private or occupational pension of over £85 a week will affect the amount of ESA payable. Some permitted work may still be possible whilst claiming new-style ESA.

At some stage many people will also find that they might need to make changes or adaptations to their homes. This could include a wet room (for easy showering and bathing) or the installation of ramps, handrails or lifts. You should contact your local authority social services team who will be able to advise you if help is available to meet these costs. Because there can be delays in assessment and in getting the work done, you should not wait until the need becomes urgent, you need to plan ahead. Our MSA Health Care Specialists and our Social Welfare Specialists can offer basic advice about this. You can find more information: www.gov.uk/disabled-facilities-grants/overview.

You can claim a reduction in your Council Tax (and water rates in Scotland) if somebody in the home is substantially and permanently disabled and one of the following is met:

- there is an additional bathroom or kitchen needed by the disabled person; *or*
- there is a room (other than bathroom, kitchen or toilet) needed by or predominantly used by that person; *or*
- you have enough space in your home for that person to use a wheelchair indoors.

If you would have been entitled before you made your claim the reduction can be backdated for up to six years. Contact your local council tax department direct for further information and to make a claim.

People who are 'severely mentally impaired' are exempt from paying council tax and other exceptions also apply (for example, some live in carers may be exempt)

The **Blue Badge Scheme** for parking allows people with severe mobility problems to park close to places they wish to visit. Pay and Display parking may have no charge or time limit for blue badge holders but you should always check.

If you have the mobility component of PIP/ADP you may be automatically eligible for a blue badge. You may also qualify via the "assessed route" if you have a *permanent and substantial disability which causes inability to walk or very considerable difficulty in walking*. You should apply to your local authority or the Blue Badge Unit in Northern Ireland.

Health Costs

In the UK prescriptions are free except in England. In England if you are over 60 then you will be exempt from paying but you can also qualify for free prescriptions if you have a disability that stops you leaving home without help from somebody else. Low income exemption and prepayment certificates can also reduce the costs.

Care Support

Most people who need help to pay for their care get it from their local authority. In England and Wales, you may be eligible for funding without means testing from the NHS if you have a 'primary health care need' as the result of a medical condition.

This is called NHS Continuing Healthcare (CHC). For information go to <http://www.beaconchc.co.uk/> or call 0345 548 0300. Our MSA Health Care Specialists and Social Welfare Specialists can also offer basic information regarding this.

This is only a snapshot of some of the benefits that you may be entitled to. You can call us at the Trust office for basic information but we also recommend you look at our website [Financial Support and Welfare Benefits – Multiple System Atrophy Trust \(msatrust.org.uk\)](https://www.msatrust.org.uk/financial-support-and-welfare-benefits) or visit www.turn2us.org.uk.

Useful contacts

Citizens Advice - click [here](#)
03444 111 444 (England) or 03444 77 20 20 (Wales)
www.citizensadvice.org.uk

In Scotland see: <https://www.citizensadvice.org.uk/scotland/>

Citizens information (Ireland) - click [here](#)
0761 07 4000 www.citizensinformation.ie

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

REVISION DATE: 04/23 | REVIEW DATE: 04/26 | VERSION: 1.5

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.

Your feedback helps us ensure we are delivering information to the highest standard. If you have any comments or suggestions, please contact us at support@msatrust.org.uk.

