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Attendance Allowance

If you have a diagnosis of Multiple System Atrophy (MSA) and are over state pension age you may be entitled to Attendance Allowance (known as AA). This is because you are likely to require support or supervision with your personal care needs.

This factsheet explains what AA is, who may qualify for it and how to claim it.

The information applies to England, Wales and Northern Ireland. It currently also applies to Scotland but responsibility for welfare benefits in Scotland is being transferred to the Scottish Parliament and may therefore be subject to change.

What is Attendance Allowance?

AA is designed to assist people to meet the additional costs where supervision or support with personal care is needed. We know that people with a diagnosis of MSA may experience difficulties with eating, drinking, communicating, continence and balance, meaning support or supervision is needed.

If you are entitled, AA will be paid to you and not your carer (you do not have to have a carer to qualify). If you have a carer they may be entitled to Carers Allowance or other benefits in their own right. AA is not means tested, not taxed and is not based on your previous National Insurance contributions. AA can be paid at one of two rates depending upon your level of need:

Lower rate - £72.65 per week

Higher rate - £108.55 per week

Who qualifies for Attendance Allowance?

You may be eligible for Attendance Allowance if:

- You are state pension age or over

- You are not receiving Personal Independence Payment (known as PIP) or Disability Living Allowance (known as DLA)
- You have had care or supervision needs for the last six months (the 'qualifying period') unless you are terminally ill
- You have been living in the UK for two of the last three years and your immigration status does not prevent you from claiming
- You are entitled to claim UK benefits and live in the UK
- You satisfy one of the disability tests (see below).

What are the disability tests?

To be eligible for AA you must show that you are disabled to the extent that you need care from another person several times throughout the day and/or night to help with personal care. This includes requiring help with things like washing, dressing, using the toilet or managing continence needs, eating, drinking and communicating. For example, you may experience poor co-ordination, pain around the shoulders and muscle stiffness making washing and dressing time consuming and difficult or you may find your speech is slurred which makes communicating your needs challenging. Alternatively, you must show that you need 'continual supervision' (that is, you need to be watched over or checked up on) to ensure your safety or the safety of others. For example, you may suffer from frequent dizzy spells meaning you are at increased likelihood of falling. MSA usually affects physical abilities but AA also takes into account support needs arising from things like anxiety, depression and cognitive function. These difficulties might, for example, affect your ability to do a task meaning that you need prompting and encouragement from someone. When applying for AA, remember to include all your support needs regardless of the condition that causes those needs to arise. You do not currently have to be receiving this support to qualify for AA as you may have 'unmet needs.'

The rules are slightly different if a person is terminally ill and unlikely to live longer than twelve months as they will qualify for the higher rate under 'special rules'. There is no need for a six-month qualifying period before a claim can be made. The person's GP will need to confirm that they are terminally ill and the GP will need to complete an SR1 form – the doctor will be familiar with the form and the process. Under the special rules a claim can be made on a person's behalf – if appropriate without their knowledge that it is a 'special rules' claim. Special rules claims are reviewed every three years. AA awarded under special rules will be at the higher rate.

How to make a claim for Attendance Allowance

For residents of England, Scotland and Wales a claim form (known as AA1A) can be requested by calling the AA helpline on 0800 731 0122 (text phone 0800 731 0317) or by downloading one from www.gov.uk/attendance-allowance/how-to-claim. Northern Ireland residents can call 0800 587 0912 (text phone 0800 012 1574) or see www.nidirect.gov.uk/articles/attendance-allowance.

Claim forms sent from the AA helpline have a date stamped on them, indicating the date of the claim. If you return the form within six weeks of this date any award will usually be paid from this date.

Useful tips if you're applying for Attendance Allowance

- Don't underestimate your needs. Discussion with a carer or relative can be very useful as they may have a different perspective.
- Think about how your diagnosis of MSA affects you and how you may have adjusted the way you complete tasks, or the frequency with which you do them (for example, do you require the use of a bath aid, or the support of a carer for bathing or have you reduced the number of baths/showers you take per week).

- Has a lack of support left you with unmet needs?
- Consider whether a task can be completed in a reasonable amount of time and whether or not you can do it without pain or discomfort. If appropriate can the task be repeated several times a day without becoming more difficult or tiring (for example, you may be able to dress yourself in the morning but struggle to change your clothes later in the day or to undress at night).
- Can the task always be completed safely or does completing it put you at risk of injury? For example, do you feel that you're more likely to fall when tired?
- Always try to quantify your answers giving details of how long it takes you and whether this varies. For example, "It takes me 15 minutes to get dressed on a good day but I only have one or two good days a week. Most days it takes me 25 minutes as I have to stop and rest because my neck and shoulder muscles are stiff".
- Is your condition unpredictable? For example, do you fall frequently or have dizzy spells? Explain the impact this has on your ability to complete personal care tasks safely and with confidence.
- Detail any difficulties with managing your MSA symptoms (and symptoms from any other condition you may have) such as changes in blood pressure, incontinence or impaired speech.
- Keeping a care diary (your own or one completed by a carer) for a few days can provide invaluable, detailed evidence.
- Remember an award of AA is based on your assessed needs and not on your diagnosis – but ensuring assessors understand your diagnosis will help. Rather than sending a fact sheet about your condition it is better to do this by giving examples when completing the form. For example, "Due to my diagnosis of MSA I experience pain around my neck and shoulders which makes dressing and undressing a struggle."
- If you are including letters from professionals try to ensure these include details about your functional abilities, for example, an occupational therapist's home visit report may include an assessment of how you get in/out of a bath/shower, a nurse's report may detail how continence needs are managed. Standard letters along the lines of 'I support this person's application for Attendance Allowance' are not helpful.
- Keep a copy of the form and any supporting evidence. These will be useful if you need to challenge a decision that has been made.

How is a decision made?

Once they have received the form the Department of Work and Pensions (in Northern Ireland the Disability and Carers Service) may contact the professionals you have listed on your form for further information before making a decision. If it is unclear how your illness or disability affects you an assessment may be arranged. They will look at any supporting evidence included with your form, for example, reports of letters from professionals involved in your care. AA can be awarded for an indefinite period or for a fixed time.

If your needs increase

As MSA is a progressive condition there is a likelihood that your needs will increase as time goes by. Possible changes may include greater problems with mobility (resulting in you needing, for example, assistance to get out of bed at night to use the toilet) or changes to the way you communicate (for example, your voice may be soft or your speech slurred). If you now need assistance during both the day and the night it may be that a transfer from the lower rate to the higher rate of AA is indicated.

You can request a review by ringing 0800 731 0122 or writing to: Attendance Allowance Unit, Mail Handling Site A, Wolverhampton WV98 2AD.

In Northern Ireland the Disability and Carers Service should be advised. The number to call is 0800 587 0912. Letters can be sent to: Castle Court, Royal Avenue, Belfast BT1 1HR.

The higher level of needs has to have existed for 6 months before a higher award is made although an application can be made earlier. This 6-month rule does not apply to people who are terminally ill and qualify under 'special rules'.

It is important to note that at review your entitlement will be fully reconsidered.

Appealing a decision

If you feel that the decision to refuse AA or refuse to increase AA is incorrect, please contact the MSA Trust as soon as possible so we can offer information and guidance. It may be worthwhile requesting a 'mandatory reconsideration' from the Department of Work and Pensions (the Disability and Carers Service in Northern Ireland). This must be done within one month of the decision being made. Providing further evidence can be useful here – for example detailed letters from a specialist nurse or therapist or a care diary.

It is possible to request copies of all the evidence used in the decision making. Requesting this may give an understanding of why the decision was made and what areas to concentrate on when appealing.

If AA is still refused, or an increase from the lower rate to the higher rate is refused, it is possible to ask for a case to be considered by an independent tribunal. The MSA Trust can provide guidance.

What happens if I go into a hospital or a care home?

If you go into hospital, or into a care/nursing home for respite care, the Department of Work and Pensions (in Northern Ireland the Disability and Carers Service) must be informed as this can affect whether the benefit is still paid. The rules are a little complex so contact us if you need information regarding this.

If you live in a care/nursing home that is fully or partially funded by your local authority or through NHS Continuing Health Care, AA is not usually paid.

Does receiving Attendance Allowance affect other benefits?

As AA is not means tested it does not have a negative effect on other benefits. It may increase the amount payable of some means tested benefits (for example, pension credit). People in receipt of AA are exempt from the benefits cap which limits the total annual amount of benefits a person (or family) may receive.

A local authority that provides care or support services may take AA into account when deciding a person's contribution towards these costs. If you live at home but receive NHS Continuing Health Care funding to meet your complex healthcare needs, AA will continue to be paid.

The MSA Trust is happy to offer information and support on AA to people living with a diagnosis of MSA and to their families/carers. Please contact us on 0333 323 4591 or email: support@msatrust.org.uk. Local agencies may also offer support including local carers centres, Age UK offices and Citizens Advice www.citizensadvice.org.uk

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

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

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