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## Personal Independence Payment

If you have Multiple System Atrophy (MSA) and are under state pension age you may be entitled to Personal Independence Payment (PIP). This is because you are likely to require support or supervision to meet your personal care needs and/or may have difficulties with walking or mobility.

This fact sheet explains what PIP 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.

Our Social Welfare Specialist is happy to assist people (by telephone/email/video) with PIP claims.

### What is PIP?

PIP can help towards costs that arise from personal care and/or mobility needs. We know that people with MSA may experience a range of difficulties including, amongst other things, issues with mobility and balance, continence problems, slurred or soft speech, and swallowing difficulties - all meaning support or supervision needs may exist.

An award of PIP is based on what help you need, not whether you actually receive such help. It does not matter whether you live alone or with other people, or if you get a lot of help, a little help or no help at all. You do not need to have a carer to be awarded PIP.

PIP is not means tested, not taxed and is not based on National Insurance contributions. You can be in work or not working and still be entitled to it. PIP is paid to the person with the illness or disability, not to a carer. A carer may be entitled to Carers Allowance or other benefits in their own right.

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PIP can carry on after someone reaches their state pension age as long as they were already getting it. If you are under state pension age and have mobility difficulties it is **very important** you claim PIP before you reach your state pension age. If you receive help with your mobility needs through PIP you will continue to receive help with these needs after you reach state pension age (assuming you still meet the criteria which, with a diagnosis of MSA, you almost certainly would).

### Who may qualify for PIP?

You may be eligible for PIP if you have MSA and:

- You are under state pension age
- You are not getting Disability Living Allowance (known as DLA)
- You have had care, supervision or mobility needs for the last three months (the 'qualifying period')
- 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 (further information on these are given below).

### How is a claim made?

PIP claims (and the completion of the basic conditions PIP1 form) are made by ringing 0800 917 2222 or 0800 917 7777 for textphone. For people in Northern Ireland the number is 0800 012 1573 or textphone 0800 587 0937. The person making the claim does not have to make the call but they must be with the caller when it is made. Questions asked during this call include name, contact details and National Insurance number; nationality, whether or not a person is in a care/nursing home or hospital, a healthcare professional contact, bank details (for payment purposes) and whether or not a disability makes it difficult to return forms.

If the basic conditions are met a PIP2 form 'looking at how your disability affects you' will be sent to you. The form must be completed within one month to ensure backdating payments to the date of the application. If you need longer let them know. The MSA Trust can offer you help with completing this by contacting 0333 323 4591 or emailing [support@msatrust.org.uk](mailto:support@msatrust.org.uk).

When completing the form it is very important to give as much information as possible. For each activity (see the disability tests section below) think whether you can do the activity safely, to an acceptable standard, repeatedly and within a reasonable time period. If, for example, you can only do the activity if you take much longer than somebody without difficulties, or not to a standard that most people would achieve, then you may qualify. If completing an activity leaves you in pain or cannot be accomplished safely then this should be explained.

### What are the disability tests?

PIP has two separate components (daily living and mobility) and two rates within each component (standard and enhanced).

The disability tests look at ten daily living activities and two areas related to mobility.

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It is a points-based assessment and the points awarded determine your eligibility for PIP and the rate awarded. Within each activity different points are awarded according to how much help you require with the task. How the points are awarded is explained in more detail in the Appendix. Understanding this is useful when completing the PIP2 form or when answering questions in an assessment if one is required. The MSA Trust can give guidance on this if you contact us either by telephone or email.

The ten daily living component activities are:

- Preparing food
- Taking nutrition (food and drink)
- Managing therapy or monitoring a health condition
- Washing and bathing
- Managing toilet needs or incontinence
- Dressing and undressing
- Communicating verbally
- Reading and understanding signs, symbols and words
- Engaging with other people face to face
- Making budgeting decisions

The two mobility component activities are:

- Planning and following journeys
- Moving around

In respect of each activity the assessment takes into account your ability to do the task:

- Safely
- To an acceptable standard
- Repeatedly
- Within a reasonable time period (more than twice as long as it would take someone without a disability to do)

### **How is a decision made?**

After sending back the form you may be required to have an assessment with a health care professional if more information is needed. The assessment can be in person, by video call or by telephone.

Following your assessment your claim will be decided.

### **Thinking about how MSA affects you**

- Don't underestimate your needs. Discussion with a carer or relative can be very useful because they may have a different perspective.

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- A partner or family member may happily provide help or take on a task (for example, cooking) but the need remains. Whether or not they have always done the task is not relevant. It is an assessment of your needs not how your household is organised.
- Think about how your 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 carer for bathing or has a lack of an aid or a carer meant you have had to reduce the number of baths or showers you take per week?
- Always try to quantify your answers giving details of how long it takes you to do a task and whether this varies. For example, "It takes me 15 minutes to get dressed on a good day but I only have 1 or 2 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."
- Consider whether a task can be completed without pain or discomfort. If appropriate can the task be repeated several times a day without causing discomfort (for example, making a cup of tea or managing toileting needs). If not, you cannot do the task repeatedly and therefore need assistance.
- Can the task always be completed safely or does completing it put you at risk? For example, if your blood pressure fluctuates are you safe moving from sitting to standing in the kitchen when cooking or in the bathroom when bathing?
- Is your condition unpredictable? For example, do you fall frequently? Do you get frequent urinary tract infections that cause troublesome or disabling symptoms affecting your ability to do tasks? Explain this on your form.
- Detail any difficulties with managing MSA symptoms (and symptoms from any other condition you may have) such as fluctuating blood pressure, incontinence, impaired speech, swallowing difficulties. Look at the effect these symptoms may have on your ability to do things.
- Maintaining a care diary (your own or one completed by a carer) for a few days can provide invaluable, detailed evidence.
- Remember an award of PIP is based on your assessed needs and not on your diagnosis but ensuring assessors understand your diagnosis will help. Generic factsheets about MSA are not looked at by the decision makers as they are not personal to you. It is better to explain by answering questions with the phrase 'Due to MSA I have difficulties with...'

With respect to the mobility components:

- Consider indoor and outdoor mobility and any risks associated with getting about. For example, is your balance sometimes poor? Do you require someone with you to help you steady yourself and to reduce the risk of falls?
- Try to measure how far you can walk – do not guess. The criteria for awarding points in this area are very specific. The same reliability factors apply – can you do the activity safely, to an acceptable standard, repeatedly and within a reasonable time period? Being able to walk 'X' metres once a day then being so tired you cannot repeat it later is not the same as being able to walk that same number of metres several times a day.

- Maintaining a diary (your own or one completed by a carer) for a few days detailing mobility difficulties can be very helpful in demonstrating your difficulties and needs.

### **Appealing a decision**

If you are refused PIP, you have a month to ask for a 'mandatory reconsideration'. A mandatory reconsideration can also be requested if you disagree with the level of PIP awarded or the length of the award. Be aware that a mandatory reconsideration will involve looking again at the whole award and any PIP awarded can be removed or reduced. At this stage additional evidence can be submitted. It is possible to request copies of all the evidence used in the decision making, including the assessment report. Requesting this may give an understanding of why the decision was made and what areas to concentrate on when appealing.

If PIP is still refused, or an increase from the standard rate to the enhanced rate is refused, it is possible to ask for a case to be considered by an independent tribunal. We can provide information and guidance about appeals.

### **Special Rules:**

If a person is terminally ill and can reasonably be expected to have less than six months to live (this is due to be changed to 12 months) they are automatically entitled to the enhanced rate for the daily living component although a claim must still be made. A doctor will need to complete a DS1500 form. A claim may be made by another person on behalf of the terminally ill person without disclosing that this is under special rules if that is appropriate. The usual assessment criteria still apply in respect of the mobility component.

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

Neither component of PIP is usually payable if an individual goes into an NHS hospital and PIP payments will stop after a period of four weeks (be aware that several short stays where the gaps are no more than four weeks apart can also affect payment of PIP). PIP can be restarted once a person is home again.

If you live in a care/nursing home that is fully or partially funded by the local authority the daily living component is not usually paid whilst the mobility component is usually still paid. If you are completely self-funding you will continue to receive both components.

Being in receipt of CHC funding whilst living in a care/nursing home will affect your entitlement to PIP.

### **Does receiving PIP affect other benefits?**

As PIP 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, Universal Credit, tax credits, Housing Benefit). People in receipt of PIP are exempt from the benefits cap (which restricts the total amount of benefits paid to a person or family) and should check to see if they qualify for income related benefits.

A local authority that provides care or support services may take PIP into account when deciding a person's contribution towards these costs.

Being in receipt of NHS Continuing Healthcare Funding will not affect entitlement to PIP if you are still living in your own home.

## Further Information

Please contact the MSA Trust for further information or for support. Telephone 0333 323 4591 or email [support@msatrust.org.uk](mailto:support@msatrust.org.uk). Local Citizens Advice Centres, Carers Centres or Age UK services may also be able to assist.



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Patient Information Forum

References for this information sheet are available by contacting [support@msatrust.org.uk](mailto:support@msatrust.org.uk).

Feedback: 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](mailto:support@msatrust.org.uk).

## Appendix

To be entitled to the standard rate a person must score at least 8 points and for the enhanced rate 12 points (only the highest score in each activity category counts). Points from each category can then be totalled. The daily living and mobility categories are distinct from one another – the points from these categories are not added together. We are happy to explain this if you contact us.

The information below is copied from:

<https://www.legislation.gov.uk/ukdsi/2013/9780111532072/schedule/1>

### Daily Living Activities

|                                                                        |                                                                                                                                                                                                    |           |
|------------------------------------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-----------|
| <b>Activity 1 - Preparing food:</b>                                    |                                                                                                                                                                                                    |           |
| a.                                                                     | Can prepare and cook a simple meal unaided                                                                                                                                                         | 0 points  |
| b.                                                                     | Needs to use an aid or appliance to be able to either prepare or cook a simple meal                                                                                                                | 2 points  |
| c.                                                                     | Cannot cook a simple meal using a conventional cooker but is able to do so using a microwave                                                                                                       | 2 points  |
| d.                                                                     | Needs prompting to be able to either prepare or cook a simple meal                                                                                                                                 | 2 points  |
| e.                                                                     | Needs supervision or assistance to either prepare or cook a simple meal                                                                                                                            | 4 points  |
| f.                                                                     | Cannot prepare and cook food                                                                                                                                                                       | 8 points  |
| <b>Activity 2 - Taking nutrition:</b>                                  |                                                                                                                                                                                                    |           |
| a.                                                                     | Can take nutrition unaided                                                                                                                                                                         | 0 points  |
| b.                                                                     | Needs:<br>(i) to use an aid or appliance to be able to take nutrition; or<br>(ii) supervision to be able to take nutrition; or<br>(iii) assistance to be able to cut up food                       | 2 points  |
| c.                                                                     | Needs a therapeutic source to be able to take nutrition                                                                                                                                            | 2 points  |
| d.                                                                     | Needs prompting to be able to take nutrition                                                                                                                                                       | 4 points  |
| e.                                                                     | Needs assistance to be able to manage a therapeutic source to take nutrition                                                                                                                       | 6 points  |
| f.                                                                     | Cannot convey food and drink to their mouth and needs another person to do so                                                                                                                      | 10 points |
| <b>Activity 3 - Managing therapy or monitoring a health condition:</b> |                                                                                                                                                                                                    |           |
| a.                                                                     | Either:<br>(i) does not receive medication or therapy or need to monitor a health condition; or<br>(ii) can manage medication or therapy or monitor a health condition unaided                     | 0 points  |
| b.                                                                     | b. Needs either:<br>(i) to use an aid or appliance to be able to manage medication; or<br>(ii) supervision, prompting or assistance to be able to manage medication or monitor a health condition. | 1 point   |
| c.                                                                     | Needs supervision, prompting or assistance to be able to manage therapy that takes no more than 3.5 hours a week                                                                                   | 2 points  |
| d.                                                                     | Needs supervision, prompting or assistance to be able to manage therapy that takes more than 3.5 but no more than 7 hours a week                                                                   | 4 points  |
| e.                                                                     | Needs supervision, prompting or assistance to be able to manage therapy that takes more than 7 but no more than 14 hours a week                                                                    | 6 points  |
| f.                                                                     | Needs supervision, prompting or assistance to be able to manage therapy that takes more than 14 hours a week                                                                                       | 8 points  |
| <b>Activity 4 - Washing and bathing:</b>                               |                                                                                                                                                                                                    |           |
| a.                                                                     | Can wash and bathe unaided                                                                                                                                                                         | 0 points  |

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|-------------------------------------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-----------|
| b.                                                                      | Needs to use an aid or appliance to be able to wash or bathe                                                                                                                                           | 2 points  |
| c.                                                                      | Needs supervision or prompting to be able to wash or bathe                                                                                                                                             | 2 points  |
| d.                                                                      | Needs assistance to be able to wash either their hair or body below the waist                                                                                                                          | 2 points  |
| e.                                                                      | Needs assistance to be able to get in or out of a bath or shower                                                                                                                                       | 3 points  |
| f.                                                                      | Needs assistance to be able to wash their body between the shoulders and waist                                                                                                                         | 4 points  |
| g.                                                                      | Cannot wash and bathe at all and needs another person to wash their entire body                                                                                                                        | 8 points  |
| <b>Activity 5 - Managing toilet needs or incontinence:</b>              |                                                                                                                                                                                                        |           |
| a.                                                                      | Can manage toilet needs or incontinence unaided                                                                                                                                                        | 0 points  |
| b.                                                                      | Needs to use an aid or appliance to be able to manage toilet needs or incontinence                                                                                                                     | 2 points  |
| c.                                                                      | Needs supervision or prompting to be able to manage toilet needs                                                                                                                                       | 2 points  |
| d.                                                                      | Needs assistance to be able to manage toilet needs                                                                                                                                                     | 4 points  |
| e.                                                                      | Needs assistance to be able to manage incontinence of either bladder or bowel                                                                                                                          | 6 points  |
| f.                                                                      | Needs assistance to be able to manage incontinence of both bladder and bowel                                                                                                                           | 8 points  |
| <b>Activity 6 - Dressing and undressing:</b>                            |                                                                                                                                                                                                        |           |
| a.                                                                      | Can dress and undress unaided                                                                                                                                                                          | 0 points  |
| b.                                                                      | Needs to use an aid or appliance to be able to dress or undress                                                                                                                                        | 2 points  |
| c.                                                                      | Needs either:<br>(i) prompting to be able to dress, undress or determine appropriate circumstances for remaining clothed; or<br>(ii) prompting or assistance to be able to select appropriate clothing | 2 points  |
| d.                                                                      | Needs assistance to be able to dress or undress their lower body                                                                                                                                       | 2 points  |
| e.                                                                      | Needs assistance to be able to dress or undress their upper body                                                                                                                                       | 4 points  |
| f.                                                                      | Cannot dress or undress at all                                                                                                                                                                         | 8 points  |
| <b>Activity 7 - Communicating verbally:</b>                             |                                                                                                                                                                                                        |           |
| a.                                                                      | Can express and understand verbal information unaided                                                                                                                                                  | 0 points  |
| b.                                                                      | Needs to use an aid or appliance to be able to speak or hear                                                                                                                                           | 2 points  |
| c.                                                                      | Needs communication support to be able to express or understand complex verbal information                                                                                                             | 4 points  |
| d.                                                                      | Needs communication support to be able to express or understand basic verbal information                                                                                                               | 8 points  |
| e.                                                                      | Cannot express or understand verbal information at all even with communication support                                                                                                                 | 12 points |
| <b>Activity 8 - Reading and understanding signs, symbols and words:</b> |                                                                                                                                                                                                        |           |
| a.                                                                      | Can read and understand basic and complex written information either unaided or using spectacles or contact lenses                                                                                     | 0 points  |
| b.                                                                      | Needs to use an aid or appliance, other than spectacles or contact lenses, to be able to read or understand either basic or complex written information                                                | 2 points  |
| c.                                                                      | Needs prompting to be able to read or understand complex written information                                                                                                                           | 2 points  |
| d.                                                                      | Needs prompting to be able to read or understand basic written information                                                                                                                             | 4 points  |
| e.                                                                      | Cannot read or understand signs, symbols or words at all                                                                                                                                               | 8 points  |
| <b>Activity 9 - Engaging with other people face to face:</b>            |                                                                                                                                                                                                        |           |



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|                                                  |                                                                                                                                                                                                                                                                     |          |
|--------------------------------------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|----------|
| a.                                               | Can engage with other people unaided                                                                                                                                                                                                                                | 0 points |
| b.                                               | Needs prompting to be able to engage with other people                                                                                                                                                                                                              | 2 points |
| c.                                               | Needs social support to be able to engage with other people                                                                                                                                                                                                         | 4 points |
| d.                                               | Cannot engage with other people due to such engagement causing either –<br>(i) overwhelming psychological distress to the claimant; or<br>(ii) the claimant to exhibit behaviour which would result in a substantial risk of harm to the claimant or another person | 8 points |
| <b>Activity 10 - Making budgeting decisions:</b> |                                                                                                                                                                                                                                                                     |          |
| a.                                               | Can manage complex budgeting decisions unaided                                                                                                                                                                                                                      | 0 points |
| b.                                               | Needs prompting or assistance to be able to make complex budgeting decisions                                                                                                                                                                                        | 2 points |
| c.                                               | Needs prompting or assistance to be able to make simple budgeting decisions                                                                                                                                                                                         | 4 points |
| d.                                               | Cannot make any budgeting decisions at all                                                                                                                                                                                                                          | 6 points |

## Mobility Activities

|                                                      |                                                                                                                                                             |           |
|------------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------|-----------|
| <b>Activity 1 - Planning and following journeys:</b> |                                                                                                                                                             |           |
| a.                                                   | Can plan and follow the route of a journey unaided                                                                                                          | 0 points  |
| b.                                                   | Needs prompting to be able to undertake any journey to avoid overwhelming psychological distress to the claimant                                            | 4 points  |
| c.                                                   | For reasons other than psychological distress cannot plan the route of a journey                                                                            | 8 points  |
| d.                                                   | For reasons other than psychological distress cannot follow the route of an unfamiliar journey without another person, assistance dog or orientation aid    | 10 points |
| e.                                                   | Cannot undertake any journey because it would cause overwhelming psychological distress to the claimant                                                     | 10 points |
| f.                                                   | For reasons other than psychological distress cannot follow the route of a familiar journey without another person, an assistance dog or an orientation aid | 12 points |
| <b>Activity 2 – Moving around</b>                    |                                                                                                                                                             |           |
| a.                                                   | Can stand and then move more than 200 metres, either aided or unaided                                                                                       | 0 points  |
| b.                                                   | Can stand and then move more than 50 metres but no more than 200 metres, either aided or unaided                                                            | 4 points  |
| c.                                                   | Can stand and then move unaided more than 20 metres but no more than 50 metres                                                                              | 8 points  |
| d.                                                   | Can stand and then move using an aid or appliance more than 20 metres but no more than 50 metres                                                            | 10 points |
| e.                                                   | Can stand and then move more than 1 metre but no more than 20 metres, either aided or unaided                                                               | 12 points |
| f.                                                   | Cannot, either aided or unaided:<br>(i) stand; or<br>(ii) move more than 1 metre                                                                            | 12 points |