

# PERSONAL INDEPENDENCE PAYMENT

## A GUIDE FOR FABRY DISEASE

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## **Personal Independence Payment**

You can get Personal Independence Payment (PIP) if ALL of the following apply to you:

- you're 16 or over
- you have a long-term physical or mental health condition or disability
- you have [difficulty doing certain everyday tasks or getting around](#)
- you expect the difficulties to last for at least 12 months from when they started

You must also be under [State Pension age](#) if you've not received PIP before.

How much Personal Independence Payment (PIP) you get depends on how difficult you find:

- everyday activities ('daily living' tasks)
- getting around ('mobility' tasks)

Having a diagnosis of Fabry disease does not guarantee that you will be eligible for PIP. However, we know that many individuals with Fabry are significantly limited in relation to their daily activities and mobility as a result of their condition. If you feel that you meet the criteria above, the MPS Society Support and Advocacy Team are ready to support you in communicating your needs and making a PIP application.

The first step in accessing support is completing the forms included in this pack. Please read the form carefully and provide as much information about your daily activities as possible.

If you are unable to complete the form without assistance, please contact your Support and Advocacy Officer directly and we can arrange support that meets your needs.

## Completing your PIP form

The tables that follow will guide you in piecing together accurate responses to each of the questions on your Personal Independence Payment (PIP) form. You will find some pointers from the MPS Society Support and Advocacy Team and an outline of the points linked with each question.

Please use the 'response' column to write some notes about your daily experiences. This will help your Support and Advocacy Officer to formulate a response that accurately reflects your needs in each area.

Once completed please email this form back to your Support and Advocacy Officer. They will then review it and arrange a time to discuss your final responses.

*If you are unable to complete the form independently and do not have anyone at home who can support you, a time can be arranged for a telephone or zoom call.*

## Daily Living

Question one: Preparing food		
Guide	Points available	Response
<p>This question aims to understand any limitations you have that impact your ability to prepare food independently.</p> <p>When we consider the impact of having Fabry on 'Preparing food' some of the key points that commonly arise are:</p> <ul style="list-style-type: none"><li>• Fatigue</li><li>• pain and heat/cold intolerance (including Fabry crises)</li><li>• Mental health and motivation to cook</li></ul>	<ul style="list-style-type: none"><li>a) Can prepare and cook a simple meal unaided - 0</li><li>b) Needs to use an aid or appliance to be able to either prepare or cook a simple meal - 2</li><li>c) Cannot cook a simple meal using a conventional cooker but is able to do so using a microwave - 2</li><li>d) Needs prompting to be able to either prepare or cook a simple meal - 2</li><li>e) Needs supervision or assistance to either prepare or cook a simple meal - 4</li><li>f) Cannot prepare and cook food - 8</li></ul>	<p><i>Please write some notes here to allow you Support and Advocacy Officer to formulate a response that reflects your needs:</i></p>

Question two: Taking nutrition		
Guide	Points available	Response
<p>This question aims to identify issues that impact and individual's ability to eat.</p> <p>When we consider the impact of having Fabry on 'taking nutrition' some of the key points that commonly arise are:</p> <ul style="list-style-type: none"> <li>• Hand function – some individuals with Fabry have poor fine motor skills (some reasons for this are fabry associated neuropathic pain). Do you need someone to assist with cutting food for this reason?</li> <li>• Mental health and motivation to eat.</li> <li>• Impact of major medical event such as stroke.</li> </ul>	<ul style="list-style-type: none"> <li>a) Can take nutrition unaided. 0</li> <li>b) Needs – <ul style="list-style-type: none"> <li>(i) to use an aid or appliance to be able to take nutrition; or</li> <li>(ii) supervision to be able to take nutrition;</li> <li>(iii) assistance to be able to cut up food. 2</li> </ul> </li> <li>c) Needs a therapeutic source to be able to take nutrition. 2</li> <li>d) Needs prompting to be able to take nutrition. 4</li> <li>e) Needs assistance to be able to manage a therapeutic source to take nutrition. 6</li> <li>f) Cannot convey food and drink to their mouth and needs another person to do so. 10</li> </ul>	<p><i>Please write some notes here to allow you Support and Advocacy Officer to formulate a response that reflects your needs:</i></p>

Question Three:

Managing Therapy or monitoring a health condition

Guide	Points available	Response
<p>This question aims to understand any limitations you have that impact your ability to manage your condition. This includes taking medication, attending appointment and undertaking therapy</p> <p>When we consider the impact of having Fabry on <b>‘Managing Therapy and Monitoring a health condition’</b> some of the key points that commonly arise are:</p> <ul style="list-style-type: none"> <li>Fabry specific therapies (ERT or Oral therapy). Consider the support that this requires. How long is your infusion? Do you need to take time off work? Can you manage your oral therapy and fasting periods independently?</li> <li>Remembering about, scheduling and attending medical reviews. Does anyone attend with you and why?</li> <li>doing therapy (such as physio), do you need support with this.</li> </ul>	<p>a) Either –</p> <p>(i) does not receive medication or therapy or need to monitor a health condition;</p> <p>(ii) can manage medication or therapy or monitor a health condition unaided. 0</p> <p>b) Needs either –</p> <p>(i) to use an aid or appliance to be able to manage medication;</p> <p>(ii) supervision, prompting or assistance to be able to manage medication or monitor a health condition. 1</p> <p>c) Needs supervision, prompting or assistance to be able to manage therapy that takes no more than 3.5 hours a week. 2</p> <p>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</p> <p>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</p> <p>f) Needs supervision, prompting or assistance to be able to manage therapy that takes more than 14 hours a week. 8</p>	<p><i>Please write some notes here to allow you Support and Advocacy Officer to formulate a response that reflects your needs:</i></p>

Question 4: Washing and Bathing		
Guide	Points available	Response
<p>This question aims to understand any limitations you have that impact your ability to wash and bathe independently:</p> <p>When we consider the impact of having Fabry on 'Washing and bathing' some of the key points that commonly arise are:</p> <ul style="list-style-type: none"> <li>• Mental Health and motivation to wash/bathe.</li> <li>• Fatigue – are there days when you stay in bed and are unable to wash/bathe</li> <li>• Pain and heat/cold intolerance. Does hot water flare up your Fabry related pain?</li> <li>• Ability to get in/out of bath or shower</li> </ul>	<ul style="list-style-type: none"> <li>a) Can wash and bathe unaided. 0</li> <li>b) Needs to use an aid or appliance to be able to wash or bathe. 2</li> <li>c) Needs supervision or prompting to be able to wash or bathe. 2</li> <li>d) Needs assistance to be able to wash either their hair or body below the waist. 2</li> <li>e) Needs assistance to be able to get in or out of a bath or shower. 3</li> <li>f) Needs assistance to be able to wash their body between the shoulders and waist. 4</li> <li>g) Cannot wash and bathe at all and needs another person to wash their entire body. 8</li> </ul>	<p><i>Please write some notes here to allow you Support and Advocacy Officer to formulate a response that reflects your needs:</i></p>

Question 5: Managing Toilet Needs or Incontinence		
Guide	Points available	Response
<p>This question aims to understand any limitations you have that impact your ability to 'Managing Toilet Needs or Incontinence'</p> <p>When we consider the impact of having Fabry on 'Managing Toilet Needs or Incontinence' some of the key points that commonly arise are:</p> <ul style="list-style-type: none"> <li>• urgency and unpredictability regarding bowel and bladder control</li> <li>• Frequent diarrhoea</li> <li>• Incontinence</li> <li>• Incomplete bladder emptying</li> </ul>	<p>a) Can manage toilet needs or incontinence unaided. 0</p> <p>b) Needs to use an aid or appliance to be able to manage toilet needs or incontinence. 2</p> <p>c) Needs supervision or prompting to be able to manage toilet needs. 2</p> <p>d) Needs assistance to be able to manage toilet needs. 4</p> <p>e) Needs assistance to be able to manage incontinence of either bladder or bowel. 6</p> <p>f) Needs assistance to be able to manage incontinence of both bladder and bowel. 8</p>	<p><i>Please write some notes here to allow you Support and Advocacy Officer to formulate a response that reflects your needs:</i></p>

Question 6: Dressing and undressing		
Guide	Points available	Response
<p>This question aims to understand any limitations you have that impact your ability to dress and undress independently.</p> <p>When we consider the impact of having Fabry on 'Preparing food' some of the key points that commonly arise are:</p> <ul style="list-style-type: none"> <li>• Fine motor skills – do you struggle with zips/buttons/fastenings</li> <li>• Sensitivity to fabrics against the skin – does this change depending on pain (think about Fabry crises)</li> <li>• Range of motion – can you bend to pull on socks and raise your arms to pull on a jumper.</li> <li>• Impact of major medical event such as stroke</li> </ul>	<ul style="list-style-type: none"> <li>a) Can dress and undress unaided. 0</li> <li>b) Needs to use an aid or appliance to be able to dress or undress. 2</li> <li>c) Needs either – <ul style="list-style-type: none"> <li>(i) prompting to be able to dress, undress or determine appropriate circumstances for remaining clothed;</li> <li>(ii) prompting or assistance to be able to select appropriate clothing. 2</li> </ul> </li> <li>d) Needs assistance to be able to dress or undress their lower body. 2</li> <li>e) Needs assistance to be able to dress or undress their upper body. 4</li> <li>f) Cannot dress or undress at all. 8</li> </ul>	<p><i>Please write some notes here to allow you Support and Advocacy Officer to formulate a response that reflects your needs:</i></p>



Question 7: Communicating verbally		
Guide	Points available	Response
<p>This question aims to understand any limitations you have that impact your ability to communicate verbally.</p> <p>When we consider the impact of having Fabry on 'communicate verbally' some of the key points that commonly arise are:</p> <ul style="list-style-type: none"> <li>• Memory and cognition – do you struggle to retain and relay important information</li> <li>• Impact of major medical event such as stroke</li> <li>• Hearing loss</li> <li>• Mental health and social functioning -</li> </ul>	<ul style="list-style-type: none"> <li>a) Can express and understand verbal information unaided. 0</li> <li>b) Needs to use an aid or appliance to be able to speak or hear. 2</li> <li>c) Needs communication support to be able to express or understand complex verbal information. 4</li> <li>d) Needs communication support to be able to express or understand basic verbal information. 8</li> <li>e) Cannot express or understand verbal information at all even with communication support. 12</li> </ul>	<p><i>Please write some notes here to allow you Support and Advocacy Officer to formulate a response that reflects your needs:</i></p>

Question 8: Reading and understanding signs, symbols and words		
Guide	Points available	Response
<p>This question aims to understand any limitations you have that impact your ability to Read and understand signs, symbols and words</p> <p>When we consider the impact of having Fabry on 'Reading and understanding signs, symbols and words' some of the key points that commonly arise are:</p> <ul style="list-style-type: none"> <li>• Vision problems</li> <li>• Retention of important information – can you retain information that you've read</li> <li>• Impact of major medical event such as stroke</li> </ul>	<p>a) Can read and understand basic and complex written information either unaided or using spectacles or contact lenses. 0</p> <p>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</p> <p>c) Needs prompting to be able to read or understand complex written information. 2</p> <p>d) Needs prompting to be able to read or understand basic written information. 4</p> <p>e) Cannot read or understand signs, symbols or words at all. 8</p>	<p><i>Please write some notes here to allow you Support and Advocacy Officer to formulate a response that reflects your needs:</i></p>

Question 9: Engaging with other people face to face		
Guide	Points available	Response
<p>This question aims to understand any limitations you have that impact your ability to engage with other people face to face</p> <p>When we consider the impact of having Fabry on 'Engaging with other people face to face' some of the key points that commonly arise are:</p> <ul style="list-style-type: none"> <li>• Mental health and social anxiety – motivation to socialise</li> <li>• Unpredictability of bladder and bowel symptoms</li> <li>• Fatigue</li> <li>• Pain</li> </ul>	<p>a) Can engage with other people unaided. 0</p> <p>b) Needs prompting to be able to engage with other people. 2</p> <p>c) Needs social support to be able to engage with other people. 4</p> <p>d) Cannot engage with other people due to such engagement causing either:</p> <p>(i) overwhelming psychological distress to the claimant;</p> <p>(ii) the claimant to exhibit behaviour which would result in a substantial risk of harm to the claimant or another person. 8</p>	<p><i>Please write some notes here to allow you Support and Advocacy Officer to formulate a response that reflects your needs:</i></p>

Question 10: Making budgeting decisions		
Guide	Points available	Response
<p>This question aims to understand any limitations you have that impact your ability to make budgeting decisions</p> <p>When we consider the imp act of having Fabry on 'Making budgeting decisions' some of the key points that commonly arise are:</p> <ul style="list-style-type: none"> <li>• Inability to focus on paperwork</li> <li>•</li> </ul>	<p>a) Can manage complex budgeting decisions unaided. 0</p> <p>b) Needs prompting or assistance to be able to make complex budgeting decisions. 2</p> <p>c) Needs prompting or assistance to be able to make simple budgeting decisions. 4</p> <p>d) Cannot make any budgeting decisions at all. 6</p>	<p><i>Please write some notes here to allow you Support and Advocacy Officer to formulate a response that reflects your needs:</i></p>

## **Mobility**

The following two questions correspond to the mobility component of PIP.

Question 1 : Planning and following journeys		
Guide	Points available	Response
<p>This question aims to understand any limitations you have that impact your ability to</p> <p>When we consider the impact of having Fabry on 'Preparing food' some of the key points that commonly arise are:</p>	<ul style="list-style-type: none"><li>a) Can plan and follow the route of a journey unaided. 0</li><li>b) Needs prompting to be able to undertake any journey to avoid overwhelming psychological distress to the claimant. 4</li><li>c) Cannot plan the route of a journey. 8</li><li>d) Cannot follow the route of an unfamiliar journey without another person, assistance dog or orientation aid. 10</li><li>e) Cannot undertake any journey because it would cause overwhelming psychological distress to the claimant. 10</li><li>f) Cannot follow the route of a familiar journey without another person, an assistance dog or an orientation aid. 12</li></ul>	<p><i>Please write some notes here to allow you Support and Advocacy Officer to formulate a response that reflects your needs:</i></p>

Question 2: Moving around		
Guide	Points available	Response
<p>This question aims to understand any limitations you have that impact your ability to</p> <p>When we consider the imp act of having Fabry on 'Preparing food' some of the key points that commonly arise are:</p>	<ul style="list-style-type: none"> <li>a) Can stand and then move more than 200 metres, either aided or unaided. 0</li> <li>b) Can stand and then move more than 50 metres but no more than 200 metres, either aided or unaided 4</li> <li>c) Can stand and then move unaided more than 20 metres but no more than 50 metres. 8</li> <li>d) Can stand and then move using an aid or appliance more than 20 metres but no more than 50 metres. 10</li> <li>e) Can stand and then move more than 1 metre but no more than 20 metres, either aided or unaided. 12</li> <li>f) Cannot, either aided or unaided, – <ul style="list-style-type: none"> <li>(i) stand;</li> <li>(ii) move more than 1 metre. 12</li> </ul> </li> </ul>	<p><i>Please write some notes here to allow you Support and Advocacy Officer to formulate a response that reflects your needs:</i></p>

Question :

Guide	Points available	Response
<p>This question aims to understand any limitations you have that impact your ability to</p> <p>When we consider the imp act of having Fabry on ‘Preparing food’ some of the key points that commonly arise are:</p>		<p><i>Please write some notes here to allow you Support and Advocacy Officer to formulate a response that reflects your needs:</i></p>