

**Muscular
Dystrophy UK**
Fighting muscle-wasting conditions



APPLYING FOR PIP

**A COMPREHENSIVE GUIDE TO PERSONAL
INDEPENDENCE PAYMENT (PIP) FOR PEOPLE
WITH MUSCLE-WASTING CONDITIONS**

CONTENTS

WHAT IS PIP?	4
HOW TO COMPLETE THE APPLICATION FORM	8
THE DAILY LIVING COMPONENT	11
THE MOBILITY COMPONENT	26
ADDITIONAL EVIDENCE	30
CHALLENGING A DECISION	35
ADDITIONAL ENTITLEMENTS AND SERVICES	40
GETTING FURTHER SUPPORT	42

People with muscle-wasting and associated neuromuscular conditions face a unique challenge when applying for PIP, as many of these conditions are not well known or understood. That's why it's important to submit a strong and detailed application.

But many people find the application process daunting. Our guide is designed to take you through the process, step-by-step, to help you complete your application. It's important to get this advice at the start of your application process, to reduce the risk of not getting the payments you're entitled to.

There is no other guide like this for people with muscle-wasting and associated neuromuscular conditions.

All that you'll read in the guide reflects the information our advocacy team would give you over the phone or on email. If you still have any questions, please do get in touch with them on 0800 652 6352 or info@musculardystrophyuk.org

We have written this guide specifically for anyone living with a muscle-wasting or associated condition. If you do not have one of these conditions, or if you have a diagnosis of a different type of condition alongside your muscle-wasting condition, please contact your local Citizens Advice branch for further information.

WHAT IS PIP?

Personal Independence Payment (PIP) is financial support for people aged 16 to your state pension age. It has replaced Disability Living Allowance (DLA) for adults.

If you are currently on DLA, in time you will receive a letter from the Department for Work and Pensions (DWP) inviting you to apply for PIP. The letter will give the date of your last DLA payment and give you a deadline that you need to ensure your PIP application is done by.

PIP is a tax-free, non-means-tested payment – this means it is not affected by your earnings, other income or by any savings you may have.

If you receive PIP, you can spend it as you wish. The money is there to help you with the added expense that living with a disability or long-term health condition can often bring.

The payment is awarded using a points-based system. You can be awarded PIP for a short period (up to two years) or a long period (five to 10 years), with ongoing awards provided where appropriate.

Towards the end of your award period, you are invited to undergo a review to see if your situation is still the same or has changed, which could mean your PIP award could alter. You will be sent a letter about this towards the end of your current award period.

PIP has two components, with two different payment rates. We'll explain this in detail further on in the guide, but here's how it looks in simple terms:

DAILY LIVING COMPONENT	MOBILITY COMPONENT
Enhanced rate	Enhanced rate
Standard rate	Standard rate

HOW IS PAYMENT AWARDED?

A really important thing to know about PIP is that payment is awarded with respect to how your condition affects you, not which condition you have.

Having a diagnosis of a muscle-wasting or associated condition doesn't guarantee that you'll be eligible for PIP.

In the application, you need to demonstrate the impact your condition has on your everyday life. This can feel daunting. It may feel more natural to talk about the parts of daily life that are going well, but it is really important you share the everyday reality of living with your condition.

PIP is considered on a points-based system and rated on how your condition affects you. The more support you need, the higher your points score will be. Dependent on how many points you score, you may be entitled to either the standard or enhanced rates under the daily living or mobility component.

You need to score:

- 8 points for the standard rate
- 12 points for the enhanced rate.

You could qualify for the enhanced rate of both the daily living and mobility components, the enhanced rate of one and standard of the other, or not qualify for one component but qualify for the other – or any combination of these.

AM I ELIGIBLE FOR PIP?

Entitlement to PIP depends on the following eligibility criteria.

You are eligible for PIP if you meet a specific set of criteria, which we detail for you below.

You must:

- have had a health condition for three months before applying, and have the condition for a further nine months after applying
- have been in the UK for two of the past three years
- be aged between 16 and your state pension age

- There are exceptions and additional rules to the eligibility criteria if you have a terminal illness, if you live abroad or if you're not a British Citizen. Please get in contact if you require further information.

Your needs are considered under the following areas, or 'descriptors':

Daily living

- Preparing food
- Taking nutrition
- 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 people face to face
- Making budgeting decisions

Mobility

- Planning and following journeys
- Moving around

When you are being assessed, you will be given the score that best fits with your description of how your condition affects you. This is why it is vital to give as much detail as possible on your application.

SO, HOW DOES PIP GET CALCULATED?

PIP is made up of two separate components:

- daily living component – for help participating in everyday life
- mobility component – for help with getting around.

Each component is paid at one of two rates: the standard or enhanced rate. Which rate you receive will depend on how your condition affects you.

If successful, you could get one component at one rate, both components at the same rate, or both components at different rates. It is decided on a points system, explained further on in the guide.

The components will be added together to make a weekly rate, which is usually paid every four weeks in arrears directly into your chosen bank account.

HOW DO I MAKE AN APPLICATION?

The first step to making an application is to call the DWP and request a PIP form. It's usually quickest to phone, on 0800 917 2222, but you can also write or text the DWP.

Making a new claim to PIP: 0800 917 2222

General enquiry line for PIP (also for existing claims): 0800 121 4433

Find out more at www.gov.uk/pip

During the initial phone call, you will be asked for details including your full name, date of birth, national insurance number, bank details, address and contact information.

If you have difficulty providing this information over the phone, ask someone to call on your behalf; you will need to be present if someone does this.

Following the call, you will be sent the *How your disability affects you* form. This is the PIP application form.

The image features a solid orange background. A white, torn-paper-like shape is cut out from the center, containing the text. The text is in a bold, orange, sans-serif font, arranged in three lines. The top line is 'HOW TO', the middle line is 'COMPLETE THE', and the bottom line is 'APPLICATION FORM'.

HOW TO COMPLETE THE APPLICATION FORM

Now we have covered what PIP is, it's time to look at the how to complete the application form. If you can, have the form with you alongside this guide, so you can take it step-by-step.

For every question, we've included the criteria for each point score under the related descriptor, along with advice and pointers about what sort of information you need to consider when answering this question.

THE INITIAL QUESTIONS

The beginning of the *How your disability affects you* form collects some basic information about your muscle-wasting condition and your current treatments.

ABOUT YOUR MEDICAL PROFESSIONALS

You are asked to list the medical professionals involved in your clinical care. This could include (but don't worry, it isn't limited to):

- general practitioner (GP)
- consultant neurologist
- specialist nurse
- care advisor
- physiotherapist
- occupational therapist
- psychologist
- cardiologist
- respiratory consultant
- speech and language therapist.

You may be able to get supporting evidence from one or more of your medical professionals. If you haven't seen a medical professional in the last three months, try to make an appointment. This helps them to have a clear picture of how things stand with you and your condition, ensuring the most current information is provided.

ABOUT YOUR HEALTH CONDITION OR DISABILITY

The next question asks you to outline your medical condition or disability. It's helpful to give as much information as possible in your answer. You should also include medical evidence (such as a recent clinic letter) to support your diagnosis.

You can apply for PIP without a firm diagnosis. Many people with a muscle-wasting or associated condition may not have a specific diagnosis at first, as tests for these conditions can take time to complete.

Your neurologist may give you what's called a 'clinical diagnosis', while genetic tests are carried out, however this may not always be possible.

In scenarios such as these, you may be given a diagnosis of an 'undiagnosed muscle-wasting condition'. You can state this diagnosis on your PIP form. In cases such as these, medical evidence is very important. It helps the DWP understand how your condition affects you.

The DWP will only assess the impact of your condition, not the condition itself. Therefore, make sure you include information about how your condition affects you and explain what your condition is. Remember, the person reading your form may not have any experience or knowledge of muscle-wasting or associated conditions, so include as much detail as you can and think about how you would describe your condition to someone hearing about it for the very first time.

THE DAILY LIVING COMPONENT

THE QUESTIONS AND THE POINTS TARIFFS

The daily living component looks at your ability to complete daily tasks to meet your basic human needs and live your everyday life. The DWP will score you based on how you are affected by your condition – not on the condition you have – and if your condition affects you on more than 50 percent of days.

Also, bear in mind how you might fare on a bad day.

Many, though not all, muscle-wasting conditions progress over time.

It's possible that over time you may have made small adjustments and changes to your everyday routine. You might be carrying out this task in your own unique way to keep you safe and independent without actually seeing that your needs are changing.

So do think about any small changes you have made and add them to the form.

Make sure you take time to think about the adjustments you've made and how these actions differ from those of someone without a disability or health condition. Give clear examples of these adjustments and why you make them. Think about whether these adjustments mean that it takes longer for you to do things too.

HOW TO ANSWER THE DAILY LIVING QUESTIONS

When thinking about answering the questions about each task, consider the below.

Any help you need from other people

- This includes whether other people complete this task for you, or if you need help with key aspects of it, (e.g. you can prepare some food but can't cut root vegetables).

Any aids or equipment you use

- This includes aids you have been given (e.g. bath board, toilet-seat riser), smaller aids you have purchased yourself (e.g. larger-handed cutlery, lighter cups) and any common items you employ as an aid (e.g. sitting down on the bed to put on your socks, holding on to the sink in order to stand up after using the toilet).

It also includes any medical equipment you have that helps you complete these tasks, such as a PEG feed or catheter.

How long it takes you

- Does it take you longer to complete this task because of how your condition affects you? Do you do the task more slowly? Or do you have to take regular breaks, meaning it takes you longer to complete the task?

Whether the task causes you discomfort during or after completing it

- Do you experience any pain, fatigue or other type of discomfort while completing a task, or afterwards? For example, if you need to rest for half an hour after showering or if you experience pain while dressing and undressing, because of your condition.

Whether you can complete these tasks as often as you need to

- Do you wash and bathe, or change your clothes less frequently because these tasks are difficult or take you a long time? Note all of this on the form.

Whether you can complete these tasks 'to an acceptable standard'

- Do symptoms of your condition mean you can't complete these tasks to a level that someone without a condition might? For example, are you able to chop food, or wash and bathe, to the same standard as someone living without the same condition as you?

Whether you are at any risk

- Have you ever hurt yourself when completing these tasks? Have you had any 'near misses', such as your hand slipping when chopping or almost slipping in the kitchen?

Whether you need prompting

- Do you need someone to prompt you or remind you to complete certain tasks, such as reminding you to eat, take medication or use the toilet? If so, make sure you add this to your form.

Does your condition affect your ability to complete a task in one of the above ways? If so, according to

PIP guidance, you cannot be deemed to be able to complete the task 'effectively'. If this is the case, we expect you would score points under the relevant questions in the form.

How many points you score depends on how much your condition affects you in these areas.

You should also think about:

- how often your condition affects you in this way (does it vary?)
- whether you need assistance but don't currently receive it
- whether you need aids and equipment but don't currently have them.

Remember, the DWP will score you based on how you are affected by your condition – not on the condition you have – and if your condition affects you on more than 50 percent of days.

A great way to figure out how often you need the most help is by starting a diary to track how your condition affects you day to day. Applicants have told us they find it makes them think of things they wouldn't have usually written on the form.

The questions cover both physical and cognitive conditions. It may be that not every question will be relevant to you. It is very normal to not score points under every question, so please don't worry. If you have another condition that is unrelated to your muscle-wasting condition, you may find it useful to contact a relevant health professional or a charity related to that condition.

Please refer back to this section of the guide as you complete your form. It will help you make sure you're considering all aspects of your condition.

PREPARING FOOD

This question assesses your ability to prepare and cook a simple one-course meal from fresh ingredients.

Remember to refer back to the 'How to answer the daily living questions' section on page 12 of this guide if you aren't sure which box to tick or what information you should include when filling in the 'additional information' box.

PREPARING FOOD: POINTS TARIFF

ACTIVITY	DESCRIPTORS	POINTS
Preparing food	• Can prepare and cook a simple meal unaided	0
	• Needs to use an aid or appliance to be able to either prepare or cook a simple meal	2
	• Cannot cook a simple meal using a conventional cooker but is able to do so using a microwave	2
	• Needs prompting to be able to either prepare or cook a simple meal	2
	• Needs supervision or assistance to either prepare or cook a simple meal	4
	• Cannot prepare and cook food	8

When thinking about what 'a simple meal' is, use this example provided by Citizens Advice: 'peel, chop and boil two large potatoes, open a tin of sweetcorn and fry a small piece of meat or fish'.

You may also want to consider other elements of your condition, and how they affect your ability to carry out the following:

- chopping vegetables with a sharp knife
- peeling vegetables
- lifting pots, both empty and full
- standing in one spot while preparing a meal
- lifting trays into and out of an oven
- opening tins, cans, bottles, food packaging
- opening and closing taps
- getting things in and out of cupboards and/or fridge.

It's important to think about any safety precautions you need to take when carrying out food preparation tasks too. For example, if you have a condition that affects your nerves or causes you to experience a loss of sensation, you may be more likely to have an accidental injury (i.e. burn yourself) and be unaware it has happened.

Potential risk is important as well. This might include being unable to carry pans in case they slip out of your hands, or avoiding holding sharp objects if you are prone to falls.

Things like choosing not to bend down to retrieve items from lower shelves in your fridge because you have poor balance can be included here.

Think about the aids you use to help you prepare a meal. These could include:

- easy-grip utensils
- lightweight pans
- kettle tipper
- electric can opener
- a stool (for sitting down when at the kitchen counter)
- orthotics for arms, wrists or legs.

Do you ever need help from another person? This includes somebody physically helping you while cooking, or supervising what you do in order to keep you safe. If so, make sure you put it on the form. It also covers any prompting or reminders you might need.

If you're unable to cook food for yourself and require another person to prepare all your meals, think about why this is. What aspects of your condition mean you cannot prepare food? Even if it seems obvious to you, remember that the DWP doesn't know anything about the way you are affected by your condition, and may not be familiar with your diagnosis. Make sure you note it all on the form.

TAKING NUTRITION

This question looks at your ability to eat and drink and addresses any help or supervision you may need in this area.

Remember to refer back to the 'How to answer the daily living questions' section on page 12 of this guide if you aren't sure which box to tick or what information you should include when filling in the 'additional information' box.

TAKING NUTRITION: POINTS TARIFF

ACTIVITY	DESCRIPTORS	POINTS
Taking nutrition	• Can take nutrition unaided	0
	• Needs - (i) to use an aid or appliance to be able to take nutrition; or (ii) supervision to be able to take nutrition; or (iii) assistance to be able to cut up food	2
	• Needs a therapeutic source to be able to take nutrition	2
	• Needs prompting to be able to take nutrition	4
	• Needs assistance to be able to manage a therapeutic source to take nutrition	6
	• Cannot convey food and drink to their mouth and needs another person to do so	10

'Taking nutrition' seems an odd way of saying 'eating and drinking' – but this is what it means. It asks about your ability to eat and drink independently. This includes cutting up food and your ability to guide it to your mouth. It takes into account if you need supervision when eating, or if you have swallowing issues that may make you prone to choking.

If you use any form of feeding tube, this is the best place to include this information. We have listed some of the aids below, but you can add anything that supports you to eat and drink.

- A straw
- Lightweight cups
- Partitioned plates with high edges
- Modified cutlery/extra sharp knives
- Higher tables (if you need food to be closer to your mouth to lift it)

- Easy-grip utensils
- Feeding tubes
- Neater eaters/arm supports
- A blender/food processor (if you can only eat blended or softer foods).

Think about any help you need with eating and drinking. This can include needing someone to:

- lift food or drink to your mouth
- lay out food and/or drink on a table for you because you are unable to carry it from the kitchen to the table
- cut up food for you (even if this is only with certain foods)
- supervise you when you are eating and/or drinking because you have difficulties with swallowing, and so are prone to choking episodes.

MANAGING THERAPY

This question looks at how you manage therapy and monitor your condition. In this section you can include information on any 'treatments' that you are currently using.

Remember to refer back to the 'How to answer the daily living questions' section on page 12 of this guide if you aren't sure which box to tick or what information you should include when filling in the 'additional information' box.

MANAGING THERAPY: POINTS TARIFF

ACTIVITY	DESCRIPTORS	POINTS
Managing therapy or monitoring a health condition	<ul style="list-style-type: none"> • Either (i) does not receive medication or need to monitor a health condition; or (ii) can manage medication or therapy or monitor a health condition unaided 	0
	<ul style="list-style-type: none"> • Needs either (i) to use an aid or appliance to be able to manage medication; or (ii) supervision, prompting or assistance to be able to manage medication or monitor a health condition 	1
	<ul style="list-style-type: none"> • Needs supervision, prompting or assistance to be able to manage therapy that takes no more than three-and-a-half hours a week 	2
	<ul style="list-style-type: none"> • Needs supervision, prompting or assistance to be able to manage therapy that takes more than three-and-a-half hours but no more than seven hours a week 	4
	<ul style="list-style-type: none"> • Needs supervision, prompting or assistance to be able to manage therapy that takes more than seven hours but no more than 14 hours a week 	6
	<ul style="list-style-type: none"> • Needs supervision, prompting or assistance to be able to manage therapy that takes more than 14 hours a week 	6

The focus is on how effectively you are able to monitor your condition, take medication or manage home treatments and whether you need any assistance or prompting in order to do so.

Think about the therapies, medication and treatments that you're currently having. These can include:

- medication (e.g. pain relief, prescribed or over-the-counter)
- physiotherapy
- exercises that you complete at home
- creams and gels
- ventilation
- cough assist
- medication via feeding tube
- injections and intravenous treatments (e.g. IVIG)
- podiatry (foot care).

Do you have any assistance from other people or use any aids when completing or keeping track of these therapies? This can include people reminding you to take medication, physical assistance from a medical professional (such as a district nurse who comes to your home) and help from family members or friends to complete exercises.

This question also covers whether, because of reduced hand strength or manual dexterity, you need someone else to open packaging for you, push tablets through a blister packet or organise your medication into a dosette box.

Remember, there is no such thing as too much information! If you need help with it, tell the DWP.

Remember to consider the impact fatigue may have on your ability to manage your treatments as well. This is easily overlooked.

Below are examples of aids you can use to help manage therapies and treatments. These are just examples, so don't limit yourself to just what is on this list.

- Dosette box
- Alarms (to remind you to take medication at specific times)
- Equipment that lifts your feet so you reach them with ease
- Long-handled applicators for creams and gels
- A chair or table to hold on to in order to do exercise safely

Do you need any supervision to monitor your condition? If you do, add this to the form. You might need supervision if you have difficulty recognising that you're unwell or tired, when you need to take medication or whether you need medical attention. This includes the monitoring of your mental health. Perhaps chat with those close to you about the support they give you, or refer to your diary.

When thinking about the length of time you need help with managing treatments, think about all the help and supervision you need throughout a week. Then calculate roughly how long each task takes so you can add it up. A rough estimate is perfectly fine. Include these details under this question, as it will help the DWP to accurately allocate points.

WASHING AND BATHING

This question assesses how effectively you are able to wash your own body, and whether you need any support to maintain your personal hygiene.

Remember to refer back to the 'How to answer the daily living questions' section on page 12 of this guide if you aren't sure which box to tick or what information you should include when filling in the 'additional information' box.

WASHING AND BATHING: POINTS TARIFF

ACTIVITY	DESCRIPTORS	POINTS
Washing and bathing	• Can wash and bathe unaided	0
	• Needs to use an aid or appliance to be able to wash or bathe	2
	• Needs supervision or prompting to be able to wash and bathe	2
	• Needs assistance to be able to wash either their hair or body below the waist	2
	• Needs assistance to be able to get in or out of the bath or shower	3
	• Needs assistance to be able to wash their body between the shoulders and waist	4
	• Cannot wash and bathe at all and needs another person to wash and bathe their entire body	8

This question addresses a number of different elements, including how you access the bathroom (i.e. has your bathroom been specially adapted), whether you are able to wash all areas of your body or if you need assistance with this, and any aids you use to help you wash and bathe effectively.

See below for a list of things to consider when answering this question.

Have you made any adaptations or added aids to your bathroom?

- A walk-in shower or wet room
- Hand rails in the shower stall or to help you get out of the bath
- A smaller step into the shower
- A particular location for your shampoo or soap to make it easier to reach
- A special container for your shampoo or soap to make it easier to use
- A stool in the shower
- A bath board or bath lift
- A long-handled sponge or brush for washing
- Grab rails
- Non-slip mats
- Shower/bath seat/board
- Wet room adaptations
- Modified soap and shampoo dispenser

Are there any everyday bathroom items or fixtures you can't use?

- Opening a bottle of shampoo
- Holding a bar of soap
- Getting in and out of a bath
- Standing in a shower

Are you able to wash all areas of your body independently or without aids?

- Are there any areas of your body you can't reach?
- Are there any areas of your body that are harder to wash? Why is this?
- Can you reach overhead to wash your hair?
- Do you lean against the wall, or sit on a seat, or bend over slightly to reach your hair?
- Have you changed your hairstyle so it's easier to maintain?
- How do you wash your feet?

Do you need any assistance from another person to wash and bathe?

- Which parts of washing and bathing do you need help with?
- If you don't have help, is there any element of washing and bathing that you think you would benefit from help with?
- Do you wash and bathe when you are home by yourself?
- What about on a bad day?
- If you slipped or fell would you need help?

Are there any other aspects of hygiene you need help with?

- Brushing your teeth – do you use a different toothbrush or get help with this?
- Washing your face?
- Washing your hands after toileting?

MANAGING TOILET NEEDS

This question looks at how you manage going to the toilet.

Remember to refer back to the 'How to answer the daily living questions' section on page 12 of this guide if you aren't sure which box to tick or what information you should include when filling in the 'additional information' box.

MANAGING TOILET NEEDS: POINTS TARIFF

ACTIVITY	DESCRIPTORS	POINTS
Managing toilet needs or incontinence	• Can manage toilet needs or incontinence unaided	0
	• Needs to use an aid or appliance to be able to manage toilet needs or incontinence	2
	• Needs supervision or prompting to be able to manage toilet needs	2
	• Needs assistance to be able to manage toilet needs	4
	• Needs assistance to be able to manage incontinence of either bladder or bowel	6
	• Needs assistance to be able to manage incontinence of both bladder and bowel	8

Some muscle-wasting and associated conditions can cause weakness of the bowels and/or bladder. Accessing a bathroom can also become difficult if your mobility is progressively affected by your condition.

Take some time to think about any difficulties that you have with going to the toilet. It's a personal subject, we know, but do explain your reality in as much detail as you can. This helps the assessor to understand how your condition affects you when going to the toilet.

If you have trouble with opening your bowels and need medication/have modified your diet to assist with this, mention that under this question. Think about whether you take longer to complete your toileting needs because of the way you are affected

by your condition. This can include difficulty urinating or opening your bowels. If it takes you longer to sit down and get up from the toilet seat, ensure you add that to the form.

If you have accidents, think about when these tend to occur and how often you have them. Do you plan your day around toileting too? This can include using the toilet before you go out or planning ahead to make sure there are accessible toilets.

Do you ever avoid going out because of a lack of facilities? Do you avoid going to the toilet as often as you should because it is difficult or there isn't help available?

Below are a number of different aids you may use to assist you when you go to the toilet. You may also use ones that are not on the list.

- Grab rails
- Raised toilet seat
- Adapted toilet (e.g. Clos-o-mat)
- Bottom wipers
- Commode
- Collecting device
- Shewee
- Incontinence pads
- Catheter

We understand this can be a difficult question to answer. This information is personal and often the last thing you might feel like sharing but it is important to share as much detail as possible to ensure your award is considered correctly.

DRESSING AND UNDRRESSING

The questions in this section look at how well you can independently dress and undress.

Remember to refer back to the 'How to answer the daily living questions' section on page 12 of this guide if you aren't sure which box to tick or what information you should include when filling in the 'additional information' box.

DRESSING AND UNDRRESSING: POINTS TARIFF

ACTIVITY	DESCRIPTORS	POINTS
Dressing and undressing	• Can dress and undress unaided	0
	• Needs to use an aid or appliance to be able to dress or undress	2
	• Needs either (i) prompting to be able to dress, undress or determine appropriate circumstance for remaining clothed; or (ii) prompting or assistance to be able to select appropriate clothing	2
	• Needs assistance to be able to dress or undress their lower body	2
	• Needs assistance to be able to dress or undress their upper body	4
	• Cannot dress or undress at all	8

This question looks at different items of clothing. Think about each item of clothing separately and ensure your answers cover each individual piece of clothing. Below are a few points you may want to consider.

Do you have difficulty:

- lifting your arms to put items of clothing above the head?
- pulling coats over your shoulders, especially during winter?
- drying your hair?
- putting on shoes and clothes on your lower body? Is this because of weak muscles, flexibility or poor balance?

Do you:

- change the clothes you wear to make dressing easier? (Do you wear elasticated or loose clothing or clothing with no buttons, zips or fasteners to make dressing and undressing easier?)
- remain standing to put on all your clothes? Or do you sit down?

- do up buttons, zips and other fasteners without any difficulty? This could include shirts, trousers, bras, coats and shoelaces. Remember to mention if you modify any of this clothing to make it easier to manage.

If you have difficulty in any aspects of getting dressed or undressed, does someone help you?

Below is a selection of the aids you may use to assist you in getting dressed or undressed. If you use any other aids that are not mentioned on the list below, be sure to mention this in your form.

- Modified buttons
- Zip pulls
- Long-handled shoe horn
- Sock aids
- Velcro fastenings
- Modified/looser clothing

COMMUNICATING VERBALLY

This question assesses your ability to speak and whether you need any help or aids in order to do this effectively.

Remember to refer back to the 'How to answer the daily living questions' section on page 12 of this guide if you aren't sure which box to tick or what information you should include when filling in the 'additional information' box.

COMMUNICATING VERBALLY: POINTS TARIFF

ACTIVITY	DESCRIPTORS	POINTS
Communicating verbally	• Can express and understand verbal information unaided	0
	• Needs to use an aid or appliance to be able to speak or hear	2
	• Needs communication support to be able to express or understand complex verbal information	4
	• Needs communication support to be able to express or understand basic verbal information	8
	• Cannot express or understand verbal information at all even with communication support	12

For some people, severe muscle weakness affecting the vocal cords or facial muscles can make communicating frustrating and difficult.

Some muscle-wasting and associated conditions can also have associated cognitive effects. Fatigue can also have an impact on effective communication, so please seek expert advice relating to these conditions.

If you have a condition that affects your cognition or if you have an associated learning disability, think about what support you have in place to help you communicate.

If you have facial weakness or if your voice is much quieter, it is important to describe how this affects your ability to communicate with others.

Do people ever find it difficult to understand you, or do you find you need to repeat yourself frequently?

Add all of this to your form. It will help the assessor get a clearer picture of how your condition impacts on your communication.

Below are some of the aids that assist with communication but there are others that you may use.

- Assistive technology communication devices
- Voice aids
- Assistance from another person to communicate with others (e.g. if your family or friends understand you better and they translate)

READING AND UNDERSTANDING WRITTEN INFORMATION

This section looks at your ability to read and understand written information.

Remember to refer back to the 'How to answer the daily living questions' section on page 12 of this guide if you aren't sure which box to tick or what information you should include when filling in the 'additional information' box.

READING AND UNDERSTANDING WRITTEN INFORMATION: POINTS TARIFF

ACTIVITY	DESCRIPTORS	POINTS
Reading and understanding signs, symbols and words	• Can read and understand basic and complex written information either aided or using spectacles or contact lenses	0
	• 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
	• Needs prompting to be able to read or understand complex written information	2
	• Needs prompting to be able to read or understand basic written information	4
	• Cannot read or understand signs, symbols or words at all	8

Some muscle-wasting and associated conditions affect the muscles around the eyes. This can affect your ability to read. Added learning difficulties and cognitive challenges can also impact on reading and being able to understand information.

If you have a visual impairment, ensure you add any aids you may use or adjustments you make such as using a larger text on your phone or computer.

Below are some of the aids you may use.

Do you ever have difficulty in this area? Why is that? Think about any help you have had from others when these situations have occurred.

- Magnifying glass
- Braille
- Easy-read guides

ENGAGING WITH OTHERS FACE-TO-FACE

This question covers any challenges you face in interacting face-to-face with other people.

Remember to refer back to the 'How to answer the daily living questions' section on page 12 of this guide if you aren't sure which box to tick or what information you should include when filling in the 'additional information' box.

ENGAGING WITH OTHERS FACE-TO-FACE: POINTS TARIFF

ACTIVITY	DESCRIPTORS	POINTS
Engaging with others face-to-face	• Can engage with other people unaided	0
	• Needs prompting to be able to engage with other people	2
	• Needs social support to be able to engage with other people	4
	• Cannot engage with other people due to such engagement causing either (i) overwhelming psychological distress to the claimant; or (ii) the claimant to exhibit behaviours, which would result in substantial risk of harm to the claimant or another person	8

Some people find mixing with others to be very challenging. This may affect you from time to time or you may always find this difficult because of anxiety or other elements of your condition.

Consider if you ever avoid mixing with other people. Do you feel able to mix with others on your own or do you need someone with you? Does mixing with others ever cause you distress or difficulty?

With some muscle-wasting and associated conditions, there may sometimes be associated learning difficulties or behavioural changes. Similarly, fatigue can also make engaging with others challenging.

Think about how you feel after mixing with others. Do you get tired? Overwhelmed? Are you only able to do so for a short amount of time before you need a break?

MAKING BUDGETING DECISIONS

This question assesses how well you are able to manage your own money and whether you need any support with this.

Remember to refer back to the 'How to answer the daily living questions' section on page 12 of this guide if you aren't sure which box to tick or what information you should include when filling in the 'additional information' box.

MAKING BUDGETING DECISIONS: POINTS TARIFF

ACTIVITY	DESCRIPTORS	POINTS
Making budgeting decisions	• Can manage complex budgeting decisions unaided	0
	• Needs prompting or assistance to be able to make complex budgeting decisions unaided	2
	• Needs prompting or assistance to be able to make simple budgeting decisions	4
	• Cannot make any budgeting decisions at all	6

This section mainly applies to people with learning disabilities or those with conditions that affect your cognition. Both can make managing money difficult.

However, fatigue, pain or stress may also make budgeting and managing money difficult for you. If this is the case, share it here.

If you are unable to manage money because of a learning disability, it's a good idea to get some evidence from a relevant professional to support your claim.

If you have a key worker or support worker who helps you sort out your bills and manage your income, or if you have a partner or family member who does this for you, make sure to explain why this is. If you attempted to do this without help, what would happen?

If you have any questions or need some further support with any of the daily living component descriptors, please get in touch with our advocacy team via our free helpline on 0800 652 6352.

THE MOBILITY COMPONENT

THE QUESTIONS AND THE POINTS TARIFFS

The mobility component looks at how your mobility is affected by your condition. This includes your ability to walk, as well as your ability to plan and follow the route of a journey.

Your eligibility for the mobility component is based on just two questions. Advice on how to answer these questions is covered in this section of the guide.

PLANNING AND FOLLOWING JOURNEYS

This question assesses any difficulty you experience or any help you need going out on your own. This question does not measure your physical ability to get around, but rather takes into account any psychological or developmental factors that make it difficult for you to plan and follow a route independently. This can include severe anxiety, depression and learning disabilities. If you have any conditions of this description, it's important to get evidence from a healthcare professional.

PLANNING AND FOLLOWING JOURNEYS: POINTS TARIFF

ACTIVITY	DESCRIPTORS	POINTS
Planning and following journeys	• Can plan and follow the route of a journey unaided	0
	• Needs prompting to be able to undertake any journey to avoid overwhelming psychological distress to the claimant	4
	• For reasons other than psychological distress, cannot plan the route of a journey	8
	• For reasons other than psychological distress, cannot follow the route of an unfamiliar journey without another person, assistance dog or orientation aid	10
	• Cannot undertake any journey because it would cause overwhelming psychological distress to the claimant	10
	• 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

If you use public transport, are you able to plan your route, deal with changes and cope with these changes independently? For example, if a train platform changes at the last minute, how would this affect you?

Do you ever feel distressed when visiting new places? Would you ever avoid going to new places on your own for this reason?

Below are a few of the aids people may require to plan and follow the route of a journey, but there may be others you can mention.

- Guide dog
- White cane
- Guide (another person to help you get around)

MOVING AROUND

This question looks at your ability to stand and then move around. It's a very important question for people with muscle-wasting and associated conditions, as the answers you give to this question are vital to assess your entitlement.

MOVING AROUND: POINTS TARIFF

ACTIVITY	DESCRIPTORS	POINTS
Moving around	• Can stand and then move more than 200 metres, either aided or unaided	0
	• Can stand and then move more than 50 metres but no more than 200 metres, either aided or unaided	4
	• Can stand and then move unaided more than 20 metres but no more than 50 metres	8
	• Can stand and then move using an aid or appliance more than 20 metres but no more than 50 metres	10
	• Can stand and then move more than one metre but no more than 20 metres, either aided or unaided	12
	• Cannot, either aided or unaided, (i) stand; or (ii) move more than one metre	12

This section looks at your physical capability to move around. You will be asked about the distance you are able to walk with the assistance of aids and your ability to stand from a seated position.

Though it is useful to provide detail about your mobility in lots of different areas, when you are considering the distance you can walk, the distance needs to be on flat, level ground.

It's not the easiest question to answer. We know that there are lots of factors that may affect your walking. When answering this question you should reflect the distance you are able to walk without experiencing:

- pain or discomfort
- excessive fatigue
- risk (e.g. risk of falling, risk of causing yourself harm).

You should be able to walk this distance without stopping. Make sure you think about whether you can walk this distance in a timeframe that could be considered 'reasonable'.

For example, if you walk at roughly half the speed that someone without a condition may walk, it is vital you let the DWP know this.

Think what would happen if you tried to repeatedly walk this distance. Does your ability to walk a distance vary throughout the day, perhaps because of fatigue or other symptoms?

Think about your very worst days. This is the scenario you need to share. Human instinct is to dismiss our difficulties, but with PIP, the assessors need to know.

If you cannot stand or walk any distance at all and use a wheelchair or mobility scooter full-time, you should qualify for the highest rate under this component.

This component of PIP scores your ability to walk on a flat surface, but to give a full picture of how your condition affects your mobility, also think about how you are affected when navigating:

- stairs
- inclines
- uneven surfaces
- kerbs
- outdoor terrain
- different weather conditions (e.g. windy or wet days).

Although not all of these are assessed under PIP, it can be helpful to have more understanding of the challenges walking brings you.

Think about any aids that you use, either full-time or periodically. These could include the following:

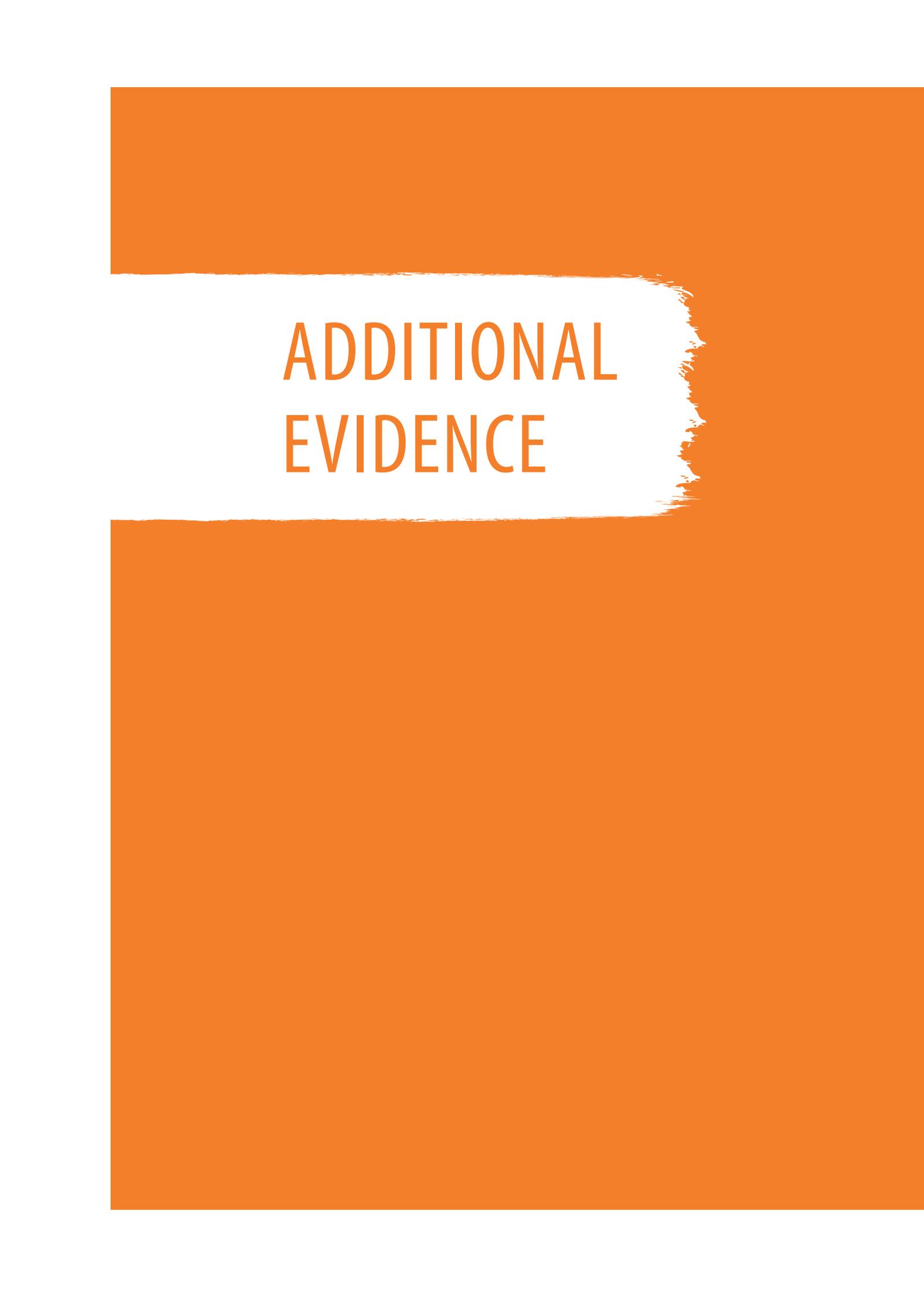
- wheelchair (electric or manual)
- mobility scooter
- walking frame
- walking stick
- hiking sticks
- prosthetics
- orthotics
- chair with support with sit-to-stand
- assistance from another person.

Think about anything you use that isn't an obvious walking aid. Examples could be shopping trolleys, pushchairs or holding on to furniture to get around your home.

This component also looks at how able you are to stand independently.

This could include needing help from another person to stand from a seated position. It also counts if you have a riser function on a wheelchair or chair or you use other manoeuvres to help you stand. You may place a chair in front of you so you have something to lean on to help with balance. All of this is important to share on the form.

Are you prone to trips or falls? How often do these occur? If you do fall, are you able to get yourself up without help from another person? Do you have a pendant alarm? Have you sustained any injuries from falls recently? All of this should be shared in this section.

The image features a solid orange background. A white, horizontal brushstroke with a rough, textured edge runs across the middle of the page. The text 'ADDITIONAL EVIDENCE' is written in orange, uppercase letters within the white brushstroke.

ADDITIONAL EVIDENCE

This section of the guide discusses the importance of including additional evidence as part of your PIP application form.

WHY IS IT IMPORTANT TO INCLUDE ADDITIONAL EVIDENCE?

Supporting medical evidence is crucial to your application. It is the strongest form of information you can provide to the DWP.

The content of a letter of support from your neurologist, for example, should never be disputed by the DWP.

Other types of evidence, such as a letter from your partner, parent or carer all help paint a picture of the impact your condition has on your life. A weekly diary, outlining all the help you need is also an excellent document to include.

There is a place on the form to write your medical professionals' contact details. However, the DWP will only contact them if they feel they don't have enough evidence to make a decision. Therefore, it's important to send in your own evidence along with your claim. This helps them to make an informed decision and can prevent the process being delayed.

WHAT EVIDENCE SHOULD I INCLUDE?

Below is a list of some of the health professionals who may be able to provide a supporting letter for your claim. You don't need to contact them all, so think about the ones you feel know you best. For example, a physiotherapist would be able to provide information about your walking, mobility and strength.

- Consultant neurologist
- Neuromuscular care advisor
- Nurse specialist
- Physiotherapist
- Occupational therapist
- General practitioner (GP)
- Psychologist
- Speech and language therapist

As soon as you begin the process of applying for PIP, let your chosen health professionals know so you can schedule an appointment with them.

It is helpful to ensure you keep up-to-date with all your medical appointments so health professionals have a clear understanding of how your condition affects your everyday life.

Don't rely solely on medical evidence. You know your condition better than anyone. If your condition fluctuates from day to day, it can be difficult to answer some of the questions on the form. Keeping a diary is a brilliant way of sharing how your condition can vary day to day. This gives you an opportunity to highlight different challenges the form may not ask you about.

You can also get a letter or statement from a friend, carer or relative.

Here, Liz shares how important the evidence she submitted was.

"Evidence is such a vital part of your application. Your answers to the questions may not be enough.

"It is important that you have evidence from a medical practitioner or therapist. If you are under a specialist, you may be able to ask for copies of your clinic letters to be sent to you to include in your PIP application."

At MDUK, we have an advocacy team who are more than happy to assist with applications and provide information concerning your condition. We are here to support you – you'll find our contact details at the end of this guide.

SENDING IN YOUR FORM AND NEXT STEPS

1. SENDING IN THE FORM TO THE DWP

Now that you have completed the 'How your disability affects you' form to the best of your ability, you will need to send this in to the DWP. Be sure to include any supporting evidence with your application.

Before you post off your application, check that you have enclosed the following:

- full and completed application form
- medical evidence
- any additional supporting letters
- diary of condition
- condition factsheet (available from MDUK).

Before you send it off, take photocopies or photos of your completed form, as well as all your supporting evidence. It is best to avoid sending originals where you can.

We would advise sending the form recorded delivery. Where this isn't possible, ask for receipt for proof of postage.

After around a week or so, if you haven't heard anything, give the DWP a quick call to ensure they have received it.

Once the DWP has confirmed that your application has been received, there is nothing more for you to do but wait to receive correspondence from the DWP either inviting you to a face-to-face assessment or informing you of a decision. Not everyone will be called to an assessment. Sometimes decisions are made on the strength of the completed application form.

2. FACE-TO-FACE ASSESSMENTS

You may be invited to a face-to-face assessment. This is a standard part of the PIP process, and it's expected that most PIP applicants will be invited to attend a face-to-face assessment (even if you have been receiving DLA previously).

The assessor will have a medical/nursing or allied health background but this doesn't mean they are familiar with your condition. It can be helpful for them to hear about your condition directly from you. MDUK can provide you with a condition factsheet to give to the assessor.

You can get in touch with our support team on 0800 652 6352 for further information.

Speak as openly and clearly as you feel able. There is no rush.

Liz shares her experience of a face-to-face assessment.

"Once you have returned your form you are likely to be asked to attend a face-to-face assessment either in an assessment centre or in your own home. If you need level access, disabled toilet and disabled parking then state it beforehand.

"If you can't attend and need the assessment to be carried out at home, you need to make it clear why.

"The assessor was very nice. Muscular dystrophy and other related conditions are incredibly rare and it is very unlikely that the assessor has come across your diagnosis before so be clear. For example, if you can't lift your arm because your bicep is wasted then clearly state it.

"Be honest when talking about the help you need. Your appearance will also be documented, even how you hand over your identification documents. This is all perfectly legitimate and actually reinforced everything I'd written, so again don't fear it. Honesty is the best and only policy and it works both ways."

3. INFORMATION REQUIRED FOR THE FACE-TO-FACE ASSESSMENT

The final section of the form offers an opportunity to mention any additional needs you have in relation to this. Here you would share any access requirements you may have, such as:

- level access
- Blue Badge parking
- ground floor room

- access to toilets
- interpreter/sign language interpreter.
- shopping
- using a computer.

4. HOME ASSESSMENTS AND AUDIO RECORDINGS

Home assessments are carried out on a case-by-case basis.

You can ask to audio record your assessment if you wish. If you require this, you should state it on the form and also liaise with the assessment centre before your appointment.

There are usually a number of rules that will need to be adhered to in order to audio record the assessment.

Typically, there are only specific types of recording equipment that can be used and you would need to provide a copy of the recording at the end of the assessment. Please speak to the assessment centre as far in advance as possible to avoid any challenges on the day.

WHAT COULD I BE ASKED AT THE ASSESSMENT?

The questions you can be asked at the assessment may vary from the form. Generally, the assessment will cover a mixture of questions from the form itself and questions not on the form. Don't be alarmed at this. It's to expand a bit more on the impact your condition has on you, day to day. It's simply to determine your eligibility under all the descriptors.

The way you communicate and answer the questions will also be noted along with assessing how you are generally in the assessment.

The assessor may ask you questions about your everyday life. This could cover the following activities:

- work
- holidays
- looking after pets
- visiting friends
- hobbies
- driving
- volunteering

Many people are able to complete all the activities listed and are still entitled to receive PIP, so don't let this worry you. None of these questions is designed to 'catch you out'. They offer you an opportunity to share what support you may need.

When answering the questions, try and keep in mind the information given throughout this guide. What do you find difficult and why? Can you complete these tasks alone? Can you complete them within a 'reasonable timeframe'?

Think about any aids you may need too, including mobility aids, adaptations or assistance from another person.

Below are a few suggestions:

- wheelchair accessible vehicle (or adapted vehicle)
- automatic vehicle
- any mobility aid
- any assistance through Access to Work or your employer
- assistive technology (environmental controls and communication devices)
- relying on online shops
- dog walker.

WILL THERE BE A PHYSICAL EXAMINATION AT THE ASSESSMENT?

The assessor may ask you to complete a few minor actions or movements. This is perfectly normal and nothing to be concerned about. It simply helps them to determine your level of muscle strength.

Remember that your assessor may not be familiar with your condition, and might ask you to complete an action that you can't do. If you can't complete an action or feel unsafe doing so, explain why this particular action isn't possible. You don't have to complete any actions that you feel unsafe or uncomfortable doing.

Mathy has congenital myopathy.

“At my PIP assessment, I was asked to explain what exactly my disability was, and what that meant.

“I was then asked to estimate, on average, how and how long it would take me to carry out various tasks: walking a certain distance unaided, getting dressed, having a shower. I was then asked to demonstrate certain movement to the assessor: sitting to standing, bending at the hip, lifting my leg when seated on a bed.”

WHAT INFORMATION SHOULD I BRING TO THE ASSESSMENT?

It may be helpful to bring some notes for yourself so you don't forget to mention anything about your condition. Preparation is key.

We know it can be a daunting experience. Some people prefer to take someone along with them for additional support.

RECEIVING A DECISION

You should receive a decision by letter shortly after your assessment. The letter will tell you whether you have been awarded PIP payments, what rate the award is and how long the award will last.

Included in the decision letter will be a breakdown of the points you scored under each descriptor, and a short written explanation of how the decision was made.

The assessor doesn't make the decision on your PIP entitlement. They file the report and a DWP decision-maker decides the outcome.

Although your assessor doesn't make the final decision, their report plays a vital part in the outcome.

You can request a copy of the assessor's report from the PIP customer service helpline if you wish to read it.

WHAT IF I'M UNHAPPY WITH THE DECISION?

The best outcome is that any decision made will be in your favour. But if not, you have the right to ask for it to be looked at again. Details on how to do this will be at the end of your decision letter.

First off, you will be required to request a mandatory reconsideration. This means the DWP will once again review your application.

Following this you can appeal to the Courts and Tribunal Services.

MDUK can help you with any requests to review a decision. Further information on how to appeal appears further on in this guide.

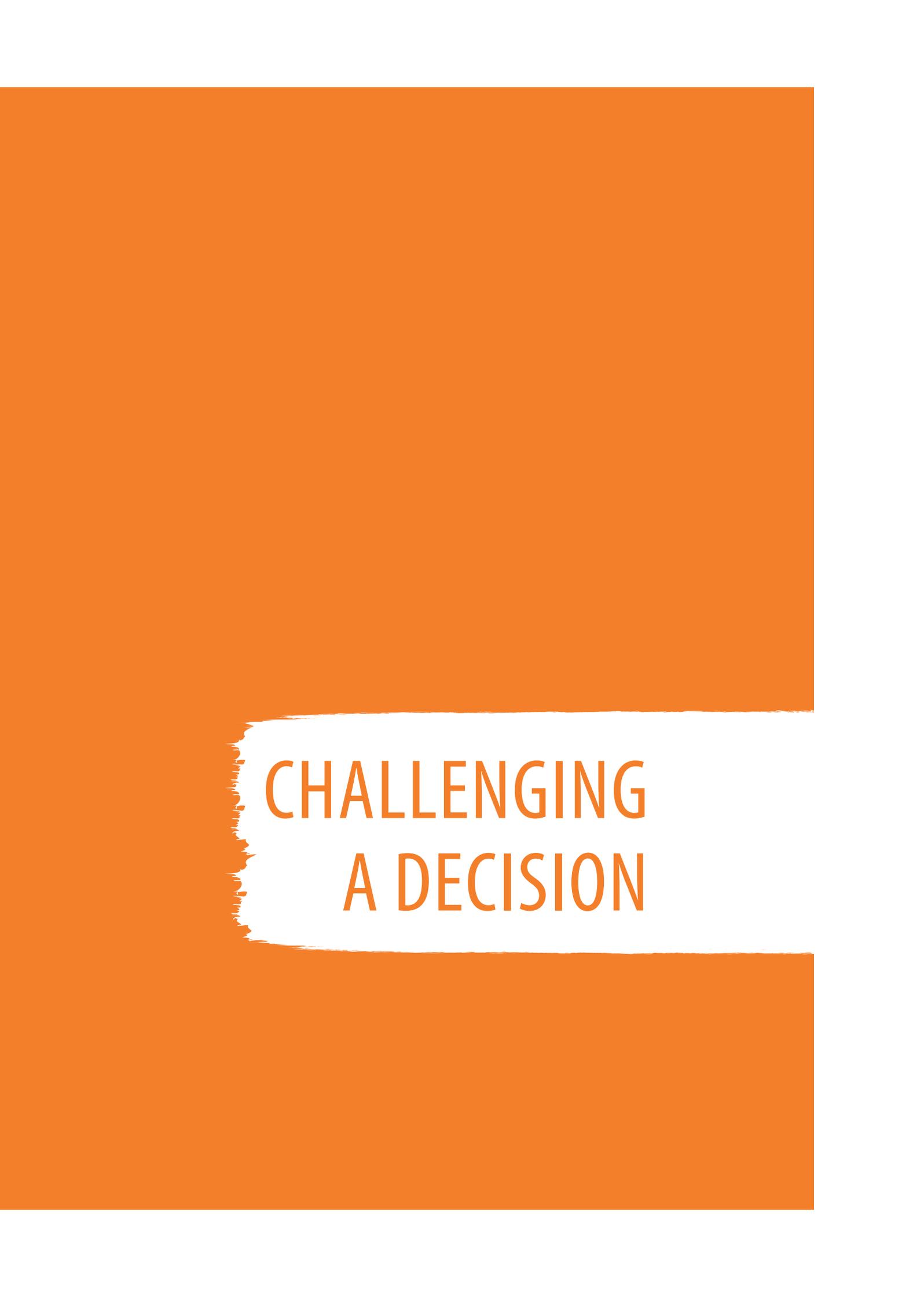
IF I FEEL MY CLAIM WAS HANDLED INAPPROPRIATELY, AM I ABLE TO MAKE A COMPLAINT?

If you feel your claim has been handled inappropriately, you can file a complaint.

This can be done alongside appealing your rate of allowance. Even if you are content with the award rates, but were unhappy with the process, you can make a complaint.

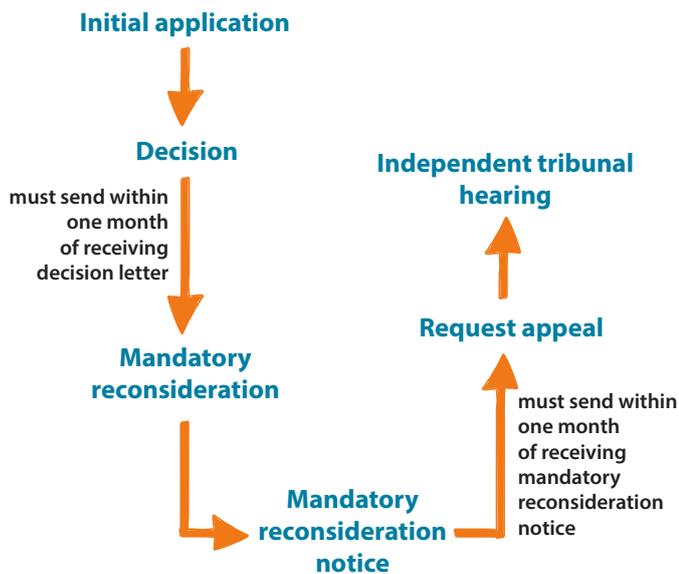
Initially, contact the PIP enquiry line and share your concerns.

If you are unsatisfied with their response, ask for your complaint to be looked at by a Complaint Resolution Manager. This can take around 15 working days. If you still feel the complaint has not been resolved, the case can be taken to an Independent Case Examiner for investigation. This is impartial and free.

The image features a solid orange background. A horizontal white strip, resembling a piece of torn paper, is positioned in the center. The left edge of this strip is jagged and irregular, while the right edge is straight. The text "CHALLENGING A DECISION" is printed in a bold, orange, sans-serif font on the white strip.

**CHALLENGING
A DECISION**

This section explains how you go about challenging a PIP application decision.



MANDATORY RECONSIDERATION

If you do not agree with a decision, you can ask the DWP to look at this decision again. This is the first step in the process and is called 'mandatory reconsideration'. A mandatory reconsideration request needs to be made within one calendar month of the date on the decision letter.

If you have missed the one-month deadline, it is still possible to ask the DWP for a mandatory reconsideration. You would be expected to demonstrate the reasons for submitting a late request. However, the DWP can refuse your request if submitted late.

Reasons to ask for a mandatory reconsideration would be:

- if you think that the level of benefit you have been awarded is incorrect (an example of this would be that you have been awarded the standard rate for the mobility component and you think you should be receiving the enhanced rate)
- if you disagree with the length of the award and feel it should be for a longer period.

Please be aware that the DWP will look at your whole application again.

This could go in your favour, but they also have the right to remove any rate of PIP that you were awarded in the DWP's initial decision.

REQUESTING A MANDATORY RECONSIDERATION

You need to write to the address or call the number outlined at the end of your decision letter. Calling is usually a quicker, more effective approach to get the process underway. When you call, do the following:

- **request a mandatory reconsideration of the decision**, and explain why you feel the decision is wrong. Keep it simple at this stage. An example of this would be that the decision does not acknowledge the extent of the support you require.
- **ask them to send you copies of their documents** so you can review them. This will include the assessor report.
- **ask them for a deadline by which you can then send in additional evidence**, and tell them they should not proceed with the reconsideration until they have received this evidence.

If you request the mandatory reconsideration in writing, make sure to keep a copy of the letter and proof of postage (sending recorded delivery where possible). If you request the mandatory reconsideration by phone, take the full name of the person you spoke to and the date and time. We advise also following this up in writing.

You should hear from the DWP within a couple of weeks. If you haven't, give them a call.

When you get the reports, they will give you a wider understanding of why a decision has been made. There will normally be two parts to their documents: a copy of your form and the face-to-face assessment report.

Once you have both of these in front of you, take a look at them side by side. Read the report in detail and see if any information about your condition has been missed or misunderstood.

Highlight these differences in your letter. Also try to get medical evidence to back up your claims. When you have gathered the evidence, make copies for your records and then send it to the DWP.

You can let the DWP know if you need additional time to collect evidence, especially if you are awaiting medical evidence.

Mathy, who has congenital myopathy, appealed against a PIP decision.

"I was awarded the standard rate of the mobility allowance. This meant I was no longer eligible for my adapted Motability car.

"After an appeal, in which I submitted further evidence from my physiotherapist and a letter from MDUK, I was awarded the higher rate of the mobility component of PIP.

"I found the lack of understanding of my condition very difficult. I felt they didn't refer to the medical letters I had provided. I had also requested they contact my GP and/or physiotherapist directly. The effects of my condition are persistent and long-term, and as such are not going to change."

Once all the information has been received, a case manager at the DWP will look at the original decision along with any new evidence. A decision will be made based on this.

The DWP will then write to you informing you of the outcome. This letter is called a 'mandatory reconsideration notice'. Keep this letter in a safe place, as you will need it if you choose to appeal to a tribunal.

INDEPENDENT TRIBUNAL

You must have been through the mandatory reconsideration process before you can appeal to an independent tribunal.

If you feel the mandatory reconsideration decision is incorrect, the next stage is to take the case to an independent tribunal. An appeal needs to be made within one calendar month of the date on

the mandatory reconsideration decision letter. If you have missed the one-month deadline, it is still possible to appeal the DWP's decision. The tribunal service will review your appeal submission and make a decision on whether your appeal can go ahead. You would be expected to demonstrate the reasons for submitting a late request.

Her Majesty's Courts and Tribunal Service (HMCTS) review appeals. This service is independent of the DWP. Any information must be submitted directly to the HMCTS.

Details will be on your mandatory reconsideration notice.

REQUESTING AN APPEAL

You can download a copy of the SSCS1 appeal form from the government website www.gov.uk/social-security-child-support-tribunal/appeal-tribunal (England, Scotland and Wales only).

Alternatively, call your local HMCTS and ask for an appeal form to be sent to you by post.

HMCTS CONTACT INFORMATION

England and Wales: 0300 123 1142
(Monday to Friday, 8.30am to 5pm)

Scotland: 0141 354 8400
(Monday to Friday, 8.30am to 5pm)

Northern Ireland: 0300 200 7812



In Northern Ireland, use appeal form NOA1(SS), which you can download from: www.nidirect.gov.uk/publications/appeals-form-noa1ss

The forms will ask for your name, address and, if you have one, details of your chosen representative.

Your representative is someone who can speak about your condition at the tribunal. You do not have to have a representative. It may be that you are representing yourself. If this is the case you can bring along a friend or relative to support you.

There is a section where you can share why you feel you have grounds to appeal. You will be asked the decision date, name of benefit and the outcome. This information can all be found on your mandatory reconsideration notice.

The next section will ask you to state why you feel the decision is incorrect. Explain in your own words why you feel the decision is wrong.

If possible, link back to any medical evidence you have provided to the DWP. For example: 'the report stated I could chop vegetables but my consultant letter stated I have a very weak grip and am unable to hold a knife safely'.

You will be asked if you wish to attend the hearing. There is no pressure to attend and it is completely down to you, but it can be helpful for the tribunal panel if you do go along. If you choose not to or are unable to attend the tribunal, a decision will be made using the evidence you submit.

Make a copy of the form and return it to HMCTS at the address on the form. A copy of the mandatory reconsideration notice also needs to be included.

Once the tribunal service or HMCTS has received the form, you will receive an acknowledgement in the post. HMCTS will then send a letter to DWP informing them of your appeal.

The DWP will write to the HMCTS outlining why they made the decision they did. This will include your original application form and their assessment report. A copy will also be sent to you and, if you have one, your representative.

Your local MP may be able to offer you support, so do let them know your situation and why you are appealing. You can find your MP here: www.parliament.uk/get-involved/contact-your-mp

WAITING FOR THE HEARING

It can take some time to have your appeal heard. We know this wait can be stressful for many people. The length of time depends on where you live and how busy your local service is. It's important that you let HMCTS know of any upcoming appointments or holidays you have booked. It can be quite time-consuming to get an appeal date moved so it's good to avoid this if you can.

While you're waiting for your hearing date to come through, think about any additional people you could approach who could provide additional evidence. You can send information through up until two weeks before the hearing date.

THE HEARING

If you have opted to attend the hearing you will receive a date in the post. Don't worry; the independent tribunal is not like attending a formal court. The venue should be accessible and the clerk of the court will be there to assist you.

If you need support from a carer or family member, they can also attend the tribunal hearing. Please ensure that you arrive promptly and allow additional time to pass through security.

You can bring notes to help you remember everything. It can be helpful to read through the information and highlight key things you want to ensure you get across in the hearing.

Karan, who has Charcot-Marie-Tooth disease, went to a hearing.

"The date of my hearing arrived and I attended the magistrate's court.

"The clerk was there to help me. She talked me through the process and told me whom everyone was. There was a lady there who was to do with my daily living, and a judge and a doctor.

“All of these people are completely independent. They are there to make their own minds up based on the information they have been given. They will all ask you questions about how your disability affects you daily.

“The DWP were there. They only asked me one question. I was also able to share my experience of living with this condition. We were then asked to leave the room whilst a decision was made. This took around five to 10 minutes. We were called back in to receive their decision which I am happy to say went in my favour.”

The tribunal panel is usually made up of three independent people. A solicitor will lead the tribunal. There will be a person with a medical background and a lay person who has some experience of disability. All will introduce themselves to you and your representative.

The DWP can send a presenting officer to put forward their position and challenge the points that you have made in the appeal document. This is standard practice and should not be anything to worry about.

The panel will then ask a series of questions based on what you have put on your form and any additional supporting information you have provided them with. Take your time and don't feel rushed – this is your chance to explain to them how your condition affects you. If you need to pause or take a moment for a drink of water, this is perfectly acceptable and most definitely understandable.

If a DWP presenting officer is there, they will have an opportunity to ask you a few questions. If you have chosen to have a representative, they will also have an opportunity to raise anything they feel may have been missed and challenge any points made by the DWP.

You will be then be asked to leave the room for the tribunal panel to discuss your case. You will either be informed that day of their decision or very soon after your hearing. You will receive a copy of the decision notice and a copy will be sent to the DWP.

If the outcome is in your favour, then the DWP will make the necessary changes and you will start to receive your award. Within a few weeks of the decision being changed, you will also receive any back payment, backdated from the date you made the claim.

If your appeal is unsuccessful, you can request (in writing) a detailed explanation of why this is.

The image features a solid orange background. A horizontal white strip, resembling a piece of torn paper, is positioned in the upper-middle section. The text is centered within this white strip.

ADDITIONAL
ENTITLEMENTS
AND SERVICES

If you are awarded PIP, there are a number of services, entitlements and discounts you may have access to. This is dependent on the rate of PIP and what your local authority offers.

- **Motability scheme**

If you receive the highest rate of the mobility component, the Motability scheme can provide either adapted vehicles or electric wheelchairs/mobility scooters. This is in exchange for some or all of your mobility allowance. Visit Motability's website at www.motability.co.uk to find out the full details of accessing this scheme.

- **Blue Badge**

The Blue Badge is available to those who receive eight points or more under the 'moving around' descriptor of the mobility component, or to those who have obtained 10 points for the 'planning and following journeys' descriptor of the mobility component. You will need to provide evidence of your PIP decision letter when applying for a Blue Badge. Contact your local council to apply.

- **Road tax deductions**

You are eligible for a road tax deduction if you receive the mobility component of PIP. The reduction is 50 percent if you are on the standard rate or 100 percent if you are on the enhanced rate. This exemption begins the next time your vehicle is taxed.

- **Transport**

There are several options to receive reduced travel fares throughout the UK. You may be eligible for a disabled person's railcard that provides a third off train fares. Contact your local council who can provide information on other options that are available locally. Some regions have bus passes that offer reduced rate. If you live in London, you may be eligible for a Freedom Pass that gives free transport around London. Visit www.nationalrail.co.uk to find out more.

- **Severe disablement premiums on Employment and Support Allowance (ESA) and Jobseeker's Allowance**

If you receive the daily living component of PIP you may be eligible for a severe disablement premium. Contact the Jobcentre Plus in order to increase your entitlement. These premiums are being phased out under Universal Credit.

- **Working tax credit**

There are two types of working tax credit that you may be able to get. The first is a disabled worker's element. This is an allowance you can get if you are in employment and currently receiving a qualifying benefit such as PIP.

You may also be entitled to the severe disability element if you or your partner works over 24 hours a week and you're in receipt of the enhanced daily living component of PIP. Contact the Tax Credit Office on 0345 300 3900 for further information and to inform them of any changes.

- **Pension credit**

If you are in receipt of the daily living component of PIP, you may be entitled to a pension credit. You should call the Pension Credit claim line on 0800 99 1234 to discuss this option.

- **Council tax reductions**

You may be entitled to a reduction in your council tax. This reduction varies between councils. It is not entirely dependent on being in receipt of PIP and there are often other criteria to fulfil. Contact your local council to get more information.

- **Housing benefit**

You may be entitled to a premium on your housing benefit if you are in receipt of PIP. Speak to your local council in order to understand what your entitlement to this is.

- **Carer's Allowance**

If you receive PIP, and someone is caring for you for 35 hours or more per week and their income is below the current financial threshold, then they may be entitled to Carer's Allowance. You can find out more about claiming Carer's Allowance by calling the MDUK helpline on 0800 652 6352.

The image features a solid orange background. A white, torn-paper-like shape is cut out from the center, revealing the white background underneath. The text is centered within this white shape.

GETTING
FURTHER
SUPPORT

This section outlines other sources of support to help you through your PIP application.

MDUK'S ADVOCACY TEAM

We support PIP claims through our advocacy service. You can call our helpline on 0800 652 6352 or email info@muscular dystrophyuk.org.

We support anyone diagnosed with a muscle-wasting or associated condition, and anyone who's been diagnosed with one of these conditions but hasn't got a specific diagnosis.

Our team provides over-the-phone advice about the process of application or appeal and can talk you through the process.

We can also provide a letter that outlines some additional details about your condition.

This can help the decision-maker to understand a little more about your experience and eligibility for PIP.

OTHER SOURCES OF SUPPORT

- **Citizens Advice**
www.citizensadvice.org.uk
- **Carers UK helpline**
advice@carersuk.org
- **Independent Case Examiner (for complaints)**
www.ind-case-exam.org.uk

We hope you have found this guide useful. If we can offer any further support please do not hesitate to contact us.

References

The Social Security (Personal Independence Payment) Regulations 2013 and The Social Security (Personal Independence Payment) Regulations 2017

The Social Security (Personal Independence Payment) Regulations 2013;
< www.legislation.gov.uk/ukdsi/2013/9780111532072/contents>

The Social Security (Personal Independence Payment) Regulations 2017;
< www.legislation.gov.uk/ukdsi/2017/194/pdfs/uksi_20170194_en.pdf>

**Muscular
Dystrophy UK**

Fighting muscle-wasting conditions



EVERY DAY COUNTS WHEN YOU'RE LIVING WITH A MUSCLE-WASTING OR ASSOCIATED CONDITION.

With over 70,000 people in the UK living with these conditions, MDUK is urgently searching for treatments and cures to improve lives today and transform those of future generations. Together, we're pressing for faster access to potential treatments and we're driving change to see better care and support to help people stay active, independent and connected.

We understand that muscle-wasting and associated conditions can change everything. That's why we're here for anyone who is affected, right from the moment of diagnosis and beyond. We're here to help people take back some control of their lives and to live well with the condition.

We understand the everyday challenges of muscle-wasting and associated conditions, so we're here with information and advice, together with emotional and practical support, a network of local groups and an online community.

www.musculardystrophyuk.org

TO FIND OUT MORE GO TO:

Helpline: 0800 652 6352

Research Line: 020 7803 4813

info@musculardystrophyuk.org

Muscular Dystrophy UK, 61A Great Suffolk Street, London SE1 0BU

Registered Charity No. 205395 and Registered Scottish Charity No. SC039445