

Guides you can trust

# The Best Possible

Personal Independence Payment (PIP) Claims and Reviews on Physical Health, Mental Health and Learning Difficulties Grounds

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### Introduction

Personal Independence Payment (PIP) began replacing Disability Living Allowance (DLA) for working age claimants from 8th April 2013. The assessment for PIP of all current working age DLA claimants was due to be completed by mid 2019. However, the redeployment of Department for Work and Pensions (DWP) staff to the correction of existing PIP awards has led to a delay in the migration of existing DLA claims. This is now due to be completed in 2020-21.

The government initially claimed that the introduction of PIP would ensure that resources are targeted where they are most needed. They also clearly stated, however, that one of the intentions behind the introduction of PIP was to reduce the cost of the current benefit by around 20%.

The DWP's initial estimates were that, once all current working age DLA recipients have been reassessed for PIP:

- 29% will have had their award increased
- 15% will remain unchanged
- 29% will have had their award decreased
- 26% will have no award at all

This means that the DWP expected 55% of all current working age DLA claimants to be worse off under PIP.

In reality, six years after the introduction of PIP, an Office of Budget Responsibility <u>report</u> in January 2019 estimated that the implementation of the new benefit had led to an increase in costs of between 15-20%. See the new story on this: <u>DWP's PIP disaster, costs have gone up instead of down.</u>

### PIP vs. DLA – similarities and difference

Like DLA, PIP is not means-tested, doesn't require National Insurance contributions, can be claimed whether you are working or not, is non-taxable and acts as a passport to other benefits and premiums.

Like DLA, PIP is divided into two components: a daily living component and a mobility component.

Unlike DLA, each component has only two rates, a lower paying standard rate and a higher paying enhanced rate – DLA has three rates to the care component.

Unlike DLA, PIP awards are based on a points system, meaning that the method of assessment has more in common with Employment and Support Allowance (ESA) than with DLA.

Like DLA, there are special rules that apply to people with a terminal illness.

Like DLA, PIP can give some claimants access to the Motability scheme and automatic entitlement to a Blue Badge.

Unlike DLA, the vast majority of awards are intended to be time limited – the majority will be for between two years and five years. So most PIP claimants can expect to have regular reassessments for as long as they remain on the benefit. Two exceptions to this are PIP claimants of State pension age and those with the most severe, lifelong conditions who receive the highest

level of support. Recent changes will mean that these groups will receive an ongoing award with a 'light touch' review every 10 years.

Like DLA, people who qualify for the benefit before they reach State Pension age can continue receiving it beyond this date provided they still meet the eligibility conditions.

# **Basic qualifying conditions**

Like DLA, PIP is a non-means tested benefit. You do not have to have paid National Insurance contributions to be awarded PIP and you can receive it whether you are in work or not.

#### Age limits

To qualify for PIP initially, you need to be aged between 16 and State Pension age. As state retirement age increases over time, the age at which you will be able to make a claim for PIP will also increase. You can check your State Pension age <u>here</u>.

People who receive PIP before they reach State Pension age will go on being able to receive it once they are over this age.

#### **Qualifying period**

For PIP, you need to have had your current level of needs for at least three months and be likely to continue having them for a further nine months. The three months test does not apply if you are transferring from DLA to PIP. Other exceptions are detailed below, in 'Linking rules' and 'Terminal illness'.

#### Linking rules

If you have claimed PIP in the past and then stopped because of an improvement or remission in your condition, you may be covered by the linking rules if you need to claim again.

If you are under State Pension age and need to reclaim PIP within **two years** of a previous award ending, then you do not need to serve the 3 month qualifying period. This only applies where your claim:

- is for the same component you received before;
- is based on substantially the same health condition or conditions; or
- is based on a condition which developed from the original condition; and
- you still meet all the other qualifying criteria, such as scoring enough points in the assessment and being likely to have your needs for at least nine months.

If you are over State Pension age, then the same linking rules apply, but the claim must be made within **one year** of your previous award ending.

#### **Terminal illness**

As with DLA, claimants whose death can reasonably be expected within six months automatically qualify for the enhanced rate of the daily living component of PIP without needing an assessment or needing to meet the qualifying period.

In these circumstances you also do not need to meet the qualifying period in relation to the mobility component of PIP, but you will still need to meet the other qualifying conditions.

#### Hospitals, care homes and prisons

PIP is suspended for people in prison after 28 days, with two periods less than a year apart being linked.

For residents of care homes where all or part of the costs are met from public funds, the daily living component of PIP ends after 28 days, but the mobility component will continue to be paid. If the costs are funded by the NHS then you will be treated as a hospital in-patient (see below)

After 28 days, neither component of PIP is payable to in-patients in hospital. You need to inform DWP of any stays in hospital. If you have a Motability vehicle, you need to contact Motability as soon as you know you are likely to be in hospital for more than 28 days to discuss your options based on your individual circumstances.

The above rules do not apply if you are funding your stay in a care home, either directly or under a 'deferred payment' agreement. Nor do they apply if you went into hospital when you were less than 18 years old, or if you are terminally ill.

You continue to have an underlying entitlement to PIP during periods in a hospital or care home, so that payment can be started again immediately when you leave, providing all the other qualifying conditions are still met.

#### Habitual residence and presence

To make a claim for PIP you need to be present in Great Britain, and habitually resident in the Common Travel Area which is the United Kingdom, the Channel Islands, the Isle of Man and the Republic of Ireland. Members of the armed forces and their families are treated as habitually resident in Great Britain whilst serving abroad.

In addition, a 'past presence' test means you need to have spent at least two out of the last three years – 104 out of the last 156 weeks - in Great Britain. Where you are accepted as terminally ill the past presence test doesn't apply.

The 2 year rule may not apply in some cases, including where you currently live, or have lived, in the European Economic Area or Switzerland. In some circumstances you may need to demonstrate 'a genuine and sufficient link to the UK social security system' which may include issues like having spent years living in the UK, worked here, or you or someone you depend upon is getting a benefit that can only be received through having paid UK national insurance contributions.

For more information, in the first instance you can contact:

Exportability Team Coordinator <u>exportability.team@dwp.gov.uk</u> (or complete the online form in link below) Exportability Team Room B215 Pension, Disability and Carers Service Warbreck House Warbreck Hill Road Blackpool FY2 0YE

https://www.gov.uk/claim-benefits-abroad/disability-benefits

If you are not happy with the response you receive you will need to try to get advice from a specialist welfare rights adviser.

#### Going abroad

You can be temporarily absent abroad for up to thirteen weeks whilst in receipt of PIP.

If you are abroad for medical treatment, this period can extend to 26 weeks unless you are a hospital patient abroad and your stay is fully funded by the NHS.

#### Length of awards

All PIP awards are for a fixed period, except in exceptional circumstances.

Short-term awards of up to two years are given where your condition is expected - by the DWP - to improve significantly.

Awards of 5-10 years are made where changes in your condition are possible but less likely.

In summer 2018, the DWP announced that claimants who are awarded the highest level of award under PIP - and who have severe or progressive conditions where their needs are expected to stay the same or increase - will receive an ongoing award of PIP with a 'light touch' review every ten years. This policy was extended to PIP claimants over State Retirement age in early 2019.

A claim can be checked at any time while the award is still in force, to verify that there has been no change of circumstances.

#### What happens to young people at the age of 16

Outside Scotland, five months before a young person who is getting DLA turns 16, their parent or guardian will be contacted to tell them about the change in benefits from DLA to PIP. They will also be asked whether the young person will need an appointee and what their preferred method of communication is.

When the young person reaches 16 they will be contacted themselves and told they need to apply for PIP. Provided the young person makes a claim for PIP their DLA award will continue beyond their sixteenth birthday, until a decision has been made on their entitlement to PIP.

This process will not apply if the young person is in hospital. When they are discharged they will have to make a claim for PIP.

The DWP says that, if they are initially unsuccessful in getting a response, they will make 'a number of attempts to engage the young person in the claiming process.'

In Scotland, young people who are getting DLA and who are 16 on September 1st 2020 will not have to apply for PIP until their 18<sup>th</sup> birthday. 16 to 18 year olds will still have the choice to apply for PIP up until the Scottish government launches its replacement for PIP, currently due in 2021.

If you are awarded daily living component someone who cares for you might be able to claim Carers Allowance. Sometimes this can be a very complicated area. See our guide *'I've Been Awarded PIP – What Else Can I Claim?'*.

### **PIP** components, rates and scores

PIP has two components:

- daily living component
- mobility component

Each component has two rates:

- standard rate
- enhanced rate

Claimants who are assessed as having:

• 'limited ability to carry out daily living activities' (minimum score 8 points) are paid the standard rate of the daily living component, currently £59.70

- 'severely limited ability to carry out daily living activities' (minimum score 12 points) are paid the enhanced rate of the daily living component, currently £89.15
- 'limited ability to carry out mobility activities' (minimum score 8 points) are paid the **standard** rate of the mobility component, currently £23.60
- 'severely limited ability to carry out mobility activities' (minimum score 12 points) are paid the enhanced rate of the mobility component, currently £62.25.

#### Daily living activities

The decision about whether you are entitled to the daily living component, and if so at what rate, is based on the number of points you score in total for the following activities:

- 1. Preparing food
- 2. Taking nutrition
- 3. Managing therapy or monitoring a health condition
- 4. Washing and bathing
- 5. Managing toilet needs or incontinence
- 6. Dressing and undressing
- 7. Communicating verbally
- 8. Reading and understanding signs, symbols and words
- 9. Engaging with other people face-to-face
- 10. Making budgeting decisions

Each of these activities is divided into a number of point scoring descriptors. To get an award of the daily living component, you need to score:

8 points for the standard rate

12 points for the enhanced rate

You can only score one set of points from each activity, if two or more apply from the same activity only the highest will count. So, for example, if:

4 d. Needs assistance to be able to wash either their hair or body below the waist. 2 points

4 f. Needs assistance to be able to wash their body between the shoulders and waist. 4 points

both apply, you will receive only the 4 points for the 'between the shoulders and waist' activity. These can then be added to points for other activities, such as 'Dressing and undressing'

#### Mobility activities

The decision about whether you are entitled to the mobility component, and if so at what rate, is based on the number of points you score in total for the following activities:

- 1. Planning and following journeys
- 2. Moving around

Both of these activities are divided into a number of point scoring descriptors. To get an award of the mobility component you need to score:

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

As with daily living above, you only score the highest points that apply to you from each activity, but you can add points from mobility activities 1 and 2 together to reach your final total.

## Activities and descriptors in brief

#### Daily living activities

#### 1. Preparing food.

a. Can prepare and cook a simple meal unaided. 0 points.

b. Needs to use an aid or appliance to be able to either prepare or cook a simple meal. 2 points.

c. Cannot cook a simple meal using a conventional cooker but is able to do so using a microwave. **2** points.

d. Needs prompting to be able to either prepare or cook a simple meal. 2 points.

e. Needs supervision or assistance to either prepare or cook a simple meal. 4 points.

f. Cannot prepare and cook food. 8 points.

#### 2. Taking nutrition.

a. Can take nutrition unaided. 0 points.

b. 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 points.

c. Needs a therapeutic source to be able to take nutrition. 2 points.

d. Needs prompting to be able to take nutrition. 4 points.

e. Needs assistance to be able to manage a therapeutic source to take nutrition. 6 points.

f. Cannot convey food and drink to their mouth and needs another person to do so. 10 points.

#### 3. Managing therapy or monitoring a health condition.

a. Either –

(i) does not receive medication or therapy or need to monitor a health condition; or

(ii) can manage medication or therapy or monitor a health condition unaided. 0 points.

b. Needs any one or more of the following -

(i) to use an aid or appliance to be able to manage medication;

(ii) supervision, prompting or assistance to be able to manage medication.

(iii) supervision, prompting or assistance to be able to monitor a health condition. **1 point.** 

c. Needs supervision, prompting or assistance to be able to manage therapy that takes no more than 3.5 hours a week. **2 points.** 

d. Needs supervision, prompting or assistance to be able to manage therapy that takes more than 3.5 but no more than 7 hours a week. **4 points.** 

e. Needs supervision, prompting or assistance to be able to manage therapy that takes more than 7 but no more than 14 hours a week. **6 points.** 

f. Needs supervision, prompting or assistance to be able to manage therapy that takes more than 14 hours a week. **8 points.** 

#### 4. Washing and bathing.

a. Can wash and bathe unaided. 0 points.

b. Needs to use an aid or appliance to be able to wash or bathe. 2 points.

c. Needs supervision or prompting to be able to wash or bathe. 2 points.

d. Needs assistance to be able to wash either their hair or body below the waist. 2 points.

e. Needs assistance to be able to get in or out of a bath or shower. 3 points.

f. Needs assistance to be able to wash their body between the shoulders and waist. 4 points.

g. Cannot wash and bathe at all and needs another person to wash their entire body. 8 points.

#### 5. Managing toilet needs or incontinence.

a. Can manage toilet needs or incontinence unaided. 0 points.

- b. Needs to use an aid or appliance to be able to manage toilet needs or incontinence. 2 points.
- c. Needs supervision or prompting to be able to manage toilet needs. 2 points.
- d. Needs assistance to be able to manage toilet needs. 4 points.

e. Needs assistance to be able to manage incontinence of either bladder or bowel. **6 points.** f. Needs assistance to be able to manage incontinence of both bladder and bowel. **8 points.** 

#### 6. Dressing and undressing.

a. Can dress and undress unaided. 0 points.

b. Needs to use an aid or appliance to be able to dress or undress. 2 points.

c. Needs either -

(i) prompting to be able to dress, undress or determine appropriate circumstances for remaining clothed; or

(ii) prompting or assistance to be able to select appropriate clothing. 2 points.

d. Needs assistance to be able to dress or undress their lower body. 2 points.

e. Needs assistance to be able to dress or undress their upper body. 4 points.

f. Cannot dress or undress at all. 8 points.

#### 7. Communicating verbally.

a. Can express and understand verbal information unaided. 0 points.

b. Needs to use an aid or appliance to be able to speak or hear. 2 points.

c. Needs communication support to be able to express or understand complex verbal information. **4 points.** 

d. Needs communication support to be able to express or understand basic verbal information. **8 points.** 

e. Cannot express or understand verbal information at all even with communication support. **12 points.** 

#### 8. Reading and understanding signs, symbols and words.

a. Can read and understand basic and complex written information either unaided or using spectacles or contact lenses. **0 points.** 

b. Needs to use an aid or appliance, other than spectacles or contact lenses, to be able to read or understand either basic or complex written information. **2 points.** 

- c. Needs prompting to be able to read or understand complex written information. 2 points.
- d. Needs prompting to be able to read or understand basic written information. 4 points.

e. Cannot read or understand signs, symbols or words at all. 8 points.

#### 9. Engaging with other people face-to-face

a. Can engage with other people unaided. 0 points.

b. Needs prompting to be able to engage with other people. 2 points.

c. Needs social support to be able to engage with other people. 4 points.

d. Cannot engage with other people due to such engagement causing either -

(i) overwhelming psychological distress to the claimant; or

(ii) the claimant to exhibit behaviour which would result in a substantial risk of harm to the claimant or another person. **8 points.** 

#### 10. Making budgeting decisions.

a. Can manage complex budgeting decisions unaided. 0 points.

b. Needs prompting or assistance to be able to make complex budgeting decisions. 2 points.

c. Needs prompting or assistance to be able to make simple budgeting decisions. 4 points.

d. Cannot make any budgeting decisions at all. 6 points.

#### Mobility activities

#### 1. Planning and following journeys.

a. Can plan and follow the route of a journey unaided. **0 points.** 

b. Needs prompting to be able to undertake any journey to avoid overwhelming psychological distress to the claimant. **4 points.** 

c. Cannot plan the route of a journey. 8 points.

d. Cannot follow the route of an unfamiliar journey without another person, assistance dog or orientation aid. **10 points.** 

e. Cannot undertake any journey because it would cause overwhelming psychological distress to the claimant. **10 points.** 

f. Cannot follow the route of a familiar journey without another person, an assistance dog or an orientation aid. **12 points.** 

#### 2. Moving around.

a. Can stand and then move more than 200 metres, either aided or unaided. **0 points.** 

b. Can stand and then move more than 50 metres but no more than 200 metres, either aided or unaided. **4 points.** 

c. Can stand and then move unaided more than 20 metres but no more than 50 metres. 8 points.

d. Can stand and then move using an aid or appliance more than 20 metres but no more than 50 metres. **10 points.** 

e. Can stand and then move more than 1 metre but no more than 20 metres, either aided or unaided. **12 points.** 

f. Cannot, either aided or unaided, -

(i) stand; or

(ii) move more than 1 metre. 12 points.

### Timetable for introduction of PIP

At first, PIP was rolled out gradually to different areas of the country, but since April 2013 all new claims for disability benefit for people between 16 and 64 are PIP rather than DLA.

In addition, in a reassessment process due to finish in 2020-21, all current DLA claimants have been asked to claim PIP instead of DLA unless:

you are under 16 – outside Scotland, you will begin the transfer process once you reach 16, in Scotland from September 2020 you can wait until your 18<sup>th</sup> birthday;

you were born on or before 8 April 1948 – you will continue to receive DLA for as long as you are eligible, because you were aged 65 or over when PIP was introduced on 8 April 2013.

You can be contacted at any time and required to claim PIP. This includes if you have a long-term award of DLA or an indefinite award with no end date.

Contact the <u>Disability Benefits helpline</u> if your DLA payment is due to end in less than 4 weeks and you haven't received a letter about making a new claim. Your payment may stop if you don't.

You'll continue to get DLA until DWP writes to you to tell you when it will end. The process of deciding who to contact appears to be entirely random, so there's no way of telling at what point you might get a letter.

It is expected that all existing DLA claimants will have been invited to claim PIP by 2020-21.

### How you will be transferred from DLA to PIP

If you currently get DLA, when you are selected for transfer you will be contacted and told that you must make a claim for PIP or your benefit will stop. You will have 28 days from the date on the notification letter in which to make your initial claim by telephone, or complete your paper claim form and return it to the DWP.

The decision maker can extend the 28 day period by any length of time they think fit if, for example, you have had to go into hospital.

If you have not made a claim within 28 days and there has been no extension, your DLA will be suspended for four weeks. If you make a claim within this additional four weeks the suspension will be lifted.

If you have still not made a claim for PIP at the end of the eight weeks, your DLA award will be terminated from the date on which it was suspended.

So long as a claim for PIP has been made in the eight week period, your DLA will continue to be paid until a decision has been made on whether you are entitled to PIP.

Whether the decision is to award you PIP or not, the decision will not take effect for four weeks after your next DLA pay day. The DWP say this is to allow time for people whose income is reduced to make adjustments.

However, if you are asked to provide further information – for example by completing a questionnaire - or attend an interview or medical in the course of your claim and fail to do so, your DLA award will end 14 days after the decision that you failed to do as required.

You can also voluntarily decline, in writing or by telephone, to make a claim for PIP. In this case, your DLA claim will end 14 days after you tell the DWP you do not want to claim PIP. This will only apply if you were informed before you declined to claim, that if you did so your DLA award would end.

If you withdraw a claim for PIP part way through the process, your DLA award will end 14 days after the day on which you withdrew your PIP claim.

### How to make a claim for PIP

For most, though not all, people, making a claim for PIP will involve:

- completing a PIP1 Personal Independence Payment claim form, initially by phone.
- completing a PIP2 How your disability affects you form.
- having a face-to-face assessment with a health professional. This will be carried out by a company appointed by the DWP, either Capita or Independent Assessment Services (formally known as Atos Healthcare), depending on where you live. N.B. For three months from 17 March 2020, all face-to-face assessments have been suspended due to coronavirus. As of July 30th 2020 this suspension is still currently in force.

### PIP1 form

Your initial claim for PIP will usually be made by telephone to:

Telephone: 0800 917 2222

Textphone: 0800 917 7777

#### Paper claim form

If you are unable to use the telephone to make a claim you can ask for an 20 page paper claim form – a PIP1 instead.

However, we have heard from a number of people who have been refused paper claim forms in the past. If you do need a paper form, make it clear that you are asking for one in connection with your health condition or disability and that you are legally entitled to request a paper form as a reasonable adjustment under the Equality Act 2010.

Details of how to make an initial claim and request different formats are available on the .gov website:

#### https://www.gov.uk/pip/how-to-claim

#### Initial claim process

The initial claim process collects basic information about you and about whether you have one of the following conditions:

- mental health condition
- behavioural condition
- learning difficulty
- developmental disorder
- memory problem

To see in detail what questions are asked at the initial claim stage, you can download a specimen copy of the PIP1 form from the DWP website <u>here</u>. This form should not be used to start your claim for PIP; you should call the DWP to obtain a barcoded, personalised form.

It is worth spending some time preparing for the telephone interview to try to ensure you have all the necessary information to hand. This will include:

- your National Insurance number
- your address
- your date of birth
- your bank or building society details
- your telephone number
- the name of your doctor or health worker you want the DWP to contact
- details of any time you've spent out of the country
- details if you're in a care home or hospital, or if you've recently been in a care home or a hospital
- whether you have a terminal illness.

### 'How your disability affects you' form

Following receipt by the DWP of the initial claim, most people will be sent a 'How your disability affects you' form to complete.

The form, including an accompanying tear-off letter, is 36 pages long and there is also an information booklet which is 12 pages long.

The form collects details about:

- which professionals you see
- your health conditions or disabilities
- your medication and treatment

There are then a series of questions about each of the daily living and mobility activities, including asking about any aids or adaptations you use, whether you can complete the activities safely, to an acceptable standard, repeatedly and in a reasonable time and how your condition varies. The questions are accompanied by detailed guidance about the kind of information you need to provide.

You are also encouraged to send supporting medical evidence such as prescription lists, care plans and information from health professionals and/or to tell the DWP who they can get supporting evidence from.

In addition, you can supply non-medical evidence, such as a letter from your social worker or a friend or relative who helps you carry out everyday activities.

You can download a specimen copy of the 'How your disability affects you' form and accompanying booklet from the DWP website <u>here</u>. This form should not be used to make your claim for PIP; you will receive a barcoded, personalised form when you register your claim.

We cover completing this form in detail in the rest of this guide.

#### If the form is not returned

If you do not return the form within the time limit and you do not have good cause for the delay, your claim will be refused. When deciding whether you have good cause the decision maker must take into account your state of health at the time and the nature of any disability you have.

However, if you do not return the form and you have been identified from your initial claim as having a 'mental or cognitive impairment' then Independent Assessment Services and Capita have been told that they must still make an assessment, either by collecting additional evidence – which might including telephoning you – and/or by asking you to attend a medical. The evidence will then be passed to the decision maker in the normal way.

#### Will you have to have a face-to-face medical assessment?

N.B. All PIP face-to-face assessments have been suspended for three months from 17 March 2020, due to coronavirus. As of 2 November 2020 this suspension is still currently in force. Claimants will have a paper assessment or a telephone assessment instead.

Once the form - and any additional evidence you include - has been returned, the health professional must review it and decide if they should send for any further evidence.

When they have all the evidence they consider that they need the health professional has to decide what sort of assessment to carry out. This may be based just on the paper information, based on the paper information plus a telephone call to you or by requiring you to attend a face-to-face assessment.

#### **Paper-based assessments**

Unlike for ESA, the health professional can decide not to call you in even if they are going to assess you as scoring zero points. Guidance from the DWP states that paper based assessments are appropriate in:

- Cases where the evidence indicates that it is unlikely that the claimant's condition has any impact on any of the daily living and mobility activities.
- Cases where the evidence indicates that the claimant's condition has a significant impact in many of the daily living and mobility activities.
- Cases where there is a strong evidence on which to advise on the case and where a face-toface consultation is likely to be stressful to the claimant.

However, during the coronavirus crisis, there are likely to be more paper-based assessments carried out.

The DWP will send all the papers relating to your PIP claim to whoever carries out PIP assessments for the area where you live – either Capita or Independent Assessment Services. They will decide whether to carry out a paper or phone assessment.

If they decide to carry out a paper assessment this means that they will consider all the written evidence that has been submitted. This could include not just the evidence you have submitted, but any written evidence obtained from elsewhere e.g. your doctor, your nurse, social services etc.

They may also consider previous claim forms, although these will be of limited value given how old they are likely to be. There have been instances of them obtaining copies of your Work Capability Assessment.

Rather confusingly, the assessor might carry out a paper assessment, but need to phone you to clarify some issues. This is not a phone assessment. You should be able to tell as they will not ask you in detail about all the PIP activities. In addition, unlike a phone assessment, they are not required to give you 7 days' notice of the call.

#### **Telephone assessments**

Because of the coronavirus crisis, at the time of writing (April 2020), there are no face-to-face assessments and the majority of assessments that are carried out will be telephone assessments.

There is detailed information about telephone assessments during the coronavirus crisis later in this guide.

#### Face-to-face assessments

The majority of claimants will have to attend a face-to-face assessment with a health professional working for Independent Assessment Services or Capita, depending on where you live.

You must be given 7 days' notice of the date, time and, in the case of a face-to-face assessment, place of the assessment. The notice must be in writing unless you have agreed to accept communication by another means, such as text or email. The 7 days will not apply if you have agreed, in writing or otherwise, to accept a shorter notice period.

Once an assessment has been made, a decision maker then considers all the evidence, including any additional medical evidence obtained by you, before making a decision about how many points should be awarded for each component. The number of points will determine whether you are eligible for an award of PIP and, if so the components and rates.

There's more about face-to-face assessments later in this guide.

# Completing the form – what you need to know before you begin

This is your opportunity to give a detailed and accurate explanation of how your condition affects you in relation to the points scoring activities. So, you need to complete the form in as much detail as you can.

It's definitely worth using additional sheets if you can't fit everything you want to say in the boxes on the form. Make sure you include your name and National Insurance number on the top of every additional sheet you use and, if possible, staple them to the back of the questionnaire.

### Keep a claim file

A claim file is just a folder, or a ring binder, in which you keep notes and copies of everything to do with your PIP claim, but it can save you months of frustration and lost benefits if the DWP either lose or shred your records.

What to keep in your claim file.

#### 1 Keep a photocopy of everything you send the DWP

Most especially, keep a photocopy of your completed claim form and keep it safe. We do know how difficult and expensive this can be, but if you don't you may regret it because:

- Your claim form may be lost by the DWP it does happen.
- Even if your claim is successful the award will be for a limited period, and you'll have to reapply for PIP towards the end of that period.
- If you're not happy with the result of your claim it will be harder to challenge the decision effectively without a copy of your original form, although you should receive a copy if you reach the appeal stage.

#### 2 Keep every letter you receive from the DWP

Put them all in a folder in date order along with copies of letters you've sent them. (We had one client who was able to claim thousands of pounds in backdated benefits because he had kept copies of letters right from the beginning of his claim).

#### 3 Keep a note of any phone calls to or from the DWP

Ask for the name of anyone you speak to and keep a note of it, along with the date and the subject of the call.

Try not to feel embarrassed or awkward about this as DWP staff are used to giving their names. In the very unlikely event that anyone refuses to give you at least their first name and the section they work on, ask to speak to their Supervisor.

At the end of this guide you will find a Claim file record sheet which you can use for making a note of calls and letters.

### Physical and mental health

When you complete the form you need to give details of any problems you have with each activity as a result of any physical and/or mental health conditions and learning difficulties. You should also include any problems caused by the effects of any medication you take.

One possible exception to this is the moving around descriptor, which the DWP says is about your physical difficulties with standing and then walking. Nonetheless, at this early stage in the development of PIP we would consider including mental health issues even in relation to this activity if they seem to you to be relevant.

### 'Reliably' - the most important PIP word

It's vital that, before you complete your form, you understand that just because you can carry out an activity, that doesn't mean you are prevented from scoring points for being unable to do it.

Guidance issued by the DWP states that you need to be able to complete an activity 'reliably' in order for it to apply. According to the guidance, 'reliably' means whether you can do so:

• Safely – in a fashion that is unlikely to cause harm to themselves or to another person. (See the 'Safety and supervision' section immediately below for more on this).

• To a necessary and acceptable standard – given the nature of the activity.

• Repeatedly – as often as is reasonably required.

• In a reasonable time period no more than twice as long as a person without a physical or mental health condition would take to carry out the activity.

Initially, the government refused to put this guidance into the regulations themselves. But after considerable pressure it has been incorporated, although the word 'reliably' itself has not been included. (See: 'General definitions you need to know' for the regulations on this).

The DWP guidance also states that 'pain, fatigue, breathlessness, nausea and motivation' will all be 'key factors' in deciding whether an activity can be done reliably.

So, for example, if you can 'wash and bathe unaided' you will not score any points for that activity. But if it takes you hours to do so or it would be dangerous to leave you alone to bathe – for example, because you might have a seizure - then you may score points.

Or if you could walk 20 metres once, but afterwards you would be so exhausted that you could not do so again for hours or you would be unable to carry out other everyday activities after walking 20 metres, then you may count as not being able to do so.

Or if you can walk, but only in considerable pain, you may be able to score more points than you think. Let's say you are someone who walks over 50 metres only by pushing through the pain, for example because you want to stay as active and independent as possible. Because the meaning of 'reliably' includes 'to an acceptable standard', you may be able to score points for walking 50 metres or less by showing that the distance you walk in considerable pain does not count as walking 'to an acceptable standard.

Or possibly you are able to feed yourself from a plate, but because of your condition you drop considerable quantities of food on yourself and on the floor, then it may be considered that you are cannot convey food and drink to your mouth to an acceptable standard and so should score points.

Decisions about issues such as what is safe, what is a reasonable time and a good enough standard are subjective ones. All you can do is give as much detailed evidence as you can and, if you are not happy with the decision, consider an appeal.

### Safety and supervision

Until now, the DWP have argued that a claimant can only score points for being unsafe if harm is likely to occur on more than 50% of the occasions on which they attempt an activity.

So a claimant with epilepsy who has seizures twice a week would not get points for needing supervision when cooking. This is because they could not show that it is 'more likely than not' that they will have a seizure on any given occasion when they prepare food.

However, on 9 March 2017, in [2017] AACR 32ws a panel of Upper Tribunal judges held that the DWP were wrong.

Instead, they said, the decision maker should look at whether there is a real possibility that harm might occur and also at how great the harm might be. The greater the potential harm, the less likely it needs to be that it would happen on any specific occasion.

So, if there is a real possibility that a claimant with epilepsy might have a seizure whilst cooking then then they reasonably require supervision for this activity, even though the chances of a seizure happening on any specific occasion may be quite small.

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They should score points for needing supervision even if they don't actually have anyone to provide it.

In the same way, someone who is deaf may be unable to hear a smoke alarm if a fire starts when they are bathing and so may reasonably require supervision.

But the Upper Tribunal went even further than this.

They ruled that where a claimant is at risk all the time, then they may also be at risk when carrying out PIP activities that do not carry any additional likelihood of harm.

So, a claimant may not be at any additional risk of harm if they have a seizure when using the toilet or taking medication, for example. But, because they are at risk whatever they are doing, then we would argue that they still reasonably require supervision during these activities, because they cannot do them safely without supervision.

#### Safety and supervision for daily living activities

Activities 1-5 all have points for needing supervision.

Other activities such as activity 6 'Dressing and undressing', don't have points for needing supervision, but in that case you may be able to argue that you cannot do them safely at all.

This decision may allow you to score additional points in relation to daily living activities if, because of a mental or physical health condition or learning difficulty you, for example:

- need someone with you in case you fall, especially if you have a condition such as osteoporosis, so that the result of a fall could be very serious;
- have angina, diabetic or asthma attacks and need someone with you to help administer your spray or other medication;
- sometimes get angry or distressed when left alone and may endanger yourself by smashing things or hitting out at chance callers;
- can experience a change in your condition without your being aware of it and, for example, you may become very high or very low and become a danger to yourself or others;
- do things like leaving the cooker on, leave taps running, put cigarettes down and forget about them, leave doors and windows open or wander off;
- take overdoses or harm yourself in some other way;
- become distracted by obsessive thoughts, the need to perform ritual actions or by hearing voices, so that you can become dangerously distracted when doing things such as handling sharp knives.

Legally, for PIP, supervision is only to protect you from danger, not other people. So, if you pose a danger to other people then you may score points for not being able to do that activity safely at all, even with supervision.

#### Giving evidence about safety and supervision for daily living activities

Where you might be at additional risk because of the nature of an activity, such as preparing food or bathing, you can give details in the 'Extra information' section for that activity.

For example, can you give examples of dangerous or distressing things that have happened to you when you have not had supervision?

Or how danger has been avoided because you did have supervision?

Can you give examples of the ways in which having someone with you might make you less likely to come to harm? What can they say or do or prevent you doing?

Have you ever been admitted to a hospital as a voluntary patient or on a compulsory section because it was not safe for you to be left alone?

Where there is no additional risk from that activity, but you are always at risk because of your condition, you can write something like:

'Because I have seizures which can be life-threatening, I require supervision at all times, including when I am dressing and undressing.'

#### Safety and supervision for mobility

The Upper tribunal held that the same arguments apply to the 'Planning and following journeys' - called 'Going out' in the PIP claim form - mobility activity, though not to the 'Moving around' activity.

The Upper Tribunal has ruled that you will not score points for 'planning and following journeys' if the only help you need is to communicate with people you meet along the journey (DA v SSWP [2015] UKUT 344 (AAC) ).

Guidance issued to DWP decision makers argues that people who have a seizure and need time to recover afterwards should not score points on this basis for daily living activities, as they can make themselves safe at home.

However, the guidance goes on to say that points may be scored for needing time to recover from a seizure outdoors because it may not be possible for the claimant to make themselves safe.

### Gaining and losing points for aids and appliances

Aids and appliances are very important in relation to PIP and you should give details of any you rely upon when completing your claim form. This does not just include specialised disability aids and appliances but also everyday ones, such as electric can openers or food processors.

Needing to use aids and appliances can result in your being awarded points for PIP, but their theoretical use can also lead to you losing points. This can happen where you say that you cannot carry out an activity, or cannot do so without help from another person, but the decision maker argues that you would be able to do the activity without help if you used an aid or appliance.

The definition given in the legislation is as follows:

"aid or appliance"-(a) means any device which improves, provides or replaces your impaired physical or mental function; and (b) includes a prosthesis.

Aids and appliances that you normally use will be taken into account and also those which you could 'reasonably be expected' to wear or use – even if you don't.

DWP guidance goes on to say that:

"Whether use of an aid or appliance could 'reasonably be expected' will reflect issues of availability, cost and cultural considerations. For example, it might be reasonable to expect someone to use adapted cutlery or a walking stick, but it would not be reasonable to expect them to use a therapeutic source for feeding or a wheelchair."

Although the legislation only refers to aids and appliances, the guidance issue by the DWP refers to a some items that most people would consider to be adaptations, such as a 'single lever arm taps' and a 'bath rail'. So, if you have had adaptations made to your home which are relevant to the PIP activities, it may be worth including details in your claim form.

#### Losing points

When deciding whether it is reasonable to expect you to use an aid or appliance that you don't currently use, but which would mean you could carry out an activity, Capita and Independent Assessment Services are told by the DWP to take into account whether:

- The claimant possesses the aid or appliance.
- The aid or appliance is widely available.
- The aid or appliance is available at no or low cost.
- It is medically reasonable for them to use an aid or appliance.
- The claimant was given specific medical advice about managing their condition, and it is reasonable for them to continue following that advice.
- The claimant would be advised to use an aid or appliance if they sought advice from a professional such as a GP or occupational therapist.
- The claimant is able to use and store the aid or appliance.
- The claimant is unable to use an aid or appliance due to their physical or mental health condition for example, they are unable to use a walking stick or manual wheelchair due to a cardiac, respiratory, upper body or mental health condition.

#### Gaining points

In order to score points for aids and appliances you will have to show that you need to use them because of your impairment, rather than just preferring to use them because they are convenient.

It is possible to score 8 points or more towards daily living component solely on the basis of points for aids and appliances.

Nevertheless, it is worth considering how many points you can get due to use of aids and appliances. For example, if you have arthritis in your hands and shoulders, you might well score points for use the following:

- An auto chopper for chopping vegetable, which might attract 2 points for 1 b). Needs to use an aid or appliance to be able to either prepare or cook a simple meal.
- Easy grip cutlery to eat with, which might attract 2 points for 2 b)(i) Needs to use an aid or appliance to be able to take nutrition.
- A flannel strap, for washing your back might attract 2 points for 4 b). Needs to use an aid or appliance to be able to wash or bathe.
- A bottom wiper, which might attract 2 points for 5 b). Needs to use an aid or appliance to be able to manage toilet needs or incontinence.

### Scoring points when your condition varies

Your condition is assessed as it is likely to be over the course of 12 months.

The descriptor that applies to you for any given activity is the one that is correct for the majority of the time. However, deciding which descriptor applies can be complicated – much more so than for ESA, for example - as there are a number of factors which must be taken into account. This includes whether a descriptor applies even for a small part of the day and whether two or more points scoring descriptors should be combined to decide if you score points on the majority of days. See below for more on this.

If you are due to have treatment which may alter your needs, you should be assessed as you are now rather than the decision maker attempting to guess what your needs will be after treatment.

#### At any point during the day

According to law a descriptor applies to you for the **whole** day if it applies **at any point** during a 24 hour period – unless it is just "momentary". So if, for example, the painkillers that you take first thing in the morning work straight away and allow you to wash and dress, etc., without delay, that would not count. But if, as in practice with most painkillers, you have to wait a disruptive amount of time for the painkillers to take effect, you may score points.

Guidance issued by the DWP clarifies this by explaining that:

'If a descriptor applies at any point during a 24 hour period, it is considered to apply for the entire day, whereas in DLA it would have to apply for 'the majority of the day' in order to apply.'

So, for example, on most days you may be unable to put a shirt or a jumper on first thing in the morning because your arthritis is at its worst, but after an hour or two your symptoms ease and you are able to dress yourself.

If this is the case, the DWP's view seems to be that you should score 4 points for:

6 e). Needs assistance to be able to dress or undress their upper body.

This should be the case even though for the majority of the day you don't need assistance to dress or undress.

#### One descriptor only applies

For each activity, where only one descriptor applies to you for over half (50%) of the time, that is the one you will get points for.

PIP law relating to variability is written in terms of percentages, but working out how your condition affects you in in this way can be challenging. It may be more straightforward – and accurate – to stick to describing your difficulties in terms of days per week.

So, if on five to six days of every week you can manage to work out change in a shop but your concentration is too poor for you to be able to cope with paying bills and checking how much money you have left to get through the month then:

10 b). Needs prompting or assistance to be able to make complex budgeting decisions. 2 points should apply.

#### Two descriptors apply

Where two descriptors apply to you for over half of the time, you will be awarded the one that scores the highest number of points.

So, for example, if because of fatigue and anxiety you need prompting to cook a meal for six days a week (which is approximately 85% of the time), then the following descriptor would apply:

1 d). Needs prompting to be able to either prepare or cook a simple meal. 2 points.

But you may also need assistance when cooking for four days a week (which is 60% of the time):

1 e). Needs supervision or assistance to either prepare or cook a simple meal. 4 points.

In this case you should be awarded be awarded the 4 points, because both descriptors apply for more than half (50%) of the time and 1 e). is the higher scoring of the two.

#### No descriptor applies for half of the time

This is where it starts getting complicated. The most important thing to bear in mind is that you need to give as much information as possible about your condition and its variability.

Where no descriptor applies to you for over half of the time but two or more descriptors – excluding the zero scoring one – added together, apply for more than half of the time you will get points for:

the descriptor which applies for the greatest number of days; or where they both or all apply for the same number of days, the one which scores the greatest number of points.

So, if for two days a week on average you need prompting to cook a meal - descriptor 1 d) - and, in addition, on another three days a week you need assistance to cook a meal - descriptor 1 e) - you should score the higher 4 points for needing assistance.

This is because you satisfy points scoring descriptors for over half the time and 1 e). applies for more days of the week than 1 d).

#### Giving evidence about variability

As we said, working out which descriptor ought to apply can be complicated. Ultimately, all you can do is give as much detailed information as you can – especially in your form where it is in writing in your own words – and then, if you are not happy with the outcome, consider appealing.

Try to give your best estimate of how many days, on average, different needs apply. You can do this using the number of days in a week you are affected, the number of weeks in a month, the number of months in a year or whatever fits best with your condition. It will then be for the decision maker to work out how this fits into percentages over a 12 month period. You can <u>read more about this</u> on the Benefits and Work website.

### General definitions you need to know

There are a number of terms which have specific legal definitions for PIP that are used repeatedly throughout the daily living and mobility descriptors. It's useful to check what these terms mean when you are trying to decide how many points you should score.

*"aid or appliance"-*(a) means any device which improves, provides or replaces your impaired physical or mental function; and (b) includes a prosthesis.

*"aided" means with –* (a) the use of an aid or appliance; or

#### (b) supervision, prompting or assistance.

See 'Gaining and losing points for aids and appliances' above for more about aids and appliances.

In relation to supervision, prompting and assistance DWP guidance explains that: 'the assessment will take into account whether individuals have an underlying need for support from another person, regardless of whether they have access to this". So, if it would be reasonable for you to have support, even if you don't actually get it, then you should be scored on the basis that you need it.

#### "Assistance" means physical intervention by another person and does not include speech.

'Assistance' may be the source of some disagreement between claimants and the DWP. At what point does the amount of assistance you need mean that, in reality, you are unable to carry out the activity? The difference is important, because for some activities you score fewer points if you can do an activity with assistance than you do if you are unable to do it at all.

The legislation defines 'assistance' as 'physical intervention'. Someone who catches you if you start to fall is clearly intervening, but is someone who holds your arm the whole time you are walking intervening or are they doing more than that?

If you can only 'move' if you lean very heavily one someone's arm, does that mean that you can 'move' with assistance or that you cannot 'move' at all? In the end, it will be up to tribunals to decide, all you can do is explain your difficulties in details and consider appealing if you are unhappy with the decision.

The guidance issued by the DWP to Capita and Independent Assessment Services is that:

'Assistance is support that requires the presence and physical intervention of another person to help the claimant complete the activity - including doing some but not all of the activity in question. To apply, this only needs to be required for part of the activity.'

"Prompting" means reminding, encouraging or explaining by another person.

Whilst supervision below specifies that the person must be present, this is not stated in relation to prompting. It may be that telephone calls, texts or emails may count as prompting.

The guidance issued by the DWP to Capita and Independent Assessment Services is that:

'Prompting is support provided by another person by reminding or encouraging a claimant to undertake or complete a task or explaining it to them but not physically helping them. To apply, this only needs to be required for part of the activity.'

Even if you can sometimes find sufficient motivation to perform a task on your own, you may still be able to score points if you can show that you **do** generally need prompting for more than half the days of the year.

# "Supervision" means the continuous presence of another person for the purpose of ensuring your safety.

The guidance issued by the DWP to Capita and Independent Assessment Services is that:

'Supervision is a need for the continuous presence of another person to avoid a serious adverse event from occurring to the claimant. The risk must be likely to occur in the absence of such supervision. To apply, supervision must be required for the full duration of the activity.'

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The main way that the meaning of the word 'supervision' is different for Disability Living Allowance (DLA) compared to PIP is in the sense that, for PIP, supervision must be 'continuous'. For DLA you could count as getting supervision even if the person looking out for your safety was not present all the time.

*"unaided" means without –* (a) the use of an aid or appliance; or (b) supervision, prompting or assistance.

The word '*Reliably*' (see 'Reliably – the most important PIP word' above) does not feature in the PIP regulations. But the concept has been incorporated in the following definitions:

Where your ability to carry out an activity is assessed, you are is to be assessed as satisfying a descriptor set out in column 2 of the table in Part 2 or 3, as the case may be, of Schedule 1 only if you can do so -

(a) safely;

(b) to an acceptable standard;

(c) repeatedly; and

(d) in a reasonable time period.

In this regulation –

"safely" means in a manner unlikely to cause harm to C or to another person, either during or after completion of the activity; and

"repeatedly" means as often as the activity being assessed is reasonably required to be completed;

"reasonable time period" means no more than twice as long as the maximum period that a person without a physical or mental condition which limits that person's ability to carry out the activity in question would normally take to complete that activity.

# Completing questions 1 and 2

#### Please list below the documents you're sending with this form.

If you send any additional evidence, such as medical evidence, try to make sure it is just a copy and keep the original for your records.

Q1 Please tell us who are the professional(s) best placed to advise us on your circumstances. For example, a GP, hospital doctor, specialist nurse, community psychiatric nurse, occupational therapist, physiotherapist, social worker, counsellor, or support worker? Bear in mind that Independent Assessment Services or Capita may never actually contact any of the people you list in this section. So if you possibly can, get supporting evidence from them yourself and include it either with this form or at a later date. But, whatever you do, don't delay returning this form because you are waiting for additional evidence.

#### Q2 About your health conditions or disabilities

# Q2a What are your health conditions or disabilities, and approximately when each of these started?

Any award of PIP will be based on the effects of all your health conditions, so make sure you list them here.

If you don't yet have a diagnosis, explain roughly what the problem is. For example: severe fatigue, not yet diagnosed. If necessary give further details about what investigations have been, or are going to be, carried out.

Think carefully about how long you have had the condition: many people go for years with symptoms before they seek help or get a proper diagnosis. The length of time you have had the condition may affect the length of any award of PIP.

#### Q2b Tell us about any:

- tablets or other medication you're taking or will be taking,
- any treatments you're having or will be having, such as chemotherapy, physiotherapy or dialysis, regardless of whether NHS or private, and
- please include information on any side effects these have on you

The medication you take, and how long you've been taking it, may be used as an indicator of the severity of your condition. The same is true of any treatment you receive.

Have you been prescribed medication in the past which you are no longer taking but which demonstrates the seriousness of your condition. We think you should put it down and explain why you are no longer taking it.

For example, you may have been prescribed steroids in the past but only take them when your condition flares. Or you may have been on a strong painkiller but decided to stop using it and put up with the pain, or seek alternative remedies, because of side-effects you were experiencing or the risks associated with long-term use of the medication. We think this is important because if, for example, you have a severe back problem but only take over the counter painkillers such as ibuprofen, the decision maker may assume that your condition cannot be very serious.

In the same way, if you have had treatment in the past which shows the seriousness of your condition then list it here, even if it was years ago. For example, you may have attended a pain clinic or had a course of physiotherapy or had to have parenteral nutrition (tube feeding) in the past.

# Q3 Preparing food (Activity 1)

#### What this activity is about

This activity is about your ability to prepare a cooked, one course meal for one person. You score points depending on what problems you have with using a normal cooker, using a microwave and with things like peeling and chopping vegetables and opening tins.

#### The descriptors: what the law says you score points for

1a. Can prepare and cook a simple meal unaided. 0 points.

1b. Needs to use an aid or appliance to be able to either prepare or cook a simple meal. 2 points.

1c. Cannot cook a simple meal using a conventional cooker but is able to do so using a microwave. **2 points.** 

1d. Needs prompting to be able to either prepare or cook a simple meal. 2 points.

1e. Needs supervision or assistance to either prepare or cook a simple meal. 4 points.

1f. Cannot prepare and cook food. 8 points.

#### Legal definitions

Remember, words like 'unaided', 'prompting', 'supervision' and 'assistance' appear in many activities and have strict legal definitions: see *General definitions you need to know*. In this activity the following words and phrases also have strict legal definitions, as shown below in italics:

"Prepare", in the context of food, means make food ready for cooking or eating.

This obviously includes things like washing, peeling and chopping and can also include things like opening tins and packets and weighing and measuring ingredients.

"Cook" means heat food at or above waist height.

"Simple meal" means a cooked one-course meal for one using fresh ingredients.

The law talks about 'using fresh ingredients'. So, if all you can manage is to heat ready-meals in a microwave oven, you should score points. Even if you microwave your food, you will still score points if you cannot cut up and prepare fresh meat and vegetables before cooking them in the microwave.

#### Remember 'reliably'

As we explained in *'Reliably- the most important PIP word'* above, you should not be considered able to do something if, for example, you aren't safe doing it or it causes you pain or discomfort or it exhausts you or you're very slow at doing it.

If it's not safe for you to handle sharp knives or hot food, for example, then e) above may apply to you.

If preparing a meal would exhaust you or if it would take you an extremely long time even with assistance or supervision then f) may apply.

You may score points if you can only cook a very limited range of meals. CPIP/3739/2016 involved a claimant who could only cook a 'fry-up'. It was decided that it would be absurd to say they could prepare and cook a main meal.

#### Q3a Do you use an aid or appliance to prepare or cook a simple meal?

 $\Box$  Yes  $\Box$  No  $\Box$  Sometimes

**Important!** If you use an aid or appliance but still need help with an activity it is vital that you say so.

If you need to use an aid or appliance to be able to prepare and cook a meal then tick Yes and give details in the 'Extra information' box on the next page. You should get 2 points for needing to use aids or appliances, unless a higher scoring descriptor also applies to you.

Law and DWP guidance suggest that various implements, utensils and adaptations may also count – even if they are not specifically designed to be used by disabled people. To score points, however, you do need to be using them due to disability and not just for convenience. The kind of things that might be relevant are:

- electric can opener
- ring-pull can opener
- jar opener
- slotted spoon
- walking stick
- perching stool
- prostheses (for example, an artificial leg)
- knob and tap turner
- lever taps (for example, quarter-turn-only and with long lever handles)
- cooking basket
- liquid level indicator
- timers
- plate holder
- auto chopper
- lightweight pans
- easy/comfort grip utensils
- peeler and clamper
- kettle tipper

If you need to use any of these, then you should score a possible 2 points under 1b.

DWP guidance states that:

'Pre-chopped vegetables are not considered an aid or appliance. However, a claimant who is reliant on them because they would be unable to peel or chop fresh vegetables may be considered as requiring an aid or appliance or support from another person to complete the activity.'

**Caution!** Decision makers may argue that you could use an aid or appliance as an alternative to having supervision or assistance from another person. If there is a reason why the aid or appliance would not mean you didn't need help, explain why.

For example, if timers wouldn't help because you would forget to set them or get confused about why they were going off, or if a perching stool wouldn't help because you have dizzy spells and might fall off, then you may wish to explain this.

Q3b Do you need help from another person to prepare or cook a simple meal?

□ Yes □ No □ Sometimes

The form explains that help includes 'help you need but don't get'. So, if you cook food even though it is dangerous for you or it often goes wrong because you don't have the help you need, then tick Yes and give details in the 'Extra information, box on the next page.

Guidance for health professionals tells them that if you need supervision because of a risk of selfharm or 'suicide intent' then you should score 4 points for this activity because descriptor e) applies. **Caution!** Guidance to health professionals tells them that "*Carrying items around the kitchen is not included in this activity.*"

However, this is guidance only and we consider that it is incorrect. The legal definition states that *"Prepare", in the context of food, means make food ready for cooking or eating.* This might well include carrying food from a worktop to the sink to wash it, to the cooker to cook it and then to another surface to serve it. If you have problems with any of these activities, give details and, if you are not happy with the decision, consider challenging it.

#### Extra information – Preparing Food

You should include details of any problems you have with:

- motivating yourself to cook, perhaps because you are too tired or depressed or because you
  have an eating disorder which means that you avoid cooking;
- concentrating to cook;
- remembering you are in the middle of cooking and not getting distracted and doing something else;
- choosing the ingredients;
- making sure they are fresh and not past their sell by date;
- reading labels, instructions and recipes;
- peeling and chopping vegetables;
- opening tins;
   timing the different tasks so everything is ready at once and nothing is burnt or underdone;
- sitting or standing at the cooker;
- putting pans on and getting them off the hob;
- adding seasoning;
- stirring and pouring;
- telling if water is boiling or simmering;
- telling if fat or oil is the right temperature;
- draining vegetables;
- cutting up meat and vegetables ready to serve;
- transferring food from pans to the plate.

If you need help with using any of these you should score a possible 4 points under 1e .

If you're struggling to know how to give detailed evidence for this activity, try writing the answers to these 6 questions:

- 1. What is the health condition and what are the symptoms that cause you problems with preparing food? For example, stiffness caused by arthritis or fatigue caused by ME.
- 2. Describe the problems you have, giving details and examples if you can.
- 3. If you use any aids or appliances, list them and explain why you use them.
- 4. If you need physical help, supervision or prompting, whether you actually get it or not, explain what you need and why you need it, including if you need help when using aids or appliances. If you can't manage even with help from another person and have to have everything done for you, say so.
- 5. Say when during the day or night you have problems. For example, is it all the time, mostly in the morning or just in the evening?
- 6. If your condition varies, from day to day or week to week, try to explain how much it varies and what problems you have when you are at your best, worst and average.

#### Sample answer

Please note: these are just examples of the kinds of information you may wish to give – they aren't 'correct' answers of any sort. But it is vital that you give detailed evidence rather than just ticking boxes. You don't need to put the numbers in – that's just to show how the system works.

- 1. Because of my severe depression I have problems motivating myself to prepare food.
- 2. I will often not eat at all unless my partner encourages and cajoles me to do so. But if I do prepare food it will just be a sandwich or a bowl of cereal as I cannot find the energy or concentration to plan and cook a meal.
- 3. I don't use any special aids or appliances for cooking.
- 4. If my partner is at home he encourages me to cook simple meals, but he has to keep reminding me what to do and encouraging me.
- 5. I am sometimes more motivated first thing in the morning, but I become very drained and depressed in the afternoon and evening.
- 6. I don't have better days, but I do have worse days on average about twice a week when nothing my partner says makes any difference at all.
- 1. Because of arthritis in my hands I have great difficulty gripping things.
- 2. I have cut myself whilst trying to use a knife to chop vegetables and have scalded myself by dropping a pan full of hot water. Trying to do most things in the kitchen is painful and I am very slow and unreliable when cooking and tend to drop things a lot.
- 3. I use a variety of kitchen aids, such as easy grip cutlery, an auto chopper, a slotted spoon and an electric can opener. However, whilst these make it slightly less dangerous for me to prepare a meal, they don't stop it being very painful.
- 4. My wife will no longer let me cook unaccompanied because she does not consider me to be safe in the kitchen. I never handle heavy or hot objects anymore and will only chop things that fit in the auto chopper.
- 5. My hands are always at their most painful in the morning, but my grip strength remains poor throughout the day.
- 6. My hands are better in warm and dry weather and worst on cold, wet winter days, but even in the best weather the difficulties I have described above would be the norm.

# Q4 Eating and drinking (Activity 2)

#### What this activity is about

This activity is about your ability to either feed yourself by cutting up food on a plate, getting it to your mouth and chewing and swallowing it or by using a tube feeding device.

#### The descriptors: what the law says you score points for

2a. Can take nutrition unaided. **0 points.** 

2b. 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 points.
- 2c. Needs a therapeutic source to be able to take nutrition. 2 points.
- 2d. Needs prompting to be able to take nutrition. 4 points.
- 2e. Needs assistance to be able to manage a therapeutic source to take nutrition. 6 points.
- 2f. Cannot convey food and drink to their mouth and needs another person to do so. 10 points.

#### Legal definitions

Remember, listed above, there are some legal definitions of terms that appear in many activities, like 'unaided', 'prompting', 'supervision' and 'assistance'. But there are also some important definitions relevant to this activity.

The regulations (in italics) state that:

#### "Take nutrition" means:

(a) cut food into pieces, convey food and drink to one's mouth and chew and swallow food and drink; or (b) take nutrition by using a therapeutic source.

"Therapeutic source" means parenteral or enteral tube feeding, using a rate-limiting device such as a delivery system or feed pump.

#### **Remember 'reliably'**

As we explained in 'Reliably- the most important PIP word' above, you should not be considered able to do something if, for example, you aren't safe doing it or it causes you pain or discomfort or it exhausts you or you're very slow at doing it.

If you are able to take nutrition, but it's not safe because you might choke or because you might eat too much or not eat enough, or if you can do it but you are likely to spill a lot of the food or drink, then you may score points for this activity.

#### Q4a Do you use an aid or appliance to eat and drink?

□ Yes □ No □ Sometimes

**Important!** If you use an aid or appliance but still need help with an activity it is vital that you say SO.

If you need to use an aid or appliance to be able to eat or drink, then tick Yes and give details in the 'Extra information' box on the next page. You should get 2 points for needing to use aids or appliances, unless a higher scoring descriptor also applies to you.

The kinds of things that might be relevant include:

- suction, scooper and two handled bowls
- partitioned dishes •
- plate surrounds
- bibs and clothing protectors •
- easy grip cutlery
- two-handled cups •
- easy hold beakers •
- straws •
- cups with lid
- If you need to use any of these to eat or drink you should score 2 points for this activity.

#### Q4b Do you use a feeding tube or similar device to eat or drink?

 $\Box$  Yes  $\Box$  No  $\Box$  Sometimes

If you need to use a feeding tube or something similar, then tick Yes and give details in the 'Extra information' box on the next page. You should score two points for this, unless a higher descriptor also applies to you.

#### Q4c Do you need help from another person to eat and drink?

 $\Box$  Yes  $\Box$  No  $\Box$  Sometimes

The form explains that help includes 'help you need but don't get'. So, if you feed yourself because you don't have help but you run the risk of choking or it takes you a very long time, then tick Yes and give details in the 'Extra information, box on the next page.

#### Extra information – Eating and drinking

You should include details of any problems you have with:

- motivating yourself to eat because, for example, you often feel too lethargic, depressed or tired to eat; (you should score a possible 4 points under 2d)
- knowing when to eat; (you should score a possible 4 points under 2d)
- remembering whether you have eaten; (you should score a possible 2 points under 2b(ii))
- getting too anxious or over excited to eat; (you should score a possible 2 points under 2b(ii))
- not being able to stop yourself eating once you have started; (you should score a possible 2 points under 2b(ii)
- eating only very small amounts because of an eating disorder; (you should score a possible 4 points under 2d)
- holding and using cutlery; (you should score a possible 2 points under 2b(ii) or (iii)
- getting food from a plate or bowl and into your mouth; (you should score a possible 10 points under 2f)
- drinking from a cup or mug; (you should score a possible 2 points under 2b(ii))
- needing someone to tell you what food is on your plate; (you should score a possible 2 points under 2b(ii))
- knowing where on your plate the food is. Spilling food and drink. (you should score a
  possible 2 points under 2b(ii)) Guidance to health professionals states that "regular spillage
  requiring a change of clothes after meals is not an acceptable standard of taking nutrition".
- needing encouragement to eat solid food because otherwise you would live on coffee, soup and the occasional sandwich which does not constitute taking nutrition. (you should score a possible 4 points under 2d)

If you are tube-fed (or receive other kinds of parenteral nutrition), describe the process involved and any help you need with keeping equipment sterile or supervising the process.

If you're struggling to know how to give detailed evidence for this activity, try writing the answers to these 6 questions:

- 1. What is the health condition and what are the symptoms that cause you problems with eating or drinking? For example, confusion caused by dementia or pain caused by multiple sclerosis.
- 2. Describe the problems you have, giving details and examples if you can.
- 3. If you use any aids or appliances, list them and explain why you use them.
- 4. If you need physical help, supervision or prompting, whether you actually get it or not, explain what you need and why you need it, including if you need help when using aids or appliances. If you can't manage even with help from another person and have to have everything done for you, say so.
- 5. Say when during the day or night you have problems. For example, is it all the time, mostly in the morning or just in the evening?
- 6. If your condition varies, from day to day or week to week, try to explain how much it varies and what problems you have when you are at your best, worst and average.

#### Sample answer

Please note: these are just examples of the kinds of information you may wish to give – they aren't 'correct' answers of any sort. But it is vital that you give detailed evidence rather than just ticking boxes. You don't need to put the numbers in – that's just to show how the system works.

- 1. Because of motor neurone disease I have muscle weakness in my hands and arms.
- 2. This means that I have difficulty using cutlery and cannot safely pick up hot drinks. I have dropped cups and glasses so many times that I no longer use them.
- 3. I now use a cup with a lid that does not spill if dropped and I have cutlery with adapted handles.
- 4. Even with adapted cutlery I do not have the strength or dexterity to cut up things like sausages or bacon and need someone to do this for me.
- 5. My condition tends to get worse as the day goes on and I become more tired.
- 6. I have these problems every day and my condition is gradually deteriorating.

### Q5 Managing treatments (Activity 3)

#### What this activity is about

This activity looks at your ability to take medication and to monitor your health by, for example, checking your blood sugar and also to carry out therapeutic activities such as exercise.

#### The descriptors: what the law says you score points for

#### a. Either -

3a. (i) does not receive medication or therapy or need to monitor a health condition; or

(ii) can manage medication or therapy or monitor a health condition unaided. **0 points.** 

3b. Needs any one or more of the following -

(i) to use an aid or appliance to be able to manage medication;

(ii) supervision, prompting or assistance to be able to manage medication.

(iii) supervision, prompting or assistance to be able to monitor a health condition. 1 point.

3c. Needs supervision, prompting or assistance to be able to manage therapy that takes no more than 3.5 hours a week. **2 points.** 

3d. Needs supervision, prompting or assistance to be able to manage therapy that takes more than 3.5 but no more than 7 hours a week. **4 points.** 

3e. Needs supervision, prompting or assistance to be able to manage therapy that takes more than 7 but no more than 14 hours a week. **6 points.** 

3f. Needs supervision, prompting or assistance to be able to manage therapy that takes more than 14 hours a week. **8 points.** 

#### Legal definitions

Remember, words like 'unaided', 'prompting', 'supervision' and 'assistance' appear in many activities and have strict legal definitions: see *General definitions you need to know*. In the 'Managing treatments' activity here are several words and phrases that also have strict legal definitions, as shown below: in italics:

"*Manage medication*" means take medication, where a failure to do so is likely to result in a deterioration in your health.

"*Manage therapy*" means undertake therapy, where a failure to do so is likely to result in a deterioration in your health.

"**Medication**" means medication to be taken at home which is prescribed or recommended by a registered –

(a) doctor; (b) nurse; or (c) pharmacist.

"**Therapy**" means therapy to be undertaken at home which is prescribed or recommended by a—

(a) registered –
(i) doctor;
(ii) nurse; or
(iii) pharmacist; or
(b) health professional regulated by the Health Professions Council, but does not include taking or applying, or otherwise receiving or administering, medication (whether orally, topically or by any other means), or any action which falls within the definition of "monitor a health condition".

**Important note – these legal definitions and the descriptors may be unlawful**: On 16 March 2017 the DWP introduced new regulations that aimed to draw a clear distinction between therapy and managing medication or monitoring a health condition. The legal definitions above were changed to state that things such as giving medication or applying cream should not be treated as therapy. At the time the DWP claimed that they were simply making the law more clear, rather than changing it.

However, in June 2018, the DWP admitted that they had been applying the law wrongly before 16 March 2017. This means that many thousands of people may be entitled to an award, or a higher award of the daily living component because they should have been awarded more points for this activity. The DWP say that they will be looking at past decisions to see who should receive back-payments.

In addition, there is also likely to be a challenge to the changes to the regulations on the grounds that no consultation was carried out even though the new regulations changed rather than clarified the law. This means that the DWP may still be applying the law wrongly now.

At present the law is uncertain. But it may be the case that if you need help with supervision, prompting or assistance to manage medication and monitor a health condition then you should score more than one point. How many points will depend on the length of time the help is required.

The most important thing at this stage is, when filling in the form, give as much detailed information as you can about the help you need with managing your condition.

If you are unhappy with the decision in your case, try to get advice in order to consider whether to appeal on the grounds that the changes to the regulations were unlawful or whether to wait for clarification of the law.

For more information on all of this, please see the news article: <u>DWP admits to getting PIP law</u> wrong again, many thousands of claimants will get back-payments

Guidance issued by the DWP states that 'home' refers to a domestic setting and could include the home of friends or family as well as your own home.

#### "Monitor a health condition" means –

(a) detect significant changes in your health condition which are likely to lead to a deterioration in C's health; and

(b) take action advised by a –

(i) registered doctor;

(ii) registered nurse; or

(iii) health professional who is regulated by the Health Professions Council, without which C's health is likely to deteriorate.

#### Remember 'reliably'

As we explained in 'Reliably- the most important PIP word' above, you should not be considered able to do something if , for example, you aren't safe doing it or it causes you pain or discomfort or it exhausts you or you're very slow at doing it.

So, if it's not safe for you to manage your therapy, for example because you might fall and be unable to get up again whilst carrying out your exercise regime, then you may score points for this activity.

#### The almost pointless point

You get only one point for 3b needing an aid or appliance to manage medication; supervision, prompting or assistance to be able to manage medication or monitor a health condition.

As far as we can tell this means that someone who has to be supervised to prevent them taking an overdose of medication will receive only one point.

It's also worth noting that only one other descriptor has an odd number score: 4e. Needs assistance to be able to get in or out of a bath or shower - 3 points.

So, unless 4e also applies to you then a single point for medication or monitoring health is absolutely worthless – it can never make a difference to whether you get an award or help you move from a standard to an enhanced award.

# Q5a Do you use an aid or appliance to monitor your health conditions, take medication or manage home treatments?

For example using a Dosette Box for tablets.  $\Box$  Yes  $\Box$  No  $\Box$  Sometimes

**Important!** If you use an aid or appliance but still need help with an activity it is vital that you say so.

If you need to use an aid or appliance to be able to monitor your health conditions, take medication or manage home treatments, then tick Yes and give details in the 'Extra information' box on the next page. You should get 1 point for needing to use aids or appliances, unless a higher scoring descriptor also applies to you.

The kinds of things that might be relevant include:

- pill organiser
- automatic pill dispenser
- medication reminder timer or mobile phone app
- medication bottle and foil wrap opener
- low blood sugar alarm
- talking thermometer

**Caution!** Guidance to health professionals tells them that the use of *"Pill boxes, dosette boxes, blister packs, alarms and reminders"* only score points if a claimant is *"unable to manage their medication due to their health condition or impairment and there is evidence to explain their use. If they are used for convenience, then descriptor A [0 points] will apply.* So, if you use aids like these it is vital that you explain why you rely on them and what would happen if you did not use them.

# Q5b Do you need help from another person to monitor your health conditions, take medication or manage home treatments?

 $\Box$  Yes  $\Box$  No  $\Box$  Sometimes

The form explains that help includes 'help you need but don't get'. So, if you manage your medication because you don't have help but you sometimes forget or take the wrong dose, for example, then tick Yes and give details in the 'Extra information, box on the next page.

Some treatments may count as either help with *medication* or help with *therapy*, although this is very much less likely since the changes in the law in March 2017 – see above. Always argue in such cases that the treatment counts as help with therapy because this scores more points than help with medication.

Guidance to health professionals tells them that:

"... keeping an eye' on how a person is doing does not count as monitoring, unless the person is monitoring a specific parameter under medical advice and is implementing treatment modifications to prevent deterioration. Asking someone how they are will not meet the criteria unless there is a medical reason for expecting a change, a defined sign of deterioration and an advised action plan."

So, if someone watches you to check whether there has been a change in your physical or mental health, explain in as much detail as possible what they are watching for, what they do if changes occur and what would happen if they did not do this.

#### Extra information – Managing treatments

You should include details of any problems you have with:

- taking the right medication at the right time, including reading labels, opening containers, measuring amounts; (you should score a possible 1 point under 3b(i),(ii) or (ii))
- being too tired, depressed or forgetful to take your medication; (you should score a possible 1 point under 3b(i),(ii) or (iii))
- stopping taking your medication because it has unpleasant side-effects; (you should score a possible 1 point under 3b(ii) or (iii))
- accidentally or deliberately overdosing on your medication; (you should score a possible 1 point under 3b(ii) or (iii))
- opening bottles and blister packs; (you should score a possible 1 point under 3b(i) or (ii))
- swallowing pills; (you should score a possible 1 point under 3b(i) or (ii))
- using an inhaler; you should score a possible 1 point under 3b(i) or (ii))
- applying creams or lotions; (you should score a possible 1 point under 3b(ii))
- changing dressings; (you should score a possible 1 point under 3b(ii))
- administering home oxygen; (you should score a possible 2,4,6 or 8 points under 3c,d,e or f depending on the severity of your disability)
- administering home dialysis; (you should score a possible 2,4,6 or 8 points under 3c,d, e or f depending on the severity of your disability)
- checking blood sugar levels; (you should score a possible 1 point under 3b(iii))
- administering injections; (you should score a possible 1 point under 3b(i), (ii) or (iii)
- administering enemas; (you should score a possible 1 point under 3b(ii))
- being massaged or having limbs manipulated; (you should score a possible 2,4,6 or 8 points under 3c,d,e or f depending on the severity of your disability)
- following a medically prescribed exercise regime.(you should score a possible 2,4, 6 or 8 points under 3c,d, e or f depending on the severity of your disability)

If you're struggling to know how to give detailed evidence for this activity, try writing the answers to these 6 questions:

- 1. What is the health condition and what are the symptoms that cause you problems with monitoring your health conditions, taking medication or managing home treatments? For example, confusion caused by ME or problems managing containers caused by arthritis.
- 2. Describe the problems you have, giving details and examples if you can.
- 3. If you use any aids or appliances, list them and explain why you use them.
- 4. If you need physical help, supervision or prompting, whether you actually get it or not, explain what you need and why you need it, including if you need help when using aids or appliances. If you can't manage even with help from another person and have to have everything done for you, say so.
- 5. Say when during the day or night you have problems. For example, is it all the time, mostly in the morning or just in the evening?
- 6. If your condition varies, from day to day or week to week, try to explain how much it varies and what problems you have when you are at your best, worst and average.

#### Sample answer

Please note: these are just examples of the kinds of information you may wish to give – they aren't 'correct' answers of any sort. But it is vital that you give detailed evidence rather than just ticking boxes. You don't need to put the numbers in – that's just to show how the system works.

- 1. Because of my ME/CFS I get very foggy and confused.
- 2. This means I cannot be relied upon to take my medication or to remember if I have taken it. In the past I have failed to take my medication for several days or have taken too much and my partner has had to contact my GP to find out if the quantity of medication I had taken was dangerous.
- 3. My partner puts all my pills in a pill dispenser with a timer that sounds an alarm when it's time to take them.
- 4. My partner also phones me every lunchtime to make sure I have taken my pills, because even with the alarm I sometimes forget or take some of the pills and forget to take the rest.
- 5. I am at my worst when I first wake up and in the evening.
- 6. I am this fatigued on at least six days out of seven.

## Q6 Washing and bathing (Activity 4)

#### What this activity is about

This activity is about your ability to wash and bathe, including washing and bathing your whole body and getting in and out of a bath or shower which has not been adapted.

#### The descriptors: what the law says you score points for

4a. Can wash and bathe unaided. **0 points.** 

- 4b. Needs to use an aid or appliance to be able to wash or bathe. 2 points.
- 4c. Needs supervision or prompting to be able to wash or bathe. 2 points.
- 4d. Needs assistance to be able to wash either their hair or body below the waist. 2 points.
- 4e. Needs assistance to be able to get in or out of a bath or shower. 3 points.
- 4f. Needs assistance to be able to wash their body between the shoulders and waist. 4 points.
- 4g. Cannot wash and bathe at all and needs another person to wash their entire body. 8 points.

#### Legal definitions

Remember, words like 'unaided', 'prompting', 'supervision' and 'assistance' appear in many activities and have strict legal definitions: see General definitions you need to know. In this activity the following words and phrases also have strict legal definitions, as shown below in italics:
"bathe" includes get into or out of an unadapted bath or shower.

Even if you have an adapted bath or shower at home, you should explain on your form what problems you would have if you tried to use an unadapted one.

Guidance to health professionals tells them that descriptor f) *"refers to the any part of the body between the shoulders and waist; front and back.* 

#### **Remember 'reliably'**

As we explained in 'Reliably - the most important PIP word' above, you should not be considered able to do something if , for example, you aren't safe doing it or it causes you pain or discomfort or it exhausts you or you're very slow at doing it.

So, if you are physically able to bathe but it's not safe for you to do so, because for example, you may fall or you may have a seizure, then you may score points for this activity. If it would take you a very long time or leave you exhausted and unable to carry out other everyday activities then you may also score points.

The August 2016 version of the PIP guide for assessors claims that 'The ability to dry oneself is not considered in this activity. It is unlikely that someone who could wash a particular area of their body would be unable to dry the same area.' There is no legal basis for this advice and if you do have difficulties with drying yourself give details.

# Q6a Do you use an aid or appliance to wash and bathe yourself, including using a bath or shower?

 $\Box$  Yes  $\Box$  No  $\Box$  Sometimes

**Important!** If you use an aid or appliance but still need help with an activity it is vital that you say so.

If you need to use an aid or appliance to be able to wash or bathe yourself, then tick Yes and give details in the 'Extra information' box on the next page. You should get 2 points for needing to use aids or appliances, unless a higher scoring descriptor also applies to you.

The kinds of things that might be relevant include:

- long-handled sponge
- long-handled toe washer
- flannel strap
- foot washing sandals
- shower seat
- shower slippers
- overflow alarm
- bath rail
- bath cushion or mattress

**Caution!** Decision makers may argue that you could use an aid or appliance as an alternative to having supervision or assistance from another person. If there is a reason why the aid or appliance would not mean you didn't need help, explain why. For example, a long-handled sponge would not help if you lack the flexibility to reach behind your back.

The DWP have changed their guidance regarding wet rooms. They now say that 'A wet room shower, if its use is reasonably required, is evidence that the claimant cannot get into an unadapted shower.' So, if you have use wet room because you need to, rather than just because it's there, explain this.

#### Q6b Do you need help from another person to wash and bathe?

 $\Box$  Yes  $\Box$  No  $\Box$  Sometimes

The form explains that help includes 'help you need but don't get'. So, if you manage to wash or bathe yourself because you don't have help but you aren't safe getting in and out of the bath, for example, then tick Yes and give details in the 'Extra information, box on the next page.

The August 2016 version of the PIP guide for assessors has a chart to help decide whether points should be scored for needing help getting in or out of a bath or shower:

Do you need help to get in or out of a BATH	Do you need help to get in or out of a SHOWER	Should you score points for descriptor 4e
Yes	Yes	Yes
Yes	No	Yes
No	Yes	Yes
No	No	No

#### Extra information – Washing and bathing

According to DWP guidance this activity does not include drying yourself, shaving, cutting nails or applying make-up. You should include details of any problems you have with:

- feeling too depressed or too tired to wash or bathe; (you should score a possible 2 points under 4c, or a possible 8 points under 4g depending on the severity of your disability)
- remembering to wash or bathe; (you should score a possible 2 points under 4c)
- having certain actions or rituals that you have to perform when you wash or bathe that take a lot of time; (you should score a possible 2 points under 4c, or a possible 8 points under 4g depending on the severity of your disability)
- washing frequently and compulsively; (you should score a possible 2 points under 4c, or a possible 8 points under 4g depending on the severity of your disability)
- feelings about your body or how you look, which make it difficult for you to wash or bathe; (you should score a possible 2 points under 4c, or a possible 8 points under 4g depending on the severity of your disability)
- turning taps on and off; (you should score a possible 2 points under 4b)
- checking water temperature; (you should score a possible 2 points under 4b or c)
- reading the labels on bottles; (you should score a possible 2 points under 4b or c)
- bending to the sink; (you should score a possible 2 points under 4b or c)
- getting in and out of the bath or shower, including transferring from a wheelchair; (you should score a possible 3 points under 4e)
- standing in the shower; (you should score a possible 3,4, or 8 points under 4e, f or g depending on the severity of your disability)
- reaching down to wash your legs; (you should score a possible 2 points under 4d)
- reaching up to wash your face and hair; (you should score a possible 2 points under 4d)
- reaching behind you to wash your back; (you should score a possible 4 points under 4f)
- cleaning your nails; (you should score a possible 2 points under 4b, note that cutting rather than cleaning your nails, does not score any points according to DWP guidance)
- making sure you don't fall in the bath or shower; (you should score a possible 3, 4 or 8 points under 4e, f and g depending on the severity of your disability)

• keeping safe if you have fits or blackouts which make bathing or showering dangerous.(you should score a possible 3,4 or 8 points depending on the severity of your disability)

If you're struggling to know how to give detailed evidence for this activity, try writing the answers to these 6 questions:

- 1. What is the health condition and what are the symptoms that cause you problems with washing and bathing? For example, severe back pain or learning difficulties.
- 2. Describe the problems you have, giving details and examples if you can.
- 3. If you use any aids or appliances, list them and explain why you use them.
- 4. If you need physical help, supervision or prompting, whether you actually get it or not, explain what you need and why you need it, including if you need help when using aids or appliances. If you can't manage even with help from another person and have to have everything done for you, say so.
- 5. Say when during the day or night you have problems. For example, is it all the time, mostly in the morning or just in the evening?
- 6. If your condition varies, from day to day or week to week, try to explain how much it varies and what problems you have when you are at your best, worst and average.

#### Sample answer

Please note: these are just examples of the kinds of information you may wish to give – they aren't 'correct' answers of any sort. But it is vital that you give detailed evidence rather than just ticking boxes. You don't need to put the numbers in – that's just to show how the system works.

- 1. Because of my obsessive compulsive disorder it takes me a very long time to wash or bathe.
- It takes me over an hour to wash every morning because I have to wash my body in a certain order and clean each part of my body a certain number of times. If I am not sure I have done it correctly I have to start again from the beginning, something which always happens several times.
- 3. I don't need any aids or appliances.
- 4. Help from another person would make things worse as it would mean I was not doing things in the way that I feel compelled to do them.
- 5. I only ever have a bath in the morning, but I also have to wash my hands in the correct way many times a day and this can take anywhere from two minutes to ten minutes.
- 6. I always have this level of problems.
- 1. Because of my emphysema I cannot stand for long or exert myself at all.
- 2. I cannot climb in and out of a bath as I get too breathless and find it too exhausting and I also cannot stand for long in the shower for the same reason.
- 3. I use a special stool to sit on in the shower and also a long handled sponge because it is less effort than trying to reach behind me to wash my back.
- 4. I don't get any help from anyone else to wash or bathe.
- 5. I am always breathless no matter what time of day.
- 6. and this does not change from day to day.

### Q7 Managing toilet needs (Activity 5)

#### What this activity is about

This activity is about your ability to get on and off the toilet, empty your bladder and bowels and clean yourself. It also covers the use of collecting devices, such as a colostomy bag.

#### The descriptors: what the law says you score points for

5a. Can manage toilet needs or incontinence unaided. 0 points.

5b. Needs to use an aid or appliance to be able to manage toilet needs or incontinence. 2 points.

5c. Needs supervision or prompting to be able to manage toilet needs. 2 points.

5d. Needs assistance to be able to manage toilet needs. 4 points.

5e. Needs assistance to be able to manage incontinence of either bladder or bowel. 6 points.

5f. Needs assistance to be able to manage incontinence of both bladder and bowel. 8 points.

#### Legal definitions

Remember, words like 'unaided', 'prompting', 'supervision' and 'assistance' appear in many activities and have strict legal definitions: see *General definitions you need to know*. In this activity the following words and phrases also have strict legal definitions, as shown below in italics:

#### "toilet needs" means –

(a) getting on and off an unadapted toilet;

- (b) evacuating the bladder and bowel; and
- (c) cleaning oneself afterwards.

If you have an adapted toilet you will need to explain what problems you would have if you tried to use an unadapted one. Guidance for health professionals tells them to ignore any problems with managing clothing, climbing stairs or getting to or from the toilet.

"manage incontinence" means manage involuntary evacuation of the bowel or bladder, including use a collecting device or self-catheterisation, and clean oneself afterwards.

#### **Remember 'reliably'**

As we explained in 'Reliably - the most important PIP word' above, you should not be considered able to do something if , for example, you aren't safe doing it or it causes you pain or discomfort or it exhausts you or you're very slow at doing it.

So, if you are physically able to use the toilet without help but, for example, it would take you a great deal of time to do so, or there would be a risk of you falling whilst getting on or off the toilet, then you may score points for this activity.

#### Q7a Do you use an aid or appliance to go to the toilet or manage incontinence?

 $\Box$  Yes  $\Box$  No  $\Box$  Sometimes

**Important!** If you use an aid or appliance but still need help with an activity it is vital that you say so.

If you need to use an aid or appliance to go to the toilet or manage incontinence, then tick Yes and give details in the 'Extra information' box on the next page. You should get 2 points for needing to use aids or appliances, unless a higher scoring descriptor also applies to you.

The kinds of things that might be relevant include:

- commode
- raised toilet seat
- bottom wiper
- incontinence pads, even if worn as a precautionary measure (CPIP/3104/2017)
- stoma bag (also known as a colostomy bag)
- large, easy press flush lever
- splash guard
- support rails

• toilet surround rails

**Caution!** Decision makers may argue that you could use an aid or appliance as an alternative to having supervision or assistance from another person. If there is a reason why the aid or appliance would not mean you didn't need help, explain why. For example, a bottom wiper would not remove the need for assistance if you lack the grip strength or dexterity to use it.

**Caution!** Guidance for health professionals tells them that the use of a commode should only score points if it is needed in relation to continence rather than mobility. So, if you would be incontinent if you did not have a commode nearby due to a bladder condition that causes urgency, you should score points. But if you use a commode because you have great difficulty walking to the toilet, that is viewed as mobility problem and no points will be awarded.

# Q7b Do you need help from another person to go to the toilet or manage incontinence?

 $\Box$  Yes  $\Box$  No  $\Box$  Sometimes

The form explains that help includes 'help you need but don't get'. So, if you cope with going to the toilet or managing incontinence because you don't have help but you aren't safe getting on and off the toilet, for example, then tick Yes and give details in the 'Extra information, box on the next page.

#### Extra information – Managing toilet needs

Tell us more information about the difficulties or help you need going to the toilet or managing incontinence.

According to law and DWP guidance, this activity does not include managing your clothing before and after using the toilet, for example undoing and doing up zips and buttons. This is because that is already covered by the dressing and undressing activity.

It is also unlikely to cover getting to and from the toilet from another room. You should include details of any problems you have with:

- remembering to empty your bladder or bowels; (you should score a possible 2 points under 5c)
- needing encouragement to use the toilet because it is painful or distressing for you; (you should score a possible 2 points under 5c)
- need reminding to use the toilet because you have an injury which means you cannot tell when your bowels or bladder are full; (you should score a possible 2 points under 5c)
- transferring from a wheelchair to the toilet and back again; (you should score a possible 4 points under 5d)
- getting on or off the toilet; (you should score a possible 4 points under 5d)
- sitting safely on the toilet; (you should score a possible 4 points under 5d)
- wiping yourself; (you should score a possible 4 points under 5d)
- dealing with leakage from a stoma device; (you should score a possible 6 or 8 points under 5e or f depending on the severity of your disability)
- remembering to check if a collecting bag is full; (you should score a possible 6 or 8 points under 5 e or f depending on the severity of your disability)
- keeping a stoma site clean; (you should score a possible 6 or 8 points under 5e or f depending on the severity of your disability)
- changing a collecting bag. (you should score a possible 6 or 8 points under 5e or f depending on the severity of your disability)

If you're struggling to know how to give detailed evidence for this activity, try writing the answers to these 6 questions:

- 1. What is the health condition and what are the symptoms that cause you problems with going to the toilet or managing incontinence? For example, a spinal injury or learning difficulties.
- 2. Describe the problems you have, giving details and examples if you can.
- 3. If you use any aids or appliances, list them and explain why you use them.
- 4. If you need physical help, supervision or prompting, whether you actually get it or not, explain what you need and why you need it, including if you need help when using aids or appliances. If you can't manage even with help from another person and have to have everything done for you, say so.
- 5. Say when during the day or night you have problems. For example, is it all the time, mostly in the morning or just in the evening?
- 6. If your condition varies, from day to day or week to week, try to explain how much it varies and what problems you have when you are at your best, worst and average.

#### Sample answer

Please note: these are just examples of the kinds of information you may wish to give – they aren't 'correct' answers of any sort. But it is vital that you give detailed evidence rather than just ticking boxes. You don't need to put the numbers in – that's just to show how the system works.

- 1. Because of my multiple sclerosis I have very little strength in my legs to the degree that I am now mainly restricted to a wheelchair. I also have tremors in my arms that prevent me from reliably supporting my weight.
- 2. Because of this I am unable to transfer from my wheelchair to a toilet.
- 3. I have a modified toilet,
- 4. but I still need help from another person with transferring to and from it.
- 5. I have these problems at any time of day or night
- 6. and every day of the week.
- 1. Because of Crohn's disease I have a stoma device and I also have arthritis in my hands.
- 2. Following my colostomy I developed a hernia below the incision site. This has affected the efficiency of the stoma causing it to leak faecal matter, which in turn has created skin problems, ulcers and a constant odour. Even a small amount of leakage means that I need to wash and change and it is not possible to apply any kind of pad because of the position of the stoma.
- 3. The stoma bag is fiddly
- 4. and I have problems changing it and cleaning up the area around it because of the arthritis in my hands.
- 5. I can manage to do this myself in the afternoon and evening but not usually in the morning when my hands are at their stiffest and most difficult to use.
- 6. I need help on average five days a week.

### Q8 Dressing and undressing (Activity 6)

#### What this activity is about

This activity looks at your ability to dress and undress yourself. The clothing should be appropriate to your culture, should not have been specially adapted, and should be 'reasonable'. For example, if you cannot pull a jumper over your head but you can wear a cardigan, it is probably reasonable to expect you to do so. But it would not be reasonable to expect you to dress always in loose, elasticated clothes with no fastenings and slip-on shoes if that is all you can manage to dress yourself in.

#### The descriptors: what the law says you score points for

6a. Can dress and undress unaided. 0 points.

6b. Needs to use an aid or appliance to be able to dress or undress. 2 points.

6c. Needs either -

(i) prompting to be able to dress, undress or determine appropriate circumstances for remaining clothed; or

(ii) prompting or assistance to be able to select appropriate clothing. 2 points.

6d. Needs assistance to be able to dress or undress their lower body. 2 points.

6e. Needs assistance to be able to dress or undress their upper body. 4 points.

6f. Cannot dress or undress at all. 8 points.

#### Legal definitions

Remember, words like 'unaided', 'prompting', 'supervision' and 'assistance' appear in many activities and have strict legal definitions: see *General definitions you need to know*. In this activity the following phrase also has a strict legal definition, as shown below in italics:

"dress and undress" includes put on and take off socks and shoes.

#### **Remember 'reliably'**

As we explained in 'Reliably - the most important PIP word' above, you should not be considered able to do something if , for example, you aren't safe doing it or it causes you pain or discomfort or it exhausts you or you're very slow at doing it.

So, if you are physically able to dress and undress without help, for example, but it would take you a great deal of time to do so, or you would be too exhausted afterwards to carry out other everyday activities, then you may score points for this activity.

#### Q8a Do you use an aid or appliance to dress or undress?

□ Yes □ No □ Sometimes

**Important!** If you use an aid or appliance but still need help with an activity it is vital that you say so.

If you need to use an aid or appliance to be able to dress or undress yourself, then tick Yes and give details in the 'Extra information' box on the next page. You should get 2 points for needing to use aids or appliances, unless a higher scoring descriptor also applies to you.

The kinds of things that might be relevant include:

- button hook
- zip puller
- long-handled shoe horn
- dressing stick
- leg lifter
- elastic shoe laces
- sock/stocking/tight aid

**Caution!** Decision makers may argue that you could use an aid or appliance as an alternative to having supervision or assistance from another person. If there is a reason why the aid or appliance would not mean you didn't need help, explain why. For example, you may not have the dexterity to use a button hook or shoe horn.

#### Q8b Do you need help from another person to dress or undress?

 $\Box$  Yes  $\Box$  No  $\Box$  Sometimes

The form explains that help includes 'help you need but don't get'. So, if you manage to dress or undress yourself because you don't have help but you aren't safe doing it or it takes you a very long time, for example, then tick Yes and give details in the 'Extra information, box on the next page.

#### Extra information – Dressing and undressing

Tell us more information about the difficulties or help you need to dress or undress.

You should include details of any problems you have with:

- motivating yourself to dress or undress because it is painful for you; (you should score a
  possible 2 points under 6c(i))
- needing encouragement to dress, undress or put on clean clothing because you experience depression, anxiety, panic attacks or some other sort of mental health problem; (you should score a possible 2 points under 6c(i) or (ii))
- putting on and taking off nightclothes, underwear, skirts, trousers, socks, blouse, shirt, coat, hat, tying and untying shoelaces, fastening and unfastening your bra and any other problems with buttons, zips, laces and braces; (you should score a possible 2 or 4 points under 6b, d or e depending on the severity of your disability)
- selecting clothes to wear because you have a visual impairment, including making sure that clothes are clean, matching and appropriate to the weather and the occasion and that nothing is inside out or back to front; (you should score a possible 2 points under 6c(ii))
- being able to choose clothes that are suitable for the weather, for the time of day or for what you are doing; (you should score a possible 2 points under 6c(ii))
- going to bed still dressed in the clothes you have worn all day; (you should score a possible 2 points under 6c(i))
- having to carry out certain actions or rituals when you dress or undress, including taking extra time to choose clothes on the basis of your appearance (CPIP/3760/2016), which mean it takes you a long time to do so. (you should score a possible 2 points under 6c(i))

If you're struggling to know how to give detailed evidence for this activity, try writing the answers to these 6 questions:

- 1. What is the health condition and what are the symptoms that cause you problems with dressing or undressing? For example, stiffness caused by arthritis or fatigue caused by ME.
- 2. Describe the problems you have, giving details and examples if you can and making it clear whether it is your upper or lower body or both that you have problems with.
- 3. If you use any aids or appliances, list them and explain why you use them.
- 4. If you need physical help, supervision or prompting, whether you actually get it or not, explain what you need and why you need it, including if you need help when using aids or appliances. If you can't manage even with help from another person and have to have everything done for you, say so.
- 5. Say when during the day or night you have problems. For example, is it all the time, mostly in the morning or just at night?
- 6. If your condition varies, from day to day or week to week, try to explain how much it varies and what problems you have when you are at your best, worst and average.

#### Sample answer

Please note: these are just examples of the kinds of information you may wish to give – they aren't 'correct' answers of any sort. But it is vital that you give detailed evidence rather than just ticking boxes. You don't need to put the numbers in – that's just to show how the system works.

1. I have problems with this activity because of stiffness caused by arthritis.

- I suffer pain in my arms upper back and neck when trying to put on anything with sleeves, such as shirts, jackets and coats and when pulling on t-shirts or jumpers over my head. Pulling on underwear, trousers, socks and shoes also causes pain in my back, neck and arms. I find the pain completely exhausting and often have to stop and rest several times while dressing.
- 3. I don't use any aids because they don't help.
- 4. My son usually helps me to dress and undress, this doesn't stop it being painful, but it does make it less so and makes it a great deal quicker.
- 5. The pain and stiffness is at its worst in the morning, up until about lunch time. If my son goes out before I am up I often end up wearing my dressing gown until lunch time. I can then usually, though not always, manage to dress myself though still with pain and very slowly.
- 6. I am like this on the vast majority of days.

### Q9 Communicating (Activity 7)

#### What this activity is about

This activity is about your ability to speak in a way that people will understand and also to understand what other people are saying to you. It is highly relevant to people who have hearing difficulties. It is also relevant to people who do not have hearing difficulties but who have verbal communication difficulties due to their mental health, for example, stress, anxiety or schizophrenia. It may overlap with Q11, *Mixing with other people and it may be possible to score points for both.* 

#### The descriptors: what the law says you score points for

7a. Can express and understand verbal information unaided. 0 points.

7b. Needs to use an aid or appliance to be able to speak or hear. 2 points.

7c. Needs communication support to be able to express or understand complex verbal information. **4 points.** 

7d. Needs communication support to be able to express or understand basic verbal information. **8 points.** 

7e. Cannot express or understand verbal information at all even with communication support. **12 points.** 

#### Legal definitions

Remember, words like 'unaided', 'prompting', 'supervision' and 'assistance' appear in many activities and have strict legal definitions: see *General definitions you need to know*. In this activity the following words and phrases also have strict legal definitions, as shown below in italics:

**"Communication support**" means support from a person trained or experienced in communicating with people with specific communication needs, including interpreting verbal information into a non-verbal form and vice versa.

"**Basic verbal information**" means information in your native language conveyed verbally in a simple sentence.

"**Complex verbal information**" means information in your native language conveyed verbally in either more than one sentence or one complicated sentence.

Guidance for health professionals gives examples of simple sentences:

"Can I help you? I would like tea please; I came home today; The time is 3 o'clock."

and also of a complex sentence:

"I would like tea please; just a splash of milk and no sugar, as I always have sweeteners with me for when I go out."

#### Remember 'reliably'

As we explained in 'Reliably - the most important PIP word' above, you should not be considered able to do something if , for example, you aren't safe doing it or it causes you pain or discomfort or it exhausts you or you're very slow at doing it.

So, for example, if it takes you a very long time to say a few words, then this may count as not being able to speak.

#### Q9a Do you use an aid or appliance to communicate with others?

 $\Box$  Yes  $\Box$  No  $\Box$  Sometimes

**Important!** If you use an aid or appliance but still need help with an activity it is vital that you say so.

If you need to use an aid or appliance to be able to communicate with others, then tick Yes and give details in the 'Extra information' box on the next page. You should get 2 points for needing to use aids or appliances, unless a higher scoring descriptor also applies to you.

The kinds of things that might be relevant include:

- hearing aid
- hearing loop
- cochlear implant (in the ear)
- electrolarynx (electronic voice box or vocal chords)
- text to speech synthesiser

**Caution!** Decision makers may argue that you could use an aid or appliance as an alternative to having help from another person. If there is a reason why the aid or appliance would not mean you didn't need help, explain why. For example, your hearing loss may be of a type that would not be assisted by a hearing aid.

Guidance to health professionals tells them:

"If the claimant is not using a prescribed hearing aid, ask why. If there is a good medical reason such as chronic ear infection, function without the aid should be assessed. If there is not a good reason, expected function with the aid should be assessed."

**Overlap with the activity of mixing with other people (see Q11).** If you have a condition or combination of conditions where you need help with *both* 'communicating verbally' *and* mixing with other people (see Q11), you may be able to score points for *both* activities.

#### Q9b Do you need help from another person to communicate with others?

 $\Box$  Yes  $\Box$  No  $\Box$  Sometimes

The form explains that help includes 'help you need but don't get'. So, if you manage to communicate with others yourself because you don't have help but it takes an extremely long time, for example, then tick Yes and give details in the 'Extra information, box on the next page.

#### Extra information – Communicating

Tell us more information about the difficulties or help you need to communicate with others.

Guidance issued by the DWP suggests that communication support can include people like professional signers, but it can also include: 'someone directly experienced in communicating with the claimant themselves (for example, a family member)'.

So, if close family members can understand what you say, but you struggle to be understood by strangers then that may count as needing communication support. Give details on the form.

Your ability to lip-read should not be taken into account when deciding whether you are able to communicate (CPIP/315/2018).

#### DWP guidance states that:

'Individuals who cannot express or understand verbal information and would need communication support to do so should receive the appropriate descriptor even if they do not have access to this support. For example, a deaf person who cannot communicate verbally and does not use sign language might need another person to support them in another way – such as by writing verbal information down – even if they do not routinely have such help.'

If you're struggling to know how to give detailed evidence for this activity, try writing the answers to these 6 questions:

- 1. What is the health condition and what are the symptoms that cause you problems with communicating with others? For example, deafness or speech problems caused by Parkinson's disease.
- 2. Describe the problems you have, giving details and examples if you can.
- 3. If you use any aids or appliances, list them and explain why you use them.
- 4. If you need help, supervision or prompting, whether you actually get it or not, explain what you need and why you need it, including if you need help when using aids or appliances. If you can't manage even with help from another person and have to have everything done for you, say so.
- 5. Say when during the day or night you have problems. For example, is it all the time, mostly in the morning or just at night?
- 6. If your condition varies, from day to day or week to week, try to explain how much it varies and what problems you have when you are at your best, worst and average.

#### Sample answers

Please note: these are just examples of the kinds of information you may wish to give – they aren't 'correct' answers of any sort. But it is vital that you give detailed evidence rather than just ticking boxes. You don't need to put the numbers in – that's just to show how the system works.

- 1. Because of Parkinson's disease I have trouble controlling both the volume and speed of my speech.
- 2. This results in me mostly speaking very slowly and very quietly. In addition, I involuntarily repeat words and in general my sentences become a slurred, jumble that people have difficulty understanding.
- 3. There are no aids or appliances that can help with this.
- 4. Family and friends have become very patient and spend a lot of time ensuring they have understood me correctly. However, when in circumstances that require me to talk to other people e.g. shops, the Jobcentre etc it is very difficult to get across what I am trying to say. On many occasions people have become impatient which makes it even more difficult to control my speech. I always try to take someone with me to help interpret what I am saying when I need to talk to someone who doesn't know me well and I no longer use the telephone.

- 5. I always have at least this level of difficulty at any time of the day and it can get even worse when I am very tired.
- 6. My condition does not vary from day to day.
- 1. I have problems with this activity because I am deaf.
- 2. My first language is British Sign Language, not English. I can speak English but people often have difficulty understanding me and many people get embarrassed or impatient and try to avoid communicating with me. This can happen in all my everyday communications in shops, on public transport and at work. Although I can lip read, this is very difficult with people who are not experienced at speaking in a way which makes lip reading easier. As a result I need people to speak slowly, often they have to repeat things several times and even then I do not always understand. In the past, when I have tried to communicate with hearing people without an interpreter I have had to cope with people being very rude and aggressive or not understanding me and getting embarrassed. Either way I've ended up not being able to communicate effectively and often been left very upset by what has happened.
- 3. There is no aid that can help me with communication.
- 4. If I have an interpreter with me they can help me to communicate with hearing people.
- 5. I have difficulties communicating with hearing people at all times of day
- 6. and every day of the week.

## Q10 Reading (Activity 8)

#### What this activity is about

This activity is about your ability to read and understand written information in your own language. To be considered able to read, you must be able to see the information.

#### The descriptors: what the law says you score points for

8a. Can read and understand basic and complex written information either unaided or using spectacles or contact lenses. **0 points.** 

8b. Needs to use an aid or appliance, other than spectacles or contact lenses, to be able to read or understand either basic or complex written information. **2 points.** 

8c. Needs prompting to be able to read or understand complex written information. 2 points.

8d. Needs prompting to be able to read or understand basic written information. 4 points.

8e. Cannot read or understand signs, symbols or words at all. 8 points.

#### Legal definitions

Remember, words like 'unaided', 'prompting', 'supervision' and 'assistance' appear in many activities and have strict legal definitions: see *General definitions you need to know*. In this activity the following words and phrases also have strict legal definitions, as shown below in italics:

"Read" includes read signs, symbols and words but does not include reading Braille.

"**Basic written information**" means signs, symbols and dates written or printed standard size text in your native language.

"**Complex written information**" means more than one sentence of written or printed standard size text in your native language.

Guidance for health professionals gives the following examples:

An example of simple information would be a green exit sign on a door in a public building.

An example of complex information: "Your home may be at risk if you do not keep up repayments on your mortgage or any other debt secured on it. Subject to terms and conditions."

## Q10a Do you use an aid or appliance other than spectacles or contact lenses to read signs, symbols and words?

 $\Box$  Yes  $\Box$  No  $\Box$  Sometimes

**Important!** If you use an aid or appliance but still need help with an activity it is vital that you say so.

If you need to use an aid or appliance read signs, symbols or words, then tick Yes and give details in the 'Extra information' box on the next page. You should get 2 points for needing to use aids or appliances, unless a higher scoring descriptor also applies to you.

The kinds of things that might be relevant include:

- magnifying glass
- electronic magnifier

**Caution!** Decision makers may argue that you could use an aid or appliance as an alternative to having supervision or assistance from another person. If there is a reason why the aid or appliance would not mean you didn't need help, explain why.

## Q10b Do you need help from another person to read or understand signs, symbols and words?

□ Yes □ No □ Sometimes

The form explains that help includes 'help you need but don't get'. So, if you manage to read because you don't have help but it takes a long time or you cannot be sure that you have read words correctly, for example, then tick Yes and give details in the 'Extra information, box on the next page.

#### **Extra information – Reading**

Tell us more information about the difficulties or help you need to read and understand signs, symbols and words.

If you can only read braille or if you rely on written information being read aloud to you, this counts as not being able to read at all.

If you have never learnt to read, or have great difficult reading because of a learning difficulty, give details.

If you can read but have difficulty understanding because of, for example, poor concentration or a learning difficulty, give details.

DWP guidance states that:

'Consideration needs to be given to whether the claimant can read and understand information both indoors and outdoors. In doing so consideration should also be given to whether the claimant uses or could reasonably be expected to use aids or appliances, such as a large magnifier to read text when indoors and a portable magnifying glass to do so when outdoors. If the claimant is unable to complete the activity as described either indoors or outdoors, the descriptor may apply.'

If you're struggling to know how to give detailed evidence for this activity, try writing the answers to these 6 questions:

- 1. What is the health condition and what are the symptoms that cause you problems with reading signs and symbols? For example, visual impairment or dementia.
- 2. Describe the problems you have, giving details and examples if you can.
- 3. If you use any aids or appliances, list them and explain why you use them.
- 4. If you need physical help, supervision or prompting, whether you actually get it or not, explain what you need and why you need it, including if you need help when using aids or appliances. If you can't manage even with help from another person and have to have everything done for you, say so.
- 5. Say when during the day or night you have problems. For example, is it all the time, mostly in the morning or just in the evening?
- 6. If your condition varies, from day to day or week to week, try to explain how much it varies and what problems you have when you are at your best, worst and average.

#### Sample answer

Please note: these are just examples of the kinds of information you may wish to give – they aren't 'correct' answers of any sort. But it is vital that you give detailed evidence rather than just ticking boxes. You don't need to put the numbers in – that's just to show how the system works.

- 1. Because of my severe visual impairment
- 2. I cannot read normal sized text even with a magnifying glass.
- 3. I have text to voice software on my computer which allows me to listen to text, but this is the only way that I can manage alone.
- If I am outdoors or away from my computer I need someone else to read written words for me. For example, I cannot read warning signs, timetables, menus or directions on signposts.
- 5. My vision is even worse outdoors in poor light, such as in the evening
- 6. and it does not vary from day to day.
- 1. Because of my learning difficulty I have not learnt to read.
- 2. I am unable to read even simple words.
- 3. There is no aid which can help me.
- 4. I need other people to read instructions and directions for me.
- 5. I have this level of need at all times of day
- 6. and every day.

### Q11 Mixing with other people (Activity 9)

#### What this activity is about

This activity is about your ability to get on with other people when you are face-to-face with them, whether this is meeting with friends or attending a medical examination, for example.

#### The descriptors: what the law says you score points for

9a. Can engage with other people unaided. 0 points.

- 9b. Needs prompting to be able to engage with other people. 2 points.
- 9c. Needs social support to be able to engage with other people. 4 points.

9d. Cannot engage with other people due to such engagement causing either -

(i) overwhelming psychological distress to the claimant; or

(ii) the claimant to exhibit behaviour which would result in a substantial risk of harm to the claimant or another person. **8 points.** 

#### Legal definitions

Remember, words like 'unaided', 'prompting', 'supervision' and 'assistance' appear in many activities and have strict legal definitions: see *General definitions you need to know*. In this activity the following words and phrases also have strict legal definitions, as shown below in italics:

#### "Engage socially" means –

- (a) interact with others in a contextually and socially appropriate manner;
- (b) understand body language; and
- (c) establish relationships.

"*Psychological distress*" means distress related to an enduring mental health condition or an intellectual or cognitive impairment.

Guidance issued by the DWP goes on to add that: "However, this condition may have a physical root cause."

"**Social support**" means support from a person trained or experienced in assisting people to engage in social situations. (It can take place prior to the activity – [2019] UKSC 34).

#### **Remember 'reliably'**

As we explained in 'Reliably - the most important PIP word' above, you should not be considered able to do something if , for example, you aren't safe doing it or it causes you pain or discomfort or it exhausts you or you're very slow at doing it.

Even if you can engage socially with other people, you may not be able to do so reliably. For example, does a single social encounter leave you so filled with shame or remorse that you find it impossible to face people again for days afterwards? Or is there always a possibility that you will become overwhelmed with anxiety and have to abandon a social engagement part way through?

Also bear in mind that this activity is about whether you can engage with people generally, not just with people you know well. And, as guidance to health professionals explains:

"This activity encompasses all forms of social engagement, whether the 'relationship' established lasts 10 minutes, 10 days or 10 years. It should be considered in the context of everyday activities in which social and verbal interaction is required."

**Overlap with the activity of communicating (see Q9).** If you have a condition or combination of conditions where you need help with *both* 'communicating verbally' *and* mixing with other people (see Q 9), you may be able to score points for *both* activities.

#### Q11a Do you need another person to help you mix with other people?

 $\Box$  Yes  $\Box$  No  $\Box$  Sometimes

Mixing with other people could be anything from a cup of coffee with an acquaintance to a visit to your GP. The form explains that help includes 'help you need but don't get'. So, if you manage to mix with other people because you don't have help but it often goes wrong, for example, then tick Yes and give details in the 'Extra information, box on the next page.

## Q11b Do you find it difficult to mix with other people because of severe anxiety or distress?

 $\Box$  Yes  $\Box$  No  $\Box$  Sometimes

If you tick Yes or Sometimes, it will be important to give more details in the Extra Information box about your level of anxiety and how this affects you.

#### Extra information – Mixing with other people

Tell us more information about the difficulties or help you need to interact with other people.

For example, if you are unable to meet and chat with other people without a close friend or family member to help prevent you having panic attacks, you need to include this information on your form.

Or if you need your partner or parent to help you prepare for a social engagement, but providing they have done so you can manage on your own once there, then you need to explain this.

Do you have problems because:

- you misunderstand or can't interpret people's facial expressions or body language; (you should score a possible 2,4 or 8 points under 9b,c or d(i) or (ii) depending on the severity of your disability)
- you suffer from extreme anxiety; (you should score a possible 2,4 or 8 points under 9b,c or d(i) or (ii) depending on the severity of your disability)
- you cause offence without meaning to; (you should score a possible 8 points under 9d(ii))
- you misunderstand what people are saying and become angry or upset; (you should score a
  possible 8 points under 9d(i))
- you are too shy or anxious to speak or make eye contact; (you should score a possible 2 or 4 points under 9c or c depending on the severity of your disability)
- you say whatever you think other people want to hear, regardless of the difficulties it may create for you; (you should score a possible 4 or 8 points under 9c or d depending on the severity of your disability)
- you suffer from extreme fatigue or very poor concentration, so have difficulty following what people are saying to you and responding appropriately; (you should score a possible 2 or 4 points under 9b or c depending on the severity of your disability)
- you have to avoid things like shopping, using public transport or going out at times and in places where you might bump into people you know. (you should score a possible 2 or 4 points under 9b or c depending on the severity of your disability)

If you have ever physically hurt someone or been hurt yourself because of the way you behave around other people, you may score 8 points for this activity, so it is important that you give full details on the form.

#### When support is given

Social support does not have to take place during or immediately before a social engagement, it could take place weeks before or even after the event.

For example, if you would not be able to cope with social engagement if it were not for the support you receive at monthly meetings with your CPN or counsellor, then you may score 4 points for this activity.

Support in advance may include things such as talking through what is going to happen at the appointment or engagement, discussing what might go wrong and how to deal with it if it does and recalling other occasions when you have managed such an occasion successfully.

Or you may need help after the event. For example, knowing that a particular trusted person will be available afterwards to help you deal with any emotions or memories that have been evoked by an engagement may give you the confidence to take part, even though that person does not come with you.

#### Who gives the support

If you need support from someone *trained or experienced in assisting people to engage in social situations* this may make a difference to the points you score.

So, if you need prompting to engage socially and that prompting could come from any well-meaning friend or relative, then you may score 2 points.

But if the prompting would only be effective if it was given by someone *'trained or experienced'*, such as a trusted and experienced friend, relative, carer or enabler then it may count as social support and score 4 points.

This means it's important to make clear on your form if there are only a limited number of experienced people who can give you the support you need.

**Important note**. The DWP had been applying the law relating to the above two points – when support is given and who gives it - wrongly up until September 2020. They have now begun a review of PIP claims going back to April 2016 to try to identify claimants who missed out on an award of the standard or enhanced rate of the daily living component of PIP and pay them the money they are owed. You can <u>read more about this</u> and what you can do if you think you may have been affected on the Benefits and Work website.

#### Engagement is needed

An upper tribunal judge has ruled that 'isolated and specific' examples of being able to interact with other people, such as being able to talk to the health professional at medical assessment or to staff in a local shop you go to regularly are not enough to prevent you scoring points. In this case the claimant went to the pub and a chip shop every day, but said she avoided any engagement with other people and would move away if anyone stood next to her. She was able to respond to the PIP heath professional's questions without prompting and had adequate eye contact and rapport.

The judge held that simply going to the pub and the chip shop or responding to questions from a health professional was not evidence that the claimant engaged socially with other people or would be able to engage with people she did not know well.

You need to be able to engage with adults. CPIP/2034/2017 involved a teenager who could engage with other teenagers, but not with adults. The first-tier tribunal was in error of law in deciding that they didn't score points for this activity.

If you're struggling to know how to give detailed evidence for this activity, try writing the answers to these 5 questions:

- 1. What is the health condition and what are the symptoms that cause you problems with interacting with other people? For example, depression or severe anxiety.
- 2. Describe the problems you have, giving details and examples if you can.
- 3. If you need physical help, supervision or prompting, whether you actually get it or not, explain what you need and why you need it. If the help needs to come from specific trained or experienced people, or if you can't manage even with help from another person, say so.
- 4. Say when during the day or night you have problems. For example, is it all the time, mostly in the morning or just in the evening?
- 5. If your condition varies, from day to day or week to week, try to explain how much it varies and what problems you have when you are at your best, worst and average.

#### Sample answer

Please note: these are just examples of the kinds of information you may wish to give – they aren't 'correct' answers of any sort. But it is vital that you give detailed evidence rather than just ticking boxes. You don't need to put the numbers in – that's just to show how the system works.

- 1. Because of my Autism Spectrum Disorder (ASD) I find social interactions confusing and difficult.
- I struggle to understand the rules of social interaction. I don't read facial expressions or body language very well. I often stand too close to people, which makes them feel uncomfortable. I sometimes stare rather than making appropriate eye contact. I say things which are inappropriate and this can sometimes offend or embarrass people.
- 3. For days before I am due to meet people I will discuss ways to behave with my mother who will remind me of issues I need to be conscious of and practise appropriate behaviour with me. We discuss what to talk about, issues that should be avoided and strategies to cope with stress and anxiety if things are not going well. My mother is the only person who knows me well enough to be able to do this.
- 4. My condition doesn't vary throughout the day
- 5. or from one day to the next.
- 1. Because of my depression I have become very isolated and get very anxious at the thought of seeing even people I know well, other than my immediate family.
- 2. I go out very little and, when I do I have to go to the shops, I try to go very early in the morning so that I am less likely to bump into people I know. Even speaking to shop assistants makes me very anxious. I virtually never go to new places and would not attend a social event under any circumstances. If I have to go to an interview or for a medical I am frightened for days beforehand. I get so worried I can't eat and feel constantly sick. When I have to talk to someone at the Jobcentre or the health centre I get very shaky and I sweat and stumble over my words. Afterwards I feel ashamed and can't face even close family for days.
- 3. Having someone with me when I have to meet other people can even make things worse because I feel embarrassed and ashamed at them seeing how awkward I am in such situations.
- 4. My condition doesn't vary throughout the day
- 5. or from one day to another.
- 1. Because of my ADHD I find it very difficult to control my temper.
- 2. I get irritated and angry very easily and for quite minor reasons. For example my wife asked me recently if I had used her hairbrush, because she couldn't find it, and I exploded. I was already frustrated because I couldn't find my house keys so I over reacted and spent the next few minutes shouting and verbally attacking her until she was in tears and visibly frightened. Similar instances occur in various situations like waiting in queues or an item being out of stock in the shop. My over-reactions often cause people to move away from me or stop serving me or talking to me. Sometimes I will be asked to leave a café, shop or doctor's waiting room.
- 3. If I have someone with me they may be able to spot the signs that I am becoming agitated and help me to calm down.
- 4. I can become angry and upset at any time of the day
- 5. and on any day of the week. Although it doesn't happen every day, because it is not predictable I really need someone with me whenever I am interacting with other people.

## Q12 Making decisions about money (Activity 10)

#### What this activity is about

This activity is about your ability to deal with your money, from working out change to making sure you manage your money so that there's enough to pay all the bills.

#### The descriptors: what the law says you score points for

10a. Can manage complex budgeting decisions unaided. **0 points.** 

10b. Needs prompting or assistance to be able to make complex budgeting decisions. 2 points.

10c. Needs prompting or assistance to be able to make simple budgeting decisions. 4 points.

10d. Cannot make any budgeting decisions at all. 6 points.

#### Legal definitions

Remember, words like 'unaided', 'prompting', 'supervision' and 'assistance' appear in many activities and have strict legal definitions: see *General definitions you need to know*. In this activity the following words and phrases also have strict legal definitions, as shown below in italics:

"Simple budgeting decisions" means decisions involving -

(a) calculating the cost of goods; and

(b) calculating change required after a purchase.

#### "Complex budgeting decisions" means decisions involving -

(a) calculating household and personal budgets;

(b) managing and paying bills; and

(c) planning future purchases.

## Q12a Do you need someone else to help you to understand how much things cost when you buy them or how much change you'll receive?

□ Yes. □ No. □ Sometimes

The form explains that help includes 'help you need but don't get'. So, if you manage to in shops because you don't have help but you need the shop assistant to tell you whether you have enough money, for example, then tick Yes and give details in the 'Extra information, box on the next page.

# Q12b Do you need someone else to help you manage your household budgets, pay bills or plan future purchases?

□ Yes. □ No. □ Sometimes

The form explains that help includes 'help you need but don't get'. So, if you manage to you household budget yourself because you don't have help but you frequently get into debt because you haven't realised you should put money aside to pay for things, for example, then tick Yes and give details in the 'Extra information, box on the next page.

#### Extra information – Making decisions about money

Tell us more information about the difficulties or help you need making decisions about spending and managing your money.

You should include details of any problems you have with:

- adding together the cost of two or three items when shopping; (you should score a possible 4 or 6 points under 10c or d depending on the severity of your disability)
- working out how much change you should get; (you should score a possible 4 or 6 points under 10c or d depending on the severity of your disability)

- working out a weekly budget and sticking to it; (you should score a possible 2 points under 10b)
- making money last until your next payment; (you should score a possible 2 points under 10b)
- setting aside money after each payment to meet future bills; (you should score a possible 2 points under 10b)
- avoiding buying items if you know you will be in serious financial difficulties if you do so. (you should score a possible 2 points under 10b)

If you are currently in, or have previously had, serious financial difficulties because you find it difficult to manage money it may be worth giving details on the form. Have you ever been taken to court, had property repossessed, services cut off or lost your home because of money problems?

Bear in mind that your problems with budgeting decisions need to be connected to a physical or mental health issue, rather than just not being very good with money.

#### Having information read out

An upper tribunal judge has held that a claimant who has dyslexia or who is blind may score points for this activity if simply having the financial information read out to them is not sufficient, even if they don't have any additional impairment. The judge explained that if, for example, they become distressed, flustered or confused when trying to remember information that has been read out to them and need prompting as a result, they may score points for this activity.

If you're struggling to know how to give detailed evidence for this activity, try writing the answers to these 5 questions:

- 1. What is the health condition and what are the symptoms that cause you problems with making decisions about spending and managing money? For example, learning difficulties or severe fatigue.
- 2. Describe the problems you have, giving details and examples if you can.
- 3. If you need physical help, supervision or prompting, whether you actually get it or not, explain what you need and why you need it. If you can't manage even with help from another person, say so.
- 4. Say when during the day or night you have problems. For example, is it all the time, mostly in the morning or just in the evening?
- 5. If your condition varies, from day to day or week to week, try to explain how much it varies and what problems you have when you are at your best, worst and average.

#### Sample answer

Please note: these are just examples of the kinds of information you may wish to give – they aren't 'correct' answers of any sort. But it is vital that you give detailed evidence rather than just ticking boxes. You don't need to put the numbers in – that's just to show how the system works.

- 1. Because of learning difficulties I have problems with numeracy and with planning ahead.
- 2. Although I can buy things in my local shops that is because they know me there and will help me to find the right money. I can manage to hand over the correct money for a single purchase but I am not able to add up the cost of two or more purchases or to work out how much change I should get.
- 3. I never deal with household bills because I would not know what to do, that is done for me by my carer.
- 4. My condition doesn't vary throughout the day
- 5. or from day to day.

## **Mobility activities**

## Q13 Going out (Activity 1)

#### What this activity is about

This is probably the most confusing of all the PIP activities, but it can lead to an award of the mobility component all by itself, so please take your time to decide if it might apply to you.

'Going out' looks at your ability to plan a journey and also your ability to actually undertake a journey. It is not intended by the DWP to include the difficulties you have with the physical activity of walking, these are covered in the next activity, *Moving around*, although falls due to seizures may be relevant. It

It is relevant if you have a mental health condition, learning disability or sensory or cognitive impairment. You may get points if you have difficulties before you go out, such as with planning or motivating yourself to go out. You may also get points if you can only go out when you are accompanied, or if you can't go out at all due to distress caused by a mental health condition.

#### The descriptors: what the law says you score points for

1a. Can plan and follow the route of a journey unaided. **0 points.** 

1b. Needs prompting to be able to undertake any journey to avoid overwhelming psychological distress to the claimant. **4 points.** 

1c. Cannot plan the route of a journey. 8 points.

1d. Cannot follow the route of an unfamiliar journey without another person, assistance dog or orientation aid. **10 points.** 

1e. Cannot undertake any journey because it would cause overwhelming psychological distress to the claimant. **10 points.** 

1f. Cannot follow the route of a familiar journey without another person, an assistance dog or an orientation aid. **12 points.** 

#### Legal definitions

Remember, words like 'unaided', 'prompting', 'supervision' and 'assistance' appear in many activities and have strict legal definitions: see *General definitions you need to know*. In this activity the following words and phrases also have strict legal definitions, as shown below in italics:

"Assistance dog" means a dog trained to guide or assist a person with a sensory impairment.

"Orientation aid" means a specialist aid designed to assist disabled people to follow a route safely.

"psychological distress" means distress related to an enduring mental health condition or an intellectual or cognitive impairment.

Descriptors 1b and 1e refer to not just psychological distress, but 'overwhelming' psychological distress. There is no legal definition of overwhelming psychological distress, but it is likely to mean more than just becoming anxious or worried. Instead it needs to be such a degree of fear, anxiety or some other form of distress that it leaves you unable to act, without prompting in 1b or at all in 1e. So, a very clear description of how you are affected is needed for these descriptors to be seen to apply.

#### **Remember 'reliably'**

As we explained in 'Reliably - the most important PIP word' above, you should not be considered able to do something if , for example, you aren't safe doing it or it causes you pain or discomfort or it exhausts you or you're very slow at doing it.

Even if you can undertake a journey, would it be safe for you to do so? For example, are you safe around traffic or do you become so anxious that you may be a danger to yourself or other people? Or, if you went out once, would it leave you completely exhausted and unable to carry out other everyday activities?

Would you be unable to follow a route if there are small disruptions or unexpected changes such as roadworks or temporary bus stops? If this is the case, DWP guidance suggest that this means you cannot reliably follow a route without support.

#### Upper Tribunal ruling on 'Going out'

An upper tribunal of three judges made the law relating to 'Going out' a little clearer early in 2017, in a decision with the reference <u>CPIP/1347/2015</u>.

#### Prompting to help you start a journey

The tribunal decided that b) is about 'prompting' such as encouragement and reassurance that a claimant needs before they are able to set out on a journey. It's what they need to get them out of the door, but It does not cover prompting needed in the course of the journey, in spite of what the DWP have argued. So, if you need prompting in the course of the journey then the higher scoring descriptors d) or f) may apply.

#### Help whilst on a journey

The tribunal decided that if a claimant suffers 'overwhelming psychological distress' then they may be able to score points for d) or for f) as well as b) or e). They are not limited to only being able to score points for b) or e), as the DWP had argued.

So if you suffer from extreme anxiety that means you need someone else with you in order to follow an unfamiliar route then you may be able to score 10 points for descriptor d) and if you need help with familiar routes you may score 12 points for f) and be eligible for the enhanced mobility component on this basis alone.

#### Help to ask directions

The tribunal decided that not being able to ask directions if you became lost was not sufficient grounds to score points. However, if you suffer overwhelming psychological distress just because you come into contact with other people when on a journey, then that would need to be taken into account.

#### f) can't apply if you never go out

The tribunal decided that if e) applies to you and you never undertake a journey because of overwhelming psychological distress, then f) cannot apply because you would not be able to follow a route even if you had another person with you.

Even if you do suffer from anxiety and distress, if there is another reason why your mental health condition or learning difficulty makes it difficult for you to plan a journey or follow a route then you should give information about it.

For example, your condition may mean that you cannot concentrate well enough to plan the route of an unfamiliar journey.

Or you may be unable to follow a route because you become distracted or confused and lose your way.

#### Upper tribunal ruling on safety and supervision

See 'Safety and supervision' earlier in this guide for more on this decision.

In [2017] AACR 32ws, the Upper Tribunal held that claimants do not have to show that they would be at risk 'more often than not' in order to reasonably require supervision when carrying out an activity.

So, if you need someone with you when walking outdoors because you have epilepsy, for example, and may need assistance if you have a seizure, then we would argue you should score 12 points for this activity.

This should be the case even if you have seizures only rarely, if they are potentially very serious.

The same may apply to some people with learning difficulties, dementia and other conditions that may put you at risk.

Falls would usually be taken into account in relation to the 'Moving around' activity below. But if the falls arise as a result of a sensory or cognitive impairment, such as seizures, then you should give details in this section as well.

#### Upper tribunal ruling on driving

The claimant being able to drive is the most common reason for refusing to award points for this activity. Legally, however, this is wrong.

The guidance issued to health professionals tells them that: 'A person should only be considered able to follow an unfamiliar journey if they would be capable of using public transport – the assessment of which should focus on ability rather than choice.'

The judge in <u>CPIP/1094/2019</u> case didn't entirely agree with that guidance. He found instead that:

"... what is required is an overall and holistic assessment encompassing a claimant's ability to follow the route of a journey through various ways, including driving, travelling on foot and utilising public transport, with neither, of themselves, being determinative."

In other words, the decision maker should look at your ability to walk, use public transport and drive and then come to a conclusion about whether you can reasonably be said to be able to follow a route.

Just being able, or unable, to use one of those methods will not necessarily be conclusive evidence.

Whilst this makes it harder to say for sure who should and shouldn't qualify, it does mean that if you are turned down simply because you can drive, then you may have good grounds for an appeal.

There's more about driving further on in this section.

#### Caution: Q13a and Q13b

Questions 13a and 13b are very badly worded.

The guidance to health professionals says that 'The route that is being planned is unfamiliar – one does not need to plan a familiar route.' Yet question 13a asks 'Do you need help from another person to plan a route to somewhere you know well?"

There isn't a question at all about planning a route to somewhere unfamiliar, even though being unable to do so scores 8 points.

So, if you are unsure about whether to tick Yes to 13a or 13b, we suggest that you simply tick both and make sure you give a detailed explanation of your difficulties in the 'Extra information' section.

# Q13a Do you need help from another person to plan a route to somewhere you know well?

 $\Box$  Yes  $\Box$  No  $\Box$  Sometimes

This question is about familiar places where you are more likely to know the route.

If you tick 'Yes' or 'Sometimes' it's really important that you give additional information.

Planning a route means working out in advance how to get where you need to go, following the route means actually undertaking the planned journey and completing it.

Although this question only asks about problems planning a route for a familiar journey, if you have problems planning routes for unfamiliar journeys, including using street maps and working out which public transport to use, you can either tick 'Yes' to this question or 13b below or both. In either case, you should give details in the 'Extra information' box.

If you need to use an orientation aid to help you to follow a familiar journey, then you should score twelve points for this. The kinds of things that might be relevant include:

- long canes
- specialist satellite navigation systems, for example a satnav built into a Motability Scheme car

You should also score 12 points if you need somebody to be with you when following a familiar journey to keep you safe or stop you getting lost. For example, to help you to avoid obstacles, to direct you or to avoid 'overwhelming psychological distress'.

# Q13b Do you need help from another person, guide dog or specialist aid to get to a location that is unfamiliar to you?

 $\Box$  Yes  $\Box$  No  $\Box$  Sometimes

This question is about journeys where you do not know the route well.

Again, if you tick 'Yes' or 'Sometimes' it's really important that you give additional information.

Although it does not ask about problems planning unfamiliar journeys, if you do have problems, then tick 'Yes' or 'Sometimes' as appropriate here or in the question above and give detailed information.

If you need to use an orientation aid to help you to follow unfamiliar journey, then you should score ten points for this. The same applies if you need somebody with you.

As above, the help you need could include help to avoid obstacles, to direct you or to avoid overwhelming psychological distress.

#### Q13c Are you unable to go out because of severe anxiety or distress?

□ Yes □ No □ Sometimes

If you tick 'Yes' or 'Sometimes' to this, you will need to give details of how your anxiety or distress affects you and whether you are ever able to go out in the 'Extra information' box below.

As explained above, the upper tribunal has decided that if you can't undertake any journey, for which you score 10 points under 1e, then you cannot score 12 points for 1f. This is because 1e applies if you can't go out at all – even if somebody offered to go with you.

Health professionals are told that if you are able to leave home once to undertake a journey on a particular day then you will not score points for being unable to undertake any journey on that day. This will be the case even if you aren't able to do any other journeys that you want or need to on that day.

However, if you are only able to undertake journeys at night, this should not count as being able to undertake a journey.

Health professionals are told that this descriptor is likely to apply to claimants with severe mental health conditions such as agoraphobia and psychotic illnesses. It may also apply to claimants with cognitive impairments such as dementia.

#### Extra information – Going out

Tell us more information about the difficulties or help you need to work out and follow a route to another place and whether severe anxiety or stress prevents you from going out.

Remember, this is not intended by the DWP to include the any difficulties you have with the physical activity of walking, these are covered in the next activity: Moving around, although falls due to seizures may be relevant.

In a Benefits and Work survey of over 1,000 claimants who had claimed the mobility component on mental health grounds, the most common reason for being refused was being able to drive, or even just having a driving licence.

Other very common reasons included being able to get to appointments, going to the shops being able to use a taxi or just attending a face-to-face assessment.

It is worth considering dealing with these issues now, when you can ensure that accurate evidence is provided. It is likely that if you have an assessment the assessor will ask you about them and get to choose what evidence they do and don't put down.

If you deal with them now, even if the assessor records something different, you will have evidence you can take to appeal that predates – and contradicts – what the assessor has written.

#### Driving

Being able to drive should not, on its own, be used as evidence that you do not score points for this activity although it frequently is. (See 'Upper tribunal ruling on driving' above).

Things you can give evidence about include:

Even if you have a driving licence, do you drive? If not, is this because of your mental health/sensory issues?

Do you need someone to help you plan your journey?

Are you able to drive on the majority of days or is it just on some days?

Are you able to drive alone or do you need someone with you?

Can you only drive on familiar journeys, such as to the shops or to your GP surgery? If you can do unfamiliar journeys, can you do so reliably or is it only occasionally that you can

manage to drive somewhere unfamiliar?

Do you have problems when you get to the other end of the journey, the part between getting out of your car and getting to your destination, because of your mental health,?

What effect does driving have on you? Would you be able to do it reliably and as often as needed or would it affect you for a considerable time afterwards?

Even if you are able to drive, this is not necessarily sufficient to show that you don't qualify for the mobility component. Your ability to follow a route on foot and by public transport should also be taken into account, so give details of any problems you have with these means of following a route as well.

#### Using a taxi

Being able to travel by taxi is often also wrongly used to disqualify claimants from scoring points for this activity.

Even if you are able to call for a taxi, does this mean you can plan a route or is that one of the reasons you use a taxi?

Do you use a taxi because it means that you do not have to travel alone, because you have the taxi driver with you?

Do you always use the same taxi firm because you know the drivers?

Do you use a taxi because you cannot reliably travel on foot, use public transport or drive? Give details of any difficulties you have with these other means of following a route.

If you use taxis, not because you have physical problems with walking, but because you need them to plan or follow the route for you, then this should count as not being able to do so yourself. (You could score a possible 10 or 12 points under 1d or 1f)

#### Getting to the shops, attending GP and hospital appointments

Some assessors will pounce on any journey you are able to make as evidence that you do not qualify for points for this activity. Clearly this is wrong.

So, if you do manage to get to the shops, get to hospital or GP appointments, go to the hairdressers or anything else explain what difficulties, if any, you have with these activities.

Even if you can do regular, familiar journeys could you do unfamiliar ones? Can you follow even familiar routes as often as you need to in the course of a day? What effect does completing these journeys have on you? Do you go alone or have someone with you?

How do you follow routes on these journeys? Could you do them on foot, using public transport or by driving yourself if necessary?

Also, these are likely to be local journeys, and CPIP/2567/2018 decided that all types of journey had to be considered.

#### Getting to the assessment

Another common reason for being turned down is that the claimant managed to attend a face-toface assessment and that they did not show signs of overwhelming distress.

Clearly this isn't something you can deal with in your PIP2 form as you have not yet had the assessment.

But if you have had a previous assessment, or you have attended a similar type of appointment, you could consider giving details of how you travelled to it, any difficulties you experienced and what effect it had on you afterwards.

#### Walking the dog

Being able to walk a dog was a surprisingly common reason for refusing to award any points for this activity.

On its own, this is not evidence that you do not score points. In particular, a number of claimants told us they only walk their dog at night or very early in the morning, when they will not encounter other people. Health assessors are specifically told: *"being able to start a journey at night time only is not considered to be undertaking a journey to an acceptable standard."* 

In addition, walking a dog will not normally involve planning a route or going to unfamiliar places. Nor will it involve driving or using public transport.

If this is the only familiar journey that you can follow, then it cannot be said that you can reliably follow the route of a familiar journey.

#### Other information you can give

Do you have a visual impairment and need someone to warn you of hazards such as oncoming traffic and to help you find your way? (You could score a possible 10 or 12 points under 1d or f)

Are you deaf and need someone to warn you of hazards that you cannot hear, such as approaching traffic? (You could score a possible 10 or 12 points under 1d or f)

Do strangers or crowds make you anxious and aggressive, perhaps because you feel threatened or vulnerable? Guidance for health professionals tells them that points may be scored in relation to violent behaviour, but that there needs to be evidence that you cannot control your behaviour and that having someone with you reduces the risk of your being violent. (You could score a possible 10 or 12 points under 1d, 1e or 1f).

Might you harm yourself if you went outdoors alone? Guidance for health professionals tells them that points may be scored in relation to 'someone who is actively suicidal' in these circumstances, but that 'There must be good evidence that the person is a high suicide risk by, for example, high level involvement of community mental health services and a care plan.' (You could score a possible 10 or 12 points under 1d or 1f)

Do you approach strangers? Do you behave in some other way that puts you, or other people, at risk? (You could score a possible 10 or 12 points under 1d, 1e or 1f)

Do you get confused and disoriented if you are in unfamiliar places? (You could score a possible 10 points under 1d)

Are you unsafe near traffic because you get distracted, perhaps by disturbing thoughts or voices or by overwhelming feelings? (You could score a possible 10 or 12 points under 1d, 1e or 1f)

Remember to include the effects of any medication you take. Does it make you drowsy, apathetic or lethargic so that it is difficult to motivate yourself to undertake a journey? Does it make you too anxious or confused to undertake a journey? Does it make you dizzy or unsteady on your feet? Does it cause involuntary movements, dribbling or other side-effects which make you feel too self-conscious and vulnerable to undertake a journey?

Can you give any examples of distressing or dangerous experiences you have had as a result of your mental health condition, when undertaking a journey?

Would it help if someone encouraged you to go outdoors and/or came with you when you were in unfamiliar places? Can they help by monitoring your condition and calming you down if you get anxious, panicky or aggressive? Can they help if you get lost, confused or distracted? If so, give details. But an upper tribunal judge has ruled (<u>CPIP/703/2018</u>) that if just having someone with you

is sufficient to avoid overwhelming distress then this is sufficient – you don't have to show what specific things they do. (You could score a possible 10 points under 1d).

If you're struggling to know how to give detailed evidence for this activity, try writing the answers to these 6 questions:

- 1. What is the health condition and what are the symptoms that cause you problems with working out and following a route to another place? For example, a visual impairment or acute anxiety.
- 2. Describe the problems you have, giving details and examples if you can.
- 3. If you use any aids or appliances, list them and explain why you use them.
- 4. If you need physical help, supervision or prompting, whether you actually get it or not, explain what you need and why you need it, including if you need help when using aids or appliances. If you can't manage even with help from another person and have to have everything done for you, say so.
- 5. Say when during the day or night you have problems. For example, is it all the time, mostly in the morning or just in the evening?
- 6. If your condition varies, from day to day or week to week, try to explain how much it varies and what problems you have when you are at your best, worst and average.

#### Sample answer

Please note: these are just examples of the kinds of information you may wish to give – they aren't 'correct' answers of any sort. But it is vital that you give detailed evidence rather than just ticking boxes. You don't need to put the numbers in – that's just to show how the system works.

- 1. Because of agoraphobia I have great difficulty going outdoors.
- 2. I cannot go anywhere on my own and just thinking about doing so makes me very anxious indeed. If I even leave my front garden I start shaking uncontrollably, my chest gets tight and I believe I'm going to stop breathing, my heart races and I break out in a sweat. The only way to control the panic is to go back inside my house.
- 3. There is no aid or appliance I can use to help me.
- 4. My doctor visits me at home because I cannot go to the surgery and I have not seen a dentist for 3 years. I do all my shopping online or get friends and family to pick things (e.g. medication) up for me.
- 5. I have these problems at all times of the day
- 6. and every day.
- 1. My sight has been affected by retinopathy and associated blurred and obscured vision.
- 2. I am now unable to walk on my own as I cannot read signs or see dangers such as cyclists. It is no longer safe for me to cross roads unaccompanied because I cannot be sure that I have seen oncoming traffic. I trip often because the dark streaks in my vision prevent me from seeing some obstacles e.g. kerbs, bollards etc and I recently walked into a small child because my sight of him was blocked. This was most upsetting and resulted in my refusal to go outside of my home without someone to guide me.
- 3. I do not use any aid or appliance.
- 4. If someone accompanies me they can warn me of dangers and keep me safe.
- 5. I have these problems at all times of the day
- 6. and every day.
- 1. Because of my learning difficulties it is not safe for me to undertake a journey to an unfamiliar place on my own.
- 2. I can only go out on my own to very nearby places such as the local shops. I often react adversely when in public places as I find crowds and loud noises distressing. I am highly impulsive and impatient so if I have to wait in a queue or the bus is late my behaviour will become unpredictable, I may start to flap my hands, repeat a particular word over and over

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or even be verbally aggressive. I find traffic noise disorientating as I cannot 'shut it out' and tend to over react to sudden bangs or shouts. This combined with my poor spatial skills and short-term memory problems means that I get lost easily even if the route is familiar.

- 3. I don't use any aids.
- 4. If someone is with me they can make sure I don't get confused and lost.
- 5. I have these problems with moving around at any time of day or night
- 6. and on every day of the week.

### Making the Best Possible PIP Mobility Claims On Mental Health Grounds

#### Training for support workers

Check online for next 3 hour Zoom dates

*"Fantastic, really informative full of great pointers and enjoyable."* Samantha, Notts YMCA . *"I am very impressed with the standard of the event and the trainer's handling of it."* Kathy, barrister *"Best course done in ages. Made a complicated topic really clear."* Emily, Thalidomide Trust

Do your service users struggle to get an award of the mobility component of Personal Independence Payment (PIP) based on their mental health conditions?

Or do they only get an award at the standard rate, even though on most days they can't reliably follow the route of a familiar journey without having someone with them?

This half-day, online training course will allow you to give your service users the best possible chance of getting the correct award of the mobility component of PIP.

We explain how to provide detailed, accurate and persuasive evidence of a claimant's entitlement to points for the activity 'Planning and Following Journeys' when filling in the PIP2 Questionnaire, attending assessments, and at mandatory reconsideration and appeal stage.

The course contains a wealth of practical tips and useful examples. And it helps ensure that you anticipate the commonest reasons for refusal and counter them, preferably before they are even used. The course covers:

The mobility component of PIP - overview The activity 'Planning and Following Journeys' Question 13 on 'Going Out' in the PIP2 Form Mobility and mental health at the assessment How to use regulations 7 and 4 in this context The decision – common reasons for refusal and how to counter them Important examples from PIP case law and how to use them

This course runs from 9.30 to 12.30, with a 30-minute break. It is delivered online, via Zoom with a maximum of 14 participants.

This course is for staff working with claimants with mental health conditions and mobility needs. It is aimed at those with experience of PIP who want to develop their skills

further. Those who are new to PIP are welcome to enrol, but may want to familiarise themselves with the basics before attending this session.

Course cost: £85 + VAT per participant (£102) Book places online

## Q14 Moving around (Activity 2)

#### What this activity is about

This activity looks at your physical ability to stand and then move around outdoors. It does not cover mental health issues, such as being too anxious to go outdoors. These are covered in question 13 above.

#### The descriptors: what the law says you score points for

2a. Can stand and then move more than 200 metres, either aided or unaided. **0 points.**2b. Can stand and then move more than 50 metres but no more than 200 metres, either aided or unaided. **4 points.** 

2c. Can stand and then move unaided more than 20 metres but no more than 50 metres. 8 points.2d. Can stand and then move using an aid or appliance more than 20 metres but no more than 50 metres. 10 points.

2e. Can stand and then move more than 1 metre but no more than 20 metres, either aided or unaided. **12 points.** 

2f. Cannot, either aided or unaided, -

(i) stand; or

(ii) move more than 1 metre. **12 points.** 

### Legal definitions

Remember, words like 'unaided', 'prompting', 'supervision' and 'assistance' appear in many activities and have strict legal definitions: see *General definitions you need to know*. In this activity the following words and phrases also have strict legal definitions, as shown below in italics:

"Stand" means stand upright with at least one biological foot on the ground.

If you are a double amputee, any distance you can walk using prosthetic legs will be ignored and you will score 12 points for this activity for 2 f (i).

"Aided" means with -

(a) the use of an aid or appliance; or (b) supervision, prompting or assistance.

A wheelchair does not count as an aid or appliance here – it is in a category of its own and there's more on this below under Question 14c and the heading, 'Wheelchairs'.

#### The descriptors in plain English

We found these descriptors so confusing that we've rewritten them in the hope it will help you understand them more clearly:

a. If you can walk more than 200 metres either with: *no help; or with an aid or appliance; or with supervision, prompting or assistance from another person* you get **0 points.** 

b. If you can walk (more than 50 metres and) up to 200 metres either with: *no help; or with an aid or appliance; or with supervision, prompting or assistance from another person* you get **4 points**.

c. If you can walk (more than 20 metres and) up to 50 metres *without needing any aid or appliance and without help of any sort from another person* you get **8 points.** 

d. If you can walk (more than 20 metres and) up to 50 metres using an aid or appliance but without any help from another person you get **10 points.** 

e. If you can walk move (more than 1 metre and) up to 20 metres either with: *no help; or with an aid or appliance; or with supervision, prompting or assistance from another person* you get **12 points**.

f. If you can't stand at all or you can't move more than 1 metre either with: *no help; or with an aid or appliance; or with supervision, prompting or assistance from another person* you get **12 points.** 

#### Assistance

One big problem with these descriptors is what is meant by 'assistance'? The guidance issued by the DWP to Capita and Independent Assessment Services on the subject of assistance generally is that:

'Assistance is support that requires the presence and physical intervention of another person to help the claimant complete the activity - including doing some but not all of the activity in question. To apply, this only needs to be required for part of the activity.'

Does holding someone up as they walk along count as assistance or would that level of support mean that the person was in reality unable to walk? Would offering a steadying hand only when the person looked like stumbling be a reasonable level of assistance? What about an arm to lean on – is the person able to move for the purposes of PIP if they can only do it with someone else to lean on?

At this stage all you can do is give as much detail as you can and, if you are unhappy with the decision, consider an appeal.

#### **Remember 'reliably'**

As we explained in '*Reliably' - the most important PIP word'* above, you should not be considered able to do something if, for example, you aren't safe doing it or it causes you pain or discomfort or it exhausts you or you're very slow at doing it.

So, if you can stand and move around but you suffer from severe discomfort caused by, for example, breathlessness, pain or fatigue then any distance you can only cover with severe discomfort may not count. For example, if you can walk 100 metres but you experience severe discomfort after 30 metres then 2 c) may apply, rather than 2 b).

Let's say your disability means that you need to stop or pause after every 30 metres of walking before you carry on in stages to walk 200 metres or more. Whether you score points in this case depends on how long your stops or pauses last – as there is no set dividing line. Therefore you can argue for more points in one of two ways. Firstly, your stops may last so long that it cannot realistically be said that you are resuming the same period of walking: therefore 30 metres is your maximum. Secondly, your stops may last so long that, even if you are resuming the same period of walking, the overall time to walk 30 or 60 or 90 metres, etc., is more than twice as long as the time it would take a person without your disability.

#### According to DWP guidance:

'When assessing whether the activity can be carried out reliably, consideration should be given to the manner in which they do so. This includes but is not limited to, their gait, their speed, the risk of

falls and symptoms or side effects that could affect their ability to complete the activity, such as pain, breathlessness and fatigue. However, for this activity this only refers to the physical act of moving. For example, danger awareness is considered as part of activity 11.'

#### Enhanced rate mobility

It came as an enormous shock when, in December 2012, the DWP produced their final version of the PIP points system and revealed that the maximum distance you need to be able to walk to qualify for enhanced rate mobility had been slashed from 50 metres to 20 metres. There had been no reference to this in previous - obscurely worded - drafts of the descriptors.

Bear in mind though that if you score points for 'Planning and following journeys' you can add these to any points you score for the 'Moving around' activity. Nonetheless, there's no doubt that hundreds of thousands of people who qualify, or would in the future have qualified, for higher rate mobility DLA will now either get only the standard rate of PIP or will not get an award at all.

#### Q14a How far can you walk taking into account any aids you use?

- $\Box$  Less than 20 metres.
- □ Between 20 and 50 metres.
- □ Between 50 and 200 metres
- □ 200 metres or more.
- □ It varies.

Remember to take into account issues such as safely, reliably and repeatedly and in a reasonable time period when deciding what distance you can walk. Whatever box you tick, you will need to give further details in the Extra Information box below if you consider you should score points for this activity

It is worth noting that the legal distances are:

*'more than 1 metre but no more than 20 metres'* rather than less than 20 metres; and *'more than 20 metres but no more than 50 metres'* rather than between 20 and 50 metres.

So someone who can walk 20 metres but no more should score 12 points rather than the 10 points suggested by the way these choices are grouped. If, in your opinion you can walk just 20 metres then you may be better off not ticking any of these boxes but, instead, explain in the Extra Information box that you can walk 'No more than 20 metres'.

#### Q14b Do you use an aid or appliance to walk?

 $\Box$  Yes  $\Box$  No  $\Box$  Sometimes

An aid or appliance would be something like a walking stick, crutches or a walking frame, but not a wheelchair. Give further details in the Extra Information box below if you have ticked Yes or Sometimes. But note that not every an aid or appliance counts. For example an asthma inhaler does not count here because it is a device that helps with *breathing*, rather than *walking*.

# Q14c Do you use a wheelchair or similar device to move around safely, reliably and repeatedly and in a reasonable time period?

 $\Box$  Yes  $\Box$  No  $\Box$  Sometimes

Using a wheelchair does not count as standing and moving, so any distance you can only cover using a wheelchair should be discounted. For more on this, see 'Wheelchairs' below.

#### Extra information – Moving around

Here you will need to explain more about your difficulties and/or help you need to physically move around.

You will need to explain how far you can walk and at what distance you experience such issues as pain, severe discomfort, fatigue or breathlessness. You will also need to give details of any aids or appliances you use and how they help.

According to DWP guidance and law: 'This activity should be judged in relation to a type of surface normally expected out of doors such as pavements and roads on the flat and includes the consideration of kerbs.' So if you have difficulty with uneven surfaces and kerbs, give details on your form.

If someone can help you walk further by supervising, prompting or assisting you in some way you may want to explain precisely what help they can give and how far you can walk with this level of support.

#### Falls

If you are in danger of falling because of a sensory issue, such as poor vision meaning that you don't see obstructions, that may be more relevant to 'Planning a journey.'

However, if your falls are caused by a physical issue such arthritis in your knees which means they sometimes give way, extreme fatigue caused by ME or CFS, dizziness caused by low blood pressure or unsteadiness caused by Parkinson's disease, then they may be more relevant to this activity.

Is there anything that makes falling particularly dangerous for you? For example, do you have osteoporosis, so that even a minor fall could lead to broken bones? If this is the case, you may be likely to be judged to need assistance or supervision, even if the risk of falling is a small one.

Can you get up without help after a fall and if so, how long does it take you? If you can't get up at all without help, or it takes a long time, then you are more likely to need assistance or supervision.

#### Aids and appliances

If you need to use an aid or appliance to help you move around, this may affect the number of points you score. The kinds of things that might be relevant include:

- walking stick
- walking frame
- crutches

**Caution!** Decision makers may argue that you could use an aid or appliance as an alternative to having supervision or assistance from another person. If there is a reason why the aid or appliance would not mean you didn't need help, explain why.

Decision makers are fond of suggesting that if you fall because, for example, your knee gives way, you should use one or two walking sticks and this will prevent you falling. Would sticks prevent you falling? Do you get enough warning and could you support your weight on your arms? If sticks would not help, say so.

#### Wheelchairs

The original descriptors for this activity caused a lot of confusion by making repeated references to wheelchairs. This final version makes no mention of wheelchairs. The requirement that you must be

able to 'stand and then move' makes it clear that any distance you can only cover using a wheelchair does not count as 'moving'.

So, if you cannot move at all without using a wheelchair then you should score 12 points.

If you can walk a short distance without pain, severe discomfort, breathlessness etc. before needing to use your wheelchair, then it is that short distance that counts as 'moving' for the purposes of this activity. So, if you can stand and walk 40 metres using a stick before needing to get into your wheelchair then you should score 10 points for 2 d).

If you're struggling to know how to give detailed evidence for this activity, try writing the answers to these 6 questions:

- 1. What is the health condition and what are the symptoms that cause you problems with standing and then moving around? For example, multiple sclerosis or CFS/ME.
- 2. Describe the problems you have, giving details, including the distance you can walk.
- 3. If you use any aids or appliances, list them and explain why you use them.
- 4. If you need physical help, supervision or prompting, whether you actually get it or not, explain what you need and why you need it, including if you need help when using aids or appliances.
- 5. Say when during the day or night you have problems. For example, is it all the time, mostly in the morning or just in the evening?
- 6. If your condition varies, from day to day or week to week, try to explain how much it varies and what problems you have when you are at your best, worst and average.

#### Sample answer

Please note: these are just examples of the kinds of information you may wish to give – they aren't 'correct' answers of any sort. But it is vital that you give detailed evidence rather than just ticking boxes. You don't need to put the numbers in – that's just to show how the system works.

- 1. Because of rheumatoid arthritis I experience a great deal of pain when walking.
- 2. It is extremely painful for me to walk even a few yards. I have had to move my bedroom to a downstairs room as I can no longer climb more than one or two steps without experiencing great pain. I can just about make it from one room to the next using either a walking frame or furniture for support before having to sit down to recover from the pain. I seldom go shopping and when I do I use a Motability scooter or my wife pushes me in a wheelchair.
- 3. I use a walking frame indoors, but outdoors I need a wheelchair or scooter.
- 4. I could not walk 10 metres even with help from someone else.
- 5. My condition is worse in the morning, but always at least at the level described above
- 6. and does not vary much from day to day or week to week.
- 1. Because of ME/CFS I get fatigued very easily.
- I can move slowly from room to room indoors, but if I walk outdoors more than about 100 -150 metres I become very fatigued. The effect is worse the day afterwards when I will have to stay in bed for most of the day due to exhaustion
- 3. If I have to travel any distance I will always get a lift or use a taxi. Walking aids, such as frames or sticks don't make any difference to my level of fatigue.
- 4. In supermarkets my partner pushes me in one of the supermarket wheelchairs.
- 5. My problems are worst in the late afternoon and evening, when I could not walk even 50 metres without being exhausted.
- 6. I have 2-3 better days a week, but only if I don't over-exert myself.

### **Q15 Additional information**

You can use this box for additional information and/or attach additional sheets. If you do use additional sheets, make sure you put your name and National Insurance number at the top of each one.

The form also says that carers, friends and family can add information here. We would advise that, if you are getting supporting information from carers, friends or family you don't ask them to write on the form, but instead get them to give you letters you can include with the form. That way, if they write anything that is inaccurate you can either ask them to correct it or not submit the letter at all.

### Face-to-face or telephone assessment: reasonable adjustments

At the time of writing – August 2020 – face-to-face assessments have been suspended because of coronavirus. Instead, assessments are done either by telephone or on the paperwork alone.

However, we do not know when face-to-face assessments might be reintroduced and it is worth considering whether there would be problem for you if they were. If the problems are related to your health condition or disability then you can ask the DWP to make reasonable adjustments to allow you to fully take part in the assessment process.

N.B. we would never advise that you refuse to take part in an assessment if the DWP fail to make the requested adjustments. This would lead to your claim being stopped. But you can use the failure as one of your grounds of appeal if you do not get what you consider to be the correct award.

If you – or anyone accompanying you - would have problems attending a face-to-face medical give details here.

This could be things like problems with stairs, travelling, including using public transport or if you need a British Sign Language signer.

You may wish to tell them about any problems you would have with waiting in a public area amongst strangers or if you need access to a lavatory at all times because of continence issues.

If you are unable to use stairs safely in an emergency, make sure you check whether the centre you are being sent to is on the ground floor as soon as you receive your appointment. If it isn't, contact Independent Assessment Services or Capita and ask them to make alternative arrangements.

You can ask for a home visit as a reasonable adjustment, but whilst Capita seem to be happy to provide these Independent Assessment Services, are very reluctant and you will need medical support to show your need for a home visit.

You could also try asking for a telephone assessment if this would be a better alternative for you.

For example:

"I wish to request a telephone assessment rather than a face-to-face assessment as a reasonable adjustment. This is because the journey to an assessment centre will cause me considerable physical pain and emotional distress. This will be made worse if I have to wait for some time in a waiting room. As a result of the pain and distress it will be difficult for me to concentrate and give the kind of detailed responses to questions that will allow the health professional to make an accurate assessment of the effects of my condition. A telephone assessment will provide more reliable evidence."

Alternatively, you may feel that a telephone assessment would be a disadvantage for you. However, do bear in mind that, at present, no face-to-face assessments are taking place, so it might be a very long wait for a decision if your request was agreed to.

"I wish to request a face-to-face assessment rather than a telephone assessment as a reasonable adjustment. Because of my mental health condition I find communicating by phone extremely difficult. I am likely to become distressed and either not answer questions or give whatever answer I think the assessor wants to hear in order to end the call as quickly as possible. However, it may not be apparent from my tone of voice that I am distressed and I may simply appear to be uncooperative. In addition, the health professional will not be able to see that I am unable to make eye contact or that I am shaking and showing other signs of distress."

### Declaration

You have to sign and date the form before you send it. Even if someone else filled it in for you, you must read the evidence given – or have it read to you – and then sign the form yourself. It is only if someone else is your appointee that they can sign the form for you.

You are signing to say that the information is 'correct and complete'. If you've followed this guide then that will certainly be the case.

You are also signing to say that you understand that you must promptly tell the office that pays your benefit of anything that may affect your entitlement to, or the amount of, that benefit. This could be something like a change in your health condition outside its normal variation;

Congratulations! You've done it. The claim pack is complete. Photocopy this pack before you send it and you'll probably never have to spend so long filling in a form again in your entire life.

### Motability, Road Tax and Blue Badges

The Motability Scheme enables you to exchange all or part of your PIP Mobility component award to fund a car, wheelchair accessible vehicle, scooter or powered wheelchair. The Department for Work and Pensions (DWP) pays your mobility component directly to a local dealer or supplier and in return they will provide a vehicle, including insurance, servicing and breakdown cover.

To be eligible for the Motability Scheme under PIP you will need to be awarded the enhanced rate of the mobility component. The points can come from the 'Planning and following journeys' or 'Moving around' activities or from both. You must also have at least 12 months remaining upon your award when you apply for the Motability Scheme in order to qualify. For more information on Motability, click <u>here</u>.

You will be exempt from Vehicle Excise Duty (road tax) if you get the enhanced rate of PIP mobility component, or get a 50% reduction if you receive the standard rate mobility component. For more information on road tax, click <u>here</u>.

The Blue Badge scheme is operated by your local authority and enables you to park closer to your destination if you are disabled. From 30 August 2019, eligibility for the Blue Badge scheme has been extended to people with 'hidden' disabilities such as autism, learning disabilities and dementia. The new criteria has extended potential eligibility if one or more of the following applies:

- you cannot walk at all
- you cannot walk without help from someone else or using mobility aids
- you find walking very difficult due to pain, breathlessness or the time it takes
- walking is dangerous to your health and safety
- you have a terminal illness, which means you cannot walk or find walking very difficult and have a DS1500 form
- you have a severe disability in both arms and drive regularly, but cannot operate pay-anddisplay parking machines
- you have a child under the age of 3 with a medical condition that means the child always needs to be accompanied by bulky medical equipment
- you have a child under the age of 3 with a medical condition that means the child must always be kept near a vehicle in case they need emergency medical treatment
- you are constantly a significant risk to yourself or others near vehicles, in traffic or car parks
- you struggle severely to plan or follow a journey
- you find it difficult or impossible to control your actions and lack awareness of the impact you could have on others
- you regularly have intense and overwhelming responses to situations causing temporary loss of behavioural control
- you frequently become extremely anxious or fearful of public/open spaces

To be **automatically** eligible for a Blue Badge under PIP you will need to:

- (a) score 8 points or more for the 'Moving around' activity of the Mobility Component; or
- (b) score 10 points for descriptor (e) in the 'Planning and following journeys' activity of the Mobility Component, which is "cannot undertake any journey because it would cause overwhelming psychological distress to the claimant"

# It is still possible to apply directly to your local authority for a Blue Badge even if you don't meet the automatic eligibility criteria.

You will need to provide more information and medical evidence on your physical or mental health condition when you complete the Blue Badge application to demonstrate that you meet one or more of the extended criteria shown above. For more information on the Blue Badge scheme, click <u>here</u>.

# Supporting evidence means more chance of success

# What counts as evidence

The decision about what you score in the PIP assessment is based entirely on evidence.

The form you complete is evidence, as is any report filled in by your GP or consultant and the report of the Independent Assessment Services or Capita health professional, if you have to have a medical.

The more relevant evidence you can submit to support your claim, the better the chances of getting the right decision. In addition, detailed supporting evidence, especially medical evidence, may reduce the chances of your having to have a face-to-face medical assessment.

# Letting Independent Assessment Services and Capita collect evidence

The DWP say they will only ask you for medical evidence you already have, they will never ask you to obtain additional medical evidence. Instead, if further medical evidence is judged to be needed by Independent Assessment Services or Capita, they will send for it. Amongst the possible sources of evidence Independent Assessment Services and Capita should consider are:

- A factual report from a GP there's more on this in the next section.
- A report from other health professionals involved in the claimant's care such as a CPN.
- A report from an NHS hospital.
- A report from a local authority funded clinic.
- Evidence from any other professional involved in supporting the claimant, such as social workers.
- Telephone conversations with any such professionals.
- Information from a disabled child school or Special Educational Needs officer.
- Contacting the claimant by telephone for further information.

This will not be automatic, however. Health professionals will only send for additional evidence if they consider it will 'add value to the assessment process'. Independent Assessment Services and Capita will have to pay for any medical evidence for which there is a charge, such as GP factual reports, and then reclaim the money from the DWP at a later date.

In addition, the DWP have informed Independent Assessment Services and Capita that consultants reports 'attract a fee', 'can take a considerable time to be returned' and 'should only be obtained in exceptional circumstances'.

So, if you let Independent Assessment Services and Capita collect the evidence, you will not know before you attend your assessment whether your chosen health professionals have been asked for, and have provided, evidence. You will also not know if they were asked the right questions to get detailed answers relevant to your claim.

For this reason many claimants would rather try to collect and submit medical evidence themselves, rather than wait for Independent Assessment Services or Capita to do it.

Even if you do want Independent Assessment Services or Capita to collect evidence, it is still worth trying to visit your health professionals, let them know you are claiming or being transferred to PIP and update them about how your condition is affecting your everyday activities.

You can submit both medical evidence from your GP and other health professionals and nonmedical evidence from friends and relatives, amongst others.

### Additional evidence for special cases

In earlier editions of the PIP Assessment Guide, Independent Assessment Services and Capita were told at 2.3.9. that they:

"should strongly consider requesting further evidence before calling for a consultation a claimant who is noted to have an appointee or in a case where there is evidence of a previous suicide attempt, suicidal ideation or self-harm – or in other cases where the claimant is vulnerable. By gathering further evidence the HP may have sufficient information to complete a paper-based review which may be preferable in these cases to avoid distress to the claimant."

This guidance has been removed from the latest editions of the handbook, with no explanation given.

However, 2.3.8. of the same guide does say that

'The circumstances where obtaining further evidence may be appropriate include (but are not limited to):

'Where they feel that further evidence will allow them to offer robust advice without the need for a face-to-face consultation – for example, because the addition of key evidence will negate the need for a consultation or where they feel that a consultation may be unhelpful because the claimant lacks insight into their condition or a consultation may be stressful to the claimant.'

If a face-to-face assessment would be very stressful for you – especially if it could make your condition worse - it is worth explaining why and, if possible, providing supporting evidence You can write about this in the Additional Information section at question 15 and also refer back to it in the next box, which asks about help you would need to attend a medical.

Ask for further evidence to be collected and say who from.

You should also bear in mind, however, that the companies have also been told that only in exceptional circumstances should they ask for a consultant's report.

You might also want to point out that you consider that seeking additional evidence is a reasonable adjustment under the Equality Act 2010 in your case and failure to do so may result in legal action being taken. You would need to get legal advice if you wanted to take this further.

# Guidelines for collecting supporting evidence

Always try to arrange to have letters sent to you rather than direct to the DWP.

If the person you are asking is reluctant to do this, point out that you want to keep a copy for your records because it is far from unknown for the DWP to lose papers. Read any evidence before you submit it. If there are points in it that are incorrect or missing, and this might damage your case, try contacting the writer and asking them to send you an altered version. If they won't do this, or if the evidence is unhelpful for any other reason, then simply don't submit it.

If you write to someone asking for evidence, it's really important that you keep a copy of the letter you sent them. If you have to go to an appeal hearing, the tribunal may insist on having a copy of any letter you wrote to your GP, for example, asking for evidence. If you don't provide it they may adjourn the hearing in order to allow you to contact your doctor and get a copy. The reason they do this is to see how much of the information the doctor provides is simply taken from the letter you wrote, rather than based on the doctor's prior knowledge. However, it may then be three months or more before the hearing gets relisted.

If you wish to avoid having to submit letters you wrote asking for evidence, then simply don't write any.

Instead, make an appointment to see your health professional or go and visit or telephone friends or relatives and explain to them in person what it is you require. Take a copy of the descriptors with you and discuss which ones you think apply to you and why, if necessary. If you do have to attend a hearing you will have to say that this is what you did, if you are asked.

# Medical evidence from your GP

Under their contracts, GPs are obliged to complete certain forms for the DWP. GPs are not under any obligation to provide supporting letters to patients, however. Some are happy to do so, some will not do so and some will only do so if paid.

The DWP pays a standard price of £33 for a GP Factual Report. Independent Assessment Services and Capita have been informed that they are not allowed to negotiate their own rates with GPs, but must instead pay the DWP rate and then claim it back from the DWP.

# Medical evidence from health professionals other than your GP

This can include letters from an occupational therapist, specialist nurse, consultant or any other health professional you see.

If possible, it's always best to make an appointment to talk to the health professional. Tell them about the kind of problems your condition causes in relation to your everyday life and the kind of evidence you would like them to provide.

Unfortunately, some health professionals may refuse to write you a letter, saying that it's now a matter for the DWP, or they may say they will only write a letter if you are willing to pay for it. Health professionals are not under any duty to provide you with supporting letters, so unfortunately they are within their rights to refuse or to ask for money.

# **Medical records**

Some people ask their GP or hospital for copies of either all their medical records or for records that are relevant to their claim. There is likely to be a charge for copies of medical records, but often it will be much less than you would have to pay for a report written by a health professional. It is worth noting that, according to DWP guidance: 'NHS hospitals and Trusts are obliged to provide the DWP with hospital case notes (or copies), X-rays and factual reports within laid down timescales and free of charge'. However, there is no certainty that Independent Assessment Services or Capita will ask for them in your case.

# **DLA medical evidence**

We have been asked by a number of members who have been getting Disability Living Allowance (DLA) and are now being assessed for PIP if they can submit medical evidence relating to their DLA claim.

There is nothing to prevent you doing this and in some cases it may be very helpful. This is particularly the case if you have had a relatively recent DLA assessment.

But you do need to be aware that the criteria for PIP are very different to DLA, so the evidence may not address the PIP descriptors very closely. You can always submit both DLA-related medical evidence and new evidence specifically relating to PIP, if you can obtain it.

If you don't have copies of your DLA medical evidence, you can ask the DWP for copies by making a Subject Access Request. There's more details on how to do this on the .gov website:

https://www.gov.uk/government/organisations/department-for-work-pensions/about/personalinformation-charter

# Non-medical evidence

Non-medical evidence can be very persuasive and is certainly worth considering.

Both Independent Assessment Services and Capita health professionals and DWP decision makers have to take into account all relevant evidence. This includes any letters from friends, relatives, carers, neighbours and support workers such as social workers and housing workers.

If you live with someone, a partner or family member for example, they may be able to provide very detailed evidence about the way your condition affects you.

Equally, a letter from a social worker, housing worker or someone else with professional knowledge of the difficulties you face can give added credibility to the evidence in your claim form.

It can be very upsetting asking people to write about you in this way, try to ensure that you have someone to give you support, or possibly to approach people for evidence on your behalf.

# How and when to submit supporting evidence

You can submit additional evidence along with your 'How your disability affects you' form and that it should be read by the Independent Assessment Services or Capita health professional who carries out your medical assessment, if you have one.

We would suggest that, as well as sending your evidence in, you also take copies along with you to any medical and actually check with the health professional that they have seen copies of it.

If you wish, you can also send copies to the DWP office dealing with your claim, so that you can be reasonably sure that they are put in front of the decision maker as well.

It's worth bearing in mind that even if your supporting evidence makes no difference at the initial claim stage, it may make a dramatic difference when considered by an impartial tribunal, if you have to appeal your PIP decision.

# ESA medical reports being used for PIP decisions

A government minister confirmed in November 2014 that ESA85 medical reports - the work capability assessment medical report that is created if you claim Employment and Support Allowance (ESA) – are being used to make decision about PIP.

We have also heard from a number of Benefits and Work members who have been moved from the work-related activity group of ESA to the support group solely as a result of evidence gathered in the course of a PIP decision. So, it appears that both ESA and PIP reports are being used for purposes that they were not designed for.

We have yet to see any guidance for decision makers on how to use ESA85s in relation to PIP, though we have asked if any exists, but it is a concern for a number of reasons.

First, there are huge differences between the two tests, even when they are looking at similar activities.

In addition, you may have successfully appealed against an ESA decision and the tribunal may have found that different descriptors applied to the ones in your ESA85.

Alternatively, you may not have needed to appeal because you got sufficient points for ESA, but still consider that some of the descriptors you were awarded were incorrect.

Areas that might be seen by the DWP or Independent Assessment Services and Capita as overlapping include:

**ESA activities** '*Getting about*' and '*Navigation and maintaining safety*' with: **PIP activity** '*Planning and following journeys*'.

**ESA activity** '*Mobilising*' with: **PIP activity** '*Moving around*'.

**ESA activities** 'Coping with social engagement' and 'Appropriateness of behaviour with other people' with **PIP activity** 'Engaging with other people face-to-face'.

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**ESA activity** 'Absence or loss of control leading to extensive evacuation of the bowel and/or bladder' with:

PIP activity 'Managing toilet needs or incontinence'.

**ESA activities** 'Making self understood through speaking, writing, typing, or other means' and 'Understanding communication by both verbal means (such as hearing or lip reading) and non-verbal means (such as reading 16 point print)' with:

**PIP activities** 'Communicating verbally' and 'Reading and understanding signs, symbols and words'.

If you are claiming both ESA and PIP, it is worth taking into account that any evidence you give in relation to one benefit may be used in relation to the other and aiming to be as precise as possible.

Given that the outcome can sometimes be positive – as with claimants being moved from the WRAG to the support group of ESA – you may even consider there is good reason to bear both sets of criteria in mind when filling in your PIP form in relation to some activities.

Aside from that, there is probably little you can do except be prepared to challenge findings in your ESA medical report as well as your PIP assessment if you have to appeal a decision in relation to PIP.

# What's in a GP Factual Report form

Your GP may be sent a factual report form to complete. Considerable importance may be attached to this by a decision maker or tribunal, so it's vital that the information in it is as accurate as possible.

If you are making a claim for PIP then you should consider talking to your GP about any of the issues below that are relevant to your claim.

Your GP is asked only to provide information about symptoms that are recorded in your medical records and 'information about disabling effects that you or another healthcare professional have directly observed'. Clearly, most people will not have been observed by a healthcare professional carrying out tasks such as cooking or washing and bathing.

# **Questions in the GP Report Form**

### Date when patient last seen by a health professional

### Where and by whom

Please record relevant information based on your knowledge of the patient and their medical records.

Please write down facts rather than opinion. We require an objective report - please only include information about symptoms that are recorded in the patient's records and information about disabling effects that you or another healthcare professional have directly observed.

Please complete all sections as fully as possible but write "not known" if appropriate. "Not known" can be helpful.

### **1** Disabling conditions

Please list conditions or impairments which affect the patient's functional ability.

## 2 History of condition(s)

Include details of any relevant special investigations

## 3 Symptoms and variability

This is especially helpful in conditions that fluctuate. It should be based on information in the clinical record. Include both day-to-day and longer-term fluctuations. Include the frequency and duration of exacerbations. Please also specify if the condition is well controlled.

## 4 Relevant clinical findings

Entitlement is based on the impact of the individual's impairment or health condition(s) on their everyday life. Please provide details of examination findings related to the severity or impact of any health conditions or impairments.

## 5 Treatment – Current, planned, response and prognosis

Please provide details of drug and non-drug treatment and aids and appliances used (prescribed or, if known, non-prescribed). Please specify frequency of treatment and, for medication, dose as relevant.

## 6 Effects of the disabling condition(s) on day to day life

If known, it would be helpful to have information on the patient's ability to:

- Manage their health conditions and treatment
- Communicate
- Walk or move around
- Get somewhere on their own
- Make simple decisions
- Prepare, cook and eat food
- Wash, bathe and use the toilet/ manage incontinence
- Dress and undress

Only include information that has been confirmed by a health professional. Please state if this is not known.

### 7 Does the patient have a history of threatening or violent behaviour?

If yes, tell us about their behaviour within the last 5 years.

# 8 Could your patient travel to an assessment centre by public transport or taxi?

If no, please tell us why.

# 9 Additional information

# What kind of assessment will you have?

All claimants for PIP have an assessment of some sort.

It may be a:

- Paper-based assessment
- Telephone assessment
- Face-to-face assessment

However, all PIP face-to-face assessments have been suspended for three months from 17 March 2020, due to coronavirus.

So, at the time of writing, you will either have a paper-based assessment or a telephone assessment instead.

Which of these options you have will be up to either Capita or IAS, depending on where you live, to decide.

It is likely that if the assessment provider thinks they have enough information, they will opt for a paper-based assessment whenever they can.

However, the majority of claimants are still likely to have a telephone assessment at the moment.

# **Paper-based assessment**

Many claimants would much prefer to have a paper-based assessment.

The main thing you can do to increase your chance of having one is to make sure your claim includes as much evidence, including supporting evidence, as possible. This means as detailed a PIP2 claim form as you can create and any other evidence you can provide. You need to be aware that the DWP can use other evidence. For example, they have been known to use evidence from a Work Capability Assessment (WCA), especially if it does not support your evidence. If in due course you challenge their decision and you discover that they have done this, it is important to argue that the tests for PIP and the WCA are different.

However, you should be aware that having a paper-based assessment does not mean you will get an award. Paper assessments are also used where the health professional considers that there is little likelihood of your having any serious impairment.

Health professionals are told that they:

"should carry out assessments using a paper-based review in cases where they believe there is sufficient evidence in the claim file, including supporting evidence, to provide robust advice to the DWP on how the assessment criteria relate to the claimant. It is vital all advice is sufficiently evidenced."

In reality, some cases are more likely to have a paper-based assessment than others. Health professionals are told this includes cases where:

- The PIP2 form suggests a low level of disability and there is nothing to suggest underreporting.
- The health condition(s) is associated with a low level of functional impairment, the claimant is under GP care only and there is no record of hospital admission. This advice applies even if the claimant maintains that they suffer from a high level of functional impairment
- There is strong evidence on which to advise on the case and a face-to-face consultation is likely to be stressful for the claimant (for example, claimants with autism, cognitive impairment or learning disability)
- The claimant questionnaire indicates a high level of disability, the information is consistent, medically reasonable and there is nothing to suggest over-reporting (examples may

include claimants with severe neurological conditions such as multiple sclerosis, motor neurone disease, dementia, Parkinson's disease, severely disabling stroke)

You may not know that you have had a paper-based assessment until you get a decision letter from the DWP.

Alternatively, you may get a brief telephone call as part of the assessment process, where the health professional considers there are small amounts of additional information they need. You will not get any notice that you are getting a call in these circumstances.

There is more about this telephone call in the section on <u>If you get no warning at all</u> below.

# Getting an appointment for a telephone assessment

The information on telephone assessments has been created in part by using almost 300 responses to our survey of claimants who have actually been through the telephone assessment process. The survey has highlighted a number of issues that you need to be aware of.

# Legal notice of a telephone assessment

PIP regulations state that if you are to have either a face-to-face assessment or a telephone assessment you must be sent written notice of the date and time at least 7 days in advance.

While there have been some legal arguments over what 'sent' means, in CIB 4012 2004 the upper tribunal held that the DWP need to show that they posted an appointment letter so that it would normally arrive at least 7 days before the appointment.

## If you get less than 7 days

So, if you don't get 7 days' notice in writing and this going to cause you difficulties, contact the assessment provider straight away and explain that you need proper notice.

If they refuse to give you a new appointment, in writing, make a formal complaint and contact your MP.

However, you will need to think very carefully about whether, in these circumstances, you refuse to take part in the scheduled assessment.

If you do refuse, it is likely that your case will be returned to the DWP. It will then be up to you to prove that you were not notified correctly. It is very likely that in order to win the argument you would have to go to Tribunal, which is likely to be a long drawn out process. Even if you think you have a good case regarding the lack of the appropriate notification, you should strongly consider submitting a fresh PIP claim. If you don't you are relying on winning the original argument, and if you lose the argument, you will have lost the right to PIP in the meantime.

# If you get no warning at all

If you get a call without warning from a health professional asking questions about your condition and how it affects you, this is not necessarily a telephone assessment. Instead, it may be a that a paper assessment (see <u>Paper-based assessment</u> above) is being carried out, but the health professional needs to clarify a small number of points before they can complete their report.

In these circumstances you do not have the right to 7 days' notice.

However, it would still be perfectly reasonable to ask the health professional to call back at an agreed time. You might, for example, be feeling unwell or expecting an important call from someone else or find calls without notice very unsettling.

You could ask the HP how long the call is likely to take and what issues they need information on, so that you can be properly prepared.

The call itself should only be a short one. If the health professional needs to ask a lot of questions then clearly a paper assessment is not appropriate.

Guidance to health professionals, <u>PIP assessment guide part 1: the assessment process</u>, states:

1.4.15 Where necessary, HPs may seek further information from claimants by telephone. Such telephone calls should be made by approved HPs, not by clerical staff.

1.4.16 HPs should identify who they are and the purpose of the call. A written record should be taken of any telephone discussion seeking further information, using the claimant's own words as precisely as possible. This information should be included in the assessment report provided to DWP or via the PIPAT [software]. The HP should always ask if there is anything else that the claimant wishes to say before concluding the call. The call should conclude by reading back what has been documented and advising the claimant that this information will be added as evidence to the file.

It is clear then, that this is very different from a full assessment which will last much longer and would not include having the evidence read back to the claimant.

If, on the other hand, the health professional says it is a full assessment, then you have the right to 7 days warning. The risks of refusing to continue if the health professional does not agree to reschedule are, as above, that your case may be returned to the DWP and you may have to go to a tribunal to argue that you were not notified correctly.

# What happens at a telephone assessment during the coronavirus crisis

All PIP face-to-face assessments have been suspended for three months from 17 March 2020, due to coronavirus. Claimants will have a paper assessment or a telephone assessment instead.

# Recording a telephone assessment

From 21 September 2020, IAS (Atos) began recording telephone assessments if a claimant requests that they do so. At the time of writing (8 October 2020) Capita have not begun to do so, but the DWP say they will begin offering recordings *'shortly'*.

It would be wise to ask as soon as possible after getting notice of a telephone assessment for your it to be recorded and to bear in mind that it may result in your appointment having to be rebooked.

Even if you have your assessment recorded, we would still recommend that you consider making a covert recording of your assessment, just in case the DWP's copy goes astray when you challenge a decision.

If you ask for permission to record your telephone assessment it will almost certainly be refused because you will not be able to use dual recording equipment and immediately provide the health professional with one copy as the DWP require.

But there is no legal reason why you should not covertly record your telephone assessment, provided the recording is only for your own use in the same way you might make and use

handwritten notes. This includes offering a copy of the recording, or a transcript, to an appeal tribunal.

Guidance given to HPs carrying out face-to-face assessments states that if you are found to be secretly recording your assessment you should be asked to stop. If you do so the assessment can continue. If you refuse, the assessment will be halted and the DWP informed of the reason why and it is likely that you will be refused an award of PIP.

It is difficult to see how the health professional could tell that you were recording your assessment or how you could show you had stopped.

But the HP may ask at some point if you are recording the assessment, so give some thought to how you would deal with that situation.

If you do decide to record your assessment, it is definitely worth practising recording a phone call a few times so that you are familiar with the technology. You might choose to use a mobile phone's call recording function or to put your phone on speaker and use a separate recording device.

Whatever method you choose, make sure you are comfortable with using it. The last thing you want to do is spend the assessment in a state of even higher anxiety because you are worried about whether the recording is working or because you are concerned you might be questioned about whether you are recording.

It is still worth considering taking a few notes, just in case the recording doesn't work properly.

# Having someone with you at a telephone assessment

It's really important that if you need someone to help you with your telephone call, that they are able to take part. The fact that this is a telephone assessment should not in any way prevent you getting support from family or friends. Yet we have heard from members who have been told by the assessment provider that they can't have anyone else take part in the call.

One member told us:

"My partner has a telephone assessment on Thursday. Told him it could last for I hour .He has copd and heart problems. I asked could I speak for him as he gets very breathless they said no he has to speak himself."

Guidance to health professionals, <u>PIP assessment guide part 1: the assessment process</u> says for face-to-face consultations:

1.6.51 Claimants have a right to be accompanied to a face-to-face consultation if they so wish. Claimants should be encouraged to bring another person with them to consultations where they would find this helpful – for example, to reassure them or to help them during the consultation. The person chosen is at the discretion of the claimant and might be, but is not limited to, a parent, family member, friend, carer or advocate.

It goes on to say:

1.6.53 Consultations should predominantly be between the HP and the claimant. However, the companions may play an active role in helping claimants answer questions where the claimant or HP wishes them to do so. HPs should allow a companion to contribute and should record any evidence they provide. This may be particularly important where the claimant has a mental, cognitive or intellectual impairment. In such cases the claimant may not be able to give an accurate

account of their health condition or impairment, through a lack of insight or unrealistic expectations of their own ability. In such cases it will be essential to get an accurate account from the companion.

We would argue very strongly that this all applies equally to telephone consultations.

And on 23 April, Justin Tomlinson, minister for disabled people, agreed with this. He told the Commons Work and Pensions Committee:

"If you are having a telephone assessment, we are allowing your friend, family, trusted partner to be part of that process which is something we introduced a few years ago for face-to-face assessments which has made a huge difference to the quality of the outcome of the assessments."

# If the person is in the same household as you

If the person you want with you lives in your household then this is very straightforward. Make sure you introduce them when the call begins and explain why they are there.

If the health professional objects, read out the guidance above and the minister's statement to them.

If they still object, suggest that they ring Capita or IAS for advice before they continue with the assessment.

## If the person is in a different household to you

If the person lives elsewhere they are unlikely to be able to join you because of the lockdown. It should be absolutely no problem for Atos or Capita to arrange a conference call to include your accompanying person.

Contact them as soon as you receive notice of the call and ask for this to be done.

If they refuse to do so, make a complaint immediately and tell them that you will be contacting your MP and getting advice on bringing a claim for breach of the Equality Act 2010.

Just in case of technical problems on the day, you might want to look into whether you can join a third party into a call yourself when it has already begun. There are some phone providers that make this possible.

Alternatively, if you have two telephones, you may be able to have them both on speakerphone and get round the problem that way.

We would not advise you to refuse to go ahead with a call if your accompanying person cannot be joined in, unless the health professional is happy to agree to rearrange for a different date. If you simply refuse to take part, your claim is likely to be returned to the DWP and you will then have to try to show that you had good cause for not taking part in the assessment.

It is likely to be safer to take part in the assessment and make a formal complaint afterwards. If you do not receive the correct PIP award, one of your grounds of appeal would be the failure to allow you to have your accompanying person at your assessment.

# Things you will need at your assessment

The better prepared you are for your assessment, the more you will be able to concentrate on giving accurate, detailed evidence. The list below covers what we think are the main things you need to have for your assessment.

**Private space.** It can be hard in a lockdown to find somewhere quiet and undisturbed in your home for a call that could well last over an hour. But this really is essential if you are to give detailed and accurate evidence.

**Your National insurance number:** You may be asked for this as proof of ID. We had one member who had to go and find a letter with it on at the start of her assessment and was then grilled on where it was and how she had got there and back.

Letter with details of your assessment date and time. This should also have contact details of the assessment provider, you'll need these if the call doesn't come through or you get cut off and they don't call back.

**Copy of your PIP form**. It's definitely worth looking through this before the assessment. Are there points you think it's really important to make or things that you didn't put in that you want to tell the health professional?

Bullet point list of the most important points you want the health professional to be aware of.

**Notebook and pen**, even if you are recording the assessment it might be worth making notes if there is anything you are concerned about.

**Phone with speakerphone**. Around half of all telephone assessments last an hour or more, so it is definitely worth having speakerphone on if at all possible. Either use a landline or make sure your mobile battery is fully charged. If possible have it plugged in, because some mobile phones will not stay charged for a call lasting over an hour. Also try to be in the area of your house with the strongest signal, so you can clearly hear and be heard.

A separate phone on a different number, if possible. This will be useful if you need to call the assessment provider because the call has not come through. (See 'No caller ID' calls blocked, below).

Water. It's going to be a long call and you are going to do a lot of talking.

**Recording equipment**. Whatever method you are using to record the assessment, if you are doing so, make sure it's tried and tested.

List of medication and treatments. If there is an up-to-date list in your form, that's fine, otherwise make sure you have one.

Last minute medical evidence. It's not possible to show further written evidence at a telephone assessment, so if you haven't already sent it in try to get the DWP address that you can post it to immediately after the call. If the evidence is very short, offer to read it out to the assessor or read out key points from longer evidence, but keep it short and relevant.

# Problems to be ready for

# 'No caller ID' calls blocked

We are hearing from an increasing number of members who have missed their PIP telephone assessment because they block calls where the caller hides their ID.

Most health professionals carrying out telephone assessments are working from home and using their own telephone, so they are hiding their number from claimants.

However, many people have set up their phones so that they either do not accept calls where the caller's number is hidden, or the call goes straight through to their answering service.

The result is that the health professional calls the claimant, can't speak to them and hands the issue back to the assessment provider, IAS or Capita.

IAS or Capita will either then contact the claimant to try to rearrange the appointment and ensure that calls are not blocked or, in the worst cases, gives the case back to the DWP on the grounds that the claimant failed to attend their telephone assessment.

So, if you are due a telephone assessment, please make sure that callers who have hidden their number can still get through to you.

## The call may come early

70% of people in our survey say that their call came on time.

However, we have heard from people who were called up to three hours before the appointment time. This probably happens where a claimant doesn't answer the phone and the assessor then to moves on to the next available claimant.

Some people were taken by surprise by an early call, left flustered and without a copy of their form. They fear the assessment went badly as a result. So, it's a good idea to have a strategy ready in advance.

One option is to have everything ready in case the call comes early.

Another option is to not answer the phone, although there is clearly an element of risk to this.

Another is to answer and insist that the call takes place at the agreed time, especially if you have arranged to have someone join you on the call. If the health professional is reluctant, tell them you wish to speak to the office you received the appointment letter from and verify if they are insisting you accept an early call. If they do insist, tell them you will be contacting your MP and making a formal complaint

### The call may come late

Some people received calls half an hour or more after the appointment time. Sometimes the call was from a central office to say that the health professional was running late.

Our advice would be to leave it no longer than 10 minutes after the appointment time to call the assessment company, (See 'The call may not come at all' above for more on this).

Again, it is good to have a strategy in place for dealing with a late call. If you have to have therapy or a visit from a carer which will interrupt a late-running call, then the sooner you make this clear to the assessment provider the better.

### The call may not come at all

We have heard form one member who told us:

"Capita did not call. My appointment was at 11.45, I waited and no call was received. I phoned them at 1215hrs and was told that I had failed to attend for my assessment and that they had called 3 times! I was sat with my phone waiting for the call. They then blamed it on Vodafone saying they must have blocked them. I confirmed with Vodafone that no blocks are on my line."

We have heard from people who were not called and, when they contacted the assessment providers later in the day their case had already been returned to the DWP marked that they failed to answer. In these circumstances it can be a long, hard fight to get the assessment reinstated.

We have no way of knowing how often this happens. But it is best to be prepared.

We would suggest that you leave it no longer than 10 minutes after the appointment time to chase up a missing call. If possible do this on a separate line, so that the health professional can get through if they try whilst you are calling IAS or Capita.

Call every 10 minutes until you get confirmation of the new time of your assessment. If it still doesn't happen on time, repeat the whole process. If the assessment is cancelled ask for a new date to be given to you whilst you are on the phone.

If they won't do that and you are not recording the call, ask for the name of the person you are speaking to and make careful notes of the conversations and the times they took place, in case you need to challenge a decision that you failed to take part in an assessment without good cause.

#### Guidance on missed calls

In their document: Coronavirus (COVID-19) DA Telephone Guidance Capita tell assessors what to do in the event that they cannot reach a claimant at the appointed time for their telephone assessment.

Assessors are told that the call should take place at the prescribed time and the claimant should be given a minimum of 12 rings, unless the voicemail kicks in sooner.

Two more attempts should be made, one after another 10 minutes and one ten minutes after that.

If there is no response a message should be left on the answering machine telling the claimant to rebook.

However, we have heard from claimants whose case has simply been returned to the DWP after they allegedly failed to answer the phone.

So, it is important to know that the assessor is required to take a screen shot of their call history and send this immediately via email to their line manager.

If you find yourself accused of failing to be available for a Capita telephone assessment you can write and ask for a copy of this screenshot.

If the screenshot cannot be provided, you would have very strong grounds to argue at an appeal that, on the balance of probabilities, the tribunal should find that there was no evidence that the calls had ever been made.

IAS do not require their assessors to take a screenshot of their phone. However, they are required to leave a voicemail message asking you to rebook and to add a 'Contact record' in their PDS software. Again, you can request a copy of this, although clearly it is easier to falsely record details of calls that were not made if a screenshot is not required.

### The call may be very long

Almost half the people who completed our survey said the assessment lasted over an hour. For some it was over two hours and we even heard from someone for whom it was three and a half hours.

Give some thought to how you will deal with a very long call.

Will you need to ask for a break, either short or longer?

Do you need to ensure that you have drinks, food or medication to hand?

One thing we do know is the fact that you have managed to stay on the phone for so long can be used as evidence to show your powers of concentration and ability to carry out demanding tasks. If you don't use speakerphone assumptions may be made about your ability to hold and manipulate objects over a long period.

So be very sure to tell the health professional of any effects such a long call is having on you.

# There may be technical problems

The main technical problem that people encounter is poor reception on phones. Not being able to hear the assessor's questions and/or the assessor not hearing your responses was a frequent issue.

"I frequently couldn't hear him and had to ask him to repeat himself again and again. He seemed to be mumbling and too far away from his phone. He became annoyed and rude just because I couldn't hear or understand him."

It would be worth ensuring that, if you are using a mobile phone, you are in a place in your home that gets a good signal. You may want to look at the possibility of using a headset or external speaker to help with volume problems.

Getting cut-off was a common occurrence too. At the start of the call, consider asking the health professional what the procedure will be if you get cut off. Will they call you back immediately? Do you have another number they can call in case there are problems getting through?

Some health professionals also had problems logging into their company's online system. There's not a lot you ca do about this except be aware it may happen and be prepared to be patient whilst the problem is resolved.

# There may be breaches of your privacy

It may seem astonishing, but we have been contacted by a number of claimants who heard other people talking and laughing in the background. Others told us the health assessor said they had a child with them.

In other cases, claimants have suspected someone else is there because they have heard doors opening and closing.

These sorts of breaches of confidentiality should never take place. If an assessor has not got a private space in which to work, then they should not take on clients.

It is worth thinking about how you will respond if this happens to you. Clearly it is a very difficult position to be placed in.

If you feel able, raise it with the health professional and say you would like an assurance that the assessment can be conducted confidentially or you would like it to be rescheduled.

You may wish to make a complaint about any breach of confidentiality. If so, be sure to copy it to your MP.

# You may not be asked enough relevant questions

Around a quarter of respondents to our survey said they had not been asked enough questions at their assessment. This particularly applied to the mobility component and especially in relation to mental health.

It is worth having a bullet point list of the most important points you want to make to the assessor and ticking them off as you go through them

A very common technique of assessors when you try to raise issues is to say 'We will deal with that *later*' and then never return to it.

So, at the end of the assessment, if there are points left on your list, tell the assessor there are some important points that have not been covered ad you wish to briefly deal with them now.

If the assessor refuses, make a note of this as evidence for any appeal.

If you have recorded your assessment the you will have evidence of what you told, or tried to tell, the assessor.

### The assessor may not have read your form

Six out of ten people thought the assessor had read their form. The rest either weren't sure or knew that the assessor hadn't.

"He actually said 'I haven't read it, have I?' when I referred to my claim from and supporting evidence as if he thought I was stupid to think he had."

Sometimes the health professional said they had read the form, but it was clear from their questions that they hadn't or that they were reading it for the first time as they carried out the assessment.

"Did not know my health condition kept naming condition not on the form."

So, please don't assume that the health professional actually knows anything about you, other than your name, before the assessment begins.

Again, it's a very good reason to have that set of bullet points that are the most important things you want the health professional to know. That may well include your health conditions.

### Your preparations may be used against you

We have head from people who said that the fact they could take part in a long telephone interview, understand and make themselves understood was evidence that they could carry out many demanding tasks.

If you are using your PIP2 form or other notes to help you answer questions, tell the assessor this and make it clear you are not relying on memory for all of your answers.

If the interview is causing you physical pain, fatigue or emotional distress make sure you make this clear to the health professional. If you record the call or keep notes, you will have evidence that you told them this, even if they do not make a note of it.

### What you will be asked at your telephone assessment

Most telephone assessments last an hour or more and people who have had them report being asked a lot of questions about care issues, though sometimes fewer about mobility issues.

So, it seems very likely that the telephone assessment is very similar to a face-to-face assessment in terms of questions asked.

Guidance issued to health professionals tells them they should go through:

A history of your conditions – when they began, any changes over time, how much they fluctuate.

Summary of treatment - already undertaken and any that is planned.

All medication – prescription and non-prescription

**Social and occupational history** - this includes where you live, who you live with, what social and leisure activities you undertake or have had to give up and whether you work now or have in the past.

**Typical day** - all the activities you do on a normal day from getting out of bed in the morning to going to bed at night.

There is a list of <u>questions you may be asked at your assessment</u> further on in this guide, along with questions you may not be asked but should be. It's definitely worth reading through these and considering how you could most accurately answer them.

One member told us that they printed off the list and used it to help them make notes as the telephone assessment took place.

# 'Fertile areas'

In their guide to *'Telephone Assessments during Covid-19 crisis'* for PIP assessors, IAS (Atos) have introduced the concept of 'fertile areas'.

The idea is that because assessors cannot carry out a physical examination of claimants, or see them to make observations about their appearance and manner, they need another source of evidence.

IAS have told assessors that they should look at four possible 'fertile areas' for additional evidence:

- Childcare
- Hobbies
- Education
- Work

For each of these areas they have created a chart showing how the activity can be broken down and how each part may provide evidence that is relevant to PIP.

So, for **childcare** they suggest assessors ask about:

Number and age of children: motivation, cognition, safety Mealtimes: limb movements, safety, sensory, motivation, cognition, sequencing Hygiene and dressing: limb movements, safety, sensory, motivation Playtime: motivation, safety, cognition, communication, sensory, School contact: Engaging with others, communication, going out Assistance needed with childcare: motivation, safety, cognition, pain, fatigue, communication School run method, to and from: Going out, moving around, anxiety School run frequency, to and from: Motivation, moving around, pain, fatigue, reliability

For **hobbies**, they suggest assessors ask about:

How often: Motivation, moving around, pain, fatigue, going out Type of hobby: Motivation, pain, fatigue, sensory Travel to and from venue: Planning and following a journey – cognition, sequencing, memory, sensory, undertaking a journey - anxiety, moving around Solo or group activity: Engaging with others, communication, sensory, going out Payment if applicable: Budgeting, cognition Age appropriate tasks: Cognition, concentration, comfort seeking For **education**, they suggest assessors ask about:

Mainstream or special school: Learning disability, learning difficulties, sensory, behaviour Reasons for special support: Cognition, sensory, concentration, anxiety, behaviour Subjects studied and exams taken: Cognition, learning difficulties, limb movement, sensory Pass or fail exam results: Cognition, concentration, behaviour, anxiety College course details – life skills or other courses: Cognition, safety, sensory Travel to and from school/college: Travel training, cognition, sensory

For **work**, they suggest assessors ask about:

Hours and days worked: motivation, pain, fatigue, concentration, reliability Job title: Cognition, memory, sensory Work tasks and responsibilities: Moving around, limb movements, motivation, memory, cognition Adaptations: Pain, fatigue, sensory, moving around Sickness: Motivation, pain, fatigue, reliability Journey to and from work: Planning and following a journey – cognition, sequencing, memory, sensory, undertaking a journey - anxiety, moving around

The problem, as always, is the risk that assessors will ask as little as possible and assume as much as possible.

So, they may ask if you do the school run. If you say yes they may simply use this as evidence that you have no problems with: going out, moving around, anxiety, motivation, pain, fatigue or reliability.

So, if you are often late on the school run, if you often have to get another parent to do it for you because you become overwhelmed with anxiety, if you have to come home and rest for hours after doing it or if you have any other problems it's vital that you volunteer the information even if you are not asked.

Likewise for all the other activities.

### Evidence that can't be collected at a telephone assessment

There are some things the health professional can do at a face-to-face assessment that they can't do on the telephone.

### Travel to the assessment

Where a claimant has to travel to an assessment centre and wait in a waiting room, lots of unfair assumptions are often made based on how long the journey and the wait were.

This source of evidence is obviously not available in a telephone interview and most claimants would probably regard this as a good thing.

#### Informal observations.

Informal observations take place when the health professional watches you doing things, such as removing your coat or opening a door and then makes often very unfair assumptions based on them.

They also look at the way you are dressed, your facial expressions and your appearance and, again, make often very unfair assumptions about you.

Most of these observations will not be possible over the phone and. Once more, most claimants would probably regard this as a very good thing.

However, even over the phone, informal observations can still be made about such things as your mood, how you respond to questions, your ability to concentrate and your ability to hear.

## **Functional examination**

If you have a physical health condition or disability the health professional at a face-to-face assessment may carry out a functional examination.

This includes:

- vision
- cardiorespiratory system
- musculoskeletal system

This could be things like a sight test, looking at how far you can raise your arms or legs, how far you can turn your head, asking you to rise from sitting or bend down, testing your lung function and so on

Clearly none of this can happen during a telephone assessment. So if, whilst you are being asked questions, you can provide the health professional with examples from your everyday life that will make up for their inability to carry out a physical function examination, that may help them to write an accurate assessment.

However, some aspects of a mental state examination can be carried out over the phone. This can includes things like may being asked to do 'serial sevens' which involves counting backwards from one hundred in sevens.

Or you may be asked how much change you would get if, for example you bought a 75p loaf with a pound coin.

Or you may be asked to spell the word 'world' backwards.

### How long until you get a decision

At the time of writing (April 2020) health professionals have been telling claimants to expect to wait six to eight weeks from the date of the assessment before they get a decision from the DWP

# Getting an appointment for a face-to-face assessment

N.B. All PIP face-to-face assessments have been suspended for three months from 17 March 2020, due to coronavirus. As of 3 November 2020 this suspension is still in place. Claimants will have a paper assessment or a telephone assessment instead.

When you receive your appointment for a face-to-face assessment, you may find that it is for an centre many miles away, even though there is one much closer to you.

This appears to be because computerised systems used by the companies involved find the first available appointment for you at any centre within90 minutes travelling time in the next 14 days, regardless of whether there are closer centres.

No check of whether you have provided information about difficulties with travelling in your 'How your disability affects you' form appears to be made before your appointment is allocated.

You can phone and ask for a different venue or time once you receive an appointment. But, if you refuse this second appointment, your file is then returned to the DWP for a decision on whether to stop your PIP claim for failing to attend a medical without good cause.

In addition, we have heard from members who have had their file returned to the DWP even though the reason they 'refused' two appointments is that the assessment provider cancelled them both at short notice by phone.

If you do have an appointment cancelled, it is worth considering writing to the DWP to inform that this has happened, so that at least you have provided evidence from the outset if there are problems later on.

You can also ask Independent Assessment Services or Capita to pay for a taxi or provide a home visit if the assessment centre you are being asked to attend is too far for you to travel. As always, it will help if you have medical evidence of your difficulties with travelling.

When deciding whether to grant a request for a home visit, Independent Assessment Services and Capita are told to take into account issues such as:

- Does the claimant have a medical condition that precludes them from travelling?
- Has there been medical verification of the severity of the condition that precludes them from attending a consultation?
- Are there health and safety implications for a home consultation? For example, the claimant or a person associated with them has had unacceptable claimant behaviour identified.
- Any accessibility issues related to the planned location of consultations.

If you are refused a home visit, it may be worthwhile asking your M.P. to take the matter up. The system for allocating appointments is clearly unfair and may even be a breach of the Equality Act.

But if you do find yourself having to travel to an unfamiliar venue for an assessment, please check our <u>listings of PIP assessment centres</u>, where other claimants may have given useful information about travel, parking and facilities for claimants.

# What happens at a face-to-face medical assessment

N.B. All PIP face-to-face assessments have been suspended for three months from 17 March 2020, due to coronavirus. As of 3 November 2020 this suspension is still in place. Claimants will have a paper assessment or a telephone assessment instead.

Two companies have been appointed to carry out face-to-face medical assessments.

Independent Assessment Services, formerly known as Atos, carry out PIP medicals in:

- Scotland
- NE England
- NW England
- Isle of Man
- London
- Southern England.

Capita carry out medicals in:

- Wales
- Central England.

### www.benefitsandwork.co.uk

Although the DWP claim that PIP medicals are not at all like ESA medicals, they do seem to be remarkably similar, including the fact that they will be computer led.

The medical consists of four parts.

First, the health professional (HP) should read any documents relating to your case.

Next, they ask you a series of questions about your condition and about your everyday life, making notes on paper or on a computer as they go.

Then they may carry out a brief physical examination, checking things like your eyesight, your blood pressure and the range of movement in your limbs, if any of these are relevant to your condition.

Finally, after you have gone, they will list which descriptors they consider apply to you and justify their conclusions.

# **PIPAT computer software**

Both Independent Assessment Services and Capita have access to the DWP's PIPAT software, although it is not clear if it can be used where a medical is carried out in the claimant's home.

Using PIPAT, HPs can see any documents relating to a PIP claim, including the claim form and supporting medical evidence, all of which is scanned and stored in .pdf format. According to DWP guidance, the health professional is supposed to have read everything on your file before beginning the assessment, including:

- The questionnaire.
- Supporting information supplied by the claimant.
- Any further medical or other evidence supplied by the claimant.
- Information from the claimant's GP or other relevant supporting professional gathered by Independent Assessment Services or Capita.
- Information from earlier claims and assessments, if the claimant is being reassessed for an existing award of PIP.

HPs can also use PIPAT to record details of any requests they make for additional evidence and to justify a decision on whether to call the claimant in for a medical.

PIPAT's main role, however, is to guide the HP through the actual medical assessment itself and to generate the report that will be used by the decision maker when deciding whether to make an award of PIP and, if so, at what rates.

PIPAT includes collections of standard phrases that HPs can choose from, as well as free text boxes they can type evidence into. They are expected to use a combination of both to create their report.

# PA1 Review form

When Independent Assessment Services or Capita receive your details from the DWP, the first thing they have to do is look through all the documents connected with your claim and complete a PA1 Review form. The HP uses this form to explain whether they are going to:

- Send for further evidence.
- Arrange a face-to-face consultation.
- Advise the DWP just on the basis of the papers they already have.

Options for further medical evidence include contacting your: general practitioner; consultant; community psychiatric nurse; counsellor; hospital doctor; occupational therapist; psychiatrist; psychologist; physiotherapist; social worker; specialist nurse; teacher.

Clearly, sending for further evidence, such as a GP factual report or a consultant's report can cause considerable delay. In addition, if the HP sends for further evidence a further review will have to be carried out when this arrives, to decide whether to call you in for a medical or not.

In the vast majority of cases a face-to-face medical does take place.

# PA4 Medical Consultation Report

Whether or not the HP uses PIPAT, a PA4 Medical Consultation Report form has to be produced. This covers the following areas:

- The evidence the health professional has looked at, such as a report from your GP.
- A list of all your health conditions.
- A history of your conditions, including recent hospital visits and tests.
- Your current medication and any treatment.
- Your social and occupational history, including who you live with and your current or former job.
- A functional history, including how you spend a typical day and night and any hobbies and interests you have. This section should also include details of how your condition varies and the effect of factors such as pain, fatigue and breathlessness. Any aids or appliances you use should also be listed in this section.
- A description of your general appearance.
- Where relevant, assessments of your:
  - o mental state
  - o vision, speech and hearing
  - o cardiovascular/ respiratory system
  - o musculoskeletal system
  - o central nervous system
  - o other systems (skin, abdomen, etc.).
- Informal observations (see below for details of these).
- The descriptors the HP considers apply to you.
- How long your difficulties with daily living and/or mobility have lasted and are likely to continue for.
- A summary justification for the conclusions the HP has reached about the effects of your condition(s).

Throughout the consultation, the HP will be making informal observations of things such as:

- Your appearance- whether you are tidy and clean.
- Your skin tone.
- Your manner.
- Your hearing ability.
- Your walking ability.
- Your mood.
- Your ability to concentrate.
- Your ability to stand, sit, move around and use your hands.
- Your ability to bend down to retrieve objects such as a handbag on the floor beside you, or reaching out for an object such as your medication.
- How you stand up.
- How you move to the examination couch and/or get on and off the couch.

- How you use your walking aids.
- How you remove your coat or hat.
- What you are carrying and if it appears light or heavy.
- Whether you show and understand the letters you have with you.
- If you smile and appear relaxed.
- If your breathing is laboured.

# Mental state examination

If you have a mental health condition or learning difficulty, the health professional may carry out a 'mental state examination' (MSE).

This will include observation of your appearance and behaviour, from which sometimes simplistic and sometimes dubious conclusions may be drawn.

You may also be asked what may seem odd questions.

For example, you may be asked to do 'serial sevens' which involves counting backwards from one hundred in sevens.

Or you may be asked how much change you would get if, for example you bought a 75p loaf with a pound coin.

Or you may be asked to spell the word 'world' backwards.

An Atos Healthcare document from 2004, *Glossary of LiMA Examination Findings* (pages 34-47) which you can download from the bottom of the <u>Incapacity Benefit page of the members area</u>, gives a detailed breakdown of MSE observations and conclusions.

Examples include:

Is tanned. Suggests good health. Looks Tired. Suggests poor sleep at night. Overweight. Suggests good appetite. Smartly dressed. Suggests good drive.

# Questions you may be asked at your medical assessment

What questions you are asked will depend on what your health conditions are, whether the HP is using PIPAT and how good they are at their job. Below are some of the questions that are likely to be asked

### Your health conditions and treatment

What are your main conditions? How long have you had these conditions? What medication do you take? What side effects are there? Who do you see about your conditions? When did you last see them? Have you seen a specialist? Have you had any hospital admissions in the last 12 months? What investigations have been carried out or are planned for the future? Has there been any change in your condition? What treatment have you had and how effective has it been? Is any further treatment planned? Does your condition vary? What are your good days and bad days like? What symptoms do you have? How do these affect you and what difficulties do they cause?

## Social and occupational history

Do you live in a house or a flat? How many stairs do you have? Is the toilet upstairs or downstairs? Does anyone else live with you? Can you get around all areas of your home? Are there any modifications or adaptations? What work do you normally do?? Have any adjustments been made to enable you to continue working? Have you given up or changed work? If so, was it due to your health condition or impairment? What social and leisure activities do you enjoy and have you given up or modified any due to your health condition or impairment?

## Functional history and the typical day

What time do you go to bed? How well do you sleep? What time do you wake up? Can you get out of bed and get dressed? Does anybody help you? Do you shower or bathe? Do you have problems getting on or off the toilet? Do you do your own cooking? What kind of cooking do you do? Can you follow a simple recipe? Do you have any problems with swallowing? Do you go to the supermarket or the local shop? Do you walk or drive to the shops? How long do you shop for? How far can you walk? Can you go to unfamiliar places? Would you ask someone you didn't know for directions? Do you need someone with you when you go to new places? Do you have any hobbies or interests? Do you watch TV? What do you watch? Do you use a computer? Do you have friends? Do you have a social life? Do you like to spend time with friends or family? Do you have a pet? Do you feed your pet? Do you have a telephone? Do you phone your friends or family? Do you use emails, texts or Facebook to contact your friends? Do you deal with you own letters and bills? How did you get here today?

Did you come on your own?

## Questions you may not be asked at your medical assessment

Just as important as the questions you may be asked are the ones you quite possibly won't be asked, but should be. If you don't get the chance to give detailed information about how your condition affects your everyday activities then there's a lot less chance of a fair decision being made. So, if you're asked questions like:

Do you do your own cooking? Can you get out of bed and get dressed? How far can you walk?

Then it's important that you also answer as if you were asked:

- How long does it take you?
- How well do you do it?
- Do you need someone to help you?
- Is it safe for you to do it?
- Do you suffer pain, fatigue or breathlessness when you do it?
- Do you suffer anxiety or get confused when you do it?
- If you do it once, how long before you can do it again?
- Do you need any aids or appliances to do it?
- Is there a time of day when you aren't able to do it, because of stiffness or fatigue, for example?
- Can you do it reliably, i.e. can you do it whenever you are asked to or need to?
- How many days a week, on average, can you do it?

## Remember the 'but' . . .

It's hard to remember all the issues above when you are being asked a whole series of questions about your life.

What you can do, though, is always try to remember the 'but', when answering any question the HP asks you. If you say 'Yes' to any question, is there a 'but' that you should add to make your answer more accurate?

'Yes I can get out of bed, but not until about 15 minutes after I wake up because I am so stiff on a morning.'

'Yes, I can cook a simple meal, but on most days I am too exhausted and depressed by the afternoon to prepare anything but a bowl of cereal or a sandwich."

### Having someone with you at your medical

There should not be any problem about bringing someone with you to your assessment or about them helping you give evidence. Independent Assessment Services and Capita are told that:

'Claimants should be encouraged to bring another person with them to consultations where they would find this helpful – for example, to reassure them or to help them during the consultation.'

They are also told that:

'the companions may play an active role in helping claimants answer questions where the claimant or HP wishes them to do so. This may be particularly important where the claimant has a mental, cognitive or intellectual impairment.' However, the DWP also say that the involvement of a companion should be at the health professional's discretion and that, if the companion becomes disruptive, then they can be asked to leave.

# Face-to-face assessment record sheet

At the end of this guide there is a face-to-face assessment record sheet for you to record what happened at the medical. Look through it before you have your medical and fill it in immediately afterwards, if you want to have a record of what happened.

The face-to-face assessment record sheet will provide very valuable evidence if you later decide you wish to make a complaint about the health professional or if you don't get the award of PIP you consider appropriate and decide to challenge the decision.

# **Independent Assessment Services versus Capita**

There are a number of differences between the way that Independent Assessment Services and Capita said in their successful bids that they would carry out assessments. We've set out some of the major differences below.

# Types of health professionals

Independent Assessment Services will be relying extremely heavily on physiotherapists to carry out medical assessments. They say they will be using:

- 933 physiotherapists
- 373 nurses,
- 75 occupational therapists
- 19 doctors.

The majority of these will come from the private sector. There will also be 35 'condition champions' to give support in specialist areas, such as mental health assessments. Independent Assessment Services will decide what type of health professional conducts each claimant's medical.

Medical assessors, who are only expected to work part-time for Independent Assessment Services as well as continuing with their private or NHS practices, will receive just 7.5 days' training. Around 5 days of this will be classroom-based and the rest "self-directed reading, web-based modules and DVD material which can be accessed by HPs on a flexible basis, both at their place of work and at home."

Training has to cover a very wide range of subjects, including PIP legislation, how to complete the medical report, disability awareness and interview skills. This raises the question of just how much training physiotherapists and nurses will receive in areas such as mental health and learning difficulties.

Capita will be using 80% general nurses and 20% mental health nurses for assessment centre medicals. The nurses will be permanent staff.

For home-based medicals they will use 20% permanent staff and 80% contracted staff. 65% will be general nurses, 25% mental health nurses and 10% will be GPs.

In reality, both companies appear to be having difficulty recruiting and retaining enough skilled and experienced staff to give the level of service that they are contracted to provide.

# **Examination centres**

Independent Assessment Services say they are using NHS hospitals, doctors surgeries and private hospital and physiotherapy premises to carry out medical assessments. They claim that over 90% of claimants will have to travel for no longer than 30 minutes to get to an assessment centre.

Capita are using their own premises, plus Remploy offices and Assist UK independent living centres. They claim that 91% of claimants will be within 90 minutes travel time of a centre and 78% within 60 minutes.

The reality appears to be that there are many fewer assessment centres than originally planned and many people are having to travel very long distances to assessment centres, even when there is one much nearer to them.

## **Recording medicals**

The DWP say that the recording of medicals is not part of the assessment process. They also say that claimants are welcome to bring their own recording equipment, with the huge proviso that it must be a dual tape or CD recorder, that they must inform Independent Assessment Services or Capita in advance and they must give a copy of the recording to the health professional at the end of the assessment.

It is quite possible that these restrictions are unlawful, according to legal advice the DWP received and was forced to publish via a Freedom of Information request.

However, if you tried to insist on recording your medical with an ordinary recorder, the medical would be stopped immediately and the DWP would be informed of the termination of the medical and the reason for it.

Under these circumstances you might well be refused an award of PIP for failing to provide information or take part in an assessment. You could appeal this decision, but with no certainty of success.

There is no legal reason why you should not covertly record your medical, however, provided the recording is only for your own use in the same way you might make and use handwritten notes. Guidance given to HPs states that if you are found to be secretly recording your assessment you should be asked to stop. If you do so the assessment can continue. If you refuse, the assessment will be halted and the DWP informed of the reason why and it is likely that you will be refused an award of PIP.

# **Complaining about your assessment**

Many people feel very unhappy and distressed after their assessment. Common complaints are – they didn't listen to what I said, they kept interrupting me, they put words in my mouth, they kept asking the same question but slightly differently to get the answer they wanted, I was made to travel a great distance, the assessor said they had phoned three times but they hadn't called at all.

This unhappiness is further compounded when you get a copy of the assessment and find it contains things you haven't said, or it leaves out things you have said. What can you do about this?

You need to be clear which issues could affect the decision about your claim and should be the subject of an appeal, as well as possibly a complaint, as opposed to things that would not form part of an appeal.

Being pressurised to travel a long distance to an assessment venue may be distressing, but it will not affect the outcome of your claim unless you are arguing that the journey left you so exhausted you could not participate properly in your assessment., Similarly, being kept waiting past your appointment time is upsetting but is less likely to affect the outcome of your claim.

These are complaints that should be addressed to the assessment provider, either Capita or IAS as appropriate. You should be realistic about what you are likely to achieve by complaining. If they accept responsibility for your distress the best you are likely to receive from them is an apology.

But complaining may mean that in the longer term the service is improved for other people.

If you are not happy with the assessment provider's response, you can go on to complain to the Independent Case Examiner. This is likely to take many months and again will at best result in an apology and possibly a 'consolatory payment' of £50 to £100.

Ignoring what you said or not recording it correctly, may adversely affect the success of your claim. Again you need to be clear what outcome you are hoping for if you complain about such issues. Capita or IAS are likely to deny that you were ignored, or that what you said was not recorded correctly.

It may not be a good idea to appeal and complain at the same time. Both processes can be exhausting and there is always the risk of missing appeal deadlines because of confusion between the appeal and the complaint..

The best way forward may be to wait for the decision, challenge it by MR and then appeal and argue that what you said at the assessment hasn't been recorded correctly, evidence has been missed out, or the assessor reached conclusions for which there is no evidence, etc. Many tribunals have heard such arguments over the years and are inclined to accept what you say about the quality of evidence obtained in your assessment.

Assuming you have still got any energy left, you can then complain to Capita or IAS when your appeal has been decided. Copying your MP into the complaint and making sure that the assessment provider knows you have done this is a good way of making them take it more seriously.

# How the decision is made and what to do when you get it

The decision maker (or 'case manager' as the DWP now refer to PIP decision makers) should consider all the evidence available to them, not just the Independent Assessment Services or Capita health professional's report, and reach their own conclusion about how many points you score. This evidence should include:

- your 'How your disability affects you' form;
- the report from the Independent Assessment Services or Capita health professional;
- any additional evidence, such as supporting evidence from your GP, consultant, relatives and friends.

Eventually you will receive a decision letter telling you whether you have been awarded PIP. If your claim has been successful the letter will tell you what components, daily living and/or mobility, you have been awarded and at what rates. It will also tell you how many years your award is for or if it is indefinite.

# If you are happy with your award

You should try to get a benefits check done at your local advice agency as you may be entitled to additional amounts in the benefits you already receive or you may be entitled to benefits you have not received in the past. (See 'Passporting', below)

You should consider asking for a copy of the assessment report even if you are happy with the award. This is because the department are likely to shred the report before your current award runs out, even though it may provide very valuable evidence to support any future claim you make. Contact the DWP office that is dealing with your claim, rather than Independent Assessment Services or Capita, and ask for a copy. It will be sent to you for free.

If your award is for a fixed number of years you should be sent another claim form to complete several months before it runs out. (See 'PIP review form below). If your award is an indefinite one you may still receive review forms to fill in every few years and your award can still be reduced or stopped depending on what you write in them. That's why you should always keep your original claim form for reference, whatever length of award you receive.

If your circumstances change - your condition improves or deteriorates - you should tell the DWP as it may mean that your PIP should be reduced or increased.

# If you are not happy with your award

The law relating to appeals changed from April 2013. From that date it is no longer possible to go straight to appeal against some benefits decisions, including PIP. Instead, if you are not happy with the decision you can apply for it to be looked at again - a mandatory reconsideration - and then, if you are still not happy, you can appeal direct to the Tribunals Service. The mandatory reconsideration will normally be carried out by a different decision maker.

But you must normally ask for a mandatory reconsideration within one month of the date of the letter giving you the decision, or have special reasons why you didn't. You also need to be aware that if you do ask for a reconsideration or appeal, the decision can be changed to increase or to decrease or end your award altogether, though this is obviously not a problem if you've been awarded nothing at all.

You should try to get help if you wish to challenge a decision, see *Help!* below. We will be publishing a guide to PIP mandatory reconsiderations and appeals in the coming months.

# Caution!

Just to remind you, because it is so important:

- there is a 'within one month' deadline for asking to have a decision looked at again;
- if you do ask to have a decision looked at again, your award could be increased, reduced or stopped altogether.

# **PIP Award Review form**

# N.B. Latest Update

Due to coronavirus the DWP have announced that there will be no new reviews of PIP awards, for three months from 24 March 2020. Awards of PIP which are due to end will be extended.

Where an assessment has already taken place, the decision making process will continue. If an assessment has been scheduled, the assessment provider should contact you to explain whether a paper or telephone assessment will take place. Justin Tomlinson, minister for disabled people, told the Commons Work and Pensions Committee on 23 April:

"What we have done, for those that would be due for reassessment in the next three months, we've automatically extended their benefit by six months. If their condition has deteriorated and they feel that they would be entitled to more money, they can still request a reassessment but otherwise they automatically are extended."

However, at this point it is not clearly precisely what is meant by '*due for reassessment*'. Update ends

The DWP now send out a form which is shorter than the 'How your disability affects you' (PIP2) form for reviews of existing awards.

This form is currently called the PIP Award Review form or the AR1 form by the DWP.

If your PIP award is for a fixed number of years, you will be sent this review form to complete up to a year before your current award ends. Your original award letter may tell you the likely review date, saying something like: *"We will also contact you while you're getting PIP to see if your needs have changed and to look at the amount you get. This will be after 22 June 2021."* for example.

You may also be sent review forms earlier than this, especially if your award is for 5 or 10 years, to check that your entitlement has not changed.

Even if you have an ongoing award you may be sent a review form to complete from time to time.

Your award can be changed or ended depending on the information you give.

### **Return deadline**

Usually, the deadline for returning the form will be a month after the date the DWP sent it out.

The front page should tell you the date by which the DWP need to have received the completed form. This means you need to put it in the post earlier than the deadline on the form, to give it time to arrive.

Because it may have taken a week to arrive and you have to allow time to return it, this means you have considerably less than a month to complete the form.

If you don't return your form within the deadline, your award may be ended even though it might be years before your award was due to finish.

If you are not going to be able to meet the deadline you will need to call the DWP on the telephone number on the front page of the letter and ask for an extension.

If you are granted an extension, make sure you make a note of the date and time of the call and the name of the person you spoke to as well as the new deadline, which will usually be an additional two weeks. You can ask for confirmation in writing, though we are not confident that this will be provided. There is no legal reason why you should not record the call, however. You are under no obligation to tell the DWP you are doing so if the recording is just for your personal use and you are not planning to share it other than as part of legal proceedings, such as a benefits appeal.

There is a freepost envelope with the form, meaning that you can return it without needing a stamp. However, you may prefer to send the form by recorded delivery or get proof of postage. Whatever you do, please try to scan or photocopy the form before sending it if you possibly can.

## What happens after you return the form

The Award Review form goes to a DWP case manager (decision maker) initially, rather than a health professional.

DWP guidance says the case manager *"will compare the new information against the evidence from the previous assessment"*. The case manager can also contact you or your carer for more information, but cannot send for more medical evidence.

If the case manager cannot make a decision, then all the information is forwarded to Independent Assessment Services or Capita for assessment by a health professional.

According to the DWP the health professional will have access to the Award Review form, any additional evidence obtained by the case manager and "*all relevant medical evidence*". What is not clear is whether the most recent PIP 2 'How your disability affects you' form must be consulted by the health professional.

The health professional will initially attempt to make their assessment solely on the papers.

Only if that isn't possible will you be required to attend a face-to-face assessment.

A decision will then be made by a case manager in the normal way.

So bear in mind when completing the Award Review form that your initial aim is initially to try to convince, not a health professional, but a DWP case manager that your evidence is sufficiently accurate and detailed for a decision to be made.

The purpose of the Award Review form is to speed up the renewal process and cut costs by not involving Independent Assessment Services or Capita. So there is pressure on the case manager to make a decision themselves where there is strong evidence to allow them to do so. So good supporting evidence, especially medical evidence, may make a big difference.

This is likely to apply whether you are arguing that your condition remains the same or that it has deteriorated.

# Completing the form

As with the standard claim form, it's definitely worth using additional sheets if you can't fit everything you want to say in the boxes on the form. Make sure you include your name and National Insurance number on the top of every additional sheet you use and, if possible, staple them to the back of the form.

# **Consent and declaration**

The first section of the review form asks you to sign to say that the information you are giving in the review form is correct and complete and that you will inform the DWP of any future change of circumstances.

In Section 2, the form asks for details of the main medical professional involved in your care and asks you to consent to allowing the DWP, Independent Assessment Services or Capita to contact them for information. It's probably best to agree to this, because otherwise you are giving the DWP grounds to say that they were prevented from collecting evidence to support your claim. But if you can possibly obtain supporting medical and other evidence yourself and enclose it with the form this is by far the best option. (See 'Letting Independent Assessment Services and Capita collect evidence' in the 'Supporting evidence means more chance of success') section of this guide.

As we explained above, the DWP case manager is not allowed to send for additional medical evidence when they receive your form. So providing medical evidence yourself means that it will be seen at the very start of the review process.

You also have to give information on your health conditions, medication, and details of any treatment, therapy, surgery and hospital admissions that have happened since the date your previous PIP claim was looked at by the DWP.

## What has changed for you

The form now takes you through each of the daily living activities covered in your original PIP claim, from Preparing Food and Eating and Drinking through to Mixing with Other People and Making Decisions About Money.

It also covers the two mobility activities, Planning and Following a Journey and Moving Around.

For each of these activities you are asked the following questions about any changes since your claim was last looked at by DWP;-

Tell us if something has changed and approximately when. Tell us how you manage this activity now, including the use of any aids you use. Tell us about any changes to help you need or the help you get from another person.

# Tell us if something has changed and approximately when

The activity may have got easier because you have new aids or adaptations, you have more effective medication, you have learnt how to manage things better or simply because your condition has improved over time.

The activity may have got harder because your condition has deteriorated or because you have developed a new condition.

Or things may not have changed at all since you made your last claim for PIP.

# No Change

If there has been no change in how hard or easy you find an activity then we consider that you should still give detailed information about the difficulties you have with each activity in the same way that we advise you complete the PIP2 'How your disability affects you' form..

We've certainly heard from claimants who have stated 'no change' and had their PIP award renewed at the same rate.

However, we have also heard from people who have stated 'no change' throughout and were still called for a face-to-face assessment. At that assessment the health professional may, or may not, have a copy of your award review form or of your most recent PIP2 'How your disability affects you' form.

So, there is a real risk that if you just state 'no change' you could end up at an assessment where the health professional has very little information about how your condition affects you. You will then be entirely reliant on their skill at asking the right questions and recording your evidence accurately.

To give a clear picture of how your conditions continue to affect you, for example, you could begin by stating:

'Because of my severe depression I continue to have problems motivating myself to prepare food'

Or:

'Because of arthritis in my hands I still have great difficulty gripping things.'

Then go on to describe the problems you have with preparing food in the same way as we describe in the Preparing food section above for the PIP2 form.

If your condition hasn't changed and you still have your previous PIP2 claim form, there is no reason why you shouldn't use this as the basis for your answers, but do try to give up-to-date examples wherever possible.

We realise that this is a lot more time consuming than simply stating 'no change'. But it means that even if the decision goes against you, if you have to go to an appeal tribunal you will be able to show that you gave consistent evidence at every stage of your claim.

## Supporting evidence

Whether you give additional information or not, we would very strongly advise that you include as much supporting evidence as you can, to show that you are still receiving the same level of medication, treatment or help from another person, if that is the case.

There may be an element of risk in submitting supporting evidence if it does not directly address the PIP descriptors. But if you don't try to obtain supporting evidence yourself then there is a real possibility that Independent Assessment Services or Capita will try to do so, or that you will be asked to attend a face-to-face assessment.

If possible, talk to your health professionals about why you need the evidence and what issues it is that you want them to deal with.

Have a look at the section in this guide on 'Supporting evidence' for more on this.

# If the DWP got your points wrong last time

If you got a lower award than you think is correct last time but decided not to challenge it, there is nothing to prevent you challenging it this time if the decision is the same.

However, many people get an award that they think is correct, but don't score all the points that they think they should have scored.

As a result, some people have told us they are worried that if they tell the DWP that there has been no change in relation to activities that they consider were scored wrongly last time, they will get the wrong points again.

This is a real possibility.

One option is to simply state 'no change' on the grounds that if you still get what you believe to be the correct rates of PIP, then that's a good result, even if it's not perfect.

The other option is to state 'no change', but explain in the review form that although your condition has not changed, you consider that you should have scored points (or more points) for this activity when you were previously assessed. Then give as much additional information about the difficulties you have with the activity as you are able.

Once again, we would strongly suggest that giving as much information as possible is the safest approach.

Whatever you decide to do, the option to request a mandatory reconsideration and to appeal are still open to you once you have a decision on your PIP renewal, if you do not consider that the award is correct.

# If things have changed

If it has got easier or harder for you to carry out a daily living or mobility activity, you are asked to give more information. This may be a gradual deterioration in your condition, a change in your medication, an operation or new adaptations to your home, for example. We go through the questions you need to answer below.

Again, if your condition has deteriorated, we advise that you give as much information as you can about the difficulties you face with each activity.

We have heard from many claimants who stated on their form that their condition had deteriorated, yet they ended up with a lower award.

In one case a claimant had their award reduced without even being asked to attend a face-to-face assessment. Instead, the decision seems to have been based on a medical assessment for their Employment and Support Allowance (ESA) claim, even though they had successfully appealed the decision that the ESA report was based on.

Example wording:-

'My myasthenia gravis and thymona conditions have continued to progressively deteriorate in the last 2 years. I cannot stand unaided due to chronic limb pain, shortness of breath and acute fatigue. I am now prescribed short release morphine to manage the pain'

# Approximate date of change

You are asked to give approximate details, relating to when any change happened.

If the change has been a gradual deterioration or improvement it will be very difficult to say when it began. All you can do is give your best estimate and add further explanation.

If you can trace it to a specific event, such as a change in medication, then you will need to give the date that this happened as nearly as you can.

For most people the change will be ongoing, but in some cases it may have been a limited period of improvement, in which case you will need to say when it ended.

You should be aware that if the change is one that you would be expected to have reported at the time, then it is possible that the DWP will consider whether you have been overpaid benefit. You may wish to get advice if you think this applies to you.

# Tell us how you manage this activity now, including the use of any aids you use

Consider the following areas when answering this question. Does it take you longer? Do you experience increased pain, fatigue or shortness of breath? Do you need to rest after completing an activity? What aids do you use? What new aids have you begun to use since your last claim? What difficulties do you have using these aids?

Example wording:-

'I cannot prepare food independently. I can only stand using a zimmer frame so I am unable to stand at a hob or worktop with my hands free, and use a perching stool. I experience chronic limb pain in legs and arms so cannot lift or carry kitchen equipment safely. I cannot cut up food as my hands shake and I drop pans'

# Tell us about any changes to help you need or the help you get from another person

Consider the following areas when answering this question. Do you need help from another person in activities that you were previously able to complete independently? Do you need more help – or different help - from another person, even if you don't actually receive it? Is it no longer safe for you to do it? Do you need supervision from another person to keep you safe?

You may want to explain what your difficulties were when you made your last claim and then go on to say how they have changed.

It is definitely worth looking back at the information in this guide for the activity you are writing about, for example 'Preparing food' to remind yourself what sort of evidence you need to give.

### Example wording

'I use a perching stool and zimmer frame in the kitchen but, on their own, this is not enough to enable me to complete this activity independently. I cannot physically complete this activity due to widespread limb weakness and pain. Fatigue from my strong painkilling medication means that I lack the concentration and focus to follow a recipe and prepare and cook food safely so I rely totally on my husband and children to help me to prepare and cook all food every day"

## If your needs change from day to day or throughout the day

You need to explain whether your needs vary. This is an important issue as it can affect how many points you score for any given activity.

If your ability to carry out an activity does vary, please see 'Scoring points when your condition varies' which you will find in the 'Completing the form –what you need to know before you begin' section of this guide.

### Supporting evidence

As with an initial claim, any supporting evidence you can provide will improve your chances of getting the correct decision. This will apply even if you are saying that there has been no change in your circumstances.

In particular, providing supporting medical evidence is likely to improve your chances of getting the right decision made without having to attend a face-to-face assessment. But don't forget all the other types of supporting evidence we talk about in this guide, including evidence from friends, relatives and carers.

Please see 'Supporting evidence means more chance of success' in this guide.

### What happens next

When the DWP get your form back they may contact you by phone to ask for further information or they may write to you asking you to attend a face-to-face medical.

Alternatively, they may make a new decision based solely on the information you have sent them.

Whatever the decision is, you will have the right challenge it via the mandatory reconsideration and appeal process in the normal way.

### What if your needs increase or decrease?

The process explained above is when PIP will, in effect, ask you to make a fresh claim for PIP, although they refer to it as 'a review'. Of course your needs may increase at any time. It is important that you don't wait for PIP to send you the review form. If your needs have increased and you think you are entitled to a higher rate of PIP you need to inform them straight away, either by

phone or in writing. Your PIP award will then be re-assessed, following the same procedure as for claims (see above).

You should think before starting this process. For example your needs could have increased, but not enough to mean that you will be awarded more points, and you will have faced the stress of going through the process without any prospect of an increased award. Legally all of your existing award can be reviewed. In effect, PIP will start with a 'clean sheet' and look at all of your award anew, and you may end up with a lower award than you had originally.

You would be strongly advised if you have any doubts about receiving an increased award to seek independent advice before you begin the process.

If your needs decrease enough so that PIP your award should be reduced you need to inform PIP, either in writing or by phone.

# Passporting

Getting an award of PIP can 'passport' you to entitlement to other benefits or additional amounts of other benefits. The DWP have said that it is their intention that passporting for PIP should mirror DLA.

For passporting purposes, the standard rate of the PIP daily living component is the equivalent of the lower and middle rate care components of DLA and the enhanced rate is the equivalent of higher rate. Standard rate PIP mobility is the equivalent of lower rate DLA mobility and enhanced rate PIP mobility is the equivalent of higher rate DLA mobility.

The table below is taken from the DWP's 'Completing the detailed design' PIP consultation document.

Passported benefits and schemes	PIP Component and rate
Disability premium in HB, IS and JSA	Any rate or component
Severe disability premium in HB, ESA, IS,	Standard or enhanced rate daily living
JSA /Additional amount for severe disability	component
in Pension Credit	
Enhanced disability premium in HB, ESA, IS,	Enhanced rate daily living component
JSA	
Carer's Allowance	Standard or enhanced rate daily living
	component
Carer premium in the income-related	Standard or enhanced rate daily living
benefits and the Additional amount for carers	component
in Pension Credit	
Carers Credit	Standard or enhanced rate daily living
	component
Disabled child premium	Any rate or component
Enhanced disability premium (child)	Enhanced rate daily living component
Childcare costs disregard in HB	Any rate or component
No non-dependant deductions in HB, ESA,	Standard or enhanced rate daily living
IS, JSA and UC	component
Child support – special expenses incurred by	Standard or enhanced rate daily living
non-resident parent due to disability of 2nd	component
child	
Student eligibility for income-related ESA	Any rate or component
Christmas bonus	Any rate or component

Motability	Enhanced rate mobility component
Disability element of Working Tax Credit	Any rate or component
Severe disability element of Working Tax	Enhanced rate daily living component
Credit	
Defining an adult as incapacitated and a	Any rate or component
child as disabled for the childcare element	
of Working Tax Credit	
Disabled child element of Child Tax Credit	Any rate or component
Severely disabled child element of Child Tax Credit	Enhanced rate daily living component
Extension to employer-provided childcare	Any rate or component
tax exemption	
Reduced VAT for grant-funded installation	Any rate or component
of heating equipment, security goods or	
connections of gas supply	
Vulnerable beneficiary trusts	Standard or enhanced rate daily living
	component
Treatment of hire cars for disabled people as short life assets	Standard or enhanced rate mobility component
Insurance Premium Tax exemption for	Enhanced rate mobility component
vehicles leased through Motability	
Zero VAT for vehicles leased through	Enhanced rate mobility component
Motability	
Vehicle Excise Duty reduction	Enhanced rate mobility component (full
	exemption) Standard rate mobility
	component (50% reduction)

# Winners and losers under PIP

In this section, based on what we know so far about PIP, we give some examples of who may be most likely to lose out and who may be most likely to gain when claimants are moved from DLA to PIP.

# Losing out

# Moving around indoors

If your DLA care component award is based in a large part on difficulties you have with moving around indoors then it may be under threat.

The current DLA claim pack has a section on 'Moving around indoors' which covers such issues as difficulties walking around, using stairs, getting in and out of a chair and transferring from a wheelchair.

PIP daily living activities, on the other hand, exclude such things as problems with using stairs or with moving around generally.

For example, the definition of 'toilet needs' appears to be so tightly drawn that it excludes any consideration of whether a claimant needs help getting to and from the toilet, although problems getting on and off the toilet will be taken into account.

# Outdoor mobility

Under DLA, in general, people who cannot walk more than 50 metres without pain or severe discomfort may qualify for the higher rate of the mobility component. Under PIP this distance has been reduced to 20 metres. Many fewer people will receive the higher rate of the mobility component under PIP.

# Night-time needs

Claimants who get the middle rate of the care component of DLA for night-time needs only may struggle to get an award of PIP.

Under DLA, care needs that are too few or brief to attract an award in the day may get an award of the middle rate of the care component if they take place at night. Under PIP no distinction is made between day and night needs. In fact, night is not mentioned in any of the daily living activities.

Nor is there any mention of help needed with getting into bed or getting out of bed or with help needed when you are in bed – for example help with being propped up on pillows or turned - in the PIP daily living activities.

# Supervision

Under DLA a claimant who has severe epilepsy, for example, may get an award because they need supervision in case they have a seizure. People who are prone to falling indoors because of Parkinson's may get an award of the middle or higher rate of the care component of DLA.

Similarly, someone who may be a danger to themselves or other people because of a mental health condition might, under DLA, get an award of the middle or higher rate of the care component.

Under PIP there is no award specifically for supervision needs. Instead, claimants will need to show how they are a danger to themselves or other people in relation to specific activities, such as cooking, managing medication and communicating in order to try to get an award of the daily living component.

# Medication

If your award of DLA is based in a large part on the help that you need with managing medication or monitoring your health condition then it is likely to be more difficult for you to get an award of PIP. This is because, astonishingly, needing supervision, prompting or assistance to manage medication or monitor a health condition appears to score just one point.

This means that, for example, someone who needs help with dressing can score more points for that activity than someone who needs help with taking vital medication.

# Main meal test

The main meal or cooking test is an important route to lower rate care component for many DLA claimants. However, claimants who need help or supervision to prepare a main meal and thus pass the current DLA cooking test would score just 4 points under the PIP 'Preparing food and drink test'. They would thus not be eligible for an award of PIP on those grounds alone.

It is true that claimants who cannot prepare a main meal even with help will qualify for the standard rate of PIP, which is the equivalent of the middle rate of the care component of DLA. But it is likely that claimants with such a high level of needs would currently qualify for at least the middle rate of DLA in any case.

# Gaining

# **Outdoor mobility**

Because points from the two mobility activities in PIP can be added together, some claimants with both a mental and physical health condition who currently only qualify for the lower rate of DLA mobility may get the higher rate of PIP mobility.

For example, someone with agoraphobia and ME/CFS which prevents them walking more than 200 metres would only get the lower rate of the mobility component of DLA, but they would be eligible for the higher rate of PIP mobility.

# Aids and appliances

Someone with arthritis in their hands which means they have difficulties with cooking, eating, bathing and dressing and undressing might qualify for the lower rate of DLA care component. But if they use aids and appliances in connection with all these activities they may be eligible for the standard rate of PIP, which is the equivalent of middle rate care.

# Conditions that vary throughout the day

For DLA, in general you need to show that you have problems with an activity for the majority of the day. With PIP, according to DWP guidance: 'If a descriptor applies at any point during a 24 hour period, it is considered to apply for the entire day, whereas in DLA it would have to apply for 'the majority of the day' in order to apply.'.

This may mean that someone who has severe difficulties first thing in the morning, for example, should score points even if they have a lot less problems for all the rest of the day.

If you have significant needs during the day and minimal needs at night, because of the distinction between 'night' and 'day' under DLA you would probably only qualify for middle rate care. Because of the abolition of the distinction under PIP you may well qualify for enhanced rate daily living.

# Where to look for help with claims and appeals

From April 2013 the government ended legal aid for benefits claims and for appeals to first tier tribunals. This means it will be very much harder to find specialist help with your PIP claim or appeal. However, not all agencies rely on legal aid funding and free advice may still be obtainable in your area.

# Voluntary sector agencies:

Voluntary sector agencies get their money mainly from local and national government and from grant making trusts. They will not charge you for helping with your benefits. Some of them employ benefits specialists and can offer an extremely knowledgeable and professional service.

# Advice agencies:

These are agencies whose main job is providing advice and information – they should be able to offer help with enquiries about any benefit. Many employ welfare benefits specialists. You can usually find numbers for advice agencies in your local Yellow Pages in one or more of the following sections: disability information and services; information services; social service and welfare organisations; counselling and advice.

### Local Authorities

Some local authorities have independent welfare rights units who may offer advice and representation.

# Advice Northern Ireland

To find your local independent advice centre in Northern Ireland, visit www.adviceni.net

# **Citizens' Advice**

There are over 750 offices in mainland Britain. Look under Citizens Advice in your phone book or visit the Citizens Advice website at: <a href="https://www.citizensadvice.org.uk">www.citizensadvice.org.uk</a>

# **Citizens Advice Scotland**

To find your nearest bureau, look under Citizens Advice Scotland in your phone book or visit the CAS website at: <u>www.cas.org.uk</u>

# **Disability Information Advice Line**

There are over 140 local DIALs, all staffed by disabled people and all offering telephone advice. If you have a local line it should be listed in your telephone directory under DIAL UK. Alternatively, visit their website at <u>www.dialuk.info</u> where you can find a directory of DIAL offices.

# Shelter

Shelter offers help with benefits, but generally only in relation to housing or if your home is at risk because of your benefits problems. For help call the Shelter helpline on 0808 800 4444 or visit their website at <u>www.shelter.org.uk</u> for details of your nearest Shelter Housing Aid Centre.

# Law Centres

Contact details of your nearest Law Centre, where you may be able to get free advice and representation at appeals, are available from the Law Centres Federation website at <u>www.lawcentres.org.uk</u>

# Disability and health related organisations

If you are disabled or have a long-term physical or mental health condition, there is almost certainly an organisation that can offer you support. Some of the larger disability organisations have helplines where trained staff can help with some benefits queries and some employ a benefits specialist.

In addition, there are often local groups with members who have claimed benefits and are prepared to share their experiences or accompany you to a medical or to a tribunal. Some mental health organisations, such as MIND, have advocacy projects with staff who will accompany you to medicals and hearings.

To find out about any groups dealing with your health condition, visit the websites below.

# Contact a family www.cafamily.org.uk

Although this is a site for families with disabled children it also contains a great deal of information that is of value to adults. The conditions index contains information on over 1,000 conditions along with details of support groups.

# NetDoctor <u>www.netdoctor.co.uk</u>

This site features a support groups index with contact details for groups covering a very wide range of conditions.

# UK Self-Help groups www.selfhelp.org.uk

Details of about 800 self-help groups, including many relating to different health conditions.

Date and	Lett Em		Pho call	ne	Name and section	Details
time		from	to	from		
04/07/20 10.27am	e	X			Jenny at Independent Assessment Services customer service on 0300 3300121	Requested extension for returning PIP2 form. Given an extra two weeks. Could not confirm in writing
05/07/20			e	5	Email PIP- customerservice@Independent Assessment Services.net	Email to Independent Assessment Services confirming conversation that I'd been granted an extension to return PIP2 form

# **Claim File Record Sheet**

# **Face-To-Face Assessment Record Sheet**

Date of assessment	
Time assessment started	
Time assessment ended	
Who else was present	

Did the length of the journey to the assessment centre, if it wasn't a home visit,	
affect your ability to give detailed evidence at the assessment?	Yes / No
If yes, please give details.	

Did the assessment start at the agreed time? If no, please give details, including any problems this caused you.	Yes / No

Did you feel relaxed and able to talk freely to the health professional?	Yes / No
If no, please give details.	

Did the health professional listen to what you had to say and give	
you time to answer questions fully?	Yes / No
If no, please give details.	

## www.benefitsandwork.co.uk

Did the health professional phrase questions in a way that suggested a particular answer? <i>If yes, please give details.</i>	Ň	Yes / No
Did you have chance to give a clear idea of the variability of your condition? If no, please give details.	Ň	Yes / No
Did the interview distress or upset you in any way? <i>If yes, please give details.</i>	Ň	Yes / No
If you had a physical examination did anything you did or the health professional asked you to do cause you pain? If yes, please give details including whether you told the Health professional you were in pain.	Ň	Yes / No
Anything else you wish to record		
Signed (your signature)	Date	
Signed (friend or carer who was present)	Date	