

Claiming PIP for a neurodegenerative disease, Dementia, Brain Injury or Probable CTE

Contents

What is PIP?	Pg2
How to apply for PIP	Pg2
General tips for filling in the form	Pg3
Key words, phrases, and explanations	Pg4
Question 1- Personal details	Pg5
Question 2- Drs & other medical professionals	Pg5
Question 3 – Activity 1 – Preparing food	Pg6
Question 4 – Activity 2 – Eating & Drinking	Pg7
Question 5 – Activity 3 - Managing therapy, medication or monitoring a health condition	Pg8
Question 6 – Activity 4 – Washing & Bathing	Pg9
Question 7 – Activity 5 - Managing incontinence or toilet needs	Pg10
Question 8 – Activity 6 – Dressing & Undressing	Pg10
Question 9 – Activity 7 - Communicating Verbally	Pg11
Question 10 – Activity 8 - Reading and understanding signs, symbols, and words	Pg12
Question 11 – Activity 9 - Engaging with other people face to face	Pg13
Question 12 – Activity 10 - Making budgeting decisions	Pg15
Question 13 - Mobility activities and descriptors - Activity 1 – Planning & following journeys	Pg16
Question 14 - Mobility activities and descriptors - Activity 2 - Moving around without severe discomfort	Pg17
Question 15 – Additional Information	Pg18
Supporting Evidence	Pg19
Your Assessment	Pg19
Tips for your assessment	Pg20
Key points for dealing with a PIP review	Pg21
Table of symptoms example	Pg22
Charities and organisations that can help you with your claim	Pg23

Claiming PIP for a neurodegenerative disease, Dementia, Brain Injury or Probable CTE

What is PIP?

Personal Independence Payment (PIP) is a non-means-tested, tax-free financial benefit provided to individuals with long-term illnesses or disabilities. The purpose of this benefit is to help cover additional costs related to health conditions or disabilities.

Eligibility for PIP depends on how an individual's illness or disability affects their daily life or mobility. It is not solely determined by diagnosis, except in cases involving a terminal illness.

PIP consists of two parts: the daily living component, which assesses any difficulties encountered in daily activities; and the mobility component, which evaluates a person's ability and challenges experienced when moving outdoors.

Both components are assessed using a point system and offer two levels of entitlement: standard and enhanced rates. To qualify for the standard rate, a minimum of 8 points is required, while at least 12 points are necessary for the enhanced rate. The current payment rates for PIP are as follows:

- Standard living component £73.90 per week
- Enhanced living component £110.40 per week
- Standard Mobility component £29.20 per week
- Enhanced Mobility component £77.05 per week

New claims for PIP in Scotland must now apply for ADP (Adult Disability Payment) as the Scottish Government have recently replaced PIP with their own social security benefit and are in the process of automatically transferring all existing PIP claimants in Scotland over to ADP, the process to claim ADP is very similar to PIP.

How to apply for PIP

To make a claim for PIP you will need to call the PIP new claims phone line on 0800 917 2222, on this initial call they will request the following information from you:

- Your full name
- Your date of birth
- Your full address and contact details such as phone number and email address.
- Your National Insurance number
- Your bank account number and sort code
- Your doctor or health workers name, address and contact telephone number.
- Dates and addresses for anytime spent in hospital or care home.
- Dates for anytime you have spent abroad for more than 4 weeks.

Claiming PIP for a neurodegenerative disease, Dementia, Brain Injury or Probable CTE

Some areas in the UK are now able to apply online, follow [this link](#) to see if you can apply online.

You will receive a form titled 'How your disability affects you' to complete, either in paper format or via an email link, depending on your location. You are required to return the completed form, along with any supporting documents, within one month. If you need additional time, you may request an extension by contacting them directly and providing a reason; extensions are typically granted for two to four weeks.

General tips for filling in the form

- Applying for PIP can be a lengthy and stressful process, but if you are awarded PIP, it will be backdated to when you made the initial call to the PIP new claims line.
- Gather all the information that you will need to fill in the form.
- It can be helpful to keep a detailed diary before filling in the form based on the different activities listed in the PIP form, detail how long it takes to do the task, what aids, assistance or supervision you need to complete the task, does the task cause pain or fatigue and any other general information or difficulties you experience on a daily basis due to your illness/disability.
- You do not have to fill the form in by yourself, you can ask a friend, family member, caregiver or anyone who has experience of completing the form to help you or even complete the form for you.
- When sending supporting documents, again give as much information as possible, we sent over 300 pages of medical evidence with one of our founder's claims! Please ensure you page number
- and label each sheet of supporting documentation with your name and national insurance number.
- When describing your illness and how it effects your ability to carry out any task think about and describe your worst days! Do not exaggerate anything but also never downplay your difficulties or struggles, even if those difficulties cause you embarrassment.
- Give as much detail and information as you can and never leave any room for interpretation in your answers, be factual and precise. Use additional sheets of paper as necessary.
- Each activity assesses if you can complete the task properly, safely, promptly, without pain, and without help or aids. Answering "no" indicates your condition is impacting your ability to perform the task.
- The questions address not only physical abilities but also cognitive abilities, mental health, and behavioural factors. For instance, an individual may have no physical limitations that affect their ability to take daily medication; however, if they require prompting or reminders due to memory concerns or motivation issues, this constitutes difficulty with the task and should be explained in the response.
- If you can do an activity but it causes pain, fatigue, worsens your condition, or you can only do it unsafely, poorly, slowly, or occasionally, clearly state this, as it indicates difficulty performing the task.

Claiming PIP for a neurodegenerative disease, Dementia, Brain Injury or Probable CTE

- For each activity that you experience difficulties with you need to state if you always experience difficulties, if it differs from time to time you need to explain how often you have 'bad days.'
- Keep a copy of all of your answers, you will need to refer to them if you are required to take an assessment. If you are required to send the form rather than complete online, then keep a copy of the completed form send it tracked delivery and obtain proof of posting.
- Please remember that in order to score the points assigned to a particular descriptor, you need to demonstrate that the descriptor applies to you on at least the majority of days.; so avoid using vague words and phrases such as "sometimes," "often", "frequently" "might," "if I'm having a good." Be very specific about how often during the day and on how many days out of the week/month/year you experience difficulties as well as describing what those difficulties are.
- For each activity it is essential you set out a few real world, recent and contextual examples of how you struggle to carry out the activity – e.g. what has happened/what would happen that means you need assistance/supervision/prompting etc.
- Create a table of your symptoms (see example at end of this document), you can use this to list every single one of your symptoms and then use this to make answering questions easier. For example: "Due to my cognitive symptoms (see attached table of symptoms), I experience difficulty in....."

Key words, phrases, and explanations

One reason some applications are not successful is that they do not include the keywords or phrases required by the DWP. Below are keywords, along with their explanations, that the DWP uses and expects to find in applications from individuals with dementia or a brain injury.

- Needs prompting – Verbal or physical reminders due to any physical, cognitive, memory or psychological impairment.
- Needs supervision – Needs someone to ensure safety, because there is a substantial risk to yourself or others whilst you carry out the task.
- Needs assistance – Physically needs help because you are unable to carry out the task independently due to safety concerns, pain, fatigue or any other physical, cognitive, or psychological impairment.
- Needs to use aids and appliances – Wheelchair, walking sticks, rails, adapted cutlery that you use due to pain, fatigue, safety concerns, or any other physical, cognitive, or psychological impairment.
- Needs communication support – Sign language, interpreter, communication aids.
- Experiences Psychological distress – Anxiety, depression, confusion, fear.
- Experiences cognitive difficulties – Difficulty concentrating, remembering, or making decisions.

Claiming PIP for a neurodegenerative disease, Dementia, Brain Injury or Probable CTE

- Experiences Social anxiety – Difficulty engaging with others, fear of social situations.
- Executive dysfunction – An important phrase the DWP expect to see in an application from someone who has a brain injury and/or dementia. It is a phrase that refers to someone experiencing problems with cognitive processes that are used to organise, plan, and manage your actions and emotions. Typical tasks that people with executive dysfunction may experience problems with are time management, decision making, social interactions, understanding social cues, regulating their emotions, understanding verbal and written instructions, and impulse control.
- Additionally, It is always useful to refer to the government published guidance for PIP assessors (particularly part 2 of the guide) to inform you how your application will be assessed and to direct you in how your explanations should be worded/focused; here is the link - [Personal Independence Payment \(PIP\) assessment guide for Assessment Providers - GOV.UK](#)

The first section of the form is made up of your personal details such as name, address etc.

Question 1 is titled 'Tell us about your health' where you will need to complete sections regarding the name of your condition, approximate start date and then details about the condition. You will need to fill out more than one of these sections if you have more than one condition. Here is an example of how to fill this section in for CTE or any other neuro degenerative disease, this section is your opportunity to explain your diagnosis, your symptoms and how these symptoms effect your daily life.

- Explain when you started developing symptoms and what those symptoms were?
- When and what testing (if any) have you had?
- What is the diagnosis?
- If your symptoms have changed since when they started, then explain when and how they changed and any new symptoms.
- List your medication for this illness/disability and any side effects caused by this medication.

Question 2 asks for details of any doctors or health workers who you see, you will need to provide name, address, contact details and when you last spoke to them for each doctor or health worker you see.

Activities

The following sections cover scoring for daily activities and mobility, with guidance on responding if you face challenges from a brain injury or neurodegenerative condition like CTE. Clearly explain how your illness or disability impacts each activity. Points increase with the level of assistance required. It is important to provide accurate information, reflecting your typical abilities rather than your best performance. These tips,

Claiming PIP for a neurodegenerative disease, Dementia, Brain Injury or Probable CTE

advice and keywords/phrases are provided as guidance to assist you in answering these questions. Do not copy or paste them directly. Using this guide is no guarantee that your claim for PIP will be successful.

Question 3: Activity 1- Preparing food

For the DWP, 'preparing a meal' involves tasks such as peeling and chopping vegetables, cooking meat or fish, and boiling potatoes or pasta. If you are unable to perform these activities independently, ensure you clearly explain the reasons.

- a. *Can prepare and cook a simple meal unaided – score 0.*
- b. *Needs to use an aid or appliance to be able to either prepare or cook a simple meal – score 2.*
- c. *Cannot cook a simple meal using a conventional cooker but is able to do so using a microwave – score 2.*
- d. *Needs reminding or encouraging to be able to either prepare or cook a simple meal. - Score 2*
- e. *Needs supervision to help me stay safe or physical help to either prepare or cook a simple meal. - Score 4*
- f. *Cannot prepare and cook food. – Score 8*

Tips for answering this section.

- Is it safe for you to prepare ingredients for a meal such as cut up food, be able to determine if something is hot? Can you do this but only with supervision or by using an aid?
- Can you cook using an oven or hob safely? Can you only do this safely if you were supervised or by using an aid?
- It might be unsafe for you to cook unsupervised due to memory problems, cognitive disabilities or executive dysfunction i.e. you might put something in oven and forget about it which could be potential for a cause of fire.
- If you can not safely use an oven or hob but are safe to use a microwave you will still get points.
- Do you have difficulties with reading and understanding a recipe or cooking instructions? Do you become frustrated and/or experience anxiety because of your symptoms and abilities whilst preparing or cooking food?
- Do you need prompting to cook? Would you cook a meal if no one were to prompt you to cook?
- Do you have to buy pre-chopped vegetables, fruit etc because you can not safely use a knife unsupervised, this is classed as using an aid so make sure you explain that you do this.

Keywords and Phrases

- The need to use aids (adapted utensils, microwave, precut vegetables), needs prompting, needs supervision, needs assistance.
- Cognitive, memory, executive dysfunction problems due to dementia or brain injury
- Prompting needed because of mental health issues, lack of motivation or memory problems.

Claiming PIP for a neurodegenerative disease, Dementia, Brain Injury or Probable CTE

Question 4: Activity 2 -Eating and drinking

This section is all about getting food into your body safely and being able to eat properly. Be honest about any challenges you face. The use of adaptive equipment, such as anti-spill cups, specialised cutlery, or plates with raised edges, qualifies as using an aid. These items may be necessary to address symptoms such as tremors, enabling individuals to eat safely.

- a. *Can take nutrition unaided. - Score 0*
- b. *Needs to use an aid or appliance, or supervision to help them stay safe, or physical help to be able to cut up food to be able to eat or drink. - Score 2*
- c. *Needs a therapeutic source to be able to eat or drink. - Score 2*
- d. *Needs reminding or encouraging to eat or drink. - Score 4*
- e. *Needs physical help to be able to manage a therapeutic source to take nutrition. - Score 6*
- f. *Cannot convey get food and drink to their mouth and needs another person to do so. Score 10*

Tips for answering this section.

- Do you need supervision or prompting to eat and drink? Why do you need prompting or supervising?
- Do you need physical help from someone such as, you need someone to cut up your food for you or need someone to feed you due to lack of spatial awareness?
- Do you lack motivation to eat or drink either due to your neurodegenerative disease or mental health, so you need reminding and prompting you to eat and/or drink.
- Are you at risk from choking due to problems with swallowing such as dystonia which means it is unsafe for you to eat unsupervised.
- Are you being prescribed drinks or shakes because you do not absorb nutrients properly?

Keywords and Phrases

- Needing aids of assistance because of problems with grip, coordination or spatial awareness due to dementia or brain injury
- Problems with swallowing causing risk of choking so needs supervision.
- Needs prompting due to mental health or memory problems.

Claiming PIP for a neurodegenerative disease, Dementia, Brain Injury or Probable CTE

Question 5: Activity 3 – Managing therapy, medication or monitoring a health condition

This is about whether you need help to manage your medication, treatments, and appointments. For example, if you have memory problems and need someone to remind you to take your medication, to attend an appointment, you need someone to attend appointments with you or if you can't be left alone because you might forget what to do.

- a. *Can manage medication or therapy and monitor their health condition without help. Score 0*
- b. *Needs to use an aid or appliance to be able to manage their medication; or needs supervision to help them stay safe, or reminding or encouraging, or physical help to manage their medication or monitor a health condition. -Score 1*
- c. *Needs supervision to help them stay safe, or reminding or encouraging, or physical help to be able to manage therapy that takes no more than 3.5 hours a week. - Score 2*
- d. *Needs supervision to help them stay safe, or reminding or encouraging, or physical help to be able to manage therapy that takes more than 3.5 but no more than 7 hours a week. - Score 4*
- e. *Needs supervision to help them stay safe, or reminding or encouraging, or physical help to be able to manage therapy that takes more than 7 but no more than 14 hours a week. - Score 6*
- f. *Needs supervision to help them stay safe, or reminding or encouraging, or physical help to be able to manage therapy that takes more than 14 hours a week- Score 8*

Tips for answering this section.

- Due to memory, cognitive, executive dysfunction or mental health reasons do you find it hard to keep track of your medication? Say if you need to use alarms, reminders or have someone physically remind you to take your medication or treatments.
- Do you have serious mental health problems that need to be monitored? Do you need someone to keep you safe due to suicidal thoughts and ideation?
- Do you need someone to attend medical appointments with you due to memory or executive dysfunction problems?
- Do you need someone to oversee all your medication as you are at risk of an accidental overdose due to memory and cognitive problems?

Keywords and Phrases

- Difficulties with remembering to take, if you have taken, organising medications or treatments due to cognitive, memory or executive dysfunction due to dementia or brain injury.
- Need reminding or prompting to take medication.
- Need assistance or prompting to take part in treatment.
- Need to be supervised during mental health crisis episodes as danger to self and/or others.

Claiming PIP for a neurodegenerative disease, Dementia, Brain Injury or Probable CTE

Question 6: Activity 4 - Washing and bathing

This section is designed to assess the level of assistance you require when washing yourself, including whether support from another individual is necessary. The Department for Work and Pensions recognises that not everyone is able to take a full shower or bath daily, and occasional missed days are acceptable. However, if you are generally limited to washing at the sink and are unable to clean yourself adequately, this may not be regarded as meeting a 'reasonable standard' of personal hygiene.

- a. *Can wash and bathe unaided. - Score 0*
- b. *Needs to use an aid or appliance to be able to wash or bathe. - Score 2*
- c. *Needs supervision, reminding, encouraging, or reassuring to be able to wash or bathe. - Score 2*
- d. *Needs physical help to be able to wash either their hair or body below the waist. - Score 2*
- e. *Needs physical help to be able to get in or out of a bath or shower. - Score 3*
- f. *Needs physical help to be able to wash their body between the shoulders and waist. - Score 4*
- g. *Cannot wash and bathe at all and needs another person to wash their entire body. - Score 8*

Tips for answering this section.

- Explain what a typical week is like and what assistance you need to stay safe, clean, and maintain hygiene.
- Do you need assistance due to lack of spatial awareness or coordination problems?
- Do you need to wash sitting down due to balance problems?
- Due to need prompting and/or encouraging to wash due to your mental health issues.
- Make clear if you need to use aids or need supervision and/or help from someone to wash safely and/or comfortably.
- Do you need to use an aid, need supervision or assistance from someone to get into or out of shower/bath due to mobility, balance, or spatial awareness problems?

Keywords and Phrases

- Need to use aids due to mobility, balance, or spatial awareness problems.
- Need supervision to do task safely because of difficulties with balance, mobility, or spatial awareness.
- Reaching and/or bending causes pain, dizziness, shortness of breath.
- Need prompting to wash due to lack of motivation because of mental health or anxiety as washing causes pain and/or dizziness.

Claiming PIP for a neurodegenerative disease, Dementia, Brain Injury or Probable CTE

Question 7: Activity 5 -Managing incontinence or toilet need

This section addresses topics such as urinary and bowel incontinence. This includes situations where an individual is unable to control urination or bowel movements, as well as cases involving difficulty reaching the toilet in time due to sudden urgency.

- a. *Can manage toilet needs or incontinence unaided. - Score 0*
- b. *Needs to use an aid or appliance to be able to manage toilet needs or incontinence. - Score 2*
- c. *Needs supervision to help them stay safe or reminding or encouraging to be able to manage toilet needs. - Score 2*
- d. *Needs physical help to be able to manage toilet needs. - Score 4*
- e. *Needs physical help to be able to manage incontinence of either bladder or bowel. - Score 6*
- f. *Need physical help to be able to manage incontinence of both bladder and bowel. - Score 8*

Tips for answering this section.

- Do you need to always carry extra clothes with you just in case you have an incontinence incident?
- Do you plan any outings around your need for accessible toilets?
- Do you need to use incontinence pads?
- Do you need to use specialist equipment, supervision, or assistance from someone to get on/off a toilet?
- Do you need prompting and/or reminding to use the toilet due to either memory problems or dementia effects your awareness of when you need to use the toilet.
- Do you need assistance to help change and clean soiled clothes if you have an incontinence incident?

Keywords and Phrases

- Need to use aids due to mobility issues, pain, difficulties with maintaining hygiene.
- Need to be prompted due to memory problems.
- Need assistance due to pain or mobility issues to maintain hygiene.

Question 8: Activity 6 - Dressing and undressing

This section addresses the level of assistance required for dressing and undressing. Be honest about any support needed as well as any difficulties encountered during these. It is helpful to specify the duration typically involved in getting dressed. If you experience delays, need to take breaks, or find these tasks tiring or painful, ensure this information is included. This shows even though you can dress yourself, it is not done within the reasonable standards.

- a. *Can dress and undress unaided. - Score 0*

Claiming PIP for a neurodegenerative disease, Dementia, Brain Injury or Probable CTE

- b. Needs to use an aid or appliance to be able to dress or undress. - Score 2
- c. Needs reminding or encouraging to be able to dress, undress or not undress inappropriately, or needs reminding or encouraging, or physical help to be able to choose appropriate clothing. - Score 2
- d. Needs physical help to be able to dress or undress their lower body. - Score 2
- e. Needs physical help to be able to dress or undress their upper body. - Score 4
- f. Cannot dress or undress at all. Score 8

Tips for answering this section.

- The use of items such as pull-over bras, front-fastening bras, slip-on shoes, or a shoehorn to assist with dressing is considered as requiring aids.
- Switching from jeans to leggings or sweatpants due to discomfort with fabrics or buttons is an example of adaptation.
- Sitting down to get dressed is not considered on its own, however, if there are difficulties getting up again without assistance, this may be considered. Needing help to stand up unaided is also considered. Additionally, if dressing while seated takes significantly longer than it would for someone without a disability, this may also be relevant. Providing detailed information about the need to sit while dressing is important when completing your application.
- If you require assistance with reminders to get dressed or selecting appropriate clothing, ensure this support is included. Such needs may result from various conditions, including dementia, anxiety, or depression, where the process can become overwhelming to manage independently.

Keywords and Phrases

- Need to use an aid to help with buttons, zips, putting clothes and shoes on/off due to balance, spatial awareness, coordination, or mobility problems.
- Need assistance with buttons, zips, putting clothes and shoes on/off due to balance, spatial awareness, coordination, or mobility issues.
- Need assistance to choose suitable clothing due to cognitive, dementia and executive dysfunction problems.

Question 9: Activity 7 – Communicating Verbally

This section addresses the physical ability to speak and hear, excluding topics related to social interaction or mental health conditions such as depression or anxiety. It examines an individual's capacity to produce speech and comprehend spoken language.

- a. Can express and understand verbal information unaided. - Score 0
- b. Needs to use an aid or appliance to be able to speak or hear. - Score 2

Claiming PIP for a neurodegenerative disease, Dementia, Brain Injury or Probable CTE

- c. Needs need help from someone trained or experienced in helping me to be able to express or understand complex verbal information. - Score 4
- d. Needs help from someone trained or experienced in helping them to be able to express or understand basic verbal information. - Score 8
- e. Cannot express or understand verbal information at all even with help from someone trained or experienced in helping them. - Score 12

Tips for answering this section.

- Do you require assistance to speak or hear, such as using a hearing aid or voice application, this will demonstrate a need for communication support. This can result from conditions including aphasia, dementia, stroke, or other factors that impact physical communication abilities.
- If you have difficulty understanding or expressing complex information, such as in decision making or detailed conversations due to dementia, cognitive, or executive dysfunction, then you require assistance. This could include having someone communicate on your behalf or assist you in following a conversation.
- If you require assistance from another person to communicate your essential needs, such as requesting help or expressing "stop," or if you rely on communication aids due to conditions such as autism or motor neurone disease, this indicates a need for support in conveying basic information.
- This section focuses solely on the physical ability to speak and hear, not on issues like brain fog that affect memory or processing.

Keywords and Phrases

- Need to use aids to enable you to hear and/or understand the spoken word.
- Need to use an aid to communicate verbally with someone.
- Need assistance to understand verbal communication due to dementia and/or brain injury causing me cognitive and/or executive dysfunction issues.
- Need assistance because unable to understand simple and/or complex verbal information due to dementia and/or brain injury causing me cognitive and/or executive dysfunction issues.

Question 10: Activity 8 - Reading and understanding signs, symbols, and words

This section addresses any assistance required to read and comprehend written information. It extends beyond difficulties with concentration, focusing on the need for additional support when interpreting written or printed material in your native language. The ability to read braille is not considered relevant for this activity.

Claiming PIP for a neurodegenerative disease, Dementia, Brain Injury or Probable CTE

- a. *Can read and understand basic and complex written information either unaided or using spectacles glasses or contact lenses. – Score 0*
- b. *Needs to use an aid or appliance, other than spectacles glasses or contact lenses, to be able to read or understand either basic or complex written information. - Score 2*
- c. *Needs reminding, encouraging, or reassuring to be able to read or understand complex written information. - Score 2*
- d. *Needs reminding, encouraging, or reassuring to be able to read or understand basic written information. - Score 4*
- e. *Cannot read or understand signs, symbols, or words at all. - Score 8*

Tips for answering this section.

- State any aids or support you use for reading, such as coloured paper, and explain what help you need to read and understand information.
- The use of assistive devices such as glasses with tinted lenses, coloured paper, or other reading adaptations may indicate the need for additional support. While standard corrective glasses are not included, specific adjustments—such as alternative background colours or enlarged text—are considered accommodations. These measures are commonly utilized by individuals with dyslexia, ADHD, or light sensitivity.
- If you use assistive technologies such as text-to-speech to support your processing of written information, please ensure this is included.
- Do you need assistance to read and understand complex information, such as a detailed medical report, this indicates a need for support. This may include having someone present to review the materials at a slower pace and clarify the content.
- Do you need help to read and understand simple things, like an appointment card or a short letter?
- If you are unable to read or comprehend written information due to a cognitive disability or condition, such as early onset dementia, include this information. This indicates that you require the highest level of support.

Keywords and Phrases

- Need to use aids to be able to read.
- Need assistance to read and/or understand signs and text.
- Need aids to write due to cognitive, coordination problems or/and executive dysfunction caused by dementia and/or brain injury.

Question 11: Activity 9 - Engaging with other people face to face

This section examines whether you require support to engage in meaningful interactions with others. Effective engagement involves more than exchanging greetings with neighbours; it encompasses the ability

Claiming PIP for a neurodegenerative disease, Dementia, Brain Injury or Probable CTE

to participate in substantive and authentic interactions, such as attending appointments or meeting with friends. Clearly describing your individual circumstances is crucial. For example, if you experience mental health conditions, anxiety, dementia, and/or a brain injury you should articulate how these factors may influence your capacity to interact with others. This section focuses on your ability to consistently and appropriately interact in person, interpret body language, and establish relationships.

- a. *Can engage with other people without help from an aid or appliance or a person. - Score 0*
- b. *Needs reminding, encouraging, or reassuring to be able to engage with other people. - Score 2*
- c. *Needs help from someone trained or experienced in helping them to be able to engage with other people. - Score 4*
- d. *Cannot engage with other people because it either makes them feel so anxious or distressed that they cannot function, or because it causes them to behave dangerously, and either they or another person might get hurt. - Score 8*

Tips for answering this section.

- Clearly state the reason you need support. For example, if you are uncomfortable approaching someone new without assistance, specify the factors involved, such as anxiety, unfamiliar social situations, or uncertainty about events. Outline how the support person's presence addresses these challenges and describes the likely outcome should their assistance be unavailable.
- Focus on how your condition affects your ability to engage with people and explain the type of support you need to do this safely and comfortably.
- Are you able to attend a new appointment or meet a friend independently, without reminders from others? If reminders or encouragement are needed to engage with others, this may indicate a need for some support.
- Requiring prompts or encouragement over the phone, or having someone available in case of feeling overwhelmed, indicates a need for support. This can occur with conditions such as anxiety or depression.
- If you require another person to be present throughout an interaction to participate safely, state this requirement. This individual does not need to be a professional; a family member may also fulfil this role. The focus should be on your need for their presence to facilitate engagement, rather than personal preference.
- If interacting with others results in significant psychological distress for you, then explain this in your answer. Conditions such as autism, PTSD, or agoraphobia can limit one's ability to interact with unfamiliar people or allow visitors at home. The challenge may not be limited to physical attendance but can also relate to whether the interactions themselves are manageable.
- If there is a possibility that your behaviour may place yourself or others at risk, it is important to mention this. This can occur because of conditions such as severe learning disabilities, dementia, or

Claiming PIP for a neurodegenerative disease, Dementia, Brain Injury or Probable CTE

brain injuries, where understanding of appropriate behaviour may be limited. For example, this could include touching others without awareness of societal expectations or exhibiting risky or violent behaviours due to things like alcohol dependency and/or executive dysfunction. These situations illustrate scenarios in which harm could occur.

Keywords and Phrases

- Experience anxiety in social interactions caused by mental health, brain injury and/or dementia.
- Need supervision to keep myself and/or others safe due to my executive dysfunction causing inappropriate behaviour.
- Need assistance to help manage my anxiety.
- Need assistance due to my communication issues.

Question 12: Activity 10 - Making budgeting decisions

This section addresses the level of support required for managing money. The need for assistance should be related to a condition such as a learning disability, ADHD, dementia, brain injury, cognitive difficulties, or a manic-depressive episode. It covers both basic tasks, like determining if you have enough funds for necessary purchases and calculating change, as well as more complex activities, such as managing bills and planning future expenses.

- a. Can manage complex budgeting decisions without help from an aid or appliance or a person. – Score 0*
- b. Needs reminding, encouraging, or reassuring, or physical help to be able to make complex budgeting decisions. - Score 2*
- c. Needs reminding, encouraging, or reassuring, or physical help to be able to make simple budgeting decisions. - Score 4*
- d. Cannot make any budgeting decisions at all. - Score 6*

Tips for answering this section.

- It is necessary to demonstrate how your condition specifically impacts your ability to manage finances. For instance, a brain injury or dementia may impair your understanding of financial decisions. A general statement indicating difficulty with money management is insufficient; and supporting medical evidence is required.
- Even if financial difficulties are not frequent, it is still important to mention them if they have significant consequences. For instance, experiencing manic episodes every few months that lead to missed rent payments or financial errors can still have an impact. These examples demonstrate that even occasional issues may result in notable effects.

Claiming PIP for a neurodegenerative disease, Dementia, Brain Injury or Probable CTE

- If you need help with tasks like setting up a direct debit or tracking rent and grocery spending, you require financial assistance. Relying on someone else to manage your money also indicates a need for help with complex budgeting.
- Do you need help with simpler money tasks, like figuring out how much money you need to buy something or knowing 50p will not be enough to buy a loaf of bread? Do you need someone to guide you through basic spending decision?

Keywords and Phrases

- Need supervision or assistance to help me budget due to my cognitive, memory and/or executive dysfunction problems cause by dementia and/or brain injury.
- If I do not have supervision and/or assistance with managing my money.... explain what would happen if you did not have the assistance/supervision.
- You make impulsive purchases that you can not afford in your budget due to mental health, memory or executive dysfunction issues which causes financial hardship.

Mobility activities and descriptors

Question 13: Activity 1 - Planning and following journeys

This section addresses the cognitive aspects involved in managing a journey. It refers to mental, cognitive, and psychological abilities required for planning, navigating, and ensuring safety during travel, rather than focusing solely on physical limitations. While the primary focus is on cognitive processes, this section also considers physical conditions, such as epilepsy, dementia, and brain injury, that may impact cognitive function. Tools or devices relevant to this activity can include navigation applications or phone reminders.

- a. Can plan and follow the route of a journey without help from an aid or appliance or a person. - Score 0*
- b. Needs reminding, encouraging, or reassuring to be able to undertake any journey to avoid it making them feel so anxious or distressed that they cannot function. - Score 4*
- c. Cannot plan the route of a journey - Score 8*
- d. Cannot follow the route of an unfamiliar journey without another person, assistance dog, or orientation aid. - Score 10*
- e. Cannot undertake any journey because it would make them feel so anxious or distressed that they cannot function. - Score 10*
- f. Cannot follow the route of a familiar journey without another person, an assistance dog, or an orientation aid. - Score 12*

Tips for answering this section.

- Tools like using a sat-nav or Google Maps are not considered aids in this context, so do not rely on those when you are explaining your needs.

Claiming PIP for a neurodegenerative disease, Dementia, Brain Injury or Probable CTE

- Do you have memory problems, are you at risk of getting lost easily, even on your regular routes?
- What is your ability to manage the unknown and unexpected while you are travelling?
- Are you able to anticipate dangers and be able to keep yourself safe?
- Do you need encouragement or someone to prompt you before every journey to avoid overwhelming psychological distress?
- Can you plan a journey, even a regular or familiar one, but can follow instructions if they are given to you step-by-step, include this information.
- Are you unable to navigate an unfamiliar route independently and require the support of another person, an assistance dog, or an aid such as a speaking cane.
- Do you find it necessary to have printed instructions or detailed directions for safety purposes?
- Are you unable to undertake a journey at all, even with someone's help or prompts, because it causes you overwhelming distress? Be specific with the physical symptoms that come up for you when considering overwhelming.
- Are you unable to follow the route of a familiar journey without another person, assistance, or an orientation aid?

Keywords and Phrases

- I am unable to follow a route in an unfamiliar place as I easily become lost without aid/assistance due to my memory and cognitive problems caused by dementia and/or brain injury.
- I am unable to follow a route in a familiar place as I easily become lost without aid/assistance due to my memory and cognitive problems caused by dementia and/or brain injury.
- Due to my executive dysfunction, I am unable to read and understand public transport timetables.
- Due to my social anxiety, I am unable to travel to an unfamiliar place/or I can visit if someone assists me.
- Due to my social anxiety, I am unable to travel to a familiar place/or I can only visit if someone assists me.
- I am unable to spot possible dangers due to my spatial awareness and cognitive dysfunction problems from my brain injury/dementia.

Question 14: Activity 2 - Moving around without severe discomfort

This section assesses your ability to stand, walk, and whether you require assistance.

- Can Walk more than 200 metres, either aided or unaided. - Score 0*
- Can Walk more than 50 metres but no more than 200 metres, either aided or unaided. - Score 4*
- Can Walk unaided more than 20 metres but no more than 50 metres. - Score 8*
- Can Walk using an aid or appliance more than 20 metres but no more than 50 metres. - Score 10*
- Can Walk more than 1 metre but no more than 20 metres, either aided or unaided. - Score 12*

Claiming PIP for a neurodegenerative disease, Dementia, Brain Injury or Probable CTE

f. Cannot, either aided or unaided, (i) stand; or (ii) move more than 1 metre. - Score 12

Tips for answering this section.

- If you can only move between 50 and 200 metres with difficulty, or between 20 and 50 metres with or without aids like a walking stick, this indicates a need for support.
- Explain how pain, fatigue, and any aids impact your ability to move around daily.

Keywords and Phrases

- Experience physical exhaustion when walking/standing due to dementia and/or brain injury.
- Experience physical pain when walking/standing.
- Need to use aid due to pain, balance, spatial awareness when walking/standing due to dementia and/or brain injury.
- I can stand aided/unaided for [length of time] before I experience pain/fatigue.
- I can walk aided/unaided [distance in metres] before I experience pain/fatigue and it takes me [how long that distance takes you to walk] and I will need to stop and rest [how many times] during this distance.
- I can not walk unaided/aided any distance without feeling pain or fatigue.

Question 15: Additional Information Section

This section is for you to provide more information regarding how your illness/condition effects your daily life, it can also be used by a family member, friend or caregiver to provide a written statement of how your illness/condition effects your daily life and also describe how they support, supervise and/or assist you in carrying out any activity that is listed in the PIP form.

Tips for answering this section.

- There is no wrong or right thing to enter on this question, it is simply an extra section to provide more information that may support your claim.
- You can provide a copy of your repeat prescriptions, your care plan, a supporting letter from your doctor or other health care provider, a letter from your care giver, social worker, occupational therapist.
- Use this space to inform DWP if you needed assistance to complete the form in this section, why you needed assistance and who from.
- Use this space to also document if you will require any reasonable adjustments for an assessment such as an interpreter, signer, video relay, an assessor of the same gender, wheelchair access or access via a lift, a large assessment room if you become anxious in small spaces or a home visit if you struggle with mobility if the assessment is more than 90 minutes away from your home.

Claiming PIP for a neurodegenerative disease, Dementia, Brain Injury or Probable CTE

Supporting evidence

More is always best when it comes to sending supporting evidence to DWP, but do not send 'fact sheets' about your condition or 'fit notes' from your doctor. Useful evidence to support your application can be:

- Xray, MRI and other types of scan reports and results.
- Assessments and/or letters from a doctor, consultant, mental health worker such as a psychologist, occupational therapist, physiotherapist, social worker, or any other professional person.
- Repeat prescription list from either pharmacist or doctor.
- Statement from family members, friends or caregiver who sees you on a regular basis so can provide a detailed description of how your illness/disability affects your daily life and/or mobility.
- Letters of referrals.
- If you kept a diary of how your illness/disability effects your day to day life and/or mobility then provide DWP with a copy of this.

Your Assessment

Four in Five PIP claims will require to be assessed by a health professional who has been trained to assess pip claimants for DWP, they will either be a nurse, physiotherapist, or an occupational therapist. They will not however necessarily be trained, have knowledge or experience of your condition however sometimes DWP will make a decision on your claim just on your claim form and supporting information, hence why it's so important that you provide as much relevant information as possible when you make your application. The assessment can take place either in person, via video call or over the phone. After the assessment, the assessor will provide DWP with a report of the assessment. A DWP decision maker will use your assessment report, claim form, all evidence you send and possibly a report from your GP or other medical practitioner that they have requested information from to decide whether you are entitled to PIP and score each of the activities to determine what rate you are entitled to. If you are required to take part in an assessment, then you will receive a letter detailing the type of assessment and date and time of the assessment. You have some rights for the assessment:

- You must be given 7 days' notice and details of how to ask for adjustments.
- Reasonable adjustments examples are requesting specific time of day for your appointment, an interpreter or signer, asking for male or female assessor.
- You are entitled to have the assessment recorded or you can use your own recording device to record the assessment.
- You can take a companion to the assessment, they can provide emotional support, take notes (the assessor cannot ask to view these notes), remind you about how you cope with activities and can

Claiming PIP for a neurodegenerative disease, Dementia, Brain Injury or Probable CTE

check the report after the assessment on your behalf. You can take a friend, family member, an advocate or benefits expert/advisor.

- If you are unable to answer a telephone, then inform them of this and they will update their system to ensure they no longer try to contact you via telephone.
- You can request to change your assessment appointment if you have a valid reason, valid reasons are hospital or other medical appointments or if your medical condition fluctuates, a holiday or birthday is not regarded as valid reasons to rearrange an assessment.
- If a face-to-face assessment is needed but the venue for the assessment is over 90 minutes away and you have mobility issues you can request a home visit instead.
- You have the right to request the assessment to be conducted in a format that is assessable for you.

Tips for your assessment

- Look over your pip claim form (this is why it is important to make a copy before submitting your claim).
- Make notes before the assessment based on all the activities that you listed as having difficulties on the claim form, use the PIP claim form and your diary to make notes, this is especially important if you have memory problems.
- Make it crystal clear to the assessor at the beginning of the assessment that you have a neurodegenerative disease that causes you to become confused, and any other symptoms such as speech and behavioural problems.
- Do tell the assessor at any point if you are in pain or struggling mentally or physically at anytime during the assessment.
- You are entitled to take short breaks as often as you need, if you are on video or phone simply say you need a break, turn camera/mic off during the break. At the end of the assessment, they will ask why you needed the breaks, answer truthfully. For example, "I had to take breaks because I was becoming frustrated as I was struggling to understand the question."
- **DO NOT** let the assessor try to rush you, there is no time limit to the assessment so if you need the assessor to repeat the question several times then that is what they must do.
- Stay calm – the assessor will ask multiple questions, repeating these same questions at different stages of the assessment but worded differently, the assessment is designed like this in an attempt to catch out claimant's that are lying or exaggerating any of their symptoms or difficulties with activities. Although it can be incredibly frustrating to be asked the same question several times, remember to stay calm and answer truthfully and refer to your notes if needed and remember the person who is supporting you can remind you of your answers.

Claiming PIP for a neurodegenerative disease, Dementia, Brain Injury or Probable CTE

Key points for dealing with a PIP review

- The PIP review should be approached as a fresh claim for PIP. In other words, as much detail as possible should be set out for each of the activities and supported by a few real-world examples for each activity.
- Never put anything along the lines of *"Nothing has changed since my original PIP application"* without any further narrative. Doing this will likely result in zero points being awarded.
- The PIP review form AR1 can be confusing in the way that it puts the questions. The way the questions are put can lead some claimants to provide very short answers (in the very limited amount of space provided in the form) which do not fully address their functional impairments. My recommendation therefore is to tick the appropriate boxes in relation to each question but then put all the substantive answers into a separate word document and deal with each descriptor as you would in the original application - make sure on the form you handwrite into each section "please refer to attached document at pages [] to [] , this *type of document should be page numbered and labelled with the person's name and NI number.*
- Evidence sent with the original PIP application does not need to be resent. Copies of any *new and relevant* evidence (e.g. medical records/reports) produced since the original PIP application should be sent with the review form, along with any witness statements from carers, family etc in support of functional impairments/care and support provided etc etc
- I would not send the form back recorded/signed for delivery because it just goes to a mailing site and requesting a signature could lead to delays. Send the form back in the prepaid envelope provided no later than 10 working days before the return date specified on the form. Use the post-office and ask for proof of posting and keep the proof of posting safe until you have received confirmation from PIP that your form has been received by them. If you need an extension of time you must ring PIP asap - you will normally get 2 weeks extension if you ask for it.

Claiming PIP for a neurodegenerative disease, Dementia, Brain Injury or Probable CTE

Table of symptoms¹ Example

	Cognitive features	Mood features	Behavioural features	Physical, Somatic and Sensory
	Neurological fatigue	Affective instability/regulatory dysfunction	Explosivity	Muscular fatigue
	Processing speed deficit	Recurrent depression	Verbal violence	Severe and chronic widespread pain/multiple joint pain/neuralgia with flare ups
	Cognitive impairment, overload, and disruption	Confused and distorted thinking	Physical violence	Sciatica
	Impaired attention and concentration	Identity disturbance/dissociation	Loss of control	Diffuse rigidity/spasticity
	Memory impairment	Anhedonia	Short fuse	Global weakness
	Reduced intelligence	Apathy	Impulsivity	Postural instability/Impaired balance
	Minimal ability to plan ahead	Agitation (including psychomotor agitation, intrusive/racing thoughts)	Transient-stress related psychosis/pseudo-psychosis ²	Tension-type and cervicogenic headaches
	Executive dysfunction	Anxiety/panic attacks	Aggression	Reduced mobility/flexibility
	Lack of insight	Mania/mixed episodes	Rage	Impaired fine motor control/dexterity
		Irritability	Inappropriate speech	Action tremor
		Insomnia	Socially inappropriate	Nausea, bloating and reflux
		Fearfulness	Disinhibited behaviour	Muscle atrophy

¹ Not exhaustive and symptoms are treatment resistant/unresponsive to conventional treatments

² N.B. .a) I have minimal stress/frustration tolerance; b) psychosis/pseudo-psychosis includes paranoia and hallucinations

Claiming PIP for a neurodegenerative disease, Dementia, Brain Injury or Probable CTE

Charities and organisations that can help you with your claim.

Do not be tempted to use one of the many companies that are offering to help you make a benefits claim on a no win no fee basis, they will charge you around 35% or even a fixed considerable sum amount. There are plenty of charities and organisations that can assist you with filling in the form or attending the assessment with you.

- [Citizens advice](#)
- [Turn2us](#)
- [Disability Support Project](#), asks for donations but will not turn you away if you cannot afford to pay.
- [Scope](#)
- [DAP Wales](#)
- [Marshalling CTE](#), we can help you complete your PIP form and can support you during an assessment, get in touch with our team.

