**Tips on applying for Personal Independence Payment**

**1.** Ordering the forms: You will need to order the PIP form by phone, from the DWP - someone can help you by being with you and speaking to the DWP on your behalf but you will need to be there to give your permission.

At this stage you can highlight yourself as a ‘vulnerable individual’ if you think that you will need extra help with the form or would find an assessment difficult. A list of what you will be asked for at this stage is in the ‘**PIP Guidance document’**

If you feel that you need someone to act fully on your behalf, for PIP and other benefits, the DWP can look at appointing someone as your ‘Appointee’, this is normally used if you don’t have capacity to make decisions. For more information please see: <https://www.gov.uk/become-appointee-for-someone-claiming-benefits>

Another option is that you can ask that someone else is responsible for the correspondence. So if you struggle to open post or might forget that a letter has come in you could ask a family member to take on that responsibility.

**2.** Get help completing the forms.  The PIP forms are long and, emotionally, can be hard to fill in. It can be very helpful if someone who knows you well can help you fill in the forms, as they may have noticed things that have become a struggle for you.

There is often professional help available when filling in the forms:

Face to Face support:

* You can ask your Specialist HD Adviser (SHDA) if there is local support available to help with form filling.
* The DWP does have a visiting service that can support more vulnerable people (primarily those who can’t leave their home).

Online support:

* CAB: <https://www.citizensadvice.org.uk/benefits/sick-or-disabled-people-and-carers/pip/help-with-your-claim/fill-in-form/>
* Turn to Us : <https://www.turn2us.org.uk/Benefit-guides/Claiming-Personal-Independence-Payment-(PIP)/Fill-in-PIP-form>
* Advice Local: https://advicelocal.uk/

**3.** When filling in the forms think about the help that would be **useful to have**, rather than what you actually have. It may be that you have chosen not to have help, or you don’t have anyone to ask for help, or you might be waiting for help from services. Make sure you tell them about adaptations that you do have such as rails or a wet room

**4.** HD rarely fits into boxes.  If the question doesn't really explain the difficulty you have, then use the free-text boxes as much as possible to explain those difficulties and give as many good examples as you can.  PIP is all about how your condition and the symptoms you experience impact on your day to day function and this should be the focus when filling out the form. Try to think about each domain and answer succinctly without writing reams or trying to cover other domains

Examples of information to include are below and this list is not exhaustive:

* Does doing the activity leave you tired? How are you after completing the task? Could you do this again later on or are you too fatigued to repeat this?
* Does it take you a very long time?  Be specific as possible here as to what aspect of the activity takes you a long time.
* Do you feel safe to do the activity? If not, say why and what symptoms do you experience that make you feel this way?
* Are there things you find difficult to get round to doing? What aspect of the activity is it that you find challenging? Any why?
* Does someone need to remind or prompt you? What would happen if they didn’t prompt you?
* Would someone else be worried about you doing that on your own?  If so, why?
* What has someone else started doing more of that you used to do?

There may also be some symptoms of Huntington’s that affect you but wouldn’t outwardly be obvious; for example, some people with Huntington’s don’t feel hot or cold as they used to so might find that they go out in cold weather just with a T-Shirt on - it would be important to include something like this on the sheet. Use prompts on the **PIP Guidance documents** to help.

**5.** With a condition like HD where things change slowly over time, we often make small adjustments without realising it (e.g., who in the family does what, etc.). It’s helpful to try and think what you have done already in this way to adjust and cope with the condition when filling out the form; for example, you may have started eating sandwiches instead of cooking a full meal.

**6.** Think about the way changes to thinking and to mood affect you - these should also be included.  For example, does doing something, e.g., talking on the telephone, make you very anxious? Often it is the changes to thinking that people find affect them most with HD, but these can be hard for other people to see and understand.

**7.** Keeping a diary can be a really helpful way to highlight the ways in which HD affects you. The DWP has produced a template that can be filled in daily, we have included it in this pack. Ideally you would do this for at least a week to get a picture across a number of days.

**8.** Try and provide additional reports - your SHDA or health professional may be able to give information about you and your condition. In cases whereby Capita or Independent Assessment Services (IAS) have enough ***relevant*** evidence, a paper based review (PBR) may be able to be undertaken without you needing to have a face to face (F2F) assessment.

Think about the health and social care professionals who are involved with your care and know you, who could contribute (for example Physiotherapist, Speech and Language Therapist, Occupational Therapist, A&E reports).

The documentation below is some examples of what will assist Capita and IAS with either a F2F, telephone/video or a PBR assessment:

* Patient summary from the GP
* Medical evidence that discusses your condition and level of functioning (Consultant, Specialist Nurse, GP, physiotherapy, Occupational Therapy etc)
* GP factual reports
* Prescriptions
* Care plans
* Non-clinical evidence e.g., carer / claimant diary, social worker reports

Letters as per below are not useful as they do not give either provider any information on how your condition affects your level of functioning:

* Hospital appointment confirmation letters
* Patient information leaflets
* Photographs

**9.** You may feel anxious about an assessment. If the assessment is inconvenient for you, you only have 1 chance to change it. If the centre is too far away or if the date isn’t possible, contact the assessment provider (Capital / IAS) and ask them if you can change it. Remember that other people can come with you to the assessment - this is often helpful and it is useful for them to help you express how your condition affects you as it might be difficult for you to do this yourself. The assessors from both providers are health care professionals and aim to make the assessment process as easy as possible. If you are feeling anxious at the beginning of the assessment or having difficulty throughout, please tell them or your companion so the assessor is aware. (NOTE FOR COMPANIONS: The assessor will be focusing on what the individual making the claim is saying, if you feel it’s not correct ideally you will make this known e.g. if the person says they can cook a meal you might gently prompt them about difficulties they have had. This might not always be appropriate, if you are having a home assessment you could try and arrange a private conversation in another room, or if in a centre you can mention to the receptionist that you might need a discussion in private and could they let the assessor know. Even trying to use body language to show that you disagree with what is being said during the assessment can help.

**10.** If you don't get the outcome you feel is right, you can request a 'mandatory reconsideration' - this will give you information about what points you scored and you can see whether this feels like it fairly reflects your condition.  If not, you can appeal the decision.  Going through an appeal may feel quite daunting, but it is worth considering. The applicant themselves does not have to attend the appeal if it will be too much for them. Occasionally people choose to re-start the process rather than going through an appeal, BUT this means that any back payments would be given from the date of the second application rather than the first.