



# THE BRITTLE BONE SOCIETY

## Applying for PIP

### STEP 1

#### How to Apply

- Call 0800 9172222 between 8am and 6pm Monday to Friday.
- During this call you will be asked to give basic information to make sure you qualify to claim PIP.
- You can also apply by post; the Department for Working Pensions (DWP) will send you a paper claim form by post if you write to them asking for one.

### STEP 2

#### How Your Disability Affects You Form

- If you satisfy the basic qualifying conditions, they'll send you the 'How your disability affects you form.'
- This form is long and asks highly personal questions. It can feel negative talking about what you can't do instead of what you can, but it's important to be clear about the difficulties you experience.
- You have one month to complete this form from the date it was sent to you, if you do not complete it (without good reason) you will have to restart your claim.
- The first question asks for details of the professionals best placed to provide advice on your circumstances, the second question asks about your health conditions or disabilities and roughly when each of these started, and the next ten questions relate to the ten daily living activities.

#### The 10 Living Daily Activities

##### 1. Preparing Food.

- Emphasise on the difficulties on preparing food. For example, difficulties standing for prolonged times, risk to injury while preparing food, more likely to eat ready meals due to difficulty in preparing food. Can need assistance/ another person to prepare food for you.
- Also, worth mentioning about adapted kitchens and equipment that is required for you to carry out this task if this is applicable to you.

##### 2. Taking Nutrition.

- Explain the difficulties of using cutlery/crockery and how spillages can occur because of this.
- Explain how it is essential to use things such as straws and lightweight crockery. Straws are essential for when people with OI have fractures and spend a long time lying down to recover.
- Also bring awareness to the fact you may have difficulty chewing due to either jaw malalignments or dentinogenesis imperfecta (brittle teeth)

### 3. Managing Therapy or Monitoring a Health Condition

- Highlight all physiotherapy and other therapies you are involved with to make daily life easier. Explain that you may need assistance due to propensity to fall and difficulties with other aspects such as changing etc. Highlight how your body can 'crash' if pushed beyond limits as it's not always easy to know your limitations.
- Explain how you don't always see medical professionals and how OIers tend to be very adept at self-treatment and are able to bind and care for injuries without need for A&E/GP intervention. They may have fractures that have not been logged in medical notes due to this.

### 4. Washing and Bathing

- Explain the difficulties of getting in and out of the bath/shower as well as the task of actually washing due to fatigue. Bathing and being submerged by water can help with pain and ease joints however, there is increase risk of slipping causing fractures and breaks.
- Discuss the issues of reaching certain areas of the body and difficulties of drying due to fatigue and pain.
- Bathrooms may have been adapted for ease of use, make sure to clearly indicate this in the form.

### 5. Managing Toilet Needs or Incontinence

- Include whether or not you need assistance to the toilet. This can be the case in severe OI.
- Explain the pain which can be caused by the simple act of going to the toilet and wiping etc.
- Include whether you have a bathroom adapted to help ease the task.

### 6. Dressing and Undressing

- Indicate the amount of time and how tiring this act can be, due to pain and further difficulties with this when you have fractures or breaks.
- State that you may need assistance if you are facing a difficult day or experiencing fractures and breaks or with difficult fastenings.
- Items such as eye and hooks, zips, bras laces will most likely need assistance or clothing adapted to make this easier.
- Clothes may have to be altered or hard to source due to short limb length etc.

### 7. Communicating Verbally

- State whether you have deafness/hearing loss and whether or not you have hearing aids.
- Explain that it can be hard to communicate in crowded, noisy, busy social settings.
- Include whether or not you need understanding on questioning as some may lip read or use sign language. Subtitles are frequently used for TV/Film.

### 8. Reading and Understanding Signs, Symbols and Words

- Explain how high dosage of medications paired with poor sleeping due to pain can cause "brain fog" delayed reactions and poor concentration.
- Any fixed positioning can be painful so must regularly change position so reading/holding papers or books can be an issue. Book rests/iPad/phone rests may be used as well as dictation/speakers or voice-activation.

### 9. Engaging with Other People Face to Face

- Explain how exhausting daily life is with OI and how this can result in socialising being difficult. If you have hearing problems, point out that this can make socialising problematic. A

day of socialising could result in a day in bed to recover. State how this can mean isolation and this can have a negative impact on your mental health. i.e. loneliness, social anxiety etc.

#### 10. Making Budgeting Decisions.

- Explain how high dosages of medication can cause brain fog and poor concentration which can affect budgeting decisions.
- Indicate difficulties with cash handling such as accessing cashpoints and how this impacts on money handling day-to-day.

#### Mobility Questions

- The mobility component questions ask about your ability to work out and follow a route safely and reliably, your physical ability to stand and move around without severe discomfort, and requests further information for how OI affects you.

##### 1. Planning and Following Journeys

- Explain how anxiety and fear of being in certain environments, accessibility routes, not able to travel for long distance without a carer can lead to isolation. Explain that certain journeys, especially long distance will need a lot of planning well in advance.

##### 2. Moving Around

- Discuss whether or not you are able to weight bare or not. If not talk in detail about the different equipment you have to use in your day-to-day life.
- Explain how if you are able to weight bare, due to fatigue you may have to use a wheelchair later on the day.
- Explain the difficulties of having to self-propel wheelchairs and the use of sticks etc. Detail the problems this can cause to your upper body and the pain this can cause.
- Explain how mobility can be slow and painful. Detail how it can be difficult to leave the house due to extreme fatigue, and how this can cause days of recovery in bed for one outing. It is also important to point out the risk of breaks and fractures on public transport and in busy crowds.
- To help with the filling out of this application, please use the Conditions Insight Booklet which will help you further with each of these sections.

### STEP THREE

#### The Face-to-Face Consultation

- Once you have returned your form it will be passed on to either Capita or Atos Healthcare.
- Capita and Atos Healthcare will allocate your case to a health care professional working for them. This health care professional may contact your doctor etc. for further information.
- They will most likely arrange a face-to-face consultation with you, which will usually take place in an Examination Centre, however home visits can be arranged if your doctor can provide evidence that this is necessary on health grounds.
- You will be given at least seven days' notice of the time and place of your consultation.
- You may be accompanied by a carer, relative or friend but they will not be able to answer question on your behalf unless the health care professional can't understand your speech or you can't understand their questions. However, they will be able to add to what you have to say.
- The health care professional will ask you questions about your day-to-day life, your home, how you manage at work if you have a job, and about any social or leisure activities that you engage in.
- Based on the health care professionals report of your consultation, a DWP case manager will decide whether or not to award you PIP and, if awarded, at what rate and for how long.

- They will send out their decision in a letter.
- You have the right to appeal this decision.

## GENERAL ADVICE

- Remember that the health care professional may not be as well versed in the symptoms of OI as you are, you should name the symptoms that apply to you, and on a separate list you should provide symptoms resulting from other conditions which you experience.
- A non-exhaustive list of OI symptoms is provided below to assist you in this.
  - No. of fractures (or rough guess)
  - Secondary arthritis and whereabouts affected
  - Ligamentous laxity
  - Subluxation
  - Dislocation
  - Excessive sweating
  - Hearing loss/ deafness
  - Fatigue
  - Insomnia
  - Prone to falls
  - Bruises easily
  - Nosebleeds
  - Mention if able to weight bear or not, crutches, chair used etc.
  - Scoliosis, kyphosis etc.
  - Surgical involvement- rodding, plates etc. and if successful or not.
- Explain your levels of pain medication, especially if you can't take maximum meds due to needing a level to function and yet be aware to say drive or be clear headed, or if you can't take certain medications due to side effects, allergies or interactions.
- If you are off the radar; explain why. This may be because you have fallen through the system in the transition between pediatric care and adult services, or having been discharged from orthopedic after surgery. Some people with OI only attend hospital when they are in acute need (e.g. A&E only), or feel that they are competent in fracture self-care and therefore do not have every break seen to at the hospital. You should do your best to explain such circumstances if they apply to you.
- If you use alternative treatments, then list them too. It may seem insignificant, but even a hot water bottle used to alleviate pain should be mentioned.
- All aids and adaptations you use to help you with tasks should be considered throughout this process. These may be self-bought, NHS issued, or homemade. These could include; grab rails, helping hand grabbers, jar openers, electric tin openers, bath boards, wet room, sticks, rollators, wheelchairs. Anything which is a way round doing something the 'typical' way.
- Don't just answer 'yes' and 'no', you should go into detail. Many people can do all aspects of daily living and mobility but due to them being extremely slow, tired, in pain or unable to repeat the tasks then this can mean they qualify for benefit help. Consider safely, timeliness, reliably and repeatability of such tasks.
- If your condition varies, let them know about what you're like on bad days as well as good days. The health care professional's opinion should not be based on a snapshot of your condition on the day of the consultation. They should consider the effects of your condition over time.
- Have a think about how fatigue may impact the timings of your everyday routine, does it take you longer to perform daily living activities? If so, how much longer?

- Many people with OI experience 'windows of energy' and 'cumulative effects' meaning they can only cope with bursts of activity and their energy levels will quickly drop. If this affects you to the extent that you cannot finish all your daily living activities independently, then you should make sure the DWP are aware of this.
- Explain how you are most of the time, but also the ups and downs. The DWP need to know how care can increase or lessen depending on injury or pain levels etc.
- Think about others who may help you in certain tasks. The DWP need to know how you would cope with mobility and daily living on your own and what difficulties might unfold if you did. You should list even the smallest ways in which another person assists you in accomplishing a task.
- Have a think about how your day-to-day living with your condition can have an impact on your mental health. (Depression, anxiety, agoraphobia, PTSD.) Explain how social stigma can exacerbate anxiety and depression when abuse has been encountered. Make the DWP aware that anxiety and fear of being in certain environments, accessibility issues, not being able to travel for long distances or not having a carer to take them can lead to isolation.

#### Keeping a Diary:

- A diary of your daily task and how you achieve them will be useful for several reasons;
- It may be helpful in answering any questions the health care professional may ask relating to, for example, the frequency at which you experience injuries and under which type of circumstance you experience them.
- A diary will also help you paint a picture of the time frame throughout which your symptoms may vary and the extent to which they do so.
- A diary can also be helpful when completing your 'How your disability affects you' form when you are unsure which descriptor applies to you.
- Additionally, it may be helpful to record the help you receive from others, especially the smallest of tasks which you may not normally notice.

Finally, many people with OI are used to telling people proudly what we can do, and often push ourselves as hard as we can, but in this instance, we are asked to point out where we need help. This can be an alien concept to the fiercely independent people like those in the OI community, but it is necessary that the DWP fully understand your condition to ensure they can help you as much as the can.

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