

Life On The Level – Members Share their Advice and knowledge

Benefits and Balance Conditions

Please see our new section on claiming benefits when suffering with a balance condition. This section is created from the contribution of members and others who have experience of navigating the UK benefits system. Having a serious balance condition can be a devastating experience and made all the worse if loss of employment, then leads to financial distress.

Our section will grow and improve over time, so do check back to see the latest information in the future.

We are not professional experts on the UK benefit systems, but we do want all of those in our balance community to have the best chance possible in successfully claiming benefits that they are entitled to. We are extremely opposed to any government organisation who does not apply the guidance and regulations as intended and in the spirit of allowing rightful benefits to those in need.

Anecdotal feedback suggests that systems appear to be aggressively managed in a way that appears to reduce the chances of succeeding in being awarded benefits. This is unfair and unjust. We hope our information supplied here helps all those applying or considering applying.

Please note that in some cases for our group members we can introduce them to other members with relevant experience in this area to help advise on a one to one basis. Contact our staff to learn more at contact@lifeonthelevel.org - this service is for our members only, but we are free to join.

Personal Independence Payment (PIP)

Personal Independence Payment (PIP) can help with extra living costs if you have both:
a long-term physical or mental health condition or disability
difficulty doing certain everyday tasks or getting around because of your condition
You can get PIP even if you're working, have savings or are getting most other benefits.
See the government site for their official information <https://www.gov.uk/pip>

Some notes for a PIP application from a member

It is important to be absolutely crystal clear about the effect that your balance problem has on you and how it affects your everyday life. Be honest and give examples:

Not being able to walk down stairs and having to go down stairs while sitting down

If feeling well enough to take a bath or a shower, doing so at night as the feeling of being unbalanced is so much worse in the morning

If unable to bathe or shower, having to stay seated on the floor and wash using a bowl

Staying seated on the edge of a bed while dressing

If unable to prepare food, have a selection of ready meals that can be heated up easily in the microwave

Place chairs/stools at certain points in the kitchen to allow you to sit down when preparing food and washing up

Needing more time than usual to process new information and to work out a reply.

Having to take regular breaks between any activity to allow your system to "regroup"

Having to allow a lot of time to do even simple tasks as you need to stop regularly for rest breaks to regain your balance/focus.

If you are able to walk, maybe you need to stop at regular intervals to lean on a wall/fence.

Looking at a screen or reading for more than a few minutes is perhaps not possible, as it triggers a sensation of dizziness.

Your constant need to focus on your balance uses up all your energy and prevents you from being able to concentrate for more than a few minutes or engage in social situations.

[End of examples.]

Filling in any paperwork is a very slow process. Completing a PIP form could take several weeks.

These are just a few ideas that may help you to work out the types of details that you need to include on a form for claiming benefits

In addition to the forms that I had to complete, I also enclosed with each form a written summary of my illness to illustrate the timeline and general progression of my condition over many years.

When you submit a benefit claim form, in most cases there will be a follow up assessment either in person or via a telephone/video link. Here again, you must include detailed explanations as to how your condition affects you and your ability to function on a daily basis. Balance conditions are very hard to describe but if you can explain how you have to adapt your life in order to cope with your condition, this will help someone else to understand the effect that your condition has on your life. These assessments are very demanding, so do not be afraid to ask to take a break if you need one.

Above all, take your time when completing your form and make sure that you include as many detailed examples as possible of how your life has changed on a day to day basis as a result of your condition.

Employment and Support Allowance (ESA)

You can apply for Employment and Support Allowance (ESA) if you have a disability or health condition that affects how much you can work.

See the government site for their official information <https://www.gov.uk/employment-support-allowance>

A member who has on going balance issues has kindly written out here detailed advice from their own experience in claiming. We hope that helps and for our members we can connect you to other members who can give your one to one advice.

Here is our members advice on successfully claiming ESA

1 You can get advice on this at the Job Centre.

2 You will be sent and asked to fill in an application booklet.

This is a lengthy document and I found difficult to navigate but get a friend or family member to help you. Citizen's Advice can fill it in for you, but they may not do as good a job as you. Obviously if you have a friend who has previous experience with ESA that is the best help you can get.

3 Most important advice I would give is when filling this in you MUST write about how you are on a very bad day.

4 If you can't fill it in yourself get someone to do it for you, I couldn't write as I was so dizzy. This can be dictated by yourself and then must be dated and signed by you in each paragraph. We did mine on word , printed it out and stapled it in as I couldn't focus for long enough to write it in one go.

5 Do it in bite size pieces and keep going even if you want to give up.

6 Send all relevant supportive medical information that will support your application e.g. from your Consultant or GP or relevant medical practitioner (in my case the vestibulopathy physio).

7 If some areas ask for similar information or you want to say the same again instead of writing it again and again simply refer them to previous text. This is acceptable and saves time.

8 Don't be afraid of stating how bad it is remember always write about how you and how it affects you on a **BAD DAY**. **NOT A REASONABLE DAY**.

9 I still have mine and am happy to help anyone fill it in. (members please contact us if you require help)

10 You will be contacted to attend for an assessment once you send in the application.

11 When you attend I advise you take someone you trust with you. I had to take my partner as I was unable to walk without his support.

12 You must behave as you have described in your application i.e. as on a **BAD** day. I appreciate you may have less difficult days but they need to assess you on a bad day in order to get your benefit you are not being dishonest.

13 Take your time with the questions.

14 You may have to wait quiet a time to be seen.

15 I know this sounds strange but don't wear you best clothes or if a female no make up .They assess you on everything its not just about what you wrote but they don't tell you that.

16 They may watch you walk to and back from the building or how you sit /behave in waiting room without you knowing so **BE AWARE** this may affect your claim.

17 It is hard to get ESA and harder to get PIP. I was told to reapply for PIP again as you are usually successful second time.

18 ESA pays your NSI which is primarily what I wanted. I had always worked so was eligible but you do have to have worked and paid NSI for a number of years, I can't remember how many. I did not know this my friend told me.

19 ESA is non contribution based.

20 Its about £ 228 approx. per fortnight. My partner works so it's all I could get but your circumstances may be different.

21 Its back dated if you're successful.

22 You will have to repeat this process again if you still want ESA not sure if its every two years as Covid has changed things .

Good luck, hope this helps to anyone applying.

Thank you to our member for this insight and great advice. As mentioned above it is important that you communicate and portray your life on the worst days. Even though we are aware that balance conditions often vary from day to day, you must focus on the worst days and how your life is affected.

More General Advice from our members for PIP and ESA

Don't feel guilty about making a claim.

If your balance condition limits your ability to either work, or lead an active life, then you are perfectly entitled to see if there is any financial support available for you

Receiving your claim forms

Firstly, don't feel daunted by the length of these forms!

Some can run to 30 Pages needing to be completed!

When you receive your claim forms, do take a photocopy of the form and when you start to fill the form in, start first on your blank photocopy where you can make any amendments, corrections etc before transposing it onto your original claim form

Before you start completing your claim form

Make sure you have all of your information close to hand i.e. prescription list, name and contact details of your GP, consultant, prescription medication list. Buy a cheap A4 folder.

This is the start of a lengthy paper collecting exercise, and it's important to be organised and make sure you have everything in the same place for any future reference.

Visit the website Benefits and Work. www.benefitsandwork.co.uk .

They have a wealth of support and information about how to effectively claim for various benefits.

They also have an area which requires member subscription and is an annual fee quite reasonably priced. often discounts are available for the membership fee.

When becoming a full member, there is a huge resource facility available to members of all sorts of very helpful information in respect of claiming benefits right up tribunal level.

Having recently lost my job owing to my illness, I was hesitant about paying out an annual membership fee - I think at the time was around £20 with a discount applied - but it was worth every penny because I actually needed to take my claim right up to upper tribunal in London and all of my information and resource material came from the benefits and work membership section of their website, and I won my case at Upper tribunal! . If you decide not to take out a membership with them then at least visit their website and see what information is available for you there.

Also have a look at Disability Rights UK website www.disabilityrightsuk.org Which has information on claiming benefits

Completing the claim form

Remember to start with completing your blank photocopied claim form. It's likely that as you respond to the questions, you may wish to change one or even several of your responses, so make your mistakes and corrections on your draft photocopied form, then transpose your final answers onto the original claim form

Aim at completing the claim form in small sections at a time over a couple of days, rather than trying to complete it all in one sitting. This will help you maintain clarity and focus, and you will be less likely to feel quite so overwhelmed by such a large task

It is important to be aware that you are living with your health Problems on a daily basis, With all of the anxiety an emotion that comes along with however the claim offices will be looking at your claim in the cold light of day with no emotion involved so it's important to try to stand back from your emotions and present your claim in a clear concise and professional manner.

Claims offices use Descriptors to decide whether or not you are entitled to any benefits and it's important that you take a look at these Descriptors and apply your condition and how it affects you on a daily basis against these descriptors. Copies of these descriptors are available on the websites I've mentioned above

Finalising the claim form

Once you are happy with how are you've completed your draft claim form go ahead and transpose your responses into your original claim form

once you have completed the original claim form, put it down have a break, and then go back and read it through again to make sure there are no mistakes

once you are satisfied with this take, a photocopy for your own records and place it in your file

it is a tiresome and laborious task as there are so many pages, but it is really worth doing this because if your appeal is rejected, and you wish to appeal against the decision, you will have a clear copy of what you have said at the point of your claim

Posting your claim form

Make sure you sent it either recorded delivery, or obtain a certificate of posting to prove when you posted it. This will help should you be told your form has not been received

Keep diary dates with reminders

It's important you know the dates of the claim process in case you need to appeal, and also to set yourself reminders of the dates when your responses need to be done by

The Assessment Visit

Once the benefits office have received your claim form they will arrange for you to have either a face-to-face or telephone assessment with one of their contracted health companies it's quite normal to feel anxious about this assessment however it is also important to remember that the health assessor will be using your claim form responses against the descriptors that I have previously mentioned . usually these assessments are carried out in their own offices but if you are not well enough or your health is unreliable to be able to be sure you can attend an appointment at a certain date you can request a home visit but she will need to provide a GP letter confirming that a home visit is appropriate.

There are lots of stories about these assessors lying on their reports I personally have had experience of this and there is a feeling that they are targeted by the benefits officers to reduce the amount of claims that are approved

whether this is true or not I don't know, but my own experience was that in the three health assessments I've had over the years 2 health assessments were completed by what I would consider to be honest and reliable health assessors and I gained the award that I believed I was entitled to, and the third visit was completed by a health assessor that's completely lied on all of the descriptors, and I went from receiving both mobility and day-to-day living scores , reduced to 0 across both areas

it was on this particular claim and assessment that I ended up needing to go to tribunal and ultimately won my award back

Receiving a response to your claim

It will take some time to receive a response to your claim but just be patient it will come eventually! if you are happy with the response to your claim then nothing more needs to be done you will be given the amount of benefit you're entitled to receive and the timeframe that you will be receiving it in

If you disagree with the response to your claim

If however you are not happy with your claim you will be given instructions in the decision ion letter on how to make an appeal. Usually the process starts with you requesting a mandatory reconsideration, so follow the guidelines in the decision letter on how to request an MR. I would advise against telephoning, you need a clear paper trail throughout the whole process

Thank you to our member for sharing such a great amount of advice and personal experience. We hope that this will help our members and non members alike for future claims.

More Advice

Here are more general tips for claiming any benefits when you have a balance condition form another member. Remember that any repetition in the advice you are reading will mean that many people think these points are very important.

Do not

- Don't feel guilty about claiming benefits.
- Don't feel bad about your condition.
- Don't try to fill forms in yourself.
- Don't assume a balance specialist, will be looking at the forms. It will be an admin team.
- Don't feel silly explaining how your balance issue affects you. I know it is hard to describe & affects us all differently. Impossible for any person without balance issues, to understand just how difficult simple things can be.

Do

- Get someone to help with form filling. Either a disability group in your area, or Age concern. If neither of these is an option, a friend or family member. Fill it in as your worst days.
- Photocopy everything you have filled in. If you do not have a photocopier, local libraries & post offices can often help with this. This helps you, every few years, you have to fill in these forms again.
- If you have to attend an assessment, go accompanied if possible. The assessor will not know about your condition, their job is to assess fitness for work.
- Describe your worst days. If your asked to do something your not capable of, say no sorry, I cannot do that, it affects me badly.
- Discuss with your GP, if you have a good GP , ask if it would be ok, for you to send the details, about how the condition affects you. Not every page, just the page describing your condition, at the end of the document, you have to fill in. My GP suggested this to me, he gets forms to fill in, about how a condition affects the patients lives. As he said, he has no idea & the form would be really helpful to him.

Another members experience and much younger than most :-

Best resource

The most useful website I used was www.benefitsandwork.co.uk/. You can see what you get points for during benefits assessments, and tailor your application so it ticks the right boxes. You can also sign up for £20 a year to get access to more detailed guides, but I didn't do this so I don't know how good they are.

Filling out the forms

Everything you write should be tailored to what you get points for. During my assessments, anything that wasn't on the list of assessment points wasn't considered and wasn't even noted down in the report. Focus on those points, and think about how your difficulties led to trouble in those areas. For example, I am completely incapacitated during my frequent vertigo attacks, and also get frequent drop attacks, so I need someone with me when I go anywhere to keep me safe. This relates to the PIP point about planning and following journeys: I cannot follow the route of a familiar journey without another person, because going on my own means I could either injure myself or end up incapacitated and vulnerable. Give examples: I could have a drop attack when crossing a road and need assistance to get to somewhere safe; I cannot see due to nystagmus when I have a vertigo attack, so I may need physical assistance to complete the journey or get back home.

Be wary about what you write about better days. Of course be truthful, but keep the focus on the worst days. I initially applied for PIP before my symptoms got even worse; when I filled out the form I could go for a short walk on good days, but by the time I had the assessment I couldn't anymore without it making me dizzy. Despite me explaining this, the PIP report stated that because I had originally said I could go for short walks on good days, I could therefore walk as often and as far as I wanted – I got no points for that part. Fortunately, I got enough mobility points for needing accompaniment everywhere, so I didn't need to appeal this. My recent reassessment still upheld that I can walk as much as I wanted, despite me providing lots of evidence and explaining that walking makes my symptoms worse most of the time. PIP guidance states that you need to be able to complete an activity reliably (safely, acceptably, and in a reasonable time), and more than 50% of the time over a year. Before you say you can do something, be sure you can actually do it safely and reliably, the majority of the time, without it causing worse symptoms.

Think about the everyday adjustments you make for your condition – do you have grab rails in the shower in case you get dizzy? Do you make sure someone else is in the house before you shower or have a bath, in case you have a drop attack? Do you avoid carrying a pot of boiling water in case of a sudden vertigo attack? Be explicit for each assessment point – exactly how does your condition make this activity difficult/unsafe, and what do you do instead?

Things that helped my case

Travelling makes my symptoms worse, so I asked my GP for a sick note to scan in to the assessment centre to excuse me from coming in for my assessment. I had both my PIP and ESA assessments at home, and I think this also helped to support my statements about not being able to travel and get around without risking a vertigo attack.

Having to surrender my driving licence due to unpredictable drop attacks also helped support what I was saying – I was specifically asked if I had a driving licence, so if you still have yours but have times when you avoid driving, it might be worth explaining this somewhere.

When I was reassessed and my PIP benefits were continued, the assessor wrote that I had seen as many consultants etc as expected for my health problems, so if there's a reason that you don't have many consultant reports to send in, it might be worth explaining why. Send in as much evidence as you can (as long as it's relevant of course). I always ask for my own copy of all medical appointments in preparation for future reassessments.

Useful links relating to Benefits and making claims

Government site about Personal Independence Payment PIP <https://www.gov.uk/pip>

YouTube video on claiming PIP <https://www.youtube.com/watch?v=BM2FBKdQ7zs>

Government site for Employment Support Allowance ESA <https://www.gov.uk/employment-support-allowance>

YouTube video on claiming ESA https://www.youtube.com/watch?v=0_M4uNufvo4

Mental Health context to claiming ESA <https://www.mentalhealthandmoneyadvice.org/en/welfare-benefits/am-i-eligible-for-employment-support-allowance-esa/>

An organisation dedicated to helping people claim benefits, but membership costs £20 per year www.benefitsandwork.co.uk

A disability Rights Organisation www.disabilityrightsuk.org

Citizens Advice web site <https://www.citizensadvice.org.uk/benefits/sick-or-disabled-people-and-carers/benefits-for-people-who-are-sick-or-disabled/>

Remember if you are a member of our support group, we may be able to connect you with a fellow member who can give you one to one advice and encouragement. If you are interested in seeking that contact please email us on contact@lifeonthelevel.org

We hope this section on our website has been useful for you . Please do give us feedback on the above and if you think you can offer any advice yourself on this subject or provide advice and support for our members applying for benefits please do get in touch.