Cluster Headaches and Personal Independence Payment

Completing form PIP2 'How your condition affects you'

Provided are some points for Cluster Headache sufferers to consider when completing the June 2018 PIP2 form.

NOTE: Not all comments will be applicable but can give you some idea as to how the form should be completed.

Section 1 – About your health professionals

Q1 Tell us about the professional(s) best placed to advise us on how your health condition or disability affects you*.*
For example, a GP, hospital doctor, specialist nurse, community psychiatric nurse, occupational therapist, physiotherapist, social worker, counsellor, or support worker.

Section 2 – About your health condition or disability

Q2a ***Ensure you include all medical conditions related to Cluster Headache, e.g. tremors, depression, etc*. *Also include any other conditions you may suffer from that are not related to Cluster Headaches.***

Q2b ***Remember to include any side effects of your medication***

Section 3 - How your health condition or disability affects your day-to-day life

Q3 Preparing food – ***this descriptor examines your ability to prepare a simple meal using fresh ingredients on a regular, reliable and safe basis. If you only cook using a microwave, make mention of this. If you cannot do this due to likelihood of dropping and spilling hot foods/liquids, make that clear.***

Things to consider when answering:

- *Length of time you have suffered from CH?*
- *Number of attacks you suffer each day and length of time they last?*
- *Other health conditions you suffer from and how they affect CH?*
  e.g. CH making depression more difficult to manage/migraine paralysis making CH less manageable, etc.
- *How CH affects your cooking and preparing food? e.g. balance, dropping things, memory*
- *What happens when a CH attack happens and what you need to do?*
- *Explain what safety concerns you have when preparing food?*
- *Explain if you need supervision and what they need to do for you?*

Q4 Taking Nutrition – *this descriptor looks at your ability to get food into your body – can you cut up food/use a knife and fork/use weighted cutlery/need a feeding tube/need a soft diet/have a mental health condition causing low motivation to eat. If you miss meals often due to pain and fatigue, they need to know how many meals you eat per day on average and how many days per week do you manage this.*

Things to consider when answering:

- *Number of attacks each day?*
- *Talk about the pain in face and the effect it has on eating?*
- *If on O2 what you need to do during an attack, length of time on O2 etc?*
- *Number of meals you may potentially skip due to CH attacks and the need to take medication or O2?*
- *Look at the results of missing meals e.g. Do you binge eat, have a poor diet?*
- *Consider how much energy a CH attack takes from you?*
- *What supervision you need in order to try and have balanced nutritious meals?*

Q5 Managing Treatment – ***this descriptor examines whether you need help to monitor or manage medication, treatments, therapy or appointments by the use of aids or with the help of another person. The more time spent by another person helping you manage this activity, the more points the award will be. If someone helps you with these things, try and calculate roughly how many hours per week on average they spend doing so.***

Things to consider when answering:

- *What medication you take and how often?*
- *Do you get any other treatment and what for? e.g. Counselling, etc.*
- *What help do you get and who from in order to receive treatment? e.g. helper/carer*
- *What would happen if you did not receive this help or treatment?*
- *What does the helper/carer do for you to deliver this treatment? How long does medication take to administer?*
- *Talk about issues you face in taking medication when leaving the house or if you can't leave the house, the reason why?*
- *Issues you face when attending appointments?*
- *Length of time helper/carer helps you each week and the consequences if you don't receive this?*

Q6 Washing and Bathing – ***this descriptor examines how much help you need to bathe yourself and maintain your hygiene on a regular and reliable basis – this could be in the form of physical assistance and motivation/prompting. If you bathed independently before having CH, compare how often you would bathe previously to how often you manage it now. If heat is a trigger to CH, mention this.***

Things to consider when answering:

- *Talk about not being able to rely on being able to wash or bathe?*
- *The reason for not being able to do it, e.g. pain you face, taking medication and how that affects it?*
- *What happens after a CH attack and the length of time it takes to recover?*
- *Look at your triggers for attacks, e.g. heat*
- *Do you have shadow attacks? Can a bath trigger an attack, e.g. hot water?*
- *Have you had an attack in the bathroom? What happened?*
- *Look at your motivation, mood? Does this affect you doing simple tasks?*
- *Are you self-conscious when you haven't been able to wash?*
- *Look at the number of times you have washed in the past compared to now? Is it less, if so, talk about how much it is reduced by?*

Q7 Managing Toilet Needs – ***this descriptor refers to urinary and bowel incontinence as well as physical barriers to getting on and off the toilet and cleaning yourself afterwards.***

Things to consider when answering:

- *Talk about how CH affects you when going to the toilet, e.g. coordination, vision*
- *Have you missed the toilet because of an attack?*
- *Has it taken time before you are able to clean it up?*
- *Have you had to get someone else to clean it up?*
- *How did this make you feel?*
- *What other assistance do you need in order to complete this task?*
- *Even with assistance, can you complete this task?*

Q8 Dressing and Undressing – ***this descriptor refers to your ability to physically put clothing on your upper/lower body and barriers to doing this. It also examines your ability to do zips/buttons/buckles/put on shoes and socks. Do you struggle to change clothes regularly due to depression, fatigue and lack of awareness of space and time.***

Things to consider when answering:

- *When having an attack do you even get dressed? If not, why?*
- *Talk about your sleeping pattern and how that affects you?*
- *Do you lose track of time? Does this result in you not changing your clothes?*
- *Refer to the number of hours each day a CH attack can leave you incapacitated? Does this affect your ability to get dressed?*
- *Does a CH attack affect your ability to get dressed when trying to? How long does it take to complete this task?*
- *Can you complete this task in an acceptable time frame?*

Q9 Communicating – ***this descriptor examines your ability to express simple information (conveying the presence of danger in a room or building) and to understand simple messages from those around you. You may not have an intellectual impairment, but during cluster attacks many people may find their ability to talk or take in information significantly impacted. If you have a lot of cluster attacks, this will be applicable as you will spend the majority of your time incapable of doing these things to a safe and acceptable standard.***

Things to consider when answering:

- *What can you communicate during an attack?*
- *Are you able to communicate or recognise potential hazards in a safe manner?*
- *Issues communicating when taking medication, e.g. O2 Mask/mouthpiece*
- *Effect of CH attacks on your energy?*
- *Effect of medication on your energy and issues in being able to communicate?*
- *Looking at whether you can communicate with others independently. Do you have memory issues or forget what has been said in conversations?*
- *What communication issues do you have with your Doctor/Consultant?*
- *How does your helper/carer help with communication?*

Q10 Reading – ***this descriptor looks at your ability to read based on your cognitive function and your vision. If you experience regular visual disturbances that are not corrected by glasses and these regularly impact your ability to read simple texts (e.g. signs in a hospital, instructions for cooking microwave meals, etc.), do make mention of this.***

Things to consider when answering:

- *Number of attacks you have each day?*
- *Look at the issues you face in reading or following understanding signs/symbols?*
- *How does a CH attack affect your vision?*
- *What do your eyes do during an attack? Do you have a sensitivity to light? If so, what do you need to do then?*
- *What happens if you cannot get out of the light?*
- *What help do you require in being able to read or understand, words, signs and symbols?*

Q11 Engaging with others face to face – ***this descriptor looks at your ability to engage with people you know as well as new people on a regular basis. If you have a mental health diagnosis which is secondary to your CCH, this is especially relevant if it stops you mixing with people. Many people with CH find it hard to engage with others because of the random nature of the attacks causing them to feel paranoid about the reactions of others when they are out and about. If you previously had an active social life but you are now isolated, make that clear. If you need to have someone with you at all times due to anxiety, make it clear why you need them and what they do to help you be safe. The assessor will only award points in this area if they consider you to be at risk of significant psychological distress if made to engage with people without support.***

Things to consider when answering:

- *Are there issues when engaging with others?*
- *Look at your behaviour during an attack? What do others think?*
- *What happens during an attack? e.g. using O2, banging of head and rocking*
- *Are you aware of your surroundings and who is in your company?*
- *During recovery how do you feel? Can you interact with anyone?*
- *Do you avoid socialising? Why do you do this?*
- *What happens if you have an attack in public? Can you communicate what is happening?*
- *How do people react to your behaviour? How do your attacks affect other people?*
- *Does your lack of being able to socialise with others affect your other conditions? e.g. anxiety, depression*
- *Can social engagements trigger attacks?*
- *What was your social life like prior to getting CH attacks?*

Q12 Making Budgeting Decisions – ***this descriptor assesses your ability to understand basic calculations involved in small purchases (e.g. can you intellectually understand how much change you would receive if buying something worth 20p out of a £1 coin) and then your ability to manage a more complex household budget without falling into debt and financial disrepair. If someone helps you with groceries, mention this. If you have fallen into debt because of neglecting your finances, mention this. Please note that this MUST be linked to your condition and impaired memory/cognition/inability to manage stress. You cannot say you cannot manage a budget if your reasoning is that a partner or a family member has always done it for you – you need to be clear that you are mentally incapable of managing this on a regular basis due to your health condition and not just personal preference.***

Things to consider when answering:

- *How do CH attacks affect your body and mind? How long does this last?*
- *Can you process what you are seeing?*
- *Can you pay bills? Do you remember to pay or forget that you have already paid?*
- *What assistance do you need with finances?*
- *How do they help you in managing this? Have they taken over?*
- *Can you go into shops to buy stuff? If not why? e.g. environmental conditions, lighting*
- *Do you buy stuff and forget you have bought it?*
- *What would happen if you never had assistance with bills etc?*
- *Have you had financial issues because of CH attacks and not being able to pay bills?*
- *Are you able to understand and make key decisions when it comes to your bills?*

MOBILITY ACTIVITIES

Q13 Planning and following journeys – ***this descriptor looks at your cognitive ability to plan, remember, understand and follow a journey safely, regularly and reliably. If you drive, this refers to your ability to follow a satnav or roadmap to new places or to remember the routes to familiar places. If you use public transport, can you remember bus/train routes and manage the stresses that come along with this – paying for and retaining a ticket, getting the right bus/train in the right direction, remembering where the bus stop is, sitting next to people and behaving appropriately. If you can journey to places you know but not those you don't know on a regular basis, make this clear.***

Things to consider when answering:

- *During an attack do you know where you are?*
- *Can you plan and follow a route/journey, either local or longer distance?*
- *Are you capable of leaving your home during an attack to go to the shop, GP surgery, or Chemist? If not, why?*
- *What do you need to take with you if you do need to leave your home? e.g. O2 bottle*
- *If you have a portable O2, how long does that last? Why can't you take the bigger bottle?*
- *How much planning is required in order for you to leave home?*
- *Can you use public transport? If not, why not?*
- *What issues are there when travelling? Are there problems being in a confined space? Is it safe for you or others?*
- *How do you feel if you do have a CH attack in public? Do you feel safe?*
- *How do you feel when recovering? Are you able to get home by yourself safely?*
- *What assistance do you require from others when making a journey? How do you get assistance from your support in this?*
- *What do you miss out on with not being able to plan a journey yourself?*

Q14 Moving Around – ***this descriptor examines your ability to use your legs to move around independently on a regular basis. This usually applies specifically to those who have conditions which affect their spine/legs and use either a wheelchair or other aids to mobilise independently. In the case of CH, you can argue that you fulfil this criteria if your balance, gait and coordination are affected for the majority of the time due to the exhausting nature of the pain and recovery times you experience. If you use walking sticks, crutches, wheelchairs or walk around your home using furniture to steady yourself, state this clearly. If you do not feel safe to walk even short distances along the street and spend most of your time at home resting, it would be fair to assume that you do not regularly move for distances longer than 10-20m at a time, based on the size of an average home. If you were active before having CH, mention this and any effects the change in lifestyle may have left you with – loss of muscle/tone, bedsores, limb weakness, shortness of breath when walking short distances, chronic fatigue, weight gain etc.***

Things to consider when answering:

- *During CH attacks are you able to walk, does it affect your balance, coordination and control?*
- *How does the pain affect your ability to move around?*
- *If on O2, do you have to stay in the one place?*
- *Look at what happens if you get a CH attack suddenly in one room and your medication is in another, can you reach it?*
- *Do you injure yourself when having CH attacks? e.g. stumbling, tripping*
- *How do you feel after an attack? e.g. dizzy, disorientated, confused*
- *Are you able to safely walk round your house or are you confined to one room, e.g. bedroom?*

General Tips and Info

When applying for PIP it is important ***not*** to apply with your best day in mind. You should instead consider your ability to carry out a task ***most of the time***- e.g. does your condition affect your ability to cook/dress/wash more than 15 days out of 30?

Working out averages

It is useful to calculate averages if your CH attacks vary in frequency and length. You can work out an average by keeping a diary and taking a period of time and looking at how many clusters you had and how long the lead-up, attack, and recovery period lasts. It is helpful to use at least a one month period, but even a week can be helpful if you can back it up with a diary. For example -

Mon – 2 clusters, 7 hours total inc recovery and build up

Tuesday – attack free

Wednesday – 1 cluster, 2 hours inc recovery and build up

Thursday – 5 clusters, 6 daytime hours and totally disturbed sleep pattern of 8 hours

Friday – spent the day in recovery from sleepless night, 2 clusters, 5 hours total inc recovery and build up

Saturday – 1 cluster, 2 hours inc recovery and build up

Sunday - 2 clusters, 6 hours inc recovery and build up

Total clusters for the week – 13

Total hours in attack – 36 hours, plus one totally disrupted daytime period due to sleepless night

13 clusters divided by 7 days – 1.85, rounds up to two clusters per day on average. 36 hours in pain divided by 7 days – 5.1 hours on average spent in debilitating pain per day.

You can then say, based on a standard week, you have on average two cluster headaches per day, causing you to be incapacitated by pain for at least five of your waking hours – this is not even including the full day you lost to fatigue as a result of nocturnal cluster attacks.

Reliability

The Department of Work and Pensions states that 'If an individual cannot reliably complete an activity in the way described in a descriptor then they should be considered unable to complete it at that level'

They go on to describe reliability as follows:

'Considering reliability involves looking at whether the claimant can complete the activity as described:

- ***Safely*** – in a manner unlikely to cause harm to themselves or to another person, either during or after completion of the activity
- ***To an acceptable standard*** – e.g. being able to perform a task well
- ***Repeatedly*** – able to repeat the activity as often as is reasonably required
- ***In a reasonable time period*** – no more than twice as long as the maximum period that a non-disabled person would normally take to complete that activity'.

Remember…

- Practise – don't write straight onto the form. Use some paper to write and phrase your answers before putting them on the form

- Photocopy the completed form before you send it off (to remember what you wrote).

- Try to get someone to check the form over for you – preferably someone who knows you well.

- Enclose statements from medical professionals, or friends/family, etc., to support your answers. This helps the assessor understand your condition from both a medical and personal perspective.

- Enclosing repeat prescriptions or a diary may also be beneficial.

- When filling in each section, if you cannot complete a task reliably (see notes above) do not just tick 'yes' – tick 'no' and explain the conditions and problems you encounter when trying to complete a task.

Just to remind you that the considerations above are theoretical and you may be able to do the tasks listed - these tips are just to help you understand how to approach questions.

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