

*These notes are intended only as a guide and are no guarantee that the applicant will be granted DLA or any other benefit.*

## Disability Living Allowance (DLA1)

You will need form DLA 1 from your local DWP office, and you must ensure you have the form dated, as if the benefit is granted, it is backdated to the date on that form. Also, you should complete it as soon as you reasonably can. The form comes in two parts, the first takes personal details and the second covers details of your disability etc. DLA is the only benefit that is not means-tested, so you are not asked for details of your finances. You can be in full time work and claim DLA. This benefit is to help your quality of life at home and to help you get around outside the home.

It is paid in two components: one to help you live at home and the second to help you get around (mobility). Each component has three levels, low, medium and high.

If your application is unsuccessful you can appeal the decision. If the benefit is granted, you may feel that it has been granted at an inappropriate level (say it was granted at medium level, but you felt it should be high etc) and you can also appeal that decision too.

One important point to remember is that if you use O2 you must have someone with you, as if you fall asleep the cylinder could run out and there is a very real risk of you suffocating! This is how one member got his DLA granted on appeal, by pointing this out.

Some of the questions seem repetitive, but do persevere. We cannot tell you what to put as your answers, as your own experience of Cluster Headache will be different to everyone else's. So state what life is like for you. The Citizens Advice Bureau were a great help with filling in the form, go along and see them and take notes.

Work on the premise that every day is a bad day and some are worse. If you bump into someone in the street and they say "How are you?", we all reply "Oh fine thanks,"; we are our own worst enemies sometimes, we don't like to burden people with how we are really feeling and do ourselves no favours at all.

The following is one sufferer's experience of chronic CH and gives some idea of what the DLA form covers.

"I get two to four + attacks a day.

I am perfectly capable of walking short distances, but the attacks come on suddenly and without warning and reach a peak in a very short time, so I cannot be on my own or far from home or the car, both of which have an oxygen supply and the wonderful Imigran. I am on the Verapamil protocol and this causes extreme fatigue, constipation (did you really want to know that!) and my feet and ankles swell to the point of aching and I cannot stand for long periods. The Verapamil causes extreme sweating, extreme fatigue and nausea and I am sensitive to strong smells.

If I have more than two attacks a day, (you can only use two Imigran injections a day), I have to take Tramadol which knock me out (when they eventually start to work) and when I come to I am dizzy, confused, have hallucinations, nausea and sometimes vomiting. Some of these side effects can last for up to twelve hours, but it's better than the excruciating pain.

I cannot use public transport because of having to carry a supply of O2 and not only that if I have an attack it is embarrassing in company as I cry, rock back and fore, swear and kick my oxygen cylinder! Also for safety reasons some forms of public transport will not allow you to carry O2 on board. The Imigran can leave me tired and confused and nauseous.

At night I can be very dizzy and confused by the pain and I stumble getting out of bed (I have to go to the loo) and have also on more than one occasion stumbled on the stairs getting my ice pack from the kitchen. I have lived in this house for 15 years, but in my pain and confusion have on several occasions forgotten where the bathroom is and my husband has had to lead me there!

The attacks always commence in the early hours and occur every day. My husband stays awake with me to ensure I do not overdose the meds in my pain and confusion and desperation, and also to make sure I don't fall down the stairs on a trip to the loo, or fall asleep on the O2 once an attack has gone. There is a very real risk of suffocation if you fall asleep on O2 and the cylinder runs out while you still have the mask on.

Because of chronic CH, the pain and the repeated daily attacks, and the extreme fatigue, I have had to give up work. At one point we almost had to sell our house as we could not keep up the mortgage. CH makes me very depressed on some days, I can't see an end to the daily pain, some attacks are terrifying to me. Being able to talk to fellow sufferers thru OUCH has been a great morale booster and has been a great help on the days when the Black Dog (depression) joins the Beast to plague me.

My attacks start in the early hours anywhere between 1.30 am and 5.30 am, sometimes twice in a night or more. I wake to excruciating pain on the right side of my head, I am boiling hot and sweating, I have earache, my nose is bugged up on that side, my right eye waters and it now has a permanent droop. I will cry, groan, swear, rock back and fore, begging the pain to go away. The attacks can last anything from 15 minutes to 2 hours. Without meds they will go on for much longer, by which time I could quite happily shoot myself. The profuse sweating means my nightdress and sometimes even the bedclothes have to be changed, which means my husband has to do it, as I am in no state to do so."

Part of the form asks for details of your GP and your consultant. I gave the details of my consultant at QS (Prof Goadsby at the time, but now of course Dr Matharu) and the report they provided to the Department of Work and Pensions was number two on the list of information considered in making their decision, so if you have been seen at QS this is a great help.

Many times we have been out to friends, out to dinner, the theatre or a concert and had to make a hasty exit because an attack is imminent. You can never make plans with any certainty, as an attack can strike at any time. Unless you make a huge effort (and that's hard when you are so exhausted), your social life is minimal. Even something as simple and every day as a trip to the supermarket can be a tense exercise in case an attack starts.

Remember, it is a lifelong condition and as yet, there is no cure. Don't minimise your condition, tell it like it is in all its horrible detail. Give as much information as possible and when sending in the form, I attached the OUCH leaflet and I also wrote my own experience of CH. If we don't tell them what its like, no-one else will!

If you are a single parent, then your burden is magnified as it is difficult for adults to cope seeing you have an attack – how would a young child cope?

If you qualify for high rate in both components, you are categorised as being severely disabled. We might not like the label, but it is true, this is a severely disabling illness and there is case law that states that it IS a disability.

If you qualify for high rate in both components of DLA, you automatically qualify for a disabled blue badge, and you should be notified of this if your application is successful.

There are other benefits which could be applied for, some of which are a follow-on from DLA. At one time there was something called Disabled Persons Tax Credit. This is now part of Working Families Tax Credit. Your income and that of your partner is assessed in this claim. If you are successful, you then qualify for free prescriptions and assistance with travel to hospital appointments, free eye tests, etc.

If you are in full time employment and have to be on sick leave you can claim Statutory Sick Pay (your employer has to pay this). It is up to your employer whether he makes up the difference between SSP and your usual wage/salary. Your employer has to pay SSP for up to 26 weeks. If you are still "signed off", then you should claim ESA [Employment Support Allowance]. This is paid at two different rates, the ordinary rate and the Long Term rate, although if you have already been off work for 26 weeks, you should qualify for the long term rate, especially as this condition is life-long and there is as yet no cure.

If you have a family, then there are a whole host of other benefits that you may qualify for, housing benefit, community charge benefits etc.

A couple of points that may help with regard to your employment, does your job include health benefits, or a staff private health scheme – this may help to speed up a neuro appointment if you can go private.

Also, if you think your employers want to sack you for health reasons (and they can! – see separate advice under “In the Workplace” on the main site navigation), are you a member of a Union – see your shop steward/local secretary to ask for assistance and guidance as to your rights.