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Disability Living Allowance

***Making it easier to claim DLA for people
with Hereditary Angioedema (HAE)***

A guide for PiA members

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*The information it contains should be
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CLAIMING DISABILITY LIVING ALLOWANCE FOR PEOPLE WITH HEREDITARY ANGIOEDEMA

Welcome!

DLA is a very important benefit for anyone with serious long-term health problems and many PiA members receive it. However, the claim form is not easy to fill in for people with HAE. This pack has been developed to make the process easier for you, by drawing on the experience gained over the years in helping members to claim DLA.

We recommend that *you* read through this pack and the forms before putting pen to paper. You have six weeks in which to return the form. If you have a partner or regular carer, we suggest that you fill them in together as this can help to make sure that nothing is missed or underestimated.

If you have any doubts at all about claiming, do refer to the section "DLA: what it is and why you should consider claiming" (page2) for further information.

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DLA: what is it and why should I consider claiming it?

Don't be put off by the name. You don't have to be wheelchair bound or need to be helped in and out of the bath. There are different levels of benefit and you may qualify for one of the lower levels if you cannot cook a main meal for yourself.

You have to have a serious long-term medical condition which causes you difficulties with "getting around" (mobility) and/or *with* "personal care".

Advantages of claiming DLA

- Although you have to meet certain conditions in order to qualify, once it is awarded it is up to you how you spend the money: you don't have to use it to pay for someone to look after you. You can use it to give someone petrol money, pay for a better diet, extra heating or a holiday to give you a break.
- It is not means-tested
- *You* do not need to have paid National Insurance contributions to qualify.
- It is paid in addition to any other income and/or savings you and your partner may have. If you are *getting any means- tested benefits*, it may **increase** the amount you receive. It is **not** a situation where you receive with one hand and then lose with the other. (See "Action following a successful claim".)
- The high rate of the mobility component can give you exemption from road tax, access to the Motability car scheme and entitlement to a blue badge, which makes parking easier.
- You can get DLA even if you are working. (If however you are receiving it and then decide to go back to work, we suggest you contact the *Welfare Rights Officer* to discuss the implications).
- If you have a carer, the fact that you are getting DLA may help them to claim benefit in their own right. (See "Carers").

Current rates of DLA (correct at April 2009)

Mobility Component

- High rate £49.10
- Low rate £18.65

Care component

- High rate £70.35
- Middle £47.10
- Low rate £18.65

Hints on claiming DLA

- 1) The form can be upsetting to fill in. It is very long and it focuses on all the problems you have: instead of thinking how you manage to overcome any problems, you have to concentrate on all your difficulties. Don't worry that you are over-exaggerating your problems: it is essential to give a full and detailed description of how your condition affects your day-to-day life at its worst.
- 2) Keep copies of **everything**: claim form, medical reports, letters from the DWP and a record of any phone conversations with staff at the department. (Staff are required to give their name if asked). This makes it easier if your application is refused and you have to go to appeal, or if papers get lost.
- 3) Strong medical support is **essential**. Our advice is that you get your own reports from your GP and/or consultant rather than leave the DWP to do this. DWP use a form with standard questions which may not give a full picture of how your condition affects you day to day.
- 4) **However**, it is important that your doctor reports on the problems you have managing your daily life as well as giving a description of your medical problems. The Welfare Rights Officer will be happy to write to your doctors on your behalf. If you prefer to ask for your own medical reports, a draft letter is *on the following page*. *Not all the questions will apply to every case so it can be adapted as needed*.
- 5) The help you need with housework, gardening, shopping and other domestic activities does not count. (However, the question about whether you can cook yourself a meal is very important: *see page*).
- 6) DLA is paid because of the help you **need**, rather than help you **get**. If you live alone, or have a working partner, you may have to manage a lot of things for yourself. If you do so in a way which is not entirely safe, with difficulty and pain, or if you are left feeling drained and exhausted, this shows a need for help and you should describe these difficulties on the form. We find that people adjust their lives to cope with their difficulties, and it is easy to overlook the extra efforts you have to make, which other people without your health condition do not need to make.
- 7) You do not have to have to have problems with each and every activity to qualify.
- 8) Several of the questions ask whether you need "encouragement". This is important if your condition makes you feel depressed. If there are days when it does not seem worth the effort of getting up, or if a relative, friend or neighbour comes in to encourage *you to* get up and dressed, and/or to make sure that you are eating properly, this needs to be mentioned on the form.
- 9) To qualify for DLA, you have to have problems on more days than not. The form asks on how many days of the week you need help, which is particularly difficult for people with HAE to answer. . Below are some suggestions.

Diary

Keep a daily record for a period of say two months, noting down what problems you are having and what help you either need or actually get.

Better to go for better and worse days to cover the progression of a swelling: bedbound when it comes up, then better for a few days and then reasonably good.

Averaging out

We suggest you look back over the last three months (or if has not been a typical period, the last six or twelve months) and average out the periods of illness to good health, then convert this into the number of days per week.

For example, if you have been ill for eight of the past twelve weeks, this averages out at two thirds of the time, which would be 4/5 days per week. Put this average in the boxes asking how often you have difficulty and explain in the long box on page 37 that your condition fluctuates and how you have worked out the average.

If you have several different problems (for example, if you need help at night to get to the toilet, take your painkillers and have a drink) put each one in the boxes separately and number them.

Although it is difficult, it is essential to answer the questions in the small boxes at the end of each section about how long you need help for, how many days per week and how many times per day. If you are not sure, then it is better to count or time yourself.

Mental Health problems

DLA takes into account both physical and mental health problems. Although primary immunodeficiencies are physical in origin, many members say that they get very depressed about their condition, and this can become a problem in itself quite apart from the other problems arising from the condition. Each question asks whether you need "motivating" to carry out the various activities and it is important to include these aspects and details of any help you have received.

Examples of how your physical problems affect your mental health could be as follows:

- feeling too depressed to go out and meet people
- Finding it difficult looking after yourself
- Having a friend, neighbour, family member popping in regularly to make sure you are ok
- Needing encouragement from other people (friends, relatives, neighbours) to get up, dress, eat, and get out and about
- If you have no-one to help you, what help would make a difference to you?

N.B. if you are having professional help from a counsellor, therapist, psychiatrist, or community psychiatric nurse or if you have been prescribed medication this should go down on the form. It may be worth while getting a medical report from your mental health professional.

- Have you been prescribed any medication for your mental health problems?
- Do you discuss your problems with say your GP and/or consultant?

The Need for Continual Supervision

In the past, many adult members with HAE were unsuccessful in getting DLA at all or if they did so only got the low rate of the care component.

This is partly because HAE is an extremely rare condition. Decision-makers and their medical advisers do not usually know much about it and underestimate how severely your condition affects your daily life.

However, there are other problems which are to do with the way in which DLA is made up.

1. DLA has two components, the Mobility Component and the Care component. You can get either of the two components separately, and any combination of the two. However, although the two components make up one benefit, they are quite separate and you have to meet the conditions for each separately: it's not possible to add them together. So for example:
 - A swelling in the feet, knees or legs can make it "impossible or virtually impossible to walk" This would qualify you for the high rate of the mobility component. However, if this only happens say twice a month, it will not be sufficiently frequent to qualify for help with mobility at the high rate.
 - A swelling in the hands will cause problems with washing, dressing etc. so that you may need "frequent attention throughout the day." However, if this only occurs for a few days per month, it will not be enough to qualify for the care component, and cannot be added to the problems with walking.

Care component

You can qualify for the middle rate of the care component in two ways:

- If you need **frequent attention** throughout the day or the night with bodily functions

OR

- If you need continual **supervision** during the day or the night to protect you from substantial danger.

(If you need help day and night you qualify for the high rate).

A need for supervision is usually the most important one for people with HAE and information in the Consensus Document published in 2005 has helped members to make successful claims using this argument.

What the Consensus Document shows (copies available from the PiA office) is that people with HAE are at substantial risk because of the danger of developing a throat swelling, which is life-threatening. We can therefore argue that they are in need of continual supervision.

This doesn't mean that you can only qualify if you actually have someone with you all the time: this is often impossible. What matters is you can show a *need* to have someone with you. (But it is also helpful if you can explain what arrangements you have put in place so that someone can come to your aid quickly if problems occur).

Because it is so important in a claim for HAE, I have taken this section out of its order on the claim form. It is the section headed:

Needing someone to keep an eye on you (page 27 on the claim form).

The argument goes like this:

- A throat swelling is potentially life-threatening
- Having someone with you means there is someone to help if for example you are finding it physically difficult to speak or if you are too anxious to think clearly
- A throat swelling is possible at any time: it can't be predicted
- Therefore no precautions can be taken to prevent it
- Therefore someone needs to be with you all the time

What I suggest is that you enclose a copy of the consensus document with your application. On the next page I have included a letter which drawn attention to the information in the document which supports your case. I suggest you go through and highlight these points before sending it to the DWP.

You may be able to argue that you should have someone both day and night. This will be easier if you have ever had problems during the night.

The way of claiming I am suggesting may seem very long-winded and time consuming. It means writing a letter to go with the consensus document; highlighting the references in the document and also writing a separate letter to your consultant. However, there are six weeks to get it off to the DWP and this method has had a good success rate.

However, each case of HAE is different and it may be that you are having problems so regularly that you also need frequent attention. For reasons of length I have not included in this guide individual information about answering all the questions but it available in the general guide.

Summary: making a claim

- 1) You can order a claim form either by calling the Benefit Enquiry Line on 0888 882200 or by printing it from the Directgov website (www.direct.gov.uk/disability-dla). You can also claim online from this website.
- 2) The form is stamped with the date you order it and then a date six weeks later. As long as you get the form back by the second date your benefit starts from the date you ordered the form. If you miss the date you can still use the form but benefit will start from the date the DWP actually get your form. It is virtually impossible to get benefit backdated.
- 3) Download the guide to claiming DLA from the PiA website or order a copy from the office. Take time to make sure the form is filled in fully and completely.
- 4) Send it back to the DWP with a copy of the consensus document and covering letter. This asks for no decision to be made until the doctor's report is received. (DWP give themselves up to eleven weeks to make a decision so this isn't a problem).
- 5) Ask your doctors for medical reports. Attached is a draft letter you may find useful. You may need to chase the reports up. When you have them then forward them on to the DWP.
- 6) If your claim is refused, you can ask for an explanation which will be fuller than the letter sent out to you. You can ask for the decision to be looked at again by another decision-maker. You have four weeks from *the date of the letter giving you the decision* to do this.
- 7) If this is not successful, you have a right of appeal. You have a further four weeks from *the date of the letter giving you the decision* to request an appeal.
- 8) If you would like help with the appeal, the following sources are suggested:
 - Some local councils have welfare rights /benefits advice offices.
 - Local Law Centres
 - Local Citizens Advice centres.
 - Any other local advice/disability centres
 - If you have other problems as well as the immune problem there may be an organisation dealing with this who can help

Draft letter to accompany consensus document

In support of my application I enclose a copy of the consensus document on the diagnosis and treatment of HAE, which is the most authoritative account available of this dangerous and demanding condition. It was published in the November edition of the Journal of Immunology and attention is particularly drawn to the very distinguished Consensus Panel and Medical Advisory Panel, which include many of the foremost UK experts. In addition to the detailed medical analysis, it contains information which is very relevant to the care and mobility needs of anyone living with HAE. I have highlighted in the text and summarised below the information in the document which supports an award of care and mobility on the grounds listed above.

HAE is a life-threatening condition

Page 6: the condition can cause fatal laryngeal oedema

Page 11: 50-75% of people with HAE have a life-threatening attack at some time.

Page 7: swelling of the upper respiratory tract is responsible for 15-33% of the mortality rate from HAE

Page 15: attacks of laryngeal oedema can occur at any age and can be life-threatening.

The speed of progression and severity of the attacks are both unpredictable

Page 13: involvement of the upper airways usually begins slowly but cases of progression within 20 minutes have been reported

Page 9: fatal episodes have occurred in patients who have previously only had mild or benign attacks

Page 14: dental work carries the risk of triggering an attack, and fatal attacks have been triggered in this way. Attacks are unpredictable: extensive work may be carried out safely and minor work may precipitate an attack.

Factors triggering an attack

Page 8: infected teeth and other foci of infection

Page 9: attacks more likely at times of physiological and physical stress

Emergency Advice

Page 15: gives detailed advice about how to ensure immediate assistance

Treatments for HAE have side effects: Pages 9 & 13

To summarise, I am at risk of substantial danger to my life from a laryngeal swelling. It is not possible to predict whether and/or when such an episode is likely to occur. No amount of supervision can prevent an attack. However an attack produces extreme pain as well as physical difficulty with speaking and a high level of anxiety because of the life-threatening consequences of such an attack. The combination of these factors makes calm action and effective communication very difficult. I need to have someone with me to get me to A&E where I can have emergency treatment. This is required all the time and is particularly important when I am out in unfamiliar surroundings. Because the danger arises from an inherent defect in my immune system, it is always present.

I am obtaining further evidence and will be grateful if no decision is made until this is received.

Dear Dr

I am writing to ask if you can provide a medical report to support my application for Disability Living Allowance. It will be very helpful if in your report you can address the following points having regard to my various health conditions:

- What is the history/diagnosis/prognosis/treatment for my condition?
- What would you say are the main disabling effects of my health conditions and how do they impact on my day-to-day life?
- In your opinion would my health conditions restrict or have any impact on my ability to mobilise outdoors due to e.g. joint pain, breathlessness, fatigue etc.?
- Do any of my health problems restrict or have any impact on my ability to get around alone, outdoors in either familiar or unfamiliar places? If so, would I ever need help from another person when walking outdoors in either familiar places or unfamiliar places?
- In your opinion, would I ever need help with self-care during the day (including help in the form of prompting and encouragement) e.g. washing and bathing, dressing and undressing, use of the toilet, preparing and cooking food and issues around medication?
- Would I ever need help with self-care during the night-time?
- Would I require supervision to keep me safe?

For children

- Is any help s/he requires substantially more than what would usually be required at this age?
- Has s/he suffered any developmental delay due to their health conditions?

Are there any other issues you would like to raise in relation to my health and how it affects my day-to-day living? Please feel free to add any other comments you feel may assist the Department for Work & Pensions in understanding my medical needs.

Thanking you.

What happens next?

It can take up to eleven weeks before you get a decision. The decision-maker can do one of four things:

- make a decision based on the application form and any medical reports you have sent with it
- send out one of their doctors to visit you at home
- ask one of their doctors for advice
- obtain further reports from your GP, consultant, child's school etc.

Your award can be made for a set period or indefinitely. (They are no longer made "for life"). Often a first award is made for a fixed period, particularly for a child, whose need for help will change as they grow and develop.

If you are given a fixed-term award, then renewal forms will be sent to you six months before the award expires. **There is no guarantee that an award will be automatically continued** and it is therefore essential that the new application is completed as fully and carefully as the original application.

It will help if you have a copy of your original application, as you will be able to see from that whether there have been any changes. It is also important that any supporting medical evidence is up to date, rather than copies of previous reports.

What can I do if I am not successful?

Do not give up! It is possible to take it further, and many of our members have done so successfully. **You need to act quickly**, as you only have four weeks from the date of the letter. (It is possible to make a late application if there are "special reasons." If you find you have missed the deadline, we suggest you contact the Welfare Rights Officer).

You can ring up and ask for an explanation. This is helpful as it gives you an idea why your application was refused. (The letter giving the decision just sets out the qualifying conditions and states that you do not qualify).

You can then ask for a reconsideration of the decision. It will be looked at again in the office by a different decision-maker and may be changed, particularly if you provide additional information such as medical reports.

If this is unsuccessful, you have a right of appeal. We suggest that you contact the Welfare Rights Officer at this stage if you have not already done so.

Action following an award of DLA

DLA is a “passport” to other entitlements.

If you have previously been turned down for any means-tested benefits because your income is too high, it may be worth applying again.

Any rate of DLA

If you are already in receipt of means –tested benefits, you may become entitled to the “disability premium” as part of the calculation. (This will not apply if you or your partners are already getting Severe Disablement Allowance, the high rate of Incapacity Benefit or Working Tax Credit as a disabled worker).

Mobility Component at the high rate

This gives you:

- exemption from road tax
- entitlement to a blue badge which makes parking easier
- the right to join the Motability Scheme. (You must either have an indefinite award or a fixed-term with at least 12 months to run).

Middle or high rate of the care component

You may qualify for the severe disability premium as part of your Income Support, so long as

- no-one is claiming as your carer
- you live alone or are treated as living alone (these rules are complicated: we suggest you contact the Welfare Rights Officer)

Your carer should claim Carers Allowance.

High rate of DLA care

If you are under sixty, you may qualify for the enhanced disability premium as part of your Income Support.

N.B. DLA and Working

There is nothing to prevent you from claiming DLA and working. The form does not ask whether you are working. However, if you are receiving DLA and decide to return to work, this may be seen as “a relevant change of circumstances” leading to a review of your benefit. If you are getting DLA and thinking about starting work, we suggest you contact the Welfare Rights Officer to discuss the implications.

CARERS

If you are caring for someone and meet the following conditions you may be able to claim Carers Allowance for yourself:

- the person you care for receives the high or middle rate of the DLA care component
- you are caring for at least 35 hours per week
- you are not in full-time education
- you do not earn more than £95 per week after deductions (correct at April 2008).

N.B. If you are getting certain other benefits yourself, or if the person you care for receives an addition for you with their benefit, then you may not be eligible. However, **if you yourself get DLA this does not prevent you claiming as a carer.**

You need to claim within three months of the person you care for being awarded Disability Living Allowance and ask for it to be backdated to the date on which the DLA started. You may be asked to attend an interview to discuss work possibilities. If you are receiving certain other benefits this will be compulsory.

If the person you care for is getting Income Support, we suggest you check with the Welfare Rights Officer before making a claim for Invalid Care Allowance, as they could lose benefit if someone claims as their carer.