

**DISABILITY AND SICKNESS BENEFITS  
FOR PEOPLE WITH ME / CFS:  
APPLICATIONS AND APPEALS**

Information and advice from the Rights for ME caseworker is available to those with ME/CFS, their carers and families. The project is available for people living in the Furness peninsula, South Lakes, and Morecambe and Lancaster area.

**This leaflet looks at the process of applying and appealing for Disability Living Allowance (DLA), Attendance Allowance (AA), Incapacity Benefit (IB) and Income Support and / or National Insurance Contributions paid because of incapacity (IS). These last two benefits are assessed by the Personal Capability Assessment (PCA).**

**AA is a modified version of DLA benefit, for people aged 65 years or over.**

**This booklet only provides general information. Please contact Rights for ME for specific information and advice.**

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**When applying for disability and other benefits, seek assistance and advice from the RfME caseworker, because of the complexity of the symptoms and effects of the illness.**

**If you want to appeal a decision made about your benefit entitlement, please speak to the caseworker.**



benefits service for people with me/cfs

**Lancaster CAB  
Morecambe Bay ME Group**

### Why apply - advantages

These benefits can provide you with important income at a time of changed circumstances due to illness. The award of both IB and DLA/AA can lead to an increase in means-tested benefits, such as Income Support.

Being in receipt of these benefits can give weight to the assessment of needs by the Social Services.

#### Disability Living Allowance / Attendance Allowance **DLA/AA**

The middle or high rate of DLA care can trigger extra benefits for yourself, or for somebody who looks after you, depending on their circumstances. You can be in work and receive DLA. It is not means tested or taxable.

The high rate of DLA mobility makes you automatically eligible for a Blue Badge and other vehicle benefits.

#### Incapacity Benefit **IB**

Entitlement to IB allows you to undertake some employment, as a means to help you get back to work. This is called 'permitted work'.

There is a 'benefit protection' scheme with IB. If you stop claiming IB because you are returning to work, you are allowed to return to the benefit within 52 weeks of starting that work if illness returns.

#### Income Support **IS**

IS is a means-tested benefit—if you are eligible under the means-testing rules, it can lead to automatic full amounts of Council Tax Benefit, and Housing Benefit if you rent your home. Any award of Income Support will mean that you are automatically eligible for free prescriptions and other health benefits.

### Caution

The process of applying for these benefits can be complex and time-consuming. The nature of the illness ME/CFS can make it more difficult to apply, as it does not always seem to fit easily into the requirements of the benefit regulations.

The benefits are linked to a complex, changing set of other direct and indirect benefits.

The assessment of your claim is initially made by non medically qualified civil servants, who may not have a full understanding of the illness.

You may be asked to undergo a medical examination, which may result in a report that does not reflect your account of how your illness affects you.

The benefit claim will have to be renewed, and because of the variability of ME/CFS, you will have to go through the process again: there is no automatic renewal.

Claiming DLA if you are under 16 is more difficult than for an adult—there are extra tests of eligibility.

The Rights for ME caseworker is experienced in assisting applications. The RfME project also collects evidence about benefit applications and other matters as part of national campaigns for changes in benefit laws and procedures.

Whether you have recently fallen ill, or have been ill for a long time, an application for one or more of these benefits is worth considering because of the increased costs of living that come with long term-illness and disability.

Other RfME guides to assist you:

*“Attending the Doctor’s Examination when Claiming Disability and Sickness Benefits”*

### **Obtaining the application forms**

Preferably you will have had a discussion with the Rights for ME project about your eligibility for these and other benefits. For DLA/AA: telephone the Benefits Enquiry Line, 0800 88 22 00, and ask for an application form. You will have 6 weeks to complete the form from the date of the telephone call.

To apply for Income Support contact your local Job Centre office: the telephone number will be in the telephone book under Job Centre or Job Centre Plus. You will be put through to a call centre handling benefit claims. Explain about your illness, and ask for the claim form for IS. They will want to complete an application over the telephone, and may ask you to attend an interview at the Job Centre. Explain to them if this would not be possible, e.g. because of being housebound. They will probably ask you to supply a sick note from your GP.

It is **usual** to be sent the application form for Incapacity Benefit after a period of sick leave from work. Your employer should usually pay you Statutory Sick Pay, which lasts for six months. At the end of this time you will need to apply for IB if the illness continues. The forms should be sent to you automatically before the six months are up. You will receive Income Support instead of Incapacity Benefit if you have not paid enough National Insurance contributions in one of the three preceding years.

In **some circumstances**, if you are under 20, or in some circumstances under 25, you can claim IB even if you haven't worked.

### **Preparing to apply for these benefits (or to appeal against a benefit decision)**

When applying for a disability or sickness benefit, or appealing against a decision, you need to represent accurately and in some detail how you live with the illness. The success of a claim or an appeal can depend on the details you provide.

Completing the RfME DLA or IB checklist, and possibly writing a diary (some people find a diary is too tiring to complete) can be useful tools to achieve this. It can also help you consider whether you have told your doctor and other health professionals about all the effects of your illness. Their knowledge of how the illness affects you can be very important in the process of claiming benefits, as well as of course in clinical diagnosis.

You may not have told your doctor about all the problems you

have with ordinary activities. Please explain now. Give the doctor a copy of the relevant checklist. Your doctor may not know about all these limitations, because they probably will not have seen you carry out these activities.

If you are not able to write a diary, it is possible to ask a friend or a member of your family to write one, as long as they have a good knowledge of how you are day to day.

It is very important to have maintained regular contact with health professionals and support workers when applying for these benefits. It is very likely that a letter from a GP or another health professional will be necessary at some stage of the application process.

If you are a patient of the NHS CFS/ME Service, and/or you have had fairly recent contact with a hospital consultant, you should make sure that they know that you are applying for benefits. The Rights for ME caseworker can advise you about this.

### **Completing the form**

It is advisable to obtain assistance from the RfME caseworker in filling out the form, unless this is the third or fourth time of doing so, and your health has not changed, and you still receive good support from health professionals.

It can take a long time to complete these forms, as well as use a lot of concentration and energy. Please consider asking the RfME caseworker to assist: it will probably take 2 or more home visits to complete the task.

If you have completed one of the checklists, or written a diary, these can be a great help in completing the form.

For IB and IS you will have to complete a form that includes the Personal Capability Assessment (PCA). Details of this are given in outline in a separate sheet.

### **Submitting your claim**

When you receive the application forms, there will be a date by

which they must be returned. You can be given up to 6 weeks to complete the disability benefit forms. If there is a substantial reason for a delay in returning the forms—to do with relapse, or some other matter—then contact the office that sent the forms to you.

Before you send the form off, have it checked by the RfME caseworker if at all possible, even if you have had no contact with the project up to this point.

Do make a copy of all the pages that you have written on, and make a note of the date that the form was posted.

If you are making a renewal claim for one of the disability benefits, the onus is on you to collect supporting medical evidence which needs to be sent in (however see *processing your claim* below).

The best practice is to submit your claim together with supporting material from a health professional. However this is not always possible. Do not delay in sending the application form in, but add a note that further evidence will be sent in if you are expecting some supporting material from a health professional.

If you are having to complete a renewal claim form for DLA or AA, you will have been sent this 6 months before the end date of your current claim. Depending on your circumstances and the state of your health, consider completing the form but delaying sending it in until six weeks before the end date of the current claim. **If you send the form in sooner, and the decision is that you are no longer eligible for benefit, than your benefit will stop straight away.** Please seek advice about this from the RfME project.

The decision makers who work with the paper evidence of your claim are located in different offices. New DLA / AA claims are decided at Bootle in Merseyside; renewal claims for these benefits are decided at Blackpool. Claims for IS are decided at the local Job Centre Plus office; claims for IB are decided in Preston and Carlisle. All the decision makers are part of the Department for Work and Pensions (DWP).

## Processing your claim form

The application forms and any further evidence are read by a decision maker. They can make a decision based on the form, but frequently they will decide to seek further evidence from one or more of the health professionals named in your application form. This is especially so for new claims, but It seems they do this if they think that you might meet the criteria for the benefit. A standard form will be sent to the GP or consultant to complete.

It is likely that good supportive evidence from a physiotherapist or occupational therapist, or from one of the CFS/ME NHS team will also carry some weight.

The decision maker might seek further evidence from a doctor, who will be employed indirectly by the DWP. The doctor will either visit you at home, if you tell them that you have legitimate difficulties leaving the house, or at an examination centre. There are important points to be made about this process, which are dealt with more fully in *“Attending the Doctor’s Examination when Claiming Disability and Sickness Benefits”*. However the most important are:

- do not miss an examination unless severely ill or a long awaited appointment with a consultant is scheduled at that the same time—let the DWP know as soon as possible if you cannot make the appointment, and they should arrange another for you.
- always try to have somebody in the room with you, to take notes, to record how long the examination lasted, the attitude of the doctor, and of course to give you moral and practical support.

Whatever the doctor says about the strength of your claim during the examination, the decision is made by the decision maker. Be prepared for the fact that the doctors are not always well informed about ME, or about the application of important legal decisions concerning the variability of symptoms to the assessment process.

### When will the decision be made

The decision making can take a long time: for DLA it can be 3 months, longer if there is a delay in collecting evidence; for AA it can take up to 6 weeks; for IS it can take several weeks, depending on how much additional information is needed about bank balances etc, to process your claim; and for IB the decision can take several weeks, but can be made a day or two after a medical examination.

### Hearing about the decision

You will usually be given one of three decisions: not to award you benefit; to award you benefit (and in the case of DLA / AA at a rate that you agree with); or to award you a smaller amount of DLA /AA or for a shorter time than you think is warranted by the severity of your illness.

If you receive a decision that you disagree with, contact the relevant office (contact information on the decision letter) and ask for a written explanation of the decision straight away. If you make this request, you have six weeks from the date of the decision letter to take further action; if you don't ask for the written explanation you have **four weeks** to take action. Do not delay.

**Ask the DWP to send to you a copy of the medical evidence used to make the decision.**

For DLA/AA you will be informed about the decision by letter. The date on this letter is very important (see below): similarly for IS. When the decision is made not to renew an award of IB, often following a medical examination, the decision can be put in place before you are told: you might find out about this when the expected payment of IB does not arrive. Again the date that the decision was made is important—it is possible to transfer **easily** to a reduced rate of Income Support **if** you are going to challenge the IB decision. This can only be done within a set time. If this deadline is missed, then the full application process for IS has to

be gone through. If you are refused IB, and don't claim IS, you will need to apply for Job Seeker's Allowance to keep some benefit income.

When applying for DLA /AA it is likely that you will receive letters stating that the application form has been received, and the process is under way.

### Action after you have received the decision

There are two possible routes to challenging the decision. For both of these it is very important to obtain further more detailed evidence. This might include asking for a further more detailed letter from a GP, or other health professional, than that supplied the first time. It is likely that you will have to pay for this. RfME will pay for medical evidence following a positive assessment of its likely usefulness by the caseworker.

The longer route is to ask for **a revision** of the decision, with further evidence being submitted by yourself. The possible advantage of revision is that you might not have to go to an appeal. If the second decision, the revision, does not alter the first after considering this new evidence, then you have the right to ask for **an appeal**. Again you have four weeks to take action from the date of the letter telling you about the revision decision. The quicker route to challenge the first decision is to **lodge an appeal** straightaway, using the 'GL24' form, produced by the DWP. RfME can supply these if required.

There are two possible types of appeal: the first is a "paper hearing", the second oral. You are given the opportunity to decide which you prefer when you receive a form called the 'enquiry form', which will be sent to you once your application to appeal has been registered by the DWP.

RfME advises that you elect to have an oral hearing whenever possible, when you will be questioned by a panel of two or three people. Statistics show that you will have a greater chance of overturning the decision if you appear before a Tribunal.

If the application for the appeal is accepted and you have returned the appeal enquiry form, you will receive a bundle of papers from the DWP. This includes all the evidence used in making the decision, and the legal references relied on to support that decision. You need to go through this bundle and check the basic facts of your application, and the evidence used. This may be the first time you see the report from the examining doctor, if you did not request it at the earlier stage.

If any of the facts are wrong, such as the papers refer to another person, or a different benefit, note these, and contact the DWP about this. If you think that there has been a misrepresentation of your illness, then that will be part of the argument to take to an appeals tribunal. Again the RfME caseworker can assist you with this stage. It is helpful to prepare a written statement that can be submitted before the hearing, whether you go in person, or you have requested a “paper hearing”. The RfME caseworker can assist you with this.

It can take several months, and sometimes over a year, to get to a tribunal, depending on whether you went down the route of asking for a revision, although the DWP and the Tribunals Service are looking to speed up the process.

### **Appeals Tribunals**

The appeal is held in the offices of The Tribunals Service. For Incapacity Benefit (PCA) and Income Support (PCA) decisions there will be two panel members, a chair (a lawyer), and a doctor. For DLA /AA tribunals there will be a third person present, somebody who is disabled or has professional experience of people with disabilities.

The Tribunals service is completely independent of the DWP.

It is possible to have an appeal hearing at home, if it is very clear that you are totally housebound. The request for these has to be made as soon as possible, preferably with the ‘GL24’ (the form used to lodge an appeal) or the ‘hearing enquiry form’ which is sent to you at a later stage of the process.

The order of the appeal is set by the chair, but the main legal responsibility on the tribunal is to assess and evaluate all evidence, especially from yourself. It is probable that you will be asked a lot of questions about how your illness affects you day to day, what diagnosis has been made, what treatment you are receiving. It is common for them to ask you to describe an **average day**, or a **typical day**—so even with variability of an illness like ME you need to have prepared for this line of questioning.

You go into the tribunal room, answer questions from the tribunal members, with the help of a friend, family member and / or a representative, and then return to the waiting room while the decision is made. The decision will nearly always be made at the tribunal unless they decide to adjourn the hearing, usually to allow for more evidence to be collected.

If you win the appeal, the benefit will be backdated to the date of the decision you are appealing against.

### **Further challenges to the decision**

If a tribunal decides against your argument, then there are sometimes grounds to challenge the decision. To make this challenge, you have to make an application to a Commissioner who decides on the rights of the case. This is specialist work, so consider obtaining advice from the RfME project.

If your claim has to go before a Commissioner, and the tribunal decision is overturned, the decision now becomes part of case law, and if significant enough, will become an important interpretation of benefit law.

The process of appealing to a Commissioner can take a long time, and with complicated cases well over a year and longer after going to the tribunal.

To contact the Rights for ME (RfME) project:

Referrals line:

tel. **01524 65842**

or email to:

**enquiries@lancastercab.org**

or

**info@bayme.org**

**Useful internet links about benefit rules and benefit changes:**

**Disability Alliance**—general information charity, with wide spectrum of useful information on website: **www.disabilityalliance.org.uk**

**Benefits and Work**—(partly subscription service) specialist campaigning organisation challenging policy and legislation: also supplies very good practical but lengthy guides for benefit applications: **www.benefitsandwork.co.uk**

**Department for Work and Pensions**—the benefit agency of the government. Forms can be downloaded from here, and you can find information about local Job Centres: **www.dwp.gov.uk**

Material tends to be internet-based, but RfME holds a list of useful telephone numbers.

Other organisations are welcome to make use of this leaflet, but are asked to inform the Rights for ME project first.

**Suggestions about or amendments to this booklet would be gratefully received via Lancaster CAB or Morecambe Bay ME Group.**

The Rights for ME project is a partnership between  
Lancaster CAB & Morecambe Bay ME Group.

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