

How to claim Disability Living Allowance

A self-help guide to claiming Disability Living Allowance for adults with Rheumatoid Arthritis



Foreword

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Since the foundation of the National Rheumatoid Arthritis Society, we have been aware of the difficulties faced by people with Rheumatoid Arthritis when the severity of their disease causes them to have to consider applying for Disability Living Allowance (DLA).

I remember only too well how many times I re-wrote my own application many years ago and I did not have a clinical nurse specialist (CNS) or anyone, apart from my husband who knew no more than I about it, to help me. It is stressful enough having to come to terms with the many daily activities you struggle to do or find impossible to do without then having to justify why you need additional help.

This is why I am particularly pleased that we have been able to commission the writing of this booklet specifically for people with RA which will, I hope, be of significant help to you if and when you apply for DLA. We, at NRAS, are also aware that many of the nurse specialists in rheumatology units around the UK spend many hours helping their patients to fill in the forms and we hope that this booklet will be of value to them too.

I know from talking to our members that many of them are self-effacing and prone to saying things like 'well, there are people who are worse off than me'. Amongst some, there is almost a view that they don't deserve to receive DLA. I would like to try and dispel that view. DLA is intended to be a benefit which enables you to gain a little more independence and help you to achieve things which you can no longer do and **YOU DO NOT NEED TO FEEL GUILTY OR UNDESERVING** about applying for it!

The following are examples of the kind of thing that you can use your DLA for:

- Getting the windows cleaned
- Getting someone to do some gardening for you
- Getting the ironing done
- Getting the housework done either regularly or from time to time
- Getting a take-away if your joints are too painful to prepare a meal
- Getting a taxi to and from the shops if you have difficulty walking
- Getting the lawn cut on a regular basis
- Getting someone to help with the children either on a regular basis or when needed
- Getting a carer in to help you get up when going through a flare period

If there is anything on which you would like further clarification in this booklet, please contact NRAS and we will be pleased to help. If your Nurse Specialist would like a copy of this booklet to enable her/him to provide help for other patients, please ask them to contact NRAS for a complimentary copy.

With best wishes



Ailsa Bosworth

Introduction

Disability Living Allowance (DLA) is an important benefit for people with rheumatoid arthritis. It helps to cover the extra costs that result from the symptoms of rheumatoid arthritis, in particular the costs of care and getting around. You do not need to have a carer or someone helping you to qualify – the benefit is based on the help you need rather than the help you actually receive.

DLA is not taxable and you don't need to have paid National Insurance contributions to get it. You can claim it if you are still working, and it is not means-tested. This means that it is not affected by any earnings or benefits you receive or savings you may have. Neither is it treated as income for other benefits that are means-tested, such as Income Support, Housing Benefit and tax credits. In fact an award of DLA can lead to higher levels of these benefits being paid. DLA can also act as a passport to other benefits, such as Carer's Allowance.

To claim DLA you will have to complete a long self-assessment form. On the plus side, it means that your opinion is extremely important, and you can give detailed information about your needs.

This booklet aims to provide adults (aged 16-64) who have rheumatoid arthritis with a brief explanation of DLA and a guide to completing the form. It can also be used by carers of anyone with rheumatoid arthritis and any professionals working with people with the condition. Children under 16 can also claim DLA, but there is a different claim-form for them to use. The Disability Alliance have produced a guide to claiming DLA for children: 'Tell it like it is!' (see Useful organisations on the back cover for contact details).

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About disability living allowance

Who is eligible?

DLA is not paid simply because you have rheumatoid arthritis, but because of the effect that the symptoms of rheumatoid arthritis have on your life; in particular on your mobility and on your ability to take care of yourself.

There are general rules that you must satisfy before you can qualify for DLA, which we list in Appendix 1.

DLA comes in two parts: the mobility component and the care component. The claim-form for DLA covers both of them. You can be awarded either, or both of these components.

The mobility component

The mobility component is paid to help cover the extra costs that you may have in getting around. It comes at two different rates: the higher and the lower rate. In many respects the two rates represent different types of benefit, paid for very different reasons.

The higher rate

If you have substantial difficulties in walking, the higher rate of the mobility component may apply to you: we list the exact conditions for it in Appendix 2. The difficulties that you have will be most likely due to joint pain or stiffness. Other symptoms of rheumatoid arthritis can also affect your mobility however, including fatigue, and chest pain or breathlessness if your heart or lungs are affected.

Most people with rheumatoid arthritis who are awarded the higher rate mobility component get it because they are considered to be *'unable to walk'* or *'virtually unable to walk'*. The first category is pretty straight forward, and can include people who can only 'walk' if there is someone with them bearing their weight. The second category includes people who can walk only very short distances.

When it is being decided whether or not you are *'virtually unable to walk'* four things matter:

- the distance you can walk;
- the speed you can walk;
- the time it takes you; *and*
- the manner in which you walk.

Any walking that you can only do whilst experiencing *'severe discomfort'* should not be counted. There is no 'maximum distance' in law, below which you become entitled to the higher rate of the mobility component. This is because the matters of speed, time and manner also need to be taken into account and are just as important. However, as a guide, a social security commissioner has offered the opinion on the matter that; *'.. if a claimant is unable to cover more than 25 or 30 yards without suffering severe discomfort, his ability to walk is not appreciable or significant, while if the distance is more than 80 or 100 yards he is unlikely to count as being virtually unable to walk.'*

The lower rate

If you are able to walk reasonably well, but need guidance or supervision to do so, the lower rate of the mobility component may apply to you. Again, we list the exact conditions for it in Appendix 2. It doesn't matter if you can manage to walk without guidance or supervision in places you know well, as long as you generally need guidance or supervision when you are in unfamiliar places. Your need for guidance or supervision may be due to a tendency for your knee or ankle joints to give way. You may also need guidance or supervision if the rheumatoid arthritis has affected your eyesight.

About disability living allowance (cont.)

The care component

The care component is paid because the symptoms of your rheumatoid arthritis are such that you need either care or supervision from another person. The care you receive must relate to some kind of *'bodily function'* (see Appendix 4). Typical examples are dressing, bathing, toileting and getting safely around the home. Generally, care does not include domestic tasks, such as cleaning the home or shopping. The supervision that you need must be necessary to avoid substantial danger to yourself or others. It does not matter if you do not actually receive the care or supervision at the moment, you may for instance live by yourself, but what you do have to show is that there is a need for it. This need has to be reasonable, but it does not have to be medically required.

There are three different rates for the care component, reflecting the amount of care or supervision that you need. The highest rate may apply if you need help throughout the day and the night. The middle rate may apply if you either need help just throughout the day or just throughout the night. The lowest rate may apply if you need help for just part of the day or you are unable to prepare a main meal for yourself. These are simplifications, the full list of conditions is listed in Appendix 3.

How much do you get?

You can get one of the three rates of the care component and one of the two rates of the mobility component. You'll always get the highest rate to which you are entitled.

Mobility component	per week
Higher rate	£43.45
Lower rate	£16.50

Care component	per week
Highest rate	£62.25
Middle rate	£41.65
Lowest rate	£16.50

These figures apply from April 2006 to April 2007. In April 2007 they will be up-rated for inflation.

Starting the claim

To claim DLA just telephone the Benefit Enquiry Line on 0800 882200 and ask for a DLA claim-pack. This will be sent to you. The claim-pack will include a claim-form, which will have a date on it by which it needs to be returned. As long as you return the claim-form by this date, the date on which you asked for the claim-pack will be normally be treated as the start date of your claim.

If you have a carer they should consider making a claim for Carer's Allowance at the same time. They should seek advice before making the claim however, to make sure that your benefits are not affected by their claim. Information on Carer's Allowance and claim-packs for it can also be obtained from the Benefit Enquiry Line.

New claim-forms

It is possible that the claim-forms currently being used in the UK will be replaced sometime in the future by new claim-forms, which are currently being tested in Northwest England. These new forms are asking for the same information as the existing forms, but do so in a multiple choice format. If the new forms are introduced nationally, it is unlikely that they will be used before summer 2006. If you live in one of the areas of Northwest England covered by the Bootle or Manchester Disability Benefits Centres and receive one of the new forms, and require advice or assistance to complete it, we list useful organisations that you can contact at the end of this guide.

Completing the form

The DLA claim-pack consists of the claim-form and some explanatory notes. Read the notes first, and have a look through the claim-form before completing any of it. You may wish to write in pencil first, or alternatively make some notes on paper or on a photocopy of the claim-form, before committing yourself to pen. You should photocopy the claim-form after you have completed it, so you have a record of what you wrote.

The first 5 pages of the claim-form and the last 15 pages are fairly straightforward and ask for general information such as your contact details, who is treating you, what other benefits you may be on and how you would like to be paid. You are asked to list your illnesses or disabilities, without going into detail; there is room later in the form for that. You are also asked to list any tablets, medicines or treatments that you have been prescribed; you can either list them on the form or attach a printed prescription list.

The middle part (*pages 6 to 24*) is more of a challenge. This is where you are asked to explain how rheumatoid arthritis affects your life. You will need to concentrate on what you cannot do, rather than what you are able to do. This can be difficult, because normally you are encouraged to dwell on the positive. Some people find completing this part of the claim-form distressing and demoralising. Try not to be discouraged. It is very important that you give a clear picture of the problems you face, including what your worst days are like. This will greatly increase your chances of receiving an award of DLA.

The forms are designed for people with stable conditions, rather than conditions that can fluctuate like rheumatoid arthritis. This may mean that you have to provide additional information to highlight either day-to-day or longer term variations in your condition. One way of doing this is to produce a diary. We cover this in the next chapter.

We now focus on the questions you are asked in the middle part of the form.

Walking outdoors

The questions on *page 6* of the claim-form relate to the higher rate of the mobility component (*see chapter 1*). You are first asked to confirm whether or not you have physical problems walking. They give examples of such problems.

You are then asked to describe in your own words the problems you have and the help you need with walking. Unfortunately there is very little room in this box to write down your problems fully; you may have to continue on *page 24* of the form – *More about the way your illnesses or disabilities affect you*.

Try to describe all the things that happen to you when you start to walk. Make sure that you only talk about the problems that you have walking on reasonably level ground. You will confuse things if you describe your problems with walking up hills, slopes or on very rough ground. Your condition may well vary, meaning your walking ability changes from day to day. In this case try to describe what you are like on an average day, as well as explaining what you are like on your worst days and how often these occur. Try to be specific about what you feel, for example, *'I get a severe pain in my left knee after I have walked about ten yards' is more helpful than 'My left leg soon hurts'*. List all the things that make walking difficult, including pain, stiffness, joint deformity and fatigue. Describe any problems that you may have with your posture and gait, such as a tendency to shuffle or limp. Describe how you feel at the point that you would normally want to stop walking and take a rest. If you need to take a rest, let them know how long you need to rest before you feel OK again and can walk further. Do not make a guess here. If you are unsure, go out and time yourself.

You are asked to tell them about anything you use to help you walk, such as crutches or a walking stick. They would be expecting you to be using such aids if they would be of assistance to you.

You are then asked if the effort of walking would be dangerous for you. This box is likely to be relevant if you have been medically advised not to walk too far. Danger from other causes besides the effort needed to walk (such as being run over) cannot be taken into account here. Two short questions follow: roughly how far can you walk before you feel severe discomfort and how long, on average, this would take. Severe discomfort does not mean just pain, but can also include extreme fatigue. Normally, when you are in severe discomfort you would not want to go any further, until the symptoms subside. Do not make guesses on these points. If you are not sure how far you can walk before feeling severe discomfort, go outside and test yourself. It would help if you had someone with you, to measure the distance in paces. One pace of an average healthy male adult is about three quarters of a metre. Don't forget to time how long it takes you to walk the distance.

Finally, you are asked how many days a week you have this amount of difficulty walking. If your answer is less than seven days for any reason, try to let them know how many days a week are worse and how many are better. It may help to keep a diary and attach a copy of this to the claim-form.

Having someone with you when you are outdoors

On *page 7* you are asked to confirm whether or not you need to have someone with you when you are outdoors. This question relates to the lower rate of the mobility component (see Chapter 1). You are asked to describe in your own words the problems you have and the help you need when you are outdoors.

If your eyesight has been affected by the rheumatoid arthritis, then this part of the claim-form could be relevant to you. It could also be relevant if your legs give way from time to time, or you otherwise have a tendency to fall or stumble, but these problems are not so serious that you could be considered virtually unable to walk (you can cross-refer to the next page of the form '*Falls or stumbles*' – see below).

You should concentrate on the problems that you have walking unfamiliar routes, rather than going to places that you know well, such as the local shop. If you have no-one to accompany you outdoors and therefore do not walk unfamiliar routes, make this clear. Explain where you would like to go if you had someone to accompany you.

List any incidents that may have already occurred when you have been outdoors or where dangerous situations have arisen that could have been avoided if help was at hand.

Finally, you are asked how many days a week you need someone with you when you are outdoors. Assume you need to go out every day. If you need someone with you whenever you go out, but currently have no-one to accompany you and therefore do not go out, the correct answer to this question would be seven days.

Falls or stumbles

Page 8. If you have a tendency to fall and stumble this will be significant for both the mobility and the care components of DLA. When you fill in the rest of the form you may find yourself cross-referring to this page, so that you don't have to keep repeating yourself.

Firstly, you are asked to write down why you fall or stumble. It could be because of joint stiffness, or because one of your legs gives way at the knee or ankle. Alternatively, you may fall over things because your vision has been affected. You may fall at different times for different reasons, or for a combination of reasons.

Next, you are asked where you might fall or stumble. List places where you have already had falls or stumbles, and what caused them. For example,

'I often fall when getting out of a chair because my right leg tends to give way at the knee'.

Or,

'I often stumble climbing stairs as I have trouble picking my feet up due to the stiffness of my leg joints'.

Include both falls in and away from your home.

Completing the form (cont.)

You are then asked to describe the problems you have and the help you need when you fall or stumble. List any injuries that you have suffered when you have fallen and any treatment that you may have needed afterwards. Give examples of occasions when you were unable to get up for any length of time following a fall. Why were you unable to get up? Did someone have to help you? Alternatively, has someone else stopped you from falling?

Finally, you are asked how often you fall or stumble. If you state how often you have fallen to the ground, clarify how often you have hurt yourself as a result. If someone has stopped you from falling, how often has this happened? A diary may make it easier to answer all these questions (see next chapter).

Help with personal care

For the next 16 pages of the claim-form, the questions relate to the care component of DLA. We explain the rules for the care component in Chapter 1 and Appendix 3.

Each page in the claim-form looks at a different area of day-to-day life:

- Moving about indoors (*page 9*)
- Getting out of bed in the morning and into bed at night (*page 10*)
- When you are in bed (*page 11*)
- Help with your toilet needs (*page 12*)
- Washing, bathing and looking after your appearance (*page 13*)
- Getting dressed and undressed (*page 14*)
- Preparing a cooked main meal for yourself (*page 15*)
- At mealtimes (*page 16*)
- Help with medical treatment (*page 17*)
- Someone keeping an eye on you (*page 18*)
- Dizzy spells, blackouts, fits, seizures (*page 19*)
- The way you feel because of your mental health (*page 20*)
- Communicating with other people (*page 21*)
- Help you need when you go out during the day or in the evening (*pages 22-23*)

These pages tend to follow a similar pattern. At the top of the page you can tick yes or no to confirm whether or not you have problems with that area of day-to-day life. Read the whole page before answering this question.

You are then asked if you need to be told, reminded or encouraged to do the things described on that page. This is aimed at people who can physically manage to do something, but need prompting or encouragement to do it, or to do it properly. This may apply if you are depressed.

Next you are asked to describe the problems that you have and the help that you need with the activity concerned. Sometimes they ask you to separately describe your problems during the day and during the night. If you have difficulties managing the activity mentioned, explain what they are. You may live alone, and thus manage alone because you have no choice. In this case it is important to let them know what help you would ask for, if it were available. You might be managing by yourself at the moment, but some of the activities mentioned cause you pain or take a great deal of time or might be risky for you without assistance from someone else.

Your condition may well be variable. If this is the case, do not concentrate on what you can or can't do on a good day. They particularly want to know about the help that you need on a *regular* basis. So try to focus on an average day (a diary may help you form a picture of an average day – see the next chapter). If there is not enough room on the page to explain things fully, you can use the large box on *page 24* of the claim-form to continue.

Following this there is usually a box for you to describe any equipment that you use or adaptations that have been made to your home in order to make things easier for you. Examples are wheelchairs, crutches, walking sticks and frames, supporting rails, wall handles, stair-lifts, monkey poles, orthopaedic beds, commodes, grabs and specially adapted cutlery or crockery. Explain how the equipment or adaptations help, how useful they are and if you still need help from someone else while using them. Make it clear if you think any of the equipment or adaptations are not safe or practical for you.

Finally, with respect to the activity concerned, you are asked how long you need help for, how many days a week you need help and how many times a day you need help. You may find a diary helps answer these questions (see the next chapter).

We now look at three of the pages of the claim-form in more detail:

Help with your toilet needs

On *page 12* you are asked about the problems you have coping with your toilet needs. This is one of the most difficult subjects to write about, because the questions are of such a personal nature. Try to put as much information down as you can; the forms are treated with strict confidentiality.

If you have difficulty walking, the most difficult part of toileting may be getting to and from the toilet, especially if there are stairs involved. In this case, it may be suggested that a commode could solve the problem, so you will need to explain why using a commode would not be easier; for instance, if there is no private space for one on the level that you are living in.

Mention any difficulties you may have in using the toilet, including sitting down or getting back up from it, wiping yourself, adjusting your clothing and washing afterwards.

If you need to visit the toilet more often than is usual, explain why. It might be as a consequence of the medication you are on.

If you have difficulties getting to and from the toilet at night (and this can include getting in and out of bed), you will need to make it clear why you could not use a commode or a bottle instead. Alternatively, you might already be using a commode or a bottle, but still need help with them.

If you are incontinent, write about the help that you need in dealing with it. This can include changing your clothes, washing yourself down, changing the bedding and also rinsing the bedclothes, if this needs to be done straight away.

Preparing a cooked main meal for yourself

On *page 15* you are asked to write down about any help you need in preparing a cooked main meal for yourself. This relates to the 'cooking test'. Even if you have no other care or supervision needs but can satisfy this test, you could be awarded the lowest rate of the care component (see Appendix 3). The test applies even if you would not normally cook anyway; what matters is whether or not you are *able* to cook. So write down any help you would need in preparing a cooked main meal for yourself even if your partner normally cooks, you use meals on wheels or you eat out most of the time.

Note that a cooked main meal means a proper meal cooked on a traditional cooker, not a ready-made microwave meal or a convenience snack. Describe any part of cooking such a meal that you would have difficulties with. For instance, if your finger or wrist joints are painful then you may have difficulties with peeling and chopping vegetables, using cooking utensils, opening tins, bottles and packets or turning taps on and off. Poor grip could make it dangerous for you to use hot pans. Painful knee or hip joints may make it difficult to stand to use the oven. If your eyesight is damaged, you may have problems in finding and measuring the correct ingredients and other aspects of cooking might be dangerous.

Someone keeping an eye on you

On *page 18* you are asked if you need someone to keep an eye on you. If you need such supervision because you have a tendency to fall, you can cross-refer to what you have already written on *page 8 – Falls or stumbles*.

You may also need supervision if you get confused. Confusion can arise as a side effect from certain types of medication, including strong pain-killers. Try to give examples of potential dangers that could result from the confusion, such as turning on the gas and not lighting it or leaving a hot appliance on. If you can, write down when such incidents have already taken place.

Completing the form (cont.)

When your problems started

You are asked on *page 26* to provide dates when your care and/or mobility problems began. This information is needed to check whether or not you satisfy the three-month qualifying period (see Appendix 1). Note that you are being asked about the length of time that you have had your current mobility problems or care and supervision needs, not the length of time that you have had rheumatoid arthritis. If there has been a slow deterioration in your condition, you may well find it impossible to give an exact date. In this case you should state roughly when the problems started.

If you have previously claimed DLA, were turned down and are making a new claim because your condition has deteriorated, you need to clearly state that the date the deterioration began was after the date of your original unsuccessful claim.

Statement from someone who knows you

On *page 30* there is space for a statement from someone who knows you. The best person to complete this part of the form is the one who is most involved with your treatment or care. It would be better if this person is medically qualified, such as your GP, consultant rheumatologist or a specialist nurse. If possible, make an appointment with them so that you can discuss the matter with them. They will need to know about your mobility problems and care or supervision needs. If you have written a diary (see the next chapter), give them a copy of it.

There is a box on this page where the person providing the statement is asked to write down what your illnesses and disabilities are and how they affect you. In this box they can clarify specific points that are central to your claim. The person may wish to confirm whether or not in their opinion, you meet the conditions for the benefit. To this end, you can copy Appendices 2 and 3 and give them to them, highlighting which conditions you think that you satisfy.

Declaration

Sign the declaration on *page 38* when you consider that what you have written on the claim-form is both correct and complete.

Keeping a diary

If you are claiming the care component of DLA, writing a short diary of your care and supervision needs can greatly improve your chances of success. It can also be very important when trying to explain symptoms that fluctuate either during a single day or over a longer period.

The simplest form of diary would be an account of your care and supervision needed over a typical day. Longer term diaries can be useful, for example when explaining more sporadic problems that result from rheumatoid arthritis such as stumbles or falls, or for showing how different joints are affected over different periods of time.

One-day diaries

Start from the time you get up in the morning, through a 24-hour period, ending with the time you get up the following morning. Try to list all the times when you need a hand from someone else or you have difficulties doing something because there is nobody around to give you a hand.

The previous chapter gives an outline of what sort of help counts. When you write something down, try to answer the following questions:

- (a) What help do you need?
- (b) Why do you need the help?
- (c) At what time do you need help? and
- (d) How long do you need the help for?

Appendix 5 gives an example of the way in which such a diary can be set out.

If your needs vary from day to day, it would be worth your while to keep the diary over a few days, to obtain a clearer picture of your care needs.

Longer diaries

For most claims, a one-day diary will be all that is needed. Sometimes, however, it is necessary to keep diaries over longer periods of time. Long-term diaries tend to be much less detailed and concentrate on one or two matters. For example, a long-term diary could detail which of your joints are affected over different periods of time. Alternatively, if you are prone to falls and stumbles, you can keep a record in a diary of when you have fallen and any injuries that you have received when you have done so. Appendix 6 gives an example of how the way in which such a diary can be set out.

Making use of the diary

Once you have finished writing the diary put your name and National Insurance number at the top of it. Then make several copies of the diary. Most post offices have a photocopier machine that you could use. Keep one copy of the diary for yourself.

Give a copy of the diary to the person you have asked to complete the 'Statement from someone who knows you' on page 30 of the DLA claim-form. If you can, make an appointment with them to fill in that part of the form. Make sure they read your diary before they do this. Explain to them that you are making a claim for DLA and that the diary is to help them in the event that they receive a questionnaire to complete about your condition. Finally, you should send copies of the diary, along with a copy of the claim-form, to anyone else you have listed in the claim-form, such as nurses or physiotherapists. Again, this will help should they receive a questionnaire to complete.

Before sending the DLA claim-form off, make a copy of it and keep this in a safe place. Send off the form in the envelope provided with the claim-pack. If you have written a diary, make sure you include a copy of that and also, if you have one, a spare printed prescription list from your doctor.

How your claim is assessed

Your claim-form will arrive at a regional Disability Benefits Centre. These centres make up part of the Department for Work and Pensions, the government department that takes care of the social security system. At the Disability Benefits Centre your form will be read by an officer called a 'Decision Maker'. They will decide what to do next. They might telephone you, to clarify any of the things that you have written on the claim-form. They might send a questionnaire to any of the people that you have mentioned on the form; this is why it is important for you to make sure that these people know all about any walking difficulties or care and supervision needs that you may have. The Decision Maker may also arrange for a medical examination to take place in your home. If the Decision Maker decides that this is appropriate, you will receive notice of a visit from one of their doctors. Contact them as soon as possible if you cannot be in at the arranged time. If your first language is not English you can ask them to provide an interpreter.

The medical examination

If you have a carer try to ensure that they are in when the doctor visits. Your carer will not be able to answer questions on your behalf, but they will be able to add to what you have to say, particularly with respect to their role as carer. Before the doctor comes, read through the copy that you made of your DLA claim-form.

The doctor will start by asking you questions about each of the areas where you stated you had problems on the form.

If you have said on the claim-form that you have physical problems walking, the doctor will ask how you manage out of doors. They will probably ask whether or not you can walk to familiar locations outside your house; the nearest lamp post, the shop on the corner, the bus-stop. They will have already estimated how far these things are away from your home. They want to make sure that what you have said on the claim-form is accurate. For instance, if you said on the form that you could only walk twenty metres, but then tell the visiting doctor that you can walk to a bus-stop 200 metres away, there will be some confusion as to how far you can actually walk. You need to give clear, accurate information to the doctor to avoid this confusion. Let them know how far you can walk on an average day. Try to make it clear at what point you feel '*severe discomfort*'. Describe how you feel at this point.

You should let the doctor know about any pain or tiredness you feel carrying out each of the activities noted on the claim-form. Let them know about any variation in your condition and about both good and bad days. Show them any medical evidence that you may already have confirming your problems. Try to make sure that what you tell the doctor is consistent with what you have already put on the DLA claim-form, unless of course there has been a marked change in your condition.

The doctor will ask you to sign the statement that they have obtained from you. Make sure that you either read the statement or have the doctor read it to you. Do not sign the statement if there is anything in it that you did not say or that you disagree with.

After they have obtained the statement the doctor will carry out a brief physical examination.

Once the doctor has completed their medical report, they will send it back to the Decision Maker who will decide whether or not to award you DLA and, if it is awarded, at what rate.

Delays and complaints

The Disability Benefits Centres aim to be able to give you a decision within 39 working days of receiving the claim-form.

If you have to wait any longer, or otherwise want to know how your claim is progressing, contact the Disability Benefits Centre dealing with your claim. If you are not satisfied with the answer that you are given, ask to be put through to the Customer Services Manager. If you want to complain about the service in any way, then write to the Customer Services Manager.



The decision

You will be informed in writing of the decision. Benefit will either be paid for a fixed period, say of one or two years, or it will be an indefinite award. If the benefit is paid for a fixed period, you will get a renewal form about six months before the benefit is due to run out. Keep the copy of your DLA claim-form to use as a guide when you need to fill in the renewal forms.

Other benefits

If you are awarded DLA, you should inform the offices that deal with any other benefits that you receive. Benefits such as Income Support, Housing Benefit and Council Tax Benefit and tax credits can often be increased when you have been awarded DLA.

If you have a carer who claimed Carer's Allowance when you first claimed DLA, they probably had their claim turned down at first. This is because, at that time, you had not actually been awarded either the middle or the highest rate care component of DLA (which open the gates to Carer's Allowance). Once you have been awarded the appropriate rate of DLA, your carer should put in another claim for Carer's Allowance, and ask for it to be backdated to the date your DLA was awarded from.



If you are not happy with the decision

Reconsidering your claim

If your claim for DLA is turned down, you have one month from the date of the decision in which to ask them to look at it again. This is officially called a 'revision', though can also be referred to as a 'reconsideration' or 'review'. It differs from an appeal, which we cover later.

You can also ask for a revision if you are unhappy with the level of the benefit that has been awarded. For instance, you might be awarded the middle rate care component of DLA because they think you need frequent help during the day, but you believe that you should receive the highest rate, because you also need repeated help at night.

Be careful, however, because when you ask for a revision, they will look at the whole claim again and they can take away the rate already awarded. If you are in any doubt, seek advice from a local advice centre such as a Citizens Advice Bureau or DIAL.

If the claim is turned down, you will need to know why. You will also need to get your revision in on time. Telephone the number on the decision letter. It will probably take a while to get through. About 8.00am and before 6.30pm are the best times to try.

When you do eventually get through, you should do the following:

- (1) Request a revision of the decision. State your grounds simply at this stage; such as *'I believe that you have underestimated the degree of my disability and consequently underestimated the extent of my mobility problems and my care and supervision needs.'*
- (2) Ask them to send you copies of all the evidence that was used in making the decision.
- (3) Ask them not to take any further action until you have had the chance of responding to that evidence.

Put your request in writing as well. Send it to the address on the decision letter. Keep a copy for yourself. If you have not received the evidence after two weeks, telephone them again to remind them to send it. When you do receive the evidence, you will gain a better idea of why the claim was refused.

Building a case

Sometimes the only evidence used will be the information you gave on the claim-form. In most cases, however, there will be a medical report as well. This will be either a short one from your GP, consultant, nurse or other healthcare professional you mentioned on the claim-form, or a longer one from a doctor who examined you on behalf of the Department for Work and Pensions. Compare the report with your claim-form. Try to find where a difference of opinion arises.

For example: you may have written on your claim-form that you could not get up and down the stairs without support but the doctor noted in their report that they thought that you could manage by yourself. Now try to get medical evidence that shows that what you said on the claim-form was correct. A letter from your doctor or consultant, for example, confirming the difficulties and risks you have in getting up and down stairs, possibly detailing any falls that you have had that they are aware of.

Once you have obtained some evidence to support your case, send it off to the address on the decision letter. If it is likely to take a while to obtain the evidence, you must inform them how long this is likely to take, so they do not make a decision straight away.

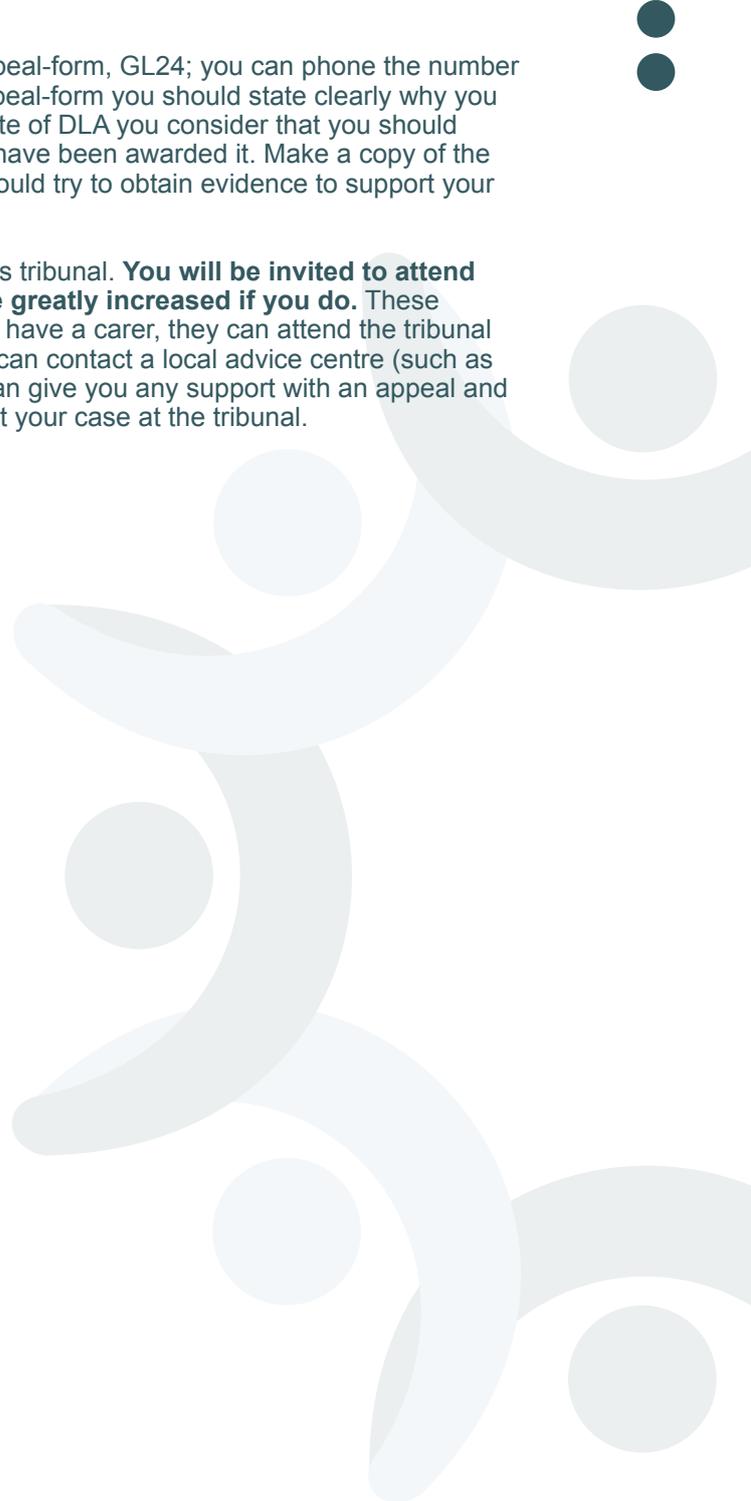
A Decision Maker will look at any further evidence that you send in. They will then either award benefit or write back to you explaining that they have been unable to change the decision. In this case all is not lost, as you now have a month from the date of the new decision to lodge an appeal to a tribunal.



Appeals

You can appeal against a decision on the official appeal-form, GL24; you can phone the number on the decision letter to ask for this form. On the appeal-form you should state clearly why you disagree with the decision. You should state what rate of DLA you consider that you should have been awarded, and why you think you should have been awarded it. Make a copy of the completed appeal-form before sending it off. You should try to obtain evidence to support your case, as with reconsiderations above.

Your appeal will be heard by an independent appeals tribunal. **You will be invited to attend this. Your chances of winning the tribunal will be greatly increased if you do.** These tribunals are informal; they are not like courts. If you have a carer, they can attend the tribunal as well, to provide their account of your needs. You can contact a local advice centre (such as a Citizens Advice Bureau or a DIAL) to see if they can give you any support with an appeal and possibly provide you with a representative to present your case at the tribunal.



What if your condition changes?

Once you have been awarded DLA, you are obliged to inform the DLA central office in Blackpool if there is any change in your condition. Such a change could lead to your DLA award being increased or reduced, depending on the type of change.

What if there is a short-term change in your condition?

You may have short-term flare-ups and remissions of your symptoms. You do not need to inform the DLA central office in Blackpool of every minor fluctuation of your condition. Awards of DLA are made for significant periods; six months is normally the minimum time an award can be made for. The fact that your condition fluctuates should have been taken into account when the original award was made anyway. So the staff at the Blackpool office are really only interested in being informed of changes in your condition that are likely to last for several months and are likely to affect the level of the award that you have been granted. If, however, you have any doubt as to whether or not a change in your condition will have an effect on your claim, you should inform the Blackpool office anyway. This way possible overpayments and underpayments can be avoided.

What if there is a long-term change in your condition?

If there has been a change in your symptoms and you feel that this will have a long-term effect on your mobility or your care needs, you can ask for your DLA award to be looked at again. This way you can claim the mobility component if you are only getting the care component, or claim the care component if you are only getting the mobility component. You can also claim a higher rate of either component. Note that you need to have satisfied the conditions for the new or higher rate of the benefit for three months before your award can be increased.

A word of caution: if you ask for your award to be looked at again, they will look at the whole claim again, and they can take away the benefit that you have already been granted. So, before requesting a review, try to obtain some evidence to back your case up.

For example: let's say you are getting the middle rate care component of DLA because of the help that you need during the day. Three months ago your condition got worse and you started needing help on most nights. Firstly, keep a 24-hour diary showing your new care needs over a typical day and night (see example in Appendix 5), then take it to someone who is treating you, such as your GP or consultant rheumatologist. See if they will write you a brief letter confirming that your condition deteriorated three months ago and your care or supervision needs as stated in your diary are 'reasonable'. Then contact the DLA central office in Blackpool (Tel; 08457 123456) and ask for a review. You will then be sent a new claim-form to complete. You can attach a copy of your support letter to the completed claim-form.

If you are in any doubt as to whether or not to request a review, seek advice from a local advice centre.

If there is an improvement in your condition and consequently an improvement in your mobility or a reduction in your care or supervision needs, you are obliged to inform the Blackpool office. Forms will duly be sent out and your benefit reviewed.

Periodic checks to your award

Occasionally existing awards of DLA are checked in order to see if they are still correct. This can happen at any time, irrespective of the length of time you have been awarded DLA. If your award is to be checked in this way, you should first be sent a DLA300 form, which you will need to complete. This will be very similar to the original claim-form that you completed before you were awarded the benefit. For this reason, it is very important to keep a photocopy of your original completed claim-form. If you do not have a copy, you can ask for one, for guidance purposes, from the Department for Work and Pensions.

If you go into hospital or long-term care

If you go into hospital, your DLA will stop after you have been in hospital for 28 days (it can stop sooner however, if you have had another stay in hospital recently). Payment of DLA can be resumed once you have left hospital.

If you move into a care home, payment of the care component of DLA will usually stop after 28 days (unless you are paying the care home fees in full yourself). You can continue to receive the mobility component. Payment of the care component can be resumed if you leave the care home.

The qualifying conditions: general rules

- You must be present and normally living in this country and have been here for at least 26 out of the previous 52 weeks.
- You must have no restriction or limitation on the right to reside in the UK (seek advice if any restrictions or limits do apply to you).
- You must have satisfied the 'disability tests' (see Appendices 2 and 3) for three months before qualifying and be likely to continue to satisfy them for at least another 6 months afterwards. You can claim before the three months are up, but you will not be paid benefit until the end of the qualifying period.
- You must be under the age of 65. If you qualify for DLA you can continue to receive it after you have reached 65. If you have not qualified for the benefit already and are over 65 you should consider claiming Attendance Allowance instead (claim-forms and general information available from the Benefit Enquiry line; 0800 882200).

The disability tests: the mobility component

Higher rate

To qualify for the higher rate mobility component your *'physical condition as a whole'* must be such that one or more of the following apply to you:

- you are unable to walk
- you are virtually unable to walk
- the exertion required to walk would constitute a danger to your life or would be likely to lead to a serious deterioration in your health
- you have no legs or feet (from birth or through amputation)
- you are both deaf and blind
- you are entitled to the highest rate care component and are severely mentally impaired with extremely disruptive and dangerous behavioural problems

Lower rate

To qualify for the lower rate mobility component you must be:

- *'so severely disabled physically or mentally that, disregarding any ability you may have to use routes which are familiar to you on your own, you cannot take advantage of the faculty out of doors without guidance or supervision from another person most of the time'*.

The disability tests: the care component

To qualify for the care component you must require from another person:

During the day

- frequent attention throughout the day in connection with your bodily functions; *or*
- continual supervision throughout the day in order to avoid substantial danger to yourself or others; *or*

During the night

- prolonged or repeated attention in connection with your bodily functions; *or*
- in order to avoid substantial danger to yourself or others you require another person to be awake for a prolonged period or at frequent intervals for the purpose of watching over you; *or*

Part-time day care

- you require, in connection with your bodily functions, attention from another person for a significant portion of the day (whether during a single period or a number of periods); *or*

Cooking test

- you cannot prepare a cooked main meal for yourself if you have the ingredients.

The meaning of the words and phrases used here is clarified in Appendix 4. The care component comes at three different levels: highest, middle and lowest. The level that you are awarded depends on which of the above criteria apply to you. It is worked out as follows:

Highest rate

You'll pass the disability test for the highest rate if you satisfy:

- either (or both) of the day-time tests; *and*
- either (or both) of the night-time tests.

In a nutshell, your care or supervision needs are spread throughout the day *and* the night. If you are terminally ill, you qualify automatically for the highest rate even if you need no care at all when you claim.

Middle rate

You'll pass the disability test for the middle rate if you satisfy:

- either (or both) of the day-time tests; *or*
- either (or both) of the night-time tests.

In brief, your care or supervision needs are spread throughout just the day or just the night.

Lowest rate

You'll pass the disability test for the lowest rate if you satisfy either (or both) the part-time day care or cooking tests.

Definitions

The following is a list of meanings of the words and phrases that are used in Appendix 3.

Frequent means several times, not once or twice.

Attention is what a non-disabled person would do for themselves with ease in connection with a bodily function. The attention needed with a bodily function must be carried out in your presence and involve personal contact.

Bodily functions includes breathing, eating, sleeping, hearing, seeing, drinking, walking, sitting, dressing, undressing, washing and using the toilet.

Supervision is more or less what it says; if you need someone to be around to prevent any accidents either to yourself, or to other people.

Continual supervision means frequent or regular, so you can apply even if you don't need supervision every single minute. Supervision and attention do tend to overlap; generally speaking however, attention tends to be active help, while supervision is more passive.

Substantial danger must be real, not just remotely possible. This does however include the possibility of infrequent or isolated incidents with potentially dire results.

Prolonged has been interpreted as at least 20 minutes.

Repeated has been defined as two times or more.

Significant portion of the day means at least an hour; though not necessarily all at once. When working out the time you should take into account the amount of disruption caused to the carer, as well as the amount of time spent actually caring.

One-day diary

This is a diary for a 47 year old man who was diagnosed as having rheumatoid arthritis eight years ago. Whilst most of his joints have at some time been affected, his knees and elbows cause him the most problems and his right knee and left elbow have permanent damage. He lives by himself and has written about the help that he really needs rather than the help he actually currently gets.

8.45-8.48am Help needed getting out of bed. My joints are particularly stiff in the morning (including my back, which gets painful at night). Also my right knee tends to give way. I have fallen on three occasions in the last two months trying to do this by myself.

8.55-9.10am Help needed climbing into the shower, which is in the bath, mainly because of the pain and limited movement in my right knee. The general stiffness makes it worse. I need help washing and drying those parts of my body that I cannot reach with my good (right) arm.

9.15-9.30am Help needed putting on trousers, underpants and shirt because of the pain and limited movement in my right knee and left elbow. I need a hand with buttons, zips and laces as my fingers tend to be stiff in the morning (I often do not attempt to dress myself until after lunch).

9.35-9.37am Help needed getting down stairs. My right knee tends to give way. I have fallen down stairs on three occasions in the last six months attempting to do this by myself. The last time I needed to go to hospital after badly spraining my left ankle.

11.20-11.30am Help needed getting up and down stairs to use the toilet (on the first floor). I cannot use a bottle because of my left elbow and the stiffness of my fingers. My front door opens straight into my front room, which together with a small kitchen, are the only rooms on the ground floor. Hence there is not private space for a commode.

12.45pm A friendly neighbour calls round to cook me a meal. I cannot safely cook a main meal. My fingers are stiff, so I have difficulty peeling and chopping vegetables properly. There is limited and painful movement in my left elbow, so I cannot drain pans or lift them safely off the hobs. My neighbour cuts up any tough food when it is on my plate.

1.30-2.45pm The neighbour takes me to the local shops. I need a hand with my jacket and getting in and out of their car. On the way back we will normally stop off by the river for some fresh air.

4.30-4.37pm Help needed getting up and down stairs to use the toilet etc. I normally have a salad at teatime, which I can prepare myself (my neighbour cuts a few tomatoes up for me at dinnertime).

6.45-6.53pm Help needed getting up and down stairs to use the toilet etc.

7.00-8.00pm A friend comes round to see me. We both like stamp collecting. We organise our collections together. He mounts the stamps in the albums for me as I find this very fiddly and have previously damaged valuable stamps trying to do this myself.

9.15-9.22pm Help needed getting up and down stairs to use the toilet etc.

12.00-12.03pm Help needed getting upstairs to go to bed.

12.04-12.06am Help needed undressing trousers and pants.

3.10-3.23am Help needed getting out of bed to use the toilet and steadying when rising from the toilet (I am very stiff when I wake up at night).

5.10-6.00am Wake up with back pain. Massage would help. It takes almost an hour to get back to sleep again.

Longer diaries

This is a longer term diary produced by a 56 year old woman, detailing the falls and stumbles that she has sustained over a period of a month. This will support the information she has given on page 8 of the claim-form (Falls or stumbles). She will also have produced a one-day diary, similar to that in the previous Appendix.

04/03/05 Fell in the front room. My left ankle gave way. I bruised my left hip. It took me 5 minutes to get up again.

09/03/05 Tripped in the hall. My left ankle again. This time fell into the cupboard. No injury or damage.

17/03/05 Stumbled on patio, carrying small plant pot. My right knee gave way. Banged my head on the door. Small cut above left eyebrow. Need a new plant pot.

19/03/05 Fell in shower. Early in the morning – just due to general stiffness and weakness. Badly bruised right shoulder. Took ten minutes to get out. Scalded my right thigh. I rang my GP, who sent nurse round to look at the injuries. Not too serious; could have been much worse. She dressed the scald.

24/03/05 Stumble in hall. Right knee again. Didn't hurt myself, but trod on the cat, who won't come near me now.

28/03/05 Fell on the patio again, left ankle this time. My son was there. Badly sprained my right ankle. My son suspected I might have broken something and took me to casualty, where the ankle was cold-compressed and dressed.

This is a longer term diary produced by a 34 year old woman, detailing which of her joints have been affected over different periods, and to what extent. She will have also produced a one-day diary.

January

Week commencing 3rd: Left ankle (moderate), both knees (severe), both elbows (moderate), fingers (moderate).

w/c 10th: Both knees (severe), both elbows (moderate), fingers (moderate).

w/c 17th: Both knees (severe), both elbows (moderate), right shoulder (mild), fingers (moderate).

w/c 24th: Both knees (moderate), both elbows (moderate), fingers (moderate).

February

w/c 31st(Jan): Both knees (moderate), lower back (moderate), both elbows (moderate), fingers (moderate).

w/c 7th: Both knees (severe), lower back (moderate), both elbows (moderate), fingers (moderate).

w/c 14th: Both knees (severe), lower back (moderate), both elbows (mild), fingers (moderate).

w/c 21st: Both knees (severe), lower back (mild), both elbows (mild), fingers (moderate).

March

w/c 28th(Feb): Both knees (severe), fingers (moderate).

w/c 7th: Both knees (severe), neck (mild), fingers (mild).

w/c 14th: Both knees (moderate), neck (mild), fingers (mild).

w/c 21st: Both knees (moderate), fingers (moderate).

w/c 28th: Both knees (severe), both elbows (mild), fingers (moderate).

Useful organisations

Benefits Enquiry Line

Confidential advice and information provided by the Department for Work and Pensions for people with disabilities, their carers and representatives, about social security benefits: how to claim them and assistance with completing claim-forms.

Helpline 0800 882200
(Monday to Friday 8.30am-6.30pm, Saturday 9am-1pm)
Textphone 0800 243355

Northern Ireland
Telephone 0800 220674
Textphone 0800 243787
www.dwp.gov.uk

Citizens Advice Bureau (CAB)

Help with welfare rights, housing and disability advice. Local CABs are listed in the telephone directory and on their website. The CAB also operates an online advice guide.

www.citizensadvice.org.uk
www.adviceguide.org.uk

DIAL – Disability Information Advice Line

Disability-related advice and information including details on benefits.

DIAL UK
St Catherine's
Tickhill Road
Doncaster
South Yorkshire DN4 8QN

Telephone 01302 310 123
www.dialuk.info

Law centres

Law centres provide free advice and representation. The Law Centres Federation can give you details of your local law centre.

Law Centres Federation
Duchess House
18-19 Warren Street
London W1T 5LR

Telephone 020 7387 8570
www.lawcentres.org.uk

Further reading

The *Disability Rights Handbook* published by Disability Alliance and updated every year, gives more details on DLA and other social security benefits for disabled people, their families and carers. In particular, there is a section devoted to the appeals process, should your claim be unsuccessful. The Disability Alliance also produce a guide for claiming DLA for children *Tell it like it is!* and a guide for claiming Attendance Allowance. You can buy a copy of any of these guides directly from Disability Alliance: telephone 020 7247 8776 or www.disabilityalliance.org.uk

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