

Disability Living Allowance

A practical guide to claiming
Disability Living Allowance
for people with
ankylosing spondylitis

Prepared by the

National Ankylosing Spondylitis Society

Registered Charity no. 272258

Message from the NASS Director

The National Ankylosing Spondylitis Society (NASS) commissioned this guide to explain what Disability Living Allowance (DLA) is and to provide help to people with AS when they apply for it.

Applying for DLA is done by completing a long and complex form: this can be quite daunting. This booklet is designed to guide you through the process and explain what you need to make clear in your replies to the questions so you give an accurate picture of your AS and how it affects you.

I would also like to take this opportunity to say to anyone who is thinking of applying or already receives DLA that you should not feel you have to justify yourself or are not worthy of claiming DLA. If AS is affecting your life a great deal then you should claim it. DLA is there to make your life a little easier.

We also receive enquiries from people who have applied for DLA and been turned down or have been awarded it, but at the lowest levels.

If this has happened to you and you think the decisions that have been made in your case are wrong, then I would encourage you to query them. This booklet will tell you how to do this. If you think that the people considering your application do not understand what kind of condition AS is and its impact, then please contact NASS and we can provide you with information to help you make this clearer.

If you would like more copies of this booklet then they are available free from NASS. You can download them from our website (www.nass.co.uk) or you can contact us for a printed copy. If your Nurse Specialist would like a copy to help them to help you fill out the application form, then please ask them to contact us for their free copy.

If you are reading this and have AS then please join NASS to receive all the benefits of being a member. It only costs £3 a year if you are not working.

I am very grateful for the skill and expertise of Ian Greaves at the Disability Alliance who has written this booklet and who has done a terrific job for NASS. I know it will help people with AS when they apply for DLA and enable them to explain clearly the impact that this condition has on their daily lives.

I would also like to express my thanks to two of our NASS members who have provided diaries of their symptoms for this booklet.

With best wishes



Jane Skerrett
Director

How to claim disability living allowance

A self-help guide to claiming Disability Living Allowance for adults with ankylosing spondylitis.

Introduction

Disability Living Allowance (DLA) is an important benefit for people with ankylosing spondylitis, which we will call AS for short. It helps to cover the extra costs that result from the symptoms of AS, 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 benefits that are means-tested, such as Housing Benefit or 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 AS with a brief explanation of DLA and a guide to completing the form. It can also be used by carers of anyone with AS 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.

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Chapter 1. About disability living allowance

Who is eligible?

DLA is not paid simply because you have AS, but because of the effect that the symptoms of AS 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 pain or stiffness in your spine, pelvis, hips, knees, ankles or heels. Your mobility may also be limited by fatigue.

Most people with AS 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:

1. The distance you can walk;
2. The speed you can walk;
3. The time it takes you; *and*
4. The manner in which you walk.

Chapter 1. About disability living allowance (continued)

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 AS has affected your eyesight.

The care component

The care component is paid because the symptoms of your AS 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.

Chapter 1. About disability living allowance (continued)

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	£49.85
Lower rate	£18.95

Care component	per week
Highest rate	£71.40
Middle rate	£47.80
Lowest rate	£18.95

These figures apply from April 2010 to April 2011. In April 2011 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. You can also download a claim-form or claim on-line using the government website (www.direct.gov.uk/disability-dla).

Chapter 2. 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 claim-form is 39 pages long and asks 62 questions. It is long-winded, but mostly straightforward. Try not to be put off by its length. You do not have to complete it all at one sitting. Much of the form has a multiple-choice format: you are just asked to tick whichever box or boxes apply to you. Occasionally you are given a short space to write down further details.

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 focus on the positive. 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 AS. 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.

About you (*Questions 1-11*)

The first part of the claim-form simply asks about who you are and where you live.

Signing the form for someone else (*Question 12*)

Anyone can help you complete the claim-form, but this question lists the circumstances where someone can *sign* the form on your behalf.

About your illnesses or disabilities and the treatment or help you receive (*Questions 13-22*)

You are asked here to list your illnesses or disabilities, without going into detail about how they affect you; there is room later in the claim-form for that. You are also asked to list any medicines or treatments that you have been receiving; you can either list them on the claim-form or attach a printed prescription list.

Chapter 2. Completing the form (continued)

Getting around outdoors (*Questions 23-34*)

This part relates to the mobility component (see Chapter 1).

You are asked how far you can normally walk before you feel severe discomfort (*Question 24*). 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 here. 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, to help you answer *Questions 25 and 26*.

Question 25 asks how many minutes you can walk before you feel severe discomfort. The answer you give here should reflect what you have already written in reply to the previous question.

Question 26 asks for you to describe your walking speed. Again, if you are unsure of this, an outside walking test as described above would help. You are asked to describe the way you walk in *Question 27*.

Question 28 asks if you need physical support from another person to help you walk. You may need such support if your knee or ankle joints frequently give way or if you cannot bear to put all your weight onto either one leg or the other.

You are asked in *Question 29* how many days a week you have 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.

There is room to provide details of any variation in your condition later under *Question 33*. You are asked if you fall or stumble in *Question 30*. You may fall or stumble 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. 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? 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 the next chapter).

Chapter 2. Completing the form (continued)

Having someone with you when you are outdoors (*Questions 31-32*)

You are asked if you need someone with you to guide or supervise you when walking outdoors in unfamiliar places (*Question 31*). This relates to the lower rate of the mobility component (see Chapter 1). If your eyesight has been affected by the AS, then this 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 actually need physical support to walk (which has been dealt with in *Question 28*).

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.

You are asked how many days a week you need someone with you when you are outdoors (*Question 32*). 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. On the other hand, if your condition varies, you may need guidance or supervision outdoors on some days, but not on others. There is room to provide details of any variation in your condition under the next question: *Question 33*.

You are asked in *Question 34* to provide the date when your walking difficulties started. 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 walking difficulties, not the length of time that you have had AS. 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 difficulties 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.

Chapter 2. Completing the form (continued)

Help with your care needs during the day (*Questions 35 to 48*)

This part relates to the care component (see Chapter 1). Each question in this part looks at a different area of day-to-day life:

- Getting out of bed in the morning and into bed at night (*Question 35*)
- Toilet needs (*Question 36*)
- Washing, bathing, showering or looking after your appearance (*Question 37*)
- Dressing or undressing (*Question 38*)
- Moving around indoors (*Question 39*)
- Falls or stumbles indoors (*Question 40*)
- Cutting up food, eating or drinking (*Question 41*)
- Help taking medicines or with medical treatment (*Question 42*)
- Communicating with other people (*Question 43*)
- Taking part in hobbies, interests, social or religious activities (*Question 44*)
- Someone to keep an eye on you (*Question 46*)
- Preparing and cooking a main meal for yourself (*Question 48*)

The questions follow a similar pattern. You are first asked to tick 'yes' or 'no' to confirm whether or not you have difficulties or need help with that area of day-to-day life; read the whole page before answering this. You are then asked more specific things about each activity; including how often and how long each time you need the help for.

At the end of each question you are given space to write down details of the difficulties you have or the help you need. 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.

Chapter 2. Completing the form (continued)

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). *Questions 45 and 47* ask how many days a week you have the needs that you have told them about; again, a diary may help you answer these.

With any of the questions, if there is not enough room on the page to explain things fully, you can use the large box in *Question 53* to continue.

We now look at a few of the questions in more detail:

Help with your toilet needs (*Question 36*)

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. If this is the case, explain why using a commode would not be easier; for instance, there may be no private space for one on the level that you are living in. You can provide more details of your difficulties moving around indoors under *Question 39*.

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. For instance you may suffer from inflammation of the urethra.

Someone to keep an eye on you (*Question 46*)

Asks about the supervision or watching over you need from another person. If you need such supervision because you have a tendency to fall, you can cross-refer to what you may have already written for *Question 40* (Do you fall or stumble ...?).

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.

Chapter 2. Completing the form (continued)

Preparing and cooking a main meal for yourself (Question 48)

Asks if you would have difficulty in preparing and cooking a main meal for yourself. This relates to the 'cooking test' (see Appendix 3). 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. 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 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. Back pain or painful knee or hip joints may make it difficult to stand to use the oven. If your eyesight is affected, you may have problems in finding and measuring the correct ingredients and other aspects of cooking might be dangerous.

Help with your care needs during the night (Questions 49 to 52)

This part relates to your needs during the night; one question focuses on care, another on supervision:

Difficulties you have or help needed during the night (Question 49)

If you find turning over at night is difficult or painful, help from someone can make things easier or ease the pain. Write down if you need such help and state if you need a hand in re-arranging the bedding afterwards.

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 bottle instead; for instance, if your wrists are stiff or painful. Alternatively you might already be using a commode or bottle, but still need help with them.

If you have bladder problems, your sheets or bedclothes may need to be changed sometime during the night. If you need help doing this, explain why. If the sheets need to be soaked straight away and you need help doing this, include this as well.

When you are asked how long on average you need help each time, you should include the time that it takes for the carer to get up, help you and go back to bed again.

Question 50 asks how many nights a week you have the needs that you have told them about; a diary may help you answer this (see the next chapter).

Chapter 2. Completing the form (continued)

Someone to watch over you (*Question 51*)

If you are a poor sleeper and tend to get up during the night, your supervision needs at those times will probably be similar to those that you have during the day. If this is the case, you can cross-refer to what you have already written for *Question 46*.

When your care needs started (*Question 54*)

You are asked to provide the date when your care needs started. 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 care needs, not the length of time that you have had AS. 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.

Further questions

Questions 55 to 57 of the claim-form ask for details about any time you have spent in a hospital, care home or a similar place. *Question 58* asks about any Industrial Injuries or War Pensions benefits you may be receiving or waiting to hear about. *Question 59* asks questions about how you would like to be paid the benefit, if it is awarded.

Statement from someone who knows you (*Question 60*)

Here 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 (*Question 62*)

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

Chapter 3. 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 AS 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:

1. What help do you need?
2. Why do you need the help?
3. At what time do you need help? *and*
4. 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.

Chapter 3. Keeping a diary (continued)

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' (*Question 60*) in 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 claim-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.

Chapter 4. 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 claim-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.

Chapter 4. How your claim is assessed (continued)

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 38 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-related Employment and Support Allowance, Housing Benefit and Council Tax Benefit and tax credits can often be increased when you have been awarded DLA.

If you have been granted the middle or highest rate of the care component and have a carer, they should consider making a claim for Carer's Allowance. 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 be obtained from the Benefit Enquiry Line on 0800 882200.

Chapter 5. 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 Disability Information Advice Line (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 9.00am 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.

Chapter 5. If you are not happy with the decision (continued)

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.

Chapter 6. What if your conditions 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 (Telephone; 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

Chapter 6. What if your conditions changes? (continued)

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 (for instance following a hip replacement) 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 under the 'Right Payment Programme'. 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 similar to the original claim-form that you completed before you were awarded the benefit. For this reason, it is 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.

Appendix 1. 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).

Appendix 2. 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'*

Appendix 3. 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.

Appendix 4. 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.

Appendix 5. One day diary

This is a diary for a 46 year old man who was diagnosed as having ankylosing spondylitis 24 years ago. His back and shoulders cause him a great amount of pain. He lives with his wife and son and has written about the help he currently receives from them.

3.10am Woke up in agony with pain and stiffness in lower back and shoulders. Shout for my wife who sleeps next door in the spare room. My wife helps me sit up in bed and on with my slippers and helps me to the toilet-my wife spends 15 minutes helping me.

3.30am Too sore to go back to bed, my wife helps me down the stairs and on to the chair. She makes me comfortable with a blanket and she goes back to her bed.

3.48am Sitting up in my chair trying to get to sleep. Pain is sore all over my body-really bad in my lower back and shoulders as it is every morning. Sitting in my chair I am very sore and stiff and feeling uncomfortable and trying to get some sleep.

5.05am Still cannot sleep. Tried to get up to put the light on to read. The pain shoots up my back and I cannot move.

6.00am Sitting stuck on my chair in agony not being able to sleep or move is very depressing. I used the remote control to put on the TV and watch morning news. I finally fall asleep sometime after 7am when watching the news headlines.

8.45am Wake up. I hear my wife in the kitchen. My pain in my back eased a bit but the pain in my neck has got worse and stiff. My neck is always in pain when I sleep in the chair. My wife helps me up from the chair and up to the toilet-my wife spends 15 minutes helping me.

9.10am I come back down from the toilet using one walking stick and the hand rail. This took me 8 minutes just to come down 12 stairs and in to the kitchen.

9.45am My wife makes me breakfast of cereal and toast which we eat at the kitchen table.

10.30am I go up the stairs to shower using the hand rail and one walking stick. I sit on my bed and my wife helps me off with my clothes. She then helps me in to the shower where I hold on to the rail in the wet room while my wife washes my back and shoulders. She helps me sit on to the shower seat and washes my hair-my wife spends 20 minutes helping me. I wash the rest of myself. My wife washes below my knees and feet as I cannot bend forward as I have no movement in back due to AS. My back has stiffened and fused over the years. This makes it impossible to reach things above my shoulder level and below knee level. Wife helps me get dried and dressed and back down the stairs-my wife spends 15 minutes helping me.

11.25am Sit at the kitchen table and check my emails and have a look on ebay.

12.15pm Make 2 cups of tea for my wife and I. Put the cups on a tray and I go and sit in the living room and my wife brings through the tray with the tea and biscuits on. Drink my tea and read the morning papers.

12.55pm Go to the toilet using my walking stick and handrail up and down 12 steps.

1.17pm Sit and watch lunchtime news. Feeling very tired I fall asleep.

Appendix 5. One day diary (continued)

3.05pm Wake up in pain, neck feeling very sore and stiff. Try to get up from chair but can't move when I try the pain is in my lower back up to my shoulders. Wife puts deep heat cream on my neck and shoulders. Need the toilet but cannot get out of my chair. My wife brings me my bottle to pee in. Sit in my chair for 45 minutes feeling depressed and fed up, getting really tired. I wait for my son to come home at 4.10pm.

4.14pm Son and wife help me out of the chair-this takes 5 minutes with their help. Hold on to son going up to toilet with walking stick. Come back using stick and handrails which takes me 8 minutes.

4.41pm Sit at the kitchen table and peel veg for evening meal. Find it hard to do much in the kitchen as due to back and shoulder stiffness cannot carry pan of water etc and cannot bend to the oven.

5.15pm Feeling all stiff and go in to the garden and walk around using 2 walking sticks.

5.20pm Sit in the garden talking to my son while the wife makes the evening meal.

6.00pm Have our evening meal.

7.00pm Go up stairs to the toilet and have a wash, as friend is picking me up to go to the pub quiz night in my local pub. Sit on my bed while my wife helps me off with my slippers and on with my shoes-my wife spends 10 minutes helping me.

7.36pm The door bell rings. My son answers the door while my wife helps me on with my jacket. It is my friend coming to collect me for the pub quiz.

7.55pm Walk along to my friend's car using two sticks. Manage to sit in the seat with my legs still out on the pavement and my friend lifts them into the car for me. Had a good night with my friend at the quiz-lost by 1 point because we thought Sydney and not Canberra was the capital of Australia.

10.55pm Back home sitting in the living room having a bit of cheese on toast with my wife watching the TV.

11.45pm Wife goes to bed. I sit and read the evening paper and watch the TV. Must have fallen asleep watching the TV as wife shakes me awake at

3.32am and helps me up from the chair.

3.50am Up stairs to the toilet and sit on the bed while my wife helps me undress and puts on my pyjama shorts and t-shirt. Wife helps me lay down.

4.08am Fall asleep very quickly while reading my book.

7.00am Wake up but cannot move due to particularly bad pain in lower back. I cannot get out of bed without help but do not want to shout for my wife. Just life in my bed feeling sorry for myself and feeling down with this illness.

8.30am Busting for the toilet so I shout for my wife to help me out of bed.

Appendix 6. Longer diary

This is a longer diary for a 37 year old male who was diagnosed with ankylosing spondylitis 2 years ago. He describes what areas of his body have been affected and to what extent.

November

w/c: 03/11/08 - Disturbed sleep, left sacroiliac (SI) joint very painful (severe), limping, cannot put weight on left foot, have difficulty standing up because of stiffness, need someone to help pull me up, lumbar spine bad, stiffness in neck, cannot turn head to the left.

w/c: 10/11/08 - Waking around 2 and 3am each morning with stiffness, left SI joint painful (severe), difficulty getting out of bed because of stiffness and swelling in thoracic region of spine, feet painful when walking.

w/c: 17/11/08 - Waking very early with stiffness in upper and lumbar spine regions, left SI joint bad (severe), not been able to go out.

w/c: 24/11/08 - Waking very early (around 4am) with stiffness in lumbar region, Left SI joint bad (moderate), lumbar spine very stiff, not sleeping well, difficulty turning over in bed because of pain in pelvis/SI region.

December

w/c: 01/12/08 - Left SI joint painful (moderate), limping, need support to walk on left foot.

w/c: 08/12/08 - Left SI joint painful (severe), limping, difficulty getting out of bed because of upper spine pain and stiffness, getting in and out of bath very difficult.

w/c: 15/12/08 - Both SI joints painful (moderate), knees painful (moderate).

w/c: 22/12/08 - Left SI joint painful (moderate), lumbar spine painful (moderate), waking in middle of night with pain and stiffness in lumbar and thoracic region.

w/c: 29/12/08 - Left SI joint painful (moderate), waking in middle of night with pain and stiffness in thoracic and lumbar area of back.

January

w/c: 05/01/09 - Left SI joint painful (moderate), waking in middle of night with pain and stiffness in thoracic and lumbar area of back, pain also in sternum and ribs (mostly on right hand side).

w/c: 12/01/09 - Left SI joint painful (moderate), limping quite often, generally walking slowly.

w/c: 19/01/09 - Left SI joint painful (moderate), lumbar region painful (moderate), hurts when walking, disturbed sleep (waking around 2 and 3 am).

Benefits of joining NASS

- **BI-ANNUAL NEWSLETTER**
- **ACCESS TO A WIDE RANGE OF RESOURCES**
including publications and exercise materials to help you understand the disease and manage your symptoms
- **TALK IN CONFIDENCE**
to someone about any issue or aspect of AS
- **ACCESS A NETWORK OF LOCAL BRANCHES**
providing regular supervised hydrotherapy and physiotherapy sessions
- **SHARE EXPERIENCES**
with other people through the Members' Forum and AS News
- **THE OPPORTUNITY TO INFLUENCE**
the future of AS by participating in research projects
- **COMMITMENT FROM NASS**
to help improve services through its continuous campaigning on behalf of people with AS
- **HAVE YOUR VOICE HEARD**
by taking part in member surveys
- **HELP YOURSELF**
and the opportunity to help others with AS throughout the UK

NASS Membership

NASS is the only charity in the UK offering membership to people with AS, supporting them and providing information to help them understand the disease and manage their condition to give them the best possible outcome in the long term.

If you wish to join NASS please see our website for more details (www.nass.co.uk)

If you would like to find out more information please contact us:

NASS, Unit 0.2

One Victoria Villas

Richmond

Surrey

TW9 2GW

Email: admin@nass.co.uk

Telephone: 020 8948 9117

RCN: 272258 SC: 041347

Useful organisations and further reading

Organisation	Contact details
<p>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.</p>	<p>Helpline 0800 882200 Monday to Friday 8.30am-6.30pm, Saturday 9am-1pm) Textphone 0800 243355</p> <p>Northern Ireland Telephone 0800 220674 Textphone 0800 243787</p>
<p>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.</p>	<p>www.citizensadvice.org.uk www.adviceguide.org.uk</p>
<p>DIAL – Disability Information Advice Line Disability-related advice and information including details of benefits</p>	<p>DIAL UK St Catherine's Tickhill Road Doncaster South Yorkshire DN4 8QN Telephone 01302 310 123 www.dialuk.info</p>
<p>Law centres Law centres provide free advice and representation. The Law Centres Federation can give you details of your local law centre.</p>	<p>Law Centres Federation 3rd Floor 293-299 Kentish Town Road London NW5 2TJ Telephone 020 7428 4401 www.lawcentres.org.uk</p>

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.

Whilst every effort has been made to check the information is complete and correct at the time of publishing, May 2010, no responsibility can be taken for any omission or error.

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