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# Claiming Attendance Allowance

**A Guide For Adults With  
Ulcerative Colitis And Crohn's  
Disease**

**May 2007**

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## Disclaimer

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# About this guide

## Who is this guide for?

This guide is for you if you are 65 or over and considering making a claim for Attendance Allowance (AA), because of Inflammatory Bowel Disease (Ulcerative Colitis or Crohn's Disease).

AA can definitely make a big difference to people's lives. It can give you back some of your feelings of independence and control. It can help pay for an improved diet, meet extra heating bills and pay for much-needed holidays. Needing a better diet, extra heating or a holiday are not grounds for claiming AA, but if you are awarded the benefit you are free to spend it as you wish – you don't have to spend it on paying for care.

## How to use this guide

Use it slowly, bit-by-bit.

This is a guide to the whole process of making a claim for AA. It will help you to make a very detailed and well supported claim and considerably improve your chances of success. But it's also very long and we often have to say the same thing in several different places, so please don't try to read it all at once. Use it like you would any other instruction manual – a car maintenance manual, say - just read the bit you need at the time and don't worry about the rest.

## A very brief glossary

Below are a few terms in the guide that you may not be familiar with, or that have particular meanings in relation to AA. Don't worry if they seem a bit obscure or confusing at this point, we explain things in detail as we take you through filling out the form.

**Attention:** when deciding whether you are eligible for AA, one of the things decision makers look at is the amount of 'attention' and/or 'supervision' you need, or would benefit from, because of your condition. Attention, for the purposes of AA, is when someone is doing something active with you. For example: physically helping you to get dressed or verbally encouraging you to get dressed.

**Decision makers:** these are the people who make decisions about your benefits, they used to be called adjudication officers.

**Department for Work and Pensions (DWP):** the new name for what used to be the Department of Social Security (DSS).

**Supervision:** this is when someone is watching over you to prevent you from coming to harm because, for example, you are unsteady on your feet and at risk of falling.

# Am I eligible?

AA is a complicated benefit and many people, including some doctors, care workers and DWP staff, pass on information and opinions that aren't correct. So we'd like to start by telling you 12 things that, no matter what you've been told before, don't affect your right to claim AA.

## 12 things that won't affect your claim:

- You're getting any other benefits - AA will be paid on top.
- You're working.
- Your partner works.
- You have savings.
- You have not paid any national insurance contributions.
- You don't consider yourself to be disabled - AA is for people with long-term health problems or impairments which affect their everyday activities.
- You've been told by a doctor, nurse, care worker - or anyone other than a welfare rights worker - that you won't get AA. Eligibility for AA is a legal question, not a matter of medical - or any other - opinion.
- You live alone and no-one is providing care for you.
- You already have someone, a partner for example, providing care for you.
- You don't want anyone to provide care for you.
- You've been turned down before. Take a look at the sections on *Using additional sheets* and *Including supporting evidence*, you may decide you could put forward a stronger case if you applied again.
- You do not want to spend money on personal care: you can spend AA on anything you wish.

## Try out 5 minute test

To help you decide if you might be eligible for AA, try our five minute AA test on the following page.

# The 5 Minute AA Test

Could you be eligible for AA? Try our five minute test to help you decide if you should make a claim.

**1 Are you aged 65 or over?**

Yes  No

If yes, go on to question 2. If no, you cannot claim Attendance Allowance. However, you may be eligible for Disability Living Allowance (DLA) instead. You can download a guide to claiming DLA from the NACC website.

**2 Has your health condition lasted at least six months?**

Yes  No

If yes, go on to question 3. If no, you can still make a claim, but payment can only begin from the date when your condition has lasted six months. Go on to question 3.

## Supervision

This is someone keeping an eye on you to prevent you, or someone else, from being in danger. This might be because you have falls, for example. For the purposes of AA, the night is from about 11pm to 7am.

**3 Do you need someone to keep an eye on you throughout the day?**

Yes  No

If yes, you needn't answer any more questions, it's definitely worth filling in a claim pack. If no, go on to question 4.

**4 Do you need someone awake to keep an eye on you at night, for at least 20 minutes or at least two or three times?**

Yes  No

If yes, you needn't answer any more questions, it's definitely worth filling in a claim pack. If no, go on to question 5.

## Attention

Attention is about someone helping you with 'bodily functions'. It doesn't matter whether you already get this help or not and it doesn't even matter if you wouldn't take it if it was offered. The question is, would it be reasonable for you to have it, bearing in mind the way your condition affects you?

**5 Do you have difficulties with any of the activities below? Tick Yes if you do. (If some days you do and some days you don't, tick yes)**

	Yes		Yes
Moving about indoors		Taking medication	
Eating and drinking		Staying safe if you're alone	
Communicating with people		Getting out of bed in the morning	
Getting into bed at night		Sleeping	
Getting to and using the toilet		Washing, having a bath or a shower	
Looking after your appearance		Getting dressed and undressed	
Social and leisure activities			

(Shopping and housework are not counted as everyday activities that are relevant to AA).

The sort of difficulties you might have with these activities include things like:

- it hurts
- you can only do it slowly
- you need to take a long rest after doing it
- you can only do it using a special technique of your own
- you need someone with you when you do it just, in case things go wrong
- it's not safe for you to do it
- you can't do it at all

If you ticked yes for any of the activities, go on to question 6. If you didn't tick yes to any it doesn't mean you are definitely not eligible for AA, you should try to get advice from one of the agencies listed in the *Help!* section.

**6 If you got help during the day, would it need to be frequently throughout the day – in the morning, in the middle of the day and in the late afternoon/evening?–**

Yes  No

If yes, you needn't answer any more questions, it's definitely worth filling in a claim pack. If no, go on to question 7.

**7 If you got help during the night, would you need it for at least twenty minutes or at least twice a night?**

Yes  No

If yes, it's definitely worth filling in a claim pack. If no, it doesn't mean you are definitely not eligible for AA, you should try to get advice from one of the agencies listed in the *Help!* section.

## Deciding whether to claim

*“I’m not sure it’s worth all the bother and fuss of filling out the form and talking to my doctor. Money isn’t going to improve my health, is it?”*

Claiming AA may not improve your health, but it can definitely make a big difference to your life. It’s paid at two rates:

£43.15 (lower rate at April 2007)

£64.50 (higher rate at April 2007-

It can give back some of the feelings of independence that dealing with a long-term health condition may have taken away. For example, you may be able to pay for help that up to now you’ve had to rely on friends and relatives for. And because you can spend your AA on anything you choose, it can also bring about a real improvement in your quality of life. These are some of the things people use their AA for:

- taxis to get to and from the shops
- someone to do the garden, clean the windows, help with housework
- the additional cost of heating if you need to keep warm when you are unwell
- a special diet that helps you to manage your health condition
- aids, adaptations and appliances to make life easier for you
- flowers or treats for friends and relatives who have helped you out
- holidays, weekend breaks or trips to see friends or relatives

*“I don’t want to claim because it feels like asking for a handout.”*

AA isn’t a handout. The government introduced AA because it recognised that people with long-term health problems need extra money to help them deal with their condition.

*“There are other people worse off than me who need this money more.”*

The amount of money available for paying AA isn’t limited. Everyone who meets the qualifying conditions is entitled to receive AA. If you get paid AA that won’t stop someone else from receiving it.

*“I’m worried that if I fill in the AA claim form and explain all the difficulties I have people will think I’m not safe living at home.”*

The AA claim form is about whether you’re entitled to extra money, it doesn’t have any effect on deciding if it’s safe for you to carry on living in your own home. In fact, getting AA may make it much more likely that you will be able to carry on living safely at home.

*“The rules about benefits are so complicated and I see all these adverts about benefits cheats, I’m worried that I might make a mistake and people might think I’m a fraud.”*

Entitlement to AA is just about your health. It doesn’t matter about your savings, your pension or anything else. All you have to do is fill in the form explaining as best you can how your health affects your everyday life. Even if you’re turned down for AA, nobody is going to suggest that you were trying to cheat the system.

# Keeping a claim file

A claim file is just a folder, or a ring binder, in which you keep notes and copies of everything to do with your AA claim, but it can save you months of frustration and lost benefits if the DWP either lose or shred your records.

What to keep in your claim file.

## *1 Keep a photocopy of everything you send the DWP.*

Most especially, keep a photocopy of your completed claim form and keep it safe. We do know how difficult and expensive this can be, but if you don't you may regret it because:

- Your claim form may be lost by the DWP – it does happen.
- Records of telephone calls, letters from you and your claim form will be shredded by the DWP. The longest the department is now likely to hold onto your claim pack is fourteen months.
- If you're not happy with the result of your claim it will be harder to challenge the decision effectively without a copy of your original form.

## *2 Keep every letter you receive from the DWP.*

Put them all in a folder in date order along with copies of letters you've sent them. (We had one client who was able to claim thousands of pounds in backdated benefits because he had kept copies of letters right from the beginning of his claim).

## *3 Keep a note of any phone calls to or from the DWP.*

Ask for the name of anyone you speak to and keep a note of it, along with the date and the subject of the call. For example:

*16.02.07 Spoke to Gemma at the Disability Benefits Centre. She said they have received my consultant's letter.*

Try not to feel embarrassed or awkward about this as DWP staff are used to giving their names. In the very unlikely event that anyone refuses to give you at least their first name and the section they work on, ask to speak to their Supervisor.

At the end of this guide you will find a *Claim file record sheet* which you can use for making a note of calls and letters.

## Getting a claim pack and meeting deadlines

In order to start your claim you need a claim pack. The best way to get one is to make a freephone call to the Benefits Enquiry Line on 0800 882 200 (8.30 am to 6.30 pm Monday to Friday and 9.00 am to 1.00 pm on a Saturday) and ask them to send you an AA claim pack.

You should then be sent an AA claim pack with two dates stamped on it. The first is the date you asked for the form and the second is the date, six weeks later, by which you should return it. (Which means you have to post it several days before that date). If they receive it after the six weeks, your claim is still valid, but it starts from when the DWP get your form back instead of the date when you first asked for it.

### While you're waiting for the claim pack

While you're waiting for your claim pack to arrive you might want to consider:

- keeping a diary (see *Including Supporting Evidence*);
- making a list of who might provide supporting evidence (see: *Including Supporting Evidence*);
- making appointments to see your health professionals (work out when you are likely to have completed the form, and ask for an appointment to take place soon afterwards);

### If you can't return the claim pack within the six week deadline.

Even if you don't manage to return the claim pack within the six week deadline, decision makers must still consider whether it would be reasonable to extend the time limit.

Issues that should be taken into account by the decision maker include:

- how long it took for the DWP to send the claim pack out to you, did you get 6 weeks or thereabouts in which to return it?
- were there any special circumstances such as illness, an operation or your house flooding which meant you were prevented from completing and returning the pack;
- how long after the time limit did you return the claim pack: did you act as promptly as you could in all the circumstances?

If you are late, return the completed claim pack as soon as you can and staple a letter with your name and national insurance number on it explaining in as much detail as possible why you are late and asking the decision maker to extend the time limit.

### Your right of appeal

If the decision maker decides not to extend the time limit they will inform you in writing, usually at the same time as they inform you of the decision about whether you have been awarded AA. You can appeal this decision. You need to do so in writing using form GL24 within one month of the date of the decision not to extend. Try to get advice before doing so using one of the agencies in the Help! Section. If you are also appealing the decision about your award of AA you can appeal both matters at the same time.

**Caution:** there is no reason why an appeal about the date on which your award should start should lead either the DWP or a tribunal to look again at the level of AA you have been awarded. Nonetheless, it is not entirely impossible that this could happen, so if you have any concerns get advice from a welfare rights worker before lodging an appeal.

## The claim pack

The AA claim pack was changed in October 2003. Previously it was 37 pages long. It is now 19 pages, with just 3 pages, rather than the previous 19, for you to describe all the problems you have during the day and at night. The DWP said that although there is now much less space for people to give information, they would make up for this by telephoning you or someone else in order to get the additional evidence needed to decide your claim.

However, in practice, very often claims are decided without the decision maker phoning anyone at all. Even if they do phone, because IBD is a condition that is not well understood by most decision makers, they may not ask all the questions that they would need to in order to arrive at the right decision.

This is why we suggest that you don't just rely on the few small boxes in the claim pack, but use additional sheets and our Day and Night charts as well.

### **The advantages of giving detailed information**

If you look at the introduction to part 7, you will see that there is a very long list of things that you are supposed to provide information about in connection with every activity you have problems with. The information required includes:

- When you need the help.
- Where you need the help.
- What happens if you don't get it.
- What things would take you longer to do.
- Any variations in your condition.
- Whether you use any equipment and how this helps.

As we said, we don't think it's practical to try to squeeze all this information into a few small boxes. This is why we suggest you use additional sheets and follow the four-step system for giving evidence instead.

After all, giving detailed, accurate information in writing about all the problems you have can only reduce the chances of misunderstandings and mistakes occurring and improve the chances of the correct decision being made in your case. Whilst this is much, much more time consuming and difficult than just writing a few sentences, it is an awful lot quicker than having to wait months to go to an appeal because the DWP have made the wrong decision based on insufficient evidence.

But, even if you decide not to use additional sheets, we very strongly recommend that you read all the information in the next section of the guide before filling in Part 7 of the form. It will help you to make sure you make the best possible job of providing information.

# Completing the claim pack

## Part 1 – About you

The DWP are relying more and more on telephone contact with people, as this is often quicker and cheaper than writing letters. If you don't wish to be phoned at home and asked questions, you may decide to leave the daytime phone number box blank, although the DWP may already have – or be able to find – your number. If the reason you would prefer not to be phoned at home is in connection with your disability then you may want to enclose a note saying so. For example, if you have a mental health condition and you get anxious or confused when phoned and asked questions by people you don't know, then you should ask not to be telephoned.

## Part 2 – For people signing this form for someone else

If you are just filling in the form for someone else, but they know what you are writing and are going to sign it themselves, then you don't need to complete this section.

## Part 3 – About this claim

The special rules relate to people who are terminally ill and where death is expected within the next six months. In these circumstances you automatically qualify for the higher rate of AA. There is a leaflet that comes with the claim pack which explains how to claim under the special rules or you can call the Benefit Enquiry Line on 0800 882 200.

## Part 4 – About your illnesses or disabilities

### Your illnesses or disabilities

List all your health conditions. As well as IBD and any other physical conditions, include any emotional or mental health problems such as depression or anxiety. Your entitlement to AA is based on the combined effects of ALL your health problems, so make sure you put them all down. However, this guide only deals with IBD, try to get support from one of the agencies listed in the *Help!* section if you also experience mental health problems.

### How long

Bear in mind that you may have had IBD, or any other condition, for a long time before it was finally diagnosed.

### Which parts of your body

If your IBD causes symptoms such as fatigue or pain in your joints, then it's fine to say something like '*All over*'.

### Current tablets, medicines or other treatments

If you have a prescription list, or can get one from your GP, you don't have to fill in the medication table. However, if you are taking any over the counter painkillers or other drugs, you may wish to list them here. Also include any food supplements that aren't on your prescription list.

If you are having any treatment, such as parenteral nutrition or tube feeding, enemas or dressings that are being changed for you by a nurse, include them here.

## Part 5 – More about treatment or help you receive

### Family doctor and other health professionals

The people you give details about in this section may be contacted by the DWP. Please don't assume your GP, nurse, specialist or other health professionals know all about the problems you have with things like moving about, dressing or washing – you may never have told them or they

may not have made notes at the time. People are often astonished by what their GP or other health professionals write about them. So try to make an appointment to give them an up-to date picture of your problems as soon as you've completed this form and BEFORE they are contacted by the DWP. You may want to look at the section on *Including supporting evidence* and the *Health professionals' sheet* before you see your health professional. You should also warn your health professional that the DWP may contact them.

There is, however, no guarantee that the DWP will contact them. So if they could give valuable evidence to support your claim, try to get a letter from them yourself rather than waiting to see if the DWP do so. You can find out more about this in the section on *Including supporting evidence*.

### **Anyone else**

You may get help from a friend or a neighbour but you may not want them to know your personal or financial business or you may simply not like the idea of having to ask them if they mind you passing on their contact details to the DWP. You might even be concerned that it could put them off helping you, because they won't want to get involved with officialdom. If they are claiming benefits, they might even be concerned that it could affect their claim if the DWP knew they were helping you.

On the other hand, if you leave this page blank it might suggest you need less help than you really do.

If your friend or relative is happy to be included on the form then there's no problem. But if you don't want to ask them, or if they're not happy to have their details given, then write on this page or an additional sheet that they are a friend and explain the help that they give. But also explain that you do not wish to give their details and explain why – for example, you don't wish people to be privy to your financial affairs or you are worried they might stop helping.

If there is more than one person who helps you, you may need several sheets to give their details – or explain why you are not going to.

### **Part 6 Consent**

This section asks for your consent for the DWP to contact your GP or other people involved with you for information in relation to your claim for AA. If you don't agree to this and the DWP decide they can't make a decision based just on what you tell them then you will not be awarded AA.

### **Part 7 – More about why you are making this claim**

Read the introduction to part 7 carefully. However, rather than fill in the boxes, we suggest you write "See additional sheets" and then give further information by following the '*Using additional sheets*' section in this guide. If you don't feel able to complete additional sheets, still try to give as much information as you can about the problems you have after reading the '*Using additional sheets*' section. And you might still find it useful to print off and fill in either or both of our *Day time and night time charts* giving details about when, how long for and how often you need help.

### **If you would like a doctor to visit you**

We wouldn't advise you to ask for a doctor's visit except as a very last resort. See '*Dealing with a medical visit*' for more about this

## **Part 8 – Anything else you wish to tell us about**

If you are going to use additional sheets as we suggest, you probably don't need to fill this box in. If you don't use additional sheets, you can put any information you couldn't squeeze into the other boxes in here.

## **Part 9 – When your difficulties began**

Your problems need to have lasted for at least six months before you can receive AA, but you can put your claim in before the six months has elapsed if you do not expect your condition to improve within that time.

## **Part 10 – More about you**

These are questions about any hospital or residential care stays you have had, any visits abroad you have made and some questions about benefits and other money that might be coming into your household.

## **Part 11 – Statement from the person who knows best about you and how your illnesses and disabilities affect you**

Photocopy this sheet and give the copy to the person you want to complete it. If you are happy with what they write staple the sheet to this page, if not give them another blank copy and ask them if it would be possible for them to change what they have written. If they won't, get someone else to fill in the statement instead.

The best person to complete this page might be your partner, carer or someone else who knows you well and sees first hand the difficulties that you have with everyday activities. Alternatively, it could be a professional involved in your care, such as your GP, specialist nurse, consultant or occupational therapist. In this case, make an appointment to see that person so you can answer any questions they might have and take the '*Health professionals sheet*' from this guide with you. Ask the person to complete the statement there and then if they can. If they can't, or wish to write a longer report, ask them to send it to you and check when it will be done by, as you may have to send off the claim pack without it in order to meet the deadline. If this happens enclose a note explaining that you will send part 11 as soon as you are able.

## **Part 12 – Making payments to you**

This section describes how AA is paid, there is nothing for you to complete.

## **Part 13 - Declaration**

Read the declaration carefully before you sign it.

## **Part 14 – What to do now**

If you are attaching additional sheets, it might be worth counting them and then writing in this box how many of them there are, in case any of them become detached. You should still staple all the extra sheets to the claim pack if possible and ensure your name and national insurance number are at the top of each page.

## **Part 15 - How we collect and use information**

This tells you what the DWP will do with the information you provide. There is nothing for you to complete.

## Using additional sheets

### Why use additional sheets?

The decision about whether to award AA is based on evidence. The form you are about to complete is evidence and so are any letters from doctors, carers or relatives.

An effective claim is made up of evidence that is clear and as detailed as possible. This is particularly so for Crohn's and Ulcerative Colitis because they are not widely known or understood conditions. The inclusion of the NACC booklet *Understanding Colitis and Crohn's Disease* can help to explain these conditions to decision makers at the DWP. It is genuinely difficult for people to understand (and perhaps to believe) that such ordinary activities as eating and going to the lavatory can have such powerful effects. Instead of simply saying that an activity is painful or tiring, it's best to try to use words to explain what it's like being inside your body.

Compare:

*Using the toilet is very painful. I have to go very frequently and end up feeling exhausted.*

with

*On most mornings I have to rush to the toilet repeatedly. I often visit it five times within an hour. Sometimes I do not make it in time and I have to change and shower. My anus is constantly very sore and there is a burning sensation that gets more painful with every bowel motion. I also have a fistula in my rectum that throbs painfully and discharges pus. Blood sprays out from the rectum during bowel motions and it's got to be cleaned up quickly or it stains the toilet bowl. I am often so weak that I can only do this very slowly and painfully, and sometimes I don't manage to do it at all. When I feel that my bowel motions have passed (for the time being) I gently wash and dry the area around my anus and apply Anusol cream and Preparation H to the anus passage and lower rectum to try and calm the painful fistula and raw flesh around the anal sphincter muscle. By the time I leave the toilet I am weary and exhausted, my head is muggy and my legs are shaky and unsteady. I can't think straight or talk to anyone. All I can do is lie down and wait for the next attack.*

The second account is much clearer, more detailed and much more effective as a result. Of course your condition may not be as severe as this, that doesn't matter, the important thing is that you describe it clearly and in detail. We do realise how difficult it is to write about such personal things on an official form. It may make it a little easier if you use formal terms like bowel movement and anus rather than everyday terms and it will also make your evidence sound more authoritative.

### How to use additional sheets

Look through the list of activities below. For each one you have difficulties with, write the heading on a sheet of paper along with your name and national insurance number. Then read what we have to say about the activity and use the information to help you to write detailed evidence about your problems. You might find it helpful to use the four-step system we explain below.

**Important:** in addition, you will also need to print off, or copy, and fill in either or both of the *Day time and night time charts* giving details about when, how long for and how often you need help. You'll find these in the next chapter.

When you've finished staple all the sheets to the back of your claim pack.

- 1 Problems getting out of bed in the morning and into bed at night
- 2 When you are in bed
- 3 Your toilet needs
- 4 Washing, bathing, showering and looking after your appearance
- 5 Getting dressed or undressed
- 6 At mealtimes
- 7 Medical treatment
- 8 Someone keeping an eye on you
- 9 Moving about indoors
- 10 Dizzy spells, blackouts, fits, seizures or something like this
- 11 Falls or stumbles
- 12 Communicating with other people
- 13 Social and leisure activities

We recommend you use our four-step system on most pages to ensure you give detailed and relevant information. This is how it works.

### **Step 1: Say what causes the problems with the activity**

Decision Makers are very fond of saying that claimants could do things if they chose, they just prefer not to. So make it clear, in your own words, that the reason you have problems is not about personal choice, but because of your health condition or because you are disabled. For example:

*I have problems with this activity because of my ulcerative colitis.  
I have problems with this activity because I have Crohn's disease.*

If there is more than one reason why you have problems then say so:

*I have problems with this activity because of colitis and the medication that I have to take.  
I have problems with this activity because of my Crohn's disease and my angina.*

You might get fed up with having to repeat the same thing on every page, but it really is worth doing.

### **Step 2: Say what the problems are – in detail**

Give as much information as you can about the problems you have. For example:

*I have problems with washing and bathing because of pain and stiffness in my limbs. I can't stand for long in the shower because of pain in my legs, feet and back. I have tried putting a stool in the shower to sit on but it was too cramped and I almost fell trying to stand up again. I need help getting in and out of the bath because it is painful stepping over the edge of the bath and I am very unsteady on my feet. Washing my hair causes a great deal of pain in my arms and shoulders and there are many days when I cannot do it at all. Washing my feet causes pain in my lower back and I cannot reach behind me to do my back, even with a long brush, because of the pain in my arms shoulders and neck. Drying myself is extremely painful, I cannot bend enough to do my calves and feet.*

### **Step 3 Give an example**

This could be:

When you tried to carry out the activity and it went badly wrong:

*About three months ago I tried to have a bath when there was no-one else at home. I managed to get in the bath but I slipped and fell while trying to stand up to wash my torso. I was not badly hurt, but it left me feeling terribly shaken thinking how much worse it could easily have been.*

A recent attempt to carry out the activity which was not successful:

*Last week I tried to wash my hair by myself because I didn't want to disturb my partner. I was in so much pain by the time I finished that I had to take extra pain killers and I was unable to do anything for the rest of the day.*

If you never attempt the activity alone anymore, say how long it has been since you did so:

*I have not a bath or shower without someone to help me since I fell in the bath about three months ago.*

#### **Step 4: Say how someone could help**

To get AA you need to show that you 'reasonably require' help or someone to watch over you. You don't have to show that you actually get, or want, help – just that it would be reasonable for you to have it. But if you have problems with activities and there's nothing anyone can ever do that would make the slightest bit of difference, then you may not be entitled to AA. So always try to show a way in which someone could help.

*If someone is with me they can help me in and out of the bath and wash my hair and back and feet for me.*

## **1 Problems getting out of bed in the morning and into bed at night**

### **Getting out of bed**

Are you sometimes too depressed or exhausted to get out of bed without someone to encourage you? Does someone – children, partner, neighbours - look in on you to make sure you have got up?

Are you sometimes too weak to get out of bed on a morning? Is getting out of bed painful? Do you need someone to help you? Do you have to get out in stages, taking rests because of stiffness and to gather your strength as you do so? Do you have to hold onto things to get out of bed? Do you need medication or tea or something else brought to you before you can get out of bed? Remember, someone without health problems can get out of bed in a few seconds, how long does it take you?

### **Getting into bed**

Do you need help getting into bed or with arranging the bedding and pillows once you are in bed? Do you have periods when you are confined to your bed so that you have to have help in and out of bed frequently throughout the day to go to the lavatory?

### **Remember the four steps**

Step 1 Say what causes the problems with this activity

Step 2 Say what the problems are. Give details of: pain; fatigue; stiffness; breathlessness; lack of strength; slowness; mobility problems; being in danger.

Step 3 Give an example

Step 4 Say how someone can help

### **Equipment**

Do you use any equipment, such as a motorised bed raiser or a walking frame by the bed, to help you with this activity? If so say what it is. But remember to also explain whether, even with the equipment, you still have problems or need someone to keep an eye on you or this activity may not count towards your attendance allowance.

## **2 When you are in bed**

If you need help at night for a period of twenty minutes or twice or more then you may be eligible for lower rate AA, so it's very important that you give any information about problems when you are in bed.

Do you need someone to bring you medication, drinks or anything else during the night? If so explain why they can't just be left within reach in case you need them. Do you need help changing position or rearranging the bedding? Do you sometimes have an episode of incontinence and need someone to strip the bed, put on fresh bedding and put the soiled bedding on to soak or wash? Do you need a hot water bottle making for you during the night or painful areas of your body massaged? Do you become distressed and need comfort and reassurance to help you go back to sleep?

### **Remember the four steps**

Step 1 Say what causes the problems with this activity

Step 2 Say what the problems are. Give details of: pain; fatigue; stiffness; breathlessness; lack of strength; slowness; mobility problems; being in danger

Step 3 Give an example

Step 4 Say how someone can help

### **Equipment**

Do you use any equipment, such as a bed raiser, special pillows or an alarm to summon help to help you with this activity? If so say what it is. But remember to also explain whether, even with the equipment, you still have problems or need someone to keep an eye on you or this activity may not count towards your attendance allowance.

## **3 Your toilet needs**

### **During the day**

Do you need someone to help or guide you to and from the toilet?

Do you have difficulty transferring from a wheelchair to the toilet and back again?

Do you have difficulty undoing and doing up buttons and zips; pulling trousers and underwear down and back up; getting on or off the toilet?

Do you sometimes not make it to the toilet in time because of continence or mobility problems?

Even if you do make it to the toilet in time are your bowel motions very violent, bloody or accompanied by a lot of mucus so that you have to wash or shower afterwards?

Do you have difficulty wiping yourself after a bowel movement?

Do you have problems cleaning the toilet afterwards?

Do you need someone to check your clothing after using the toilet?

Do bowel movements leave you exhausted and in pain so that you have to rest afterwards?

Do you need help with continence pads or a colostomy bag or something similar? For example, if you need help changing the bags during the day or if you have problems with leakage during the day, give details in this section in this box.

The DWP very often argue that people who have difficulty getting to the lavatory or who suffer from urgency or incontinence could use a bottle or a commode (a chamber pot in a chair, alternatives would be a bedpan, a potty, a portaloos or a bucket) instead. Would you need help using or emptying and cleaning a bottle or a commode? Is there a danger that you might have an attack of incontinence whilst trying to carry the commode up (or down) the stairs potentially causing an even more distressing situation? Are there other reasons why it would not be practical

to use a commode? For example: your condition may mean that your motions have a very strong smell and it would be extremely unpleasant to use a commode in a room that you use to sit in; there may not be room for a commode in the rooms you use. Do you need to wash or shower after a bowel movement so that you would have to go to the bathroom afterwards anyway? How would you wash and dry your hands afterwards? How long would you have to sit in a room with a used commode during the day and would it be reasonable to expect you to do so?

If you don't think it would be reasonable to expect you to use a bottle or commode say so and, if possible, explain why. For example:

*Please do not suggest that I should use a bottle or commode. I would find it deeply embarrassing and undignified have to sit in a room with a used commode or urine bottle during the day or night. It is accepted that prisoners in jail should no longer be forced to do such things and I do not believe I should be either. I would feel the same about having to use a commode or urine bottle in front of my partner or having someone empty a commode or bottle that I have used. I understand that, for AA, attention to help someone carry on an ordinary life is attention that is reasonably required. Using a toilet is 'ordinary life' for an adult, using bottles and commodes is not. As long as I am able to use a toilet with help then I reasonably require that help.*

### **Remember the four steps**

Step 1 Say what causes the problems with this activity

Step 2 Say what the problems are. Give details of: pain; fatigue; stiffness; breathlessness; lack of strength; slowness; mobility problems; being in danger

Step 3 Give an example

Step 4 Say how someone can help

### **At night**

Night for the purposes of AA is from about 11pm to 7am. If you have problems or need watching over at night as well as, or rather than, during the day it's very important that you give details. As little as an average of twenty minutes or two lots of help or watching over at night could entitle you to an award of AA. (See *Day time and night time chart*).

Decision makers are particularly keen on people using commodes at night, so do point out any reasons why this may not be practical or why you consider it unreasonable. As well as the issues listed above, you might find having to empty your bowel or bladder distressing if you share a bedroom with your partner. This may be particularly the case if you have prolonged, frequent or noisy bowel movements.

### **Equipment**

Do you use any equipment, such as rails by the toilet or a raised toilet seat to help you with this activity? If so say what it is. But remember to also explain whether, even with the equipment, you still have problems or need someone to keep an eye on you or this activity may not count towards your attendance allowance.

## **4 Washing, bathing, showering and looking after your appearance**

Are you sometimes too depressed or exhausted to wash or bathe and need encouragement?

Do you have problems or pain getting in and out of the bath? Do you have problems bending in the shower? Do you have problems or pain washing or drying your feet, your hair, your back? Do you have problems or pain standing to wash or shave?

Do you have problems because you have dressings, a line into a vein or a stoma appliance that needs to be kept dry or sterile. Are you in danger of falling in the bath or shower because of dizziness, fatigue or muscle weakness? If you need to wash or bath or shower more than once a day say so and explain why.

### **Remember the four steps**

Step 1 Say what causes the problems with this activity

Step 2 Say what the problems are. Give details of: pain; fatigue; stiffness; breathlessness; lack of strength; slowness; mobility problems; being in danger

Step 3 Give an example

Step 4 Say how someone can help

### **Equipment**

Do you use any equipment, such as a bath hoist, bath seat or grab rails, to help you with this activity? If so say what it is. But remember to also explain whether, even with the equipment, you still have problems or need someone to keep an eye on you or this activity may not count towards your attendance allowance.

## **5 Getting dressed or undressed**

Do you sometimes feel too depressed to bother dressing and need encouragement?

Do you have problems or pain reaching down to put on underwear, socks or shoes? Problems or pain with using zips, buttons and bra fastenings? Do you have to wear loose fitting clothes or ones that are easy to get on and off, such as ones with velcro or elasticated waists?

Do you need to dress or undress more than once a day because of, for example, continence problems; changing dressings or other medical procedures; needing to sleep during the day?

The Decision Maker may argue that if you have problems with fastenings such as buttons, zips, belts, laces etc. you should wear slip on shoes, trousers with elasticated waists and clothing with velcro fastenings. Do you have enough of such clothes and is it reasonable to expect you to go out and buy an entire new wardrobe in one go? Would you still have problems with these clothes? For example, would elasticated waistbands be painfully constricting; would it be difficult to get your feet into slip-on shoes?

### **Remember the four steps**

Step 1 Say what causes the problems with this activity

Step 2 Say what the problems are. Give details of: pain; fatigue; stiffness; breathlessness; lack of strength; slowness; mobility problems; being in danger

Step 3 Give an example

Step 4 Say how someone can help

### **Equipment**

Do you use any equipment, such as button hooks and shoe horns, to help you with this activity? If so say what it is. But remember to also explain whether, even with the equipment, you still have problems or need someone to keep an eye on you or this activity may not count towards your attendance allowance.

## 6 At mealtimes

Do you need encouraging or coaxing to eat because you associate food with pain, discomfort and illness? Do you get too depressed to be able to face eating? Do you have special dietary regimes that you need encouragement to stick to?

Have you suffered from malnutrition or weight loss as a result of not eating? Does it help if someone prepares food for you? Do you need help monitoring what you eat or reminding to eat or drink supplements? Do you have to eat frequent small meals?

Does pain in your joints mean you are unable to cut up food? Do you have pain or problems holding cutlery?

If you are receiving parenteral nutrition or tube feeding: describe the process involved and any help you need with feeding yourself, keeping equipment sterile or supervising the process.

### Remember the four steps

Step 1 Say what causes the problems with this activity

Step 2 Say what the problems are. Give details of: pain; fatigue; stiffness; breathlessness; lack of strength; slowness; mobility problems; being in danger.

Step 3 Give an example

Step 4 Say how someone can help

### Equipment

Do you use any equipment, such as special cutlery or a feeding cup, to help you with this activity? If so say what it is. But remember to also explain whether, even with the equipment, you still have problems or need someone to keep an eye on you or this activity may not count towards your attendance allowance.

## 7 Medical treatment

Do you need reminding to take your medication or food supplements because your concentration is poor or because you get very tired and forgetful? Do you need someone to monitor what you take?

Do you need help with emptying or changing a stoma appliance?

Do you need help with dressing wounds or administering enemas or eye drops?

Do you need medication brought to you when you are ill?

Are you receiving parenteral nutrition or tube feeding? If so what problems does this cause you and what help do you need from another person?

You may be having an 'alternative therapy', such as homeopathy, which the decision maker may not accept as medical treatment. However, an increasing number of alternative remedies are being recognised by the medical profession, so it is worth including details here if you have problems or need help with it, particularly if the treatment was recommended by your GP.

### Remember the four steps

Step 1 Say what causes the problems with this activity

Step 2 Say what the problems are. Give details of: pain; fatigue; stiffness; breathlessness; lack of strength; slowness; mobility problems; being in danger.

Step 3 Give an example

Step 4 Say how someone can help

## Equipment

Do you use any equipment to help you with this activity? If so say what it is. But remember to also explain whether, even with the equipment, you still have problems or need someone to keep an eye on you or this activity may not count towards your attendance allowance.

## Problems at night

Night for the purposes of AA is from about 11pm to 7am. If you have problems or need watching over at night, perhaps because you are on parenteral nutrition, as well as, or rather than, during the day it's very important that you give details. As little as an average of twenty minutes or two lots of help or watching over at night could entitle you to an award of AA. See *Day time and night time charts*.

## 8 Someone keeping an eye on you

This is a very important subject because you may be entitled to the lower rate of AA if you need someone to keep an eye on you during the day or at night, or the higher rate if you need both. The reason you need someone with you must be to avoid substantial danger to yourself or to others.

### During the day

Do you need someone with you during the day in case you fall, especially if you are unable to get up again or because you have a condition such as osteoporosis, so that the result of a fall could be very serious? Do you need someone to keep an eye on you because you are on parenteral nutrition? Do you need someone to monitor your food intake throughout the day?

### During the night

Night for the purposes of AA is from about 11pm to 7am. If you need watching over at night as well as, or rather than, during the day it's very important that you give details. As little as an average of twenty minutes or two lots of watching over at night could entitle you to an award of AA. (See *Day time and night time charts*). As well as the issues above, do you need someone to be awake when you go to the lavatory because you are unsteady on your feet due to medication, weakness or fatigue?

## Remember the four steps

Step 1 Say what causes the problems with this activity

Step 2 Say what the problems are. Give details of: pain; fatigue; stiffness; breathlessness; lack of strength; slowness; mobility problems; being in danger.

Step 3 Give an example

Step 4 Say how someone can help

## 9 Moving about indoors

Indoors can include your home, your workplace if you work, a day centre if you attend one or anywhere else where you spend time indoors.

**Moving about:** does someone have to remind you, jolly you along or spur you on to move around to do things? Do you need support from another person? Do you have to move very slowly? Do you need someone to open and close doors? Do you have to hang onto furniture to steady yourself? Do you suffer discomfort or pain if you stand for any length of time? Does standing make your bowel urgency worse?

**Stairs:** do you have to stay downstairs, or upstairs, all the time because you can't use stairs? Is it difficult/painful/exhausting going up or down stairs? Do you need someone to help you? Do you need someone with you in case you become dizzy or unsteady on your feet? Do you have to go

very slowly, one step at a time? Do you need to hold on to the handrail? Remember to include all the times you go up and down the stairs, including all the times you go up or down stairs to the toilet. If you don't have problems with stairs simply because you avoid using them at all, perhaps you have even moved into a bungalow, then explain why it is you avoid stairs.

**Getting out of chairs and off sofas (and in and out of bed if you have periods when you stay in bed for a large part of the time):** do you take a long time to get in or out of chairs? Do you stiffen up if you sit or lay too long? Do you need someone to help you off chairs and sofas? Have you developed special techniques such as rolling off sofas onto your knees? Do you have to hold onto things to get upright? Are you sometimes too exhausted to get up? Is rising from sitting painful? Do you have to get up and down a lot because of pain and soreness around the anus or because of frequent trips to the lavatory? Do you ask people to fetch you things like books, cups of tea or sweaters because it is too difficult or painful to get up yourself? Do you only sit on firm chairs with arms, so that you can push yourself up?

### **Remember the four steps**

Step 1 Say what causes the problems with this activity

Step 2 Say what the problems are. Give details of: pain; fatigue; stiffness; breathlessness; lack of strength; slowness; mobility problems; being in danger.

Step 3 Give an example

Step 4 Say how someone can help

### **Equipment**

Do you use any equipment, such as a stair lift, raised chair or rails, to help you with this activity? If so say what it is. But remember to also explain whether, even with the equipment, you still have problems or need someone to keep an eye on you or this activity may not count towards your attendance allowance.

## **10 Dizzy spells, blackouts, fits, seizures or something like this**

Do you lose your balance getting up to hurry to the toilet, for example? Do you get any warning of dizzy spells? Do you have to sit or lie down when you have one? Do you need someone to help you, steady you or watch over you when you do things that make you feel dizzy or faint? How often do they happen? Have you ever hurt yourself as a result?

## **11 Falls or stumbles**

If you experience falls you may be eligible for AA on the basis of needing continual supervision to avoid danger. Alternatively, you may need attention with specific activities such as using stairs, getting out of chairs or getting out of the bath which will count towards your AA entitlement.

Explain why you fall or stumble? Do you get dizzy or disoriented because you are tired or exhausted, possibly after bouts of diarrhoea? Does your medication make you drowsy or dopey? Are you unsteady on your feet due to joint pains? Do your legs get shaky and give out due to weakness or exhaustion?

If you haven't had any falls, but are worried that you might, you need to explain very clearly the reasons for your worries.

Do you mainly fall indoors or outdoors or both? Is it only on uneven surfaces, sharp inclines or steps or stairs that you fall, or are you likely to fall on flat, even surfaces as well?

Is there a pattern to your falls? For example, do they occur mostly in the morning when you first get up, only when you reach up to high shelves or are they entirely unpredictable? The less predictable your falls the more likely you are to need attention or supervision.

If your falls are predictable, the decision maker is likely to argue that you can avoid the activities that cause falls or take precautions to reduce the likelihood of injury. For example, if you only fall when reaching into high cupboards the decision maker is likely to say that you should simply avoid this activity. However, the decision maker should not suggest that you take unreasonable precautions, such as staying in the same chair or same room all day or wearing a crash helmet.

Can you get up without help after a fall and if so, how long does it take you? If you can't get up at all without help, or it takes a long time, then you are more likely to need attention or supervision.

Is there anything that makes falling particularly dangerous for you? For example, do you have osteoporosis, so that even a minor fall could lead to broken bones? If this is the case, you are more likely to be judged to need help or supervision even if the risk of falling is a small one.

Have you suffered any injuries as a result of falls? If so give details.

What help can someone give you when you fall or stumble? Can they steady you so you don't fall in the first place? Help you to your feet if you do fall? Help you recover from the effects of falling?

The decision maker may suggest that if you fall because, for example, your knee gives way, you should use one or two walking sticks and this will prevent you falling. Would sticks prevent you falling? Do you get enough warning and could you support your weight on your arms? If sticks would not help, say so.

Explain roughly how often you fall or stumble. Remember to include falls and stumbles indoors and outdoors. The more frequently you fall and stumble and the more recently it has happened, the more likely you will be considered to need attention or supervision.

Is there any supporting evidence you can provide for your falls or stumbles? For example, have you ever injured yourself and had to go to the doctor or to casualty? If so, give details and, if available, a copy of the record of your visit there. Has anyone seen you fall or had to help you up after you've fallen? If so, would they be prepared to write a letter confirming what happened? (See *Including supporting evidence*).

## **12 Communicating with other people**

Has your condition caused you to lose your self-confidence? Do you become anxious and self-conscious around other people? Do you avoid people, perhaps even friends and family? Do you avoid answering the phone or answering the door? Do you avoid social situations or new situations because of lack of self-confidence or fear of incontinence? Or do you get so exhausted that you can't find the energy to hold a conversation?

Do you find it hard to meet and talk to people because of the effects of your medication? For example, have steroids caused hair loss, excess facial hair, weight gain, skin problems? What help can other people give you? Do they encourage you to meet people, accompany you and reassure you in social situations, answer the telephone or the door for you?

### **Remember the four steps**

Step 1 Say what causes the problems with this activity

Step 2 Say what the problems are. Give details of: pain; fatigue; breathlessness; slowness; being in danger.

Step 3 Give an example

Step 4 Say how someone can help

## **13 Hobbies, interests, social or religious activities**

### **Do you need help from another when you go out?**

Examples include: going shopping for pleasure (rather than for necessities), walking, holidays, cinema, theatre, restaurant, pub, library, bingo hall, post office, doctors, hospital, physiotherapist, counsellor, church, evening classes, local park, day-trips, visiting friends and relatives, swimming, gym, sports centre.

### **What help do you need from another person?**

Describe what help you get or would need in order to carry out this activity. Do you need someone to drive you to and from places? Do you need someone to carry things for you, to lean on, to help you find a lavatory, to help you get to and from the lavatory? Do you need someone to offer you support and reassurance because of the possibility of an episode of incontinence? Do you need someone with you in case you have a dizzy spell or a fall?

### **At home**

This can be hobbies, or pastimes or activities that you used to do, still do or would like to take up. For example, could you do gardening, decorating or DIY if you had someone to help with the bits that require heavy lifting, bending, stretching or kneeling? Is your concentration too poor to read but you would like someone to read to you?

### **What help do you need from another person?**

Would someone do the lifting, the hammering, climb ladders, fetch things, steady you, encourage you, get out or put away equipment?

## Day time and night time charts

The new short form doesn't make it very easy to show how often, how long for and how many days a week you have problems. But the answers to these questions are very important in deciding whether you qualify for AA and at what rate. The charts on the next two pages provide a simple way for you to answer these questions.

### Problems during the day

'Day' for the purposes of AA is from about 7am to 11pm. To qualify for AA for help during the day you need to show that you need help frequently and throughout the day. When we say 'need help', you don't have to want or get this help, it's just a question of whether it would be reasonable for you to have it. If you just need help during the day you may qualify for the lower rate of AA.

Alternatively, if you need someone to keep an eye on you during the day this needs to be pretty much all the time through the day, with no more than the occasional break, for you to qualify for the lower rate.

Whether you need help or someone keeping an eye on you, it needs to be for most days of the week – so at least 4 or 5 days in order to qualify. Use the *Day time needs* chart to give this information.

### Problems at night

Night for the purposes of AA is from about 11pm to 7am. To qualify for AA for help during the night you need to show that you need help or someone to watch over you for *at least 20 minutes* a night, or at least *twice* a night, for it to count. Once again, when we say 'need help', you don't have to want or get this help, it's just a question of whether it would be reasonable for you to have it. If you have problems at night you may get the lower rate of AA. Use the *Night time needs* chart to give this information.

### Day and night

If you need help or someone watching over you during the day *and* at night you may get the higher rate of AA.

### Example

Activity	How many times a day do you need help with this activity?	How long do you need help for each time with this activity?	Tick if you need help with this activity in the morning	Tick if you need help with this activity during the day	Tick if you need help with this activity in the evening	How many days a week do you need help with this activity?
Using the toilet or a bottle or commode	3-5	5-15 mins	✓	✓	✓	5-7
Washing and bathing	1	40 mins	✓			7
Getting dressed and undressed	4 (includes help with outdoor clothes)	5- 30 mins	✓	✓	✓	5-7

**Daytime needs chart** – if you have problems during the day fill in this sheet and include it with your claim pack

Name: \_\_\_\_\_ National insurance number: \_\_\_\_\_

Activity	How many times a day do you need help with this activity?	How long do you need help for each time with this activity?	Tick if you need help with this activity in the morning	Tick if you need help with this activity during the day	Tick if you need help with this activity in the evening	How many days a week do you need help with this activity?
Getting out of bed						
Getting into bed						
Using the toilet or a bottle or commode						
Washing and bathing						
Getting dressed and undressed						
Problems at mealtimes						
Help with medical treatment						
Someone keeping an eye on you						
Moving about indoors						
Dizzy spells, blackouts, fits and seizures						
Falls or stumbles						
Communicating with other people						
Social and leisure activities						

Would it be reasonable for someone to keep an eye out for you to protect you from harm throughout the day on most days, for example, because you have falls? (Circle your choice)

**Yes / No**

**Night-time needs chart** - if you have problems during the night fill in this sheet and include it with your claim pack

Name: \_\_\_\_\_ National insurance number: \_\_\_\_\_

Activity	How many times a night do you need help	How long do you need help for each time	How many nights a week do you need help
Help getting to the toilet or using a bottle or commode			
Help with changing position in bed			
Help with rearranging covers or pillows			
Help with getting a drink			
Help with taking medicine			
Help with treatment, such as tube feeding or massaging painful limbs			
Help with getting back to sleep			
Something else you need help with (give details):			

Would it be reasonable for someone to watch over you at night on most nights for at least twenty minutes or at least two or three times to protect you from harm, for example because you might have a fall? (Circle your choice)

**Yes / No.**

# The importance of supporting evidence

As well as your claim pack the decision maker has to take into account any other evidence you provide, this includes additional evidence from you and evidence from other people.

## Medical evidence

This can make an enormous difference to whether your claim succeeds. Detailed evidence from health professionals such as your GP, or consultant if you have one, may also mean that your claim is dealt with more quickly and that you are less likely to have a visit from a DWP doctor. (Always inform your GP that you are making a claim for AA as it is quite likely the DWP will contact them without telling you first, even if your GP has have very little contact with you).

Ask the health professional(s) most involved in your care if they will write a letter supporting your claim. Make an appointment to see them so you can answer any questions they might have and take the health professionals sheet at the end of this guide with you. Ask them to send any letter to you so you can keep a copy (and if necessary ask them to change anything you think is inaccurate or unhelpful). Remember: it is up to you to decide what evidence you submit. Do not feel obliged to use a letter that may not be helpful or might actually harm your case.

But you should bear in mind that health professionals are under no obligation to provide you with a letter of support for your claim. Some may refuse to supply you with a letter, others may only do so only if you pay. If you are eligible for Legal Help (what used to be called legal aid) some solicitors and advice agencies may be able to pay for medical evidence for you. See the *Help!* section for more about this.

## Non-medical evidence

Carers, friends or relatives who accompany you when you go out, help you up and down stairs, accompany you to social occasions or give other sorts of support, can write letters explaining what they do. They should give the letter to you so that you can keep a copy. If it says things that you think are unhelpful, then ask the writer to change them or simply do not submit the letter. Whatever you do, don't feel obliged to submit a letter just because someone has been kind enough to write it. A letter that says the wrong things can be very damaging to your claim.

## Keeping a diary

A diary kept for five days detailing all the things you have problems with, cannot do unless you have help or cannot do at all is very useful. If you keep a diary before you fill in your claim pack it can make the job a lot easier. In addition, you can send it in with your claim form as additional evidence. But beware: if yours is a fluctuating condition then don't keep a diary when you're having a better spell, it'll give a very misleading impression.

**Remember:** you must send section 1 of your form before the deadline runs out. You can send other evidence later if necessary. Enclose a letter with your claim form telling the DWP that you intend to send further evidence and when you hope to be able to send it to them.

## Dealing with a medical visit

After you send in your claim pack, you should receive an acknowledgement within five working days from the DWP, at least that's what it says in the Charter Standard Statement.

Your claim pack will be looked at by a decision maker who may make a decision based just on the information you have sent or may decide he requires more. He may contact your GP for further information and/or he may ask the Medical Services department to send a doctor to visit you.

### Who gets a medical visit?

There's no way of knowing when you make your claim whether you will have to have a medical or not. The first you will know about it is when you receive a letter, or possibly a phone call, telling you that the DWP wish to send a doctor to your home. If you refuse to have a medical your claim for AA will automatically be turned down. However, you can ask for the appointment to be made, or changed to, a time when you can have someone else present, (see below). You can also ask to be visited by a female doctor if you would find a visit from a male doctor distressing, or vice versa.

### Who visits?

Some people are visited at home by a polite and interested doctor who takes the time to listen and who writes an accurate account of his visit. Sadly, not everyone is so fortunate. Doctors, who are often either retired GPs or local GPs squeezing these visits in with their other work, are paid a fee of over £100 for each visit. Many people we've spoken to reported that the visiting doctor seemed in a rush, stayed only a very short time and wasn't interested in what they had to say. Some found the doctor positively rude. Others reported that although the doctor seemed sympathetic and encouraging, they later discovered that the medical report was very dismissive of their needs.

### Having someone with you

Having a friend, relative, carer or support worker with you can make it much easier to deal with difficult situations, it can also provide you with a witness to what happened at the medical. If possible, tell the DWP that you intend to have someone with you, but don't worry if you don't have chance to inform them.

### Getting an appointment

You may be phoned by the doctor who is going to examine you to arrange an appointment. Doctors are warned in their handbook *Guidance for Examining Medical Practitioners* (which can be downloaded from the Members area of the Benefits and Work website) that '*arrangements for making appointments are one of the major sources of complaints against examining doctors particularly about insufficient notice of the visit. It is very important to follow the recommended practice . . .*'

In spite of this some doctors still don't follow the recommended practice, so here's what you should be able to expect.

The appointment may be arranged by telephone or letter but '*it is vital to offer sufficient (7 days) notice*'. If a date less than 7 days in advance is agreed this should be recorded on the report that the doctor writes and should be signed by you.

The doctor may be keen to arrange an appointment at short notice, perhaps because they already have another visit arranged in your area or because they are trying to fit you in around some other engagement. But if you want time to prepare or need to arrange for someone else to be present then please don't allow yourself to be pressured into agreeing to short notice. Remember, the doctor is getting paid over £100 to visit you, so it's only fair that they set aside sufficient time to do their work for the DWP, not just try to squeeze you in between other engagements.

If necessary tell the doctor that you will have to consult with the person you want to have with you before you agree a time.

If the appointment is arranged by telephone the doctor is told it is good practice to confirm the appointment by letter. They are also told that telephone calls should be made at reasonable times, that they should allow themselves a maximum of a 1 hour window and they should call you if they are running late.

If the doctor turns up too early or too late and, for example, your accompanying person is not present, you can politely refuse to let the doctor come in and tell them that they will need to arrange a new appointment. Doctors are told by their handbook that in these circumstances they should ensure that you are given '*reasonable notice*' for a second visit.

If the doctor calls at the correct time and you are not in, they are told by their handbook that they should leave a form giving you a new appointment and that this time they do not have to give you seven days notice, but that they should still give you '*reasonable notice*' in case you wish to have a representative present.

## **Medical Visit Record sheet**

At the end of this guide there is a medical visit record sheet for you to record what happened at the medical. Look through it before you have your medical and fill it in *immediately* afterwards, if you want to have a record of what happened. Remember to make a note of the time the doctor arrived and left: if they only stay a short time you can use this as evidence that the report is less likely to be reliable.

The Medical Visit Record sheet will provide very valuable evidence if you later decide you wish to make a complaint about the doctor or if you don't get the award of AA you consider appropriate and decide to challenge the decision. (Do read the section below about 'Taking notes' if you intend to complete one of these sheets)

## **The medical**

Until mid 2006 the medical report form completed by the visiting doctor was divided into two parts. The first part was a statement of the claimant's needs taken by the doctor and signed by the claimant. However, this practice has now ended and you will not be asked to sign anything as part of your medical. Nor will you be given the opportunity to read anything the doctor has written. However, you will automatically receive a copy of the whole report if you appeal against the decision in your case and we advise you to ask for a copy for your records even if your claim is successful.

The new medical report form used by doctors is 29 pages long and, in theory, the doctor has to record a lot more information and justify their opinions in much more detail than was the case in the past. One of the most important new features is the section on how you spend a 'Typical day'. Questions on this will usually come early on in the medical, after you've been asked about:

- your main medical conditions

- your medical history
- your medication
- your impairments and functional restrictions (how your condition affects you)

Try to ensure that the information you give relates to what you consider to be a 'typical day'. If your condition varies and you don't have such a thing as a 'typical day' then make this clear to the doctor. It's also very definitely worth completing the Medical Visit Record sheet if you have expressed concerns to the doctor about the idea of a typical day – just in case the doctor hasn't made a note of these concerns.

Beware of leading questions like '*You don't have any trouble with ... do you?*', or '*You can manage ... can't you?*'. Try not to be persuaded, or feel pressured, into giving an answer that isn't correct. If you do have problems with an activity, or can't manage it at all, say so and explain why.

As well as asking questions, the doctor may carry out a brief physical examination and ask you to perform simple activities such as standing up and walking across the room. However, they should not ask you to do anything that you tell them would be painful.

## **Preparing for the medical**

So, if possible, before the medical:

read through the photocopy of your AA claim pack to refresh your memory about the most important things you need to tell the doctor;

have a look through the Medical Visit Record sheet so you know the kind of problems you need to be looking out for during the medical.

## **Examining your home**

We've been hearing from an increasing number of people who were very unhappy that the doctor appeared to feel they had a right to go into every room in their home. Some people said the doctor had told them that they were "*Checking to see what aids or adaptations you might need*". This is clearly not true, the doctor has no power to recommend to anyone that you be provided with aids or adaptations.

In fact, the doctor is probably doing two things.

The first is answering a question in the medical report which asks that they '*Describe any features of the current accommodation that cause increased problems for the customer e.g. upstairs toilet, steep steps.*'

The second is, in accordance with their training, checking to see if you are genuinely living the life of a disabled person. This means they will be looking out for things which they consider do not fit in with what you have said. For example, is there a heavy bolt which you have to draw to open the back door, even though you've said you can't manage to turn taps on and off because of poor grip strength? Of course, there may be very good explanation for this: you never bolt the door. But the doctor may simply observe and not ask.

If the doctor says they wish to look round your home it may be worth asking them what they are looking for and requesting that they ask you about anything they see which they consider significant. If there are rooms which you consider private, for example because they are used solely by a lodger or a relative, it seems reasonable to say that you do not wish them to go into

those rooms. If the doctor ignores your wishes you should complain very strongly indeed – we'd suggest going straight to your MP.

## **Taking notes**

If you, or someone with you takes any notes whilst the doctor is actually present, visiting doctors have been instructed to issue an “oral warning” as follows:

*1 It is your right to take notes for your own use and benefit*

*2 The notes will not be included in the Report I make save for the fact that notes were taken and further, they are not accepted by myself or the DWP as an official record of this examination.*

*3 If the notes are subsequently produced at any time for any purpose, such as part of appeal process, I the Examining Doctor, my employer and the Department for Work and Pensions reserve all rights to challenge anything in the notes in the event we are asked to comment on the content of the notes at a future time.*

*4 You are free to use the notes as you choose but if you choose to publicise the notes (other than in connection with correspondence with the DWP or under any appeal procedure) I would ask that you do not publicise my name.*

It makes good sense not to publicise the doctor's name other than in appeal or a complaint, as this might leave you open to action for defamation. But that aside being given an ‘oral warning’ should not affect your actions in any way: it simply tells you that the DWP won't necessarily agree with what you write should your notes be used as part of an appeal.

## **Be prepared**

We don't want to leave you feeling terrified about having a visit from a DWP doctor. But many people say they had no idea what to expect before they had their medical and that they were very disappointed with how quick and irrelevant the whole thing seemed to be. We also know that many AA claims are turned down because of the visiting doctor's report. By being properly prepared for your medical you can reduce the chances of this happening to you.

## The decision

Eventually you will receive a decision letter telling you whether you have been awarded AA. If your claim has been successful the letter will tell you what rate you have been awarded. It will also tell you whether your award is for fixed number of years or indefinite.

### **If you are happy with your award**

You should try to get a benefits check done at your local advice agency as you may be entitled to additional amounts in the benefits you already receive or you may be entitled to benefits you have not received in the past.

If your award is for a fixed number of years you should be sent another claim form to complete several months before it runs out. If your award is an indefinite one you may still receive review forms to fill in every few years.

If your circumstances change - your condition improves or deteriorates - you should tell the DWP as it may mean that your AA should be reduced or increased

### **If you are not happy with your award**

If you are not happy with the decision you can apply for it to be looked at again (a revision) or, better still, appeal. But you must do this within one month of the date of the letter giving you the decision, or have special reasons why you didn't. You also need to be aware that if you do ask for a revision or appeal, the decision can be changed to increase or decrease your award, (though this is obviously not a problem if you've been awarded nothing at all). You should try to get help if you wish to challenge a decision, see *Help!* on the next page.

# Help!

## Help From NACC

### Benefits

Information and support for people with Colitis and Crohn's Disease in claiming AA is provided through the Information Service. Anybody wishing to have more information about an AA claim should ring the NACC Information Line on **0845 130 2233**.

Information Officers can make an appointment for you to be rung by a Support volunteer or direct you to other sources of help, when needed, with claiming AA and other benefits.

### NACC-in-Contact Support Line 0845 130 3344

Even if you feel entirely able to complete the claim pack without help you may well find the process emotionally disturbing. You will have to think hard about all the ways in which life is more difficult or more restricted for you and have to pass on very personal information to strangers in the benefits system. What may be worse, if your claim is not successful, you may feel that you have not been taken seriously or believed. Contacts are NACC members who are trained to give supportive listening over the telephone. They are not there to deal with any questions to do with AA, but if you find the process of claiming is causing you distress they can offer support.

**Family, friends, carers and other NACC members.** If you can arrange emotional support from amongst your family and friends it may make claiming AA easier to cope with. Bear in mind that if you are unhappy with the decision and choose to appeal, the process may take many months (or even years).

### Advice agencies and advice workers.

These may be able to help with filling forms and with challenging the decision if you're unhappy with it. However, advice agencies may be almost impossible to get through to on the phone, have no appointment system, long queues and no public lavatory. If you can't get through to your local agency on the phone, try writing to them explaining your health problems and asking if they do home visits, or if they can telephone you at home and offer advice. You can usually find numbers for advice agencies in your local Yellow Pages in one or more of the following sections: disability information and services; information services; social service and welfare organisations; counselling and advice.

**Please note:** you may have to try repeatedly before you can get through to agencies on the telephone. You should also be aware that help from advice agencies is very much in demand, so the sooner you seek help the better.

### CLS Direct helpline and website

The Community Legal Service offers free initial (30 minutes) advice from a qualified legal adviser about Welfare Benefits between 9am and 5pm weekdays. And if you call outside office hours, just leave a message and they say they'll call you back. If you are eligible for Legal Aid you can then get further free legal help with your case by phone and post. To use the helpline call **0845 345 4345**. After you choose the welfare benefits option you will be advised to listen to recorded messages about benefits. We recommend that you don't, the messages are long, sometimes confusing and you can read them at your leisure on the CLS website at [www.clsdirect.org.uk](http://www.clsdirect.org.uk) if you wish to. Instead go straight for the option of speaking to an adviser.

You can also get information about your nearest CLS funded advice providers by visiting the CLS website at: [www.clsdirect.org.uk](http://www.clsdirect.org.uk) or calling the CLS Directory Line on **0845 608 1122**.

### **Citizens' Advice Bureaux (CAB)**

There are over 750 bureaux in mainland Britain. Look under Citizens Advice Bureau in your phone book for details of your nearest one. You can also find details of your nearest bureau at: [www.citizensadvice.org.uk](http://www.citizensadvice.org.uk)

### **Citizens Advice Scotland**

To find your nearest bureau, look under Citizens Advice Scotland in your phone book or visit the CAS website at: [www.cas.org.uk](http://www.cas.org.uk)

### **AdviceUK**

Over 900 advice agencies are members of AdviceUK. Details of your nearest ones are available from AdviceUK's website at [www.adviceuk.org.uk](http://www.adviceuk.org.uk)

### **Association of Independent Advice Centres (Northern Ireland)**

AIAC is the umbrella body for independent advice centres in Northern Ireland. You can get details of your local independent advice centre in Northern Ireland from their website at: [www.aiac.net](http://www.aiac.net)

### **Disability Information Advice Line**

There are over 140 local DIALs, all staffed by disabled people and all offering telephone advice. If you have a local line it should be listed in your telephone directory under DIAL UK. Alternatively, call the national office on **01302 310 123** or visit their website at [www.dialuk.info](http://www.dialuk.info) where you can find a directory of DIAL offices.

### **Housing Associations**

Some housing associations employ a welfare rights worker. If you live in a housing association property contact your local office.

### **Doctor's surgeries**

An increasing number of surgeries and health centres have a welfare rights worker on the premises, part-time or full-time. Check with the receptionist.

### **Local Authority**

Your local council may employ Welfare Rights Workers who can help you with your claim. Start by asking your council's main switchboard if they can put you through to a Welfare Rights Worker. If the operator doesn't know of one ask to be put through to the Social Services Department and if they can't help try the Housing Department, either department may employ Welfare Rights Workers.



# Medical Visit Record Sheet

Date of doctor's visit

Time doctor arrived

Time doctor left

Who else was present

Did the doctor arrive at the agreed time?  
*If no, please give details.*

Yes / No

Did you feel relaxed and able to talk freely to the doctor?  
*If no, please give details.*

Yes / No

Did the doctor listen to what you had to say and give you  
time to answer questions fully?  
*If no, please give details.*

Yes / No

Did the doctor phrase questions in a way that suggested  
a particular answer?  
*If yes, please give details.*

Yes / No

Did you discuss with the doctor whether you have such a thing as a 'Typical day' and give a clear idea of the variability of your condition? Yes / No  
*If yes, please give details.*

Did the interview distress or upset you in any way? Yes / No  
*If yes, please give details.*

If you had a physical examination did anything you did or the doctor asked you to do cause you pain? Yes / No  
*If yes, please give details including whether you told the doctor you were in pain.*

Did the doctor go into rooms in your house without your permission or without adequately explaining why they were doing so? Yes / No  
*If yes, please give details.*

Anything else you wish to record

Signed (your signature) Date

Signed (friend or carer who was present) Date

# Health Professionals' Sheet

*Use this sheet when you see your health professional. By health professional we mean the doctor, nurse, consultant or other health worker you feel can best give information about your condition. For convenience we have referred to your doctor throughout this sheet. When you see your doctor please try to follow the steps below. You may want to show your doctor this sheet and leave it with him or her after your appointment.*

**Step 1** Before seeing your doctor try to complete the checklist overleaf.

**Step 2** Tell your doctor that you are making a claim for Attendance Allowance. Explain that a letter from your doctor may make a big difference to whether your claim is successful or not.

**Step 3** Explain that the evidence you need is:

- a) how long your doctor has been seeing you;
- b) diagnosis – what it is you suffer from;
- c) prognosis – how your condition is likely to change in the future;
- d) how the symptoms of the condition affect your everyday activities. In other words, whether your condition means that you need someone with you to make sure you are safe or someone to help you do things like wash, bathe, dress or walk.

**Step 4** You may not have told your doctor before about all the problems you have with ordinary activities. It would be a good idea to explain them now. You could show your doctor the checklist you have completed on the back of this sheet and go through it with him or her.

**Step 5** Bear in mind that your doctor may not have seen you carry out most of these activities and so may be reluctant to say what problems you have. If this is the case ask your doctor if s/he is willing to say whether the problems you report are consistent with what your doctor knows of your condition.

**Step 6** If your doctor is willing to write a letter, ask him or her to send it to you rather than the DWP and, if possible, to give you an idea of when you might receive it. Keep a copy of the letter in case it gets lost in the system.

## Checklist

Activity	✓	Very brief details of the problems you have with this activity. For example 'I am in pain and unsteady when I use the stairs. It helps to have someone to lean on'.
Getting out of bed in the morning		
Getting into bed at night		
When you are in bed		
Toilet needs.		
Washing and bathing		
Getting dressed and undressed		
Problems at mealtimes		
Help with medical treatment		
Someone keeping an eye on you		
Moving about indoors		
Dizzy spells, blackouts, fits and seizures		
Falls or stumbles		
Mental health		
Communicating with other people		
Social and leisure activities		