



Notes on Applying for Disability Living Allowance

GENERAL

The notes set out below give a commentary upon the questions asked by the DLA application forms. We have indicated which questions are the most important and to which age group. In addition, guidance is given on the type of information that needs to be given. The aim is to make the process of filling in the forms simpler and to ensure that information that is most relevant and most advantageous to the individual's application is supplied.

Section One - *Your claim for Disability Living Allowance*

This section (the ORANGE Section) is straightforward and you should be able to complete it easily for yourself or on behalf of a child. Do remember that you can ask someone who is not a doctor to give information about how your condition affects you.

Section Two - *How your illness or disability affects you*

The GREEN section deals with the help you will need to move around (Mobility Component) and the help you need with personal care (Care Component).

Check first of all whether you are applying for both components (Mobility and Care) or only one of them. The form no longer splits into two distinct parts, but the part relating to mobility is on pages three, four and five. However, any information relating to falls or mobility in the house will relate to care rather than mobility. The rest deals mostly with personal care.

Whenever a box asks for more information you should clarify, amplify and summarise relevant points to your personal position.

About help with getting around

The message to get across is that you have haemophilia, the level of factor deficiency, the frequency of bleeds, the effect of bleeds on mobility, how long it takes to recover from a bleed, any weak joints or joint damage you may have and the need to restrict mobility to protect your joints. Obviously no one will have identical problems to the next person; it depends on the individual's particular condition.

Page 3 If applicable tick yes to the question "Do you have physical problems with walking." Indicate any walking aids which you use.

MOST IMPORTANT is the statement to be completed "If the effort of walking would be dangerous for you, tell us about this" you are expected to give details in the large box:

1. Are any of your weight bearing joints 'target joints', if so mention them.
2. Mention that these limbs bleed most frequently. Also mention if you have any joint damage.
3. Point out that repeated bleeding will lead to further joint damage and chronic degenerative arthritis. Say (if this is the case) that walking can bring on bleeds, and can exacerbate joint damage. Walking must therefore be restricted to avoid a serious deterioration in your health. Be honest and express an average weekly figure in relation to the number of days which you encounter difficulties. If in any

month you experienced four bleeds in one week but none in the other three weeks, this would average out as one bleed a week. It may be that if you already have arthritis, you experience mobility problems on a daily basis. If this is the case, tell them.

At the bottom of page - three, you are asked to give details of "How far you can walk before you feel severe discomfort". Please be careful when providing this information since we find that too often people state the MAXIMUM distance they can walk on "a good day". We suggest that the information should be the MINIMUM distance on an average/poor day for you. Distance will vary from person to person but if your honest answer is over a few hundred yards, we suggest you talk to us about taking your application any further.

When it comes to describing the length of time - think carefully! If you give the impression of being able to skip along at great speed your application could well fail.

Page 4

If you have arthritis/joint damage you may find that you need someone to support you most of the time. Some people will only experience these problems when they have a bleed or in the recovery period afterwards.

The larger boxes on the page are for amplifying information about your mobility problems. In the largest one at the bottom of page four you could stress your factor levels, damaged joints, the ability to walk in terms of the distance and time and the long-term effects of bleeding into joints. You can also give details of any pain, fatigue stiffness and breathlessness that you experience.

Page 5

Falls or stumbles

If your application is based solely on your haemophilia you may well tick the box to indicate that "You sometimes fall in places you know well".

Use the large box to amplify your answer. For example, you may fall because your legs are very stiff and you suffer from arthritis and therefore you need someone to support you. Do you need someone to pick you up? Are you likely to suffer a bleed and require urgent treatment? How often do you fall? If falls are infrequent but could be dangerous, explain this.

STRESS that you have been advised to MINIMISE the amount of walking you do because of the long-term effects of repeated bleeds etc. Stress features which are personal to you, e.g. the damage to wrists/elbows from using crutches, etc. Also emphasise the fact that you have had haemophilia from birth, there is no cure, etc., and your condition can and will only deteriorate because of the degenerative nature of haemophilic arthritis.

Some General Points – Care Component

Children - very young children and babies should base their claims on the need for the parent/carer to supervise them continuously in order to prevent bleeds occurring and to ensure that bleeds are detected early and prompt treatment given.

If the child is at school, you would need to stress that the parent/ carer has to be on call at all times to intervene with treatment by being "tied" to a phone and by being ready to assist.

You must show that the supervision required by the child is **substantially in excess** of the supervision that a normal child would require.

Older children do not need so much supervision but they may need more **attention** with everyday activities when experiencing a bleed and in the recovery period just afterwards. For example, help may be required with personal hygiene, getting into and out of bed, feeding etc. Again the attention required must be **substantially in excess** of the attention a normal child would require.

Adults - adults will not require supervision generally but if they have frequent bleeds, joint damage or arthritis or a combination of all these, there are likely to be periods when attention with everyday needs will be required. Also, if you have HCV and suffer from aching joints, depression and 'brain fog' so that you need reminding or encouraged to look after yourself this counts as supervision with personal care and should be mentioned.

In all cases, you will need to say something about the frequency of bleeds and the length of the recovery period so that the Decision Maker has a clear idea of the amount of help that you need say, in any given week. If you have arthritis and you need help most of the time regardless of whether you are having a bleed, say so.

On each page there is a larger box asking you to give more details. Stress that in the event of bleeds immediate hospital treatment must be sought or treatment administered at home. In the long-term, repeated bleeds lead to permanent joint damage and eventual disablement. Give the Decision Maker as many details as you can. Try to amplify your needs in these boxes. You can also repeat basic information about haemophilia, for example, details of your haemophilia, factor level, and affected joints.

The form is straightforward. JUST THINK CAREFULLY before you start to answer questions.

- Page 6** This relates to the care component. Tick yes if you have problems moving about indoors. Describe any pain and discomfort you have when moving about. How far do you have to go to get to the bathroom, toilet or kitchen? Do you need help getting up and down stairs? WOULD TRYING TO MOVE ABOUT ON YOUR OWN WORSEN YOUR CONDITION? This may well be the case when you have a bleed. If you have joint damage this may be the case the whole time. Again, think about the number of bleeds you have, the length of the recovery periods and arrive at an average number of days per week that you require help.
- Page 7** You may require help with getting in and out of bed if experiencing a bleed or if you suffer from arthritis.
- Page 8** This may be relevant if you are experiencing a bleed or are in a recovery period. It may also be relevant if you suffer from night sweats as a result of HCV.
- Page 9** Answer as applicable to your own circumstances e.g. help in getting to the toilet, turning taps, personal hygiene etc. With young children think about maintaining their port-a-caths.
- Page 10** Remember hair washing, shaving, showering, cutting toenails and drying yourself.
- Page 11** Give as much detail as possible thinking through the difficulties you encounter. Consider doing up buttons, laces etc. and bending down to put on socks or tights.
- Page 12** This only applies to those over 16, it is called the "cooking test". If you only qualify under this section you will receive the lowest rate of DLA. The meal is a fresh meal involving fresh vegetables and pans of hot water so if you live on sandwiches and microwave meals because you can't peel or chop vegetables, lift pans of water etc. you may well qualify under this section.
N.B. You will not qualify because you have never learned to cook.

- Page 13** This may be relevant if you are experiencing a bleed, or are in the recovery period or if you have arthritis, particularly where bleed is in elbow, wrists or fingers.
- Page 14** VERY RELEVANT – injections are relevant to children but also to those who are subject to bleeds in the arms. Again, state CLEARLY that you have haemophilia, identify the factor involved and the levels appropriate to you or your child. If you are applying on behalf of a baby that should be clear but there is a space to amplify points like this.
- Page 15** (P. 5 in the form for children) This page is tailor made for children who need to have an adult in constant attention SEVEN DAYS A WEEK and 24 HOURS EACH DAY. Again, there is an opportunity in the large box to explain about schools only accepting children on the basis that you are constantly available to intervene in the event of an emergency. You could also mention the need to identify internal bleeding and respond promptly and the need for constant supervision to prevent possible bleeding episodes. Explain the difference between your child's needs and those of normal children for whom a knock would not be a problem. You can say that if it were not for your preventative supervision, your child would experience far more bleeds. This is particularly relevant for young children
- Pages 16/17/18** In adult forms unlikely to be relevant though some people with HCV report altered psychological states such as depression and anger and impaired judgement.
- Page 19/20** These deal with the help you need to lead as full a life as possible. For the section "Help you need when you go out during the day or evening," think of the things you would like to do if not restricted by haemophilia e.g. going to the pub, supermarket, dancing etc. Do you need support going to the shops, climbing stairs, etc?
- Help that you need at home.**
Do you need help getting up and down stairs, reaching into cupboards, cooking, cleaning, etc? The question may require an answer already given on a different section of the form. **Do not ignore it.** Complete each section even if you have already stated the answer elsewhere in the claim pack.
- Page 21** Repeat the most important points again: restate your condition(s), factor level, frequency of bleeds, treatment required, how long it takes to make up, administer and clear up after treatment. If you have young children stress the fact that the child needs checking during the night and may need soothing to sleep after a bleed. It is an opportunity to make any points that you could not make in any other section of the form.
- Pages 22/23** Must be completed by everyone. You should note that there are TWO statements to be completed. The statement on Page 12 of the orange section can be completed by anyone who knows you – a relative, member of staff at your centre, GP, etc. The second statement on Page 21 of the green section should be completed by your Centre Director or another member of staff at your haemophilia centre. Ask them to put some useful details about your condition in the box "Please tell us what their illnesses....." You could also ask them to write a letter in support.

Remember that you do not serve your best interests by putting down the least possible number of times a night you are required to give attention or the amount of time involved.

When you have completed your application form please:

1. Look through the application to make sure it is in order
2. Keep a photocopy for your treatment records
3. Write a letter of support which is based on the information in the form

IF THEN YOUR APPLICATION DOES NOT SUCCEED

- Write to or telephone the DLA stating that you wish to ask for a revision of their decision, stating the reason why you cannot accept the decision. Advise DLA that the Society will be helping you with your revision application. You can consult the Society first before requesting the revision if you prefer.
- Keep a copy of the letter, which you send to DLA and send it to us.
- We will then support you further if appropriate.
- We may require additional information from you and will contact you to ask questions. We will keep you fully informed and let you have copies of all correspondence.

**In the meantime DO let us know if you are awarded DLA - how much and for how long!
To get a DLA form telephone: 08457 123 456**

This fact sheet can be reproduced in a larger print.
Please contact the Haemophilia Society for details.

The fact sheet can only give basic general information drawing on evidence available at the time of writing. Different people may give you different advice on certain issues and there may be some variations in the forms. It is important that you contact your local Citizens Advice Bureau or Social Security office for further information and advice on your own individual circumstances.

Revised May 2006

The Haemophilia Society
Petersham House, 57a Hatton Garden, London, EC1N 8JG
HELPLINE: 0800 018 6068
Tel: 020 7831 1020
Fax: 020 7405 4824
Email: info@haemophilia.org.uk
Website: www.haemophilia.org.uk

Evaluation Form

In order to find out whether this fact sheet does benefit our members, we have an evaluation form which you can send to our freepost address below. Please answer the following:

How did you obtain this fact sheet?

Did you find the fact sheet useful? Did it address the relevant issues?

Are there any other issues you feel need addressing in the fact sheet?

Any other comments?

Thank you very much for your time and cooperation in completing the evaluation form,
your help is greatly appreciated.

**Return to:
Freepost RLTJ - ZGTG - ZHJS,
The Haemophilia Society
Petersham House
57a Hatton Garden
London
EC1N 8JG**