

Advice to patients for making benefit applications

It is important to establish how you are *most of the time* in terms of the functional criteria for the incapacity or disability benefits. This can be difficult for people with ME/CFS. When applying for benefits, you need to describe your day to day life, based on what you actually do and how you manage your walking and care difficulties.

For people with ME/CFS, these activities (functions) should not be considered in isolation. Think about which activities you can manage over the course of a week.

This process is crucial to a successful benefit application. The claim will be decided on the basis of how you are most of the time, not just on your worse days if they occur once or twice a week on average.

Tactics for establishing level of walking / care difficulties as this can be difficult for people with ME/CFS

Produce a simple diary to record the range of difficulty with the relevant activities, and establish how you usually are.

Imagine you live alone and then imagine what you would do in terms of care and mobility each day / each week.

What have you actually managed to do in the last week / 2 weeks relative to these functions.

Listen to the observation of somebody who knows you well, about what you can and cannot do, and how you do things.

Compile a list of symptoms.

After the above actions, you should:

Complete an application form, based on the information collected about how you usually are.

Complete a DLA/AA or ESA checklist and hand a copy to relevant health professionals.

Make sure your GP is aware of your day to day difficulties.

Collect a statement from somebody who knows you well.

Checklists, and booklets from: Morecambe Bay ME Group - 01524 65842
or: http://www.bayme.org/rights_for_me_docs.htm

Advice for patients and health professionals when patients apply for incapacity and disability benefits.

This booklet can be given to a patient prior to their making a claim for benefit, or having to renew an existing claim.

It includes information about the main health criteria for incapacity and disability benefits (pp2-3), and ways to collect the necessary information to make these claims (p4).

This booklet sets out some of the actions patients might consider when applying for benefits because of illness. A health professional's information / opinion can be very important in the benefit decision, especially when it covers the relevant functional criteria (pp2-3) and includes information about the patient's day to day life. This can be collected from the relevant patient completed checklist—see p4 for information about the patient completing this.

Health professionals should realise that their contact with the patient probably occurs when the patient has rested before hand, and will afterwards, possibly for a day or more. They may look fairly well, for a short time—an extended appointment might start to produce signs of fatigue and poor concentration. Patients tend to organise activity by reserving their available capacity for any contact time and living with worsening symptoms and reduced function afterwards. Benefit claims are assessed on the effects of illness(es) on specific functional criteria (see over) and not on diagnosis. Successful claims have to focus on these criteria.

possible ME/CFS symptoms

The common symptoms affecting physical and mental health include but are not limited to:

un-refreshing rest, un-refreshing sleep and often insomnia, physical and mental fatigue, joint or muscle pain, cognitive impairment (memory, language, concentration all affected), malaise following exertion, (often like having the flu), sensitivity to light and sound, recurrent sore throats, problems of balance, headaches, digestive disturbance, low grade fevers and generally lowered immunity to virus.

Symptoms vary from patient to patient in nature and intensity.

Disability Living Allowance (DLA) and Attendance Allowance (AA) (for people 65 and over) criteria.

AA only assesses for the care criteria.

Assessment for both benefits is on the basis of difficulty with these functional criteria. This assessment has to take into account the help needed, if available to complete the following functions.

WALKING— (Mobility)

- Not able or virtually unable to walk on level ground
- Needing physical support from another person to help you walk
- Having someone with you outdoors for guidance and/or supervision in familiar / unfamiliar places
- Any other reasons for restrictions on walking outside

CARE AT HOME

- Getting in and out of bed - day time and / or at night
- Using the toilet - day time and / or at night
- Washing, bathing showering or looking after appearance
- Dressing and/or undressing
- Moving around indoors
- Falling or stumbling at home, and outside
- Preparing a cooked main meal for yourself
- Eating, cutting up food, drinking
- Taking medication - during day and / or at night
- Communicating with others
- Requiring supervision during the day and / or at night
- Needing to turn over or being made comfortable at night in bed
- Subject to dizzy spells / blackouts / loss of consciousness

Employment and Support Allowance (ESA) criteria.

ESA is the new incapacity benefit for people who are not well enough to work. The first stage of an application will include an assessment based on the functional criteria below. This assessment is to establish the degree of difficulty with one or more of these functions.

PHYSICAL FUNCTION

1. Walking on level ground with a walking stick or other aid if such aid is normally used, and going up / down 2 steps
2. Standing and sitting and rising from a chair
3. Bending and kneeling
4. Reaching with arms
5. Lifting and moving
6. Manual dexterity
7. Speech
8. Hearing with a hearing aid or other aid if normally worn
9. Vision in normal daylight or bright electric light with glasses or other aid to vision is such aid is normally worn
10. Bowel or bladder incontinence
11. Episodes of lost or altered consciousness

MENTAL, COGNITIVE AND INTELLECTUAL FUNCTION

12. Learning tasks
13. Awareness of hazard
14. Problems with memory and concentration
15. Completing tasks
16. Start and sustain personal action
17. Cope with changes in routine
18. Able to travel to familiar places alone
19. Fear or anxiety in new places / social contact
20. Strong reactions to others
21. Unaware of effect of behaviour on others