

## Writing a diary

When applying for a disability or sickness benefit, or appealing against a decision, you need to represent accurately and in some detail how you live your life with the illness or illnesses. The success of a claim or an appeal can depend on how well you manage this. Writing a diary can be a useful tool to achieve this. It can also help you consider whether you have **told your doctor and other health professionals** about all the effects of your illness. Their knowledge of how the illness affects you can be very important in the process of claiming benefits.

Because ME/CFS can be very variable in its symptoms, it is important to put over as full as a picture as possible of how the illness affects your life. Record how illness affects you normally. If you regularly have bad days make sure this is shown in the record. If you have good days, record these also. If you do have a minority of good days, make sure it is very clear that these occur only for some of the time. If you manage to have a bath, for example, and this is out of the ordinary, perhaps because you have had help, please make it very clear that these are occasional events. The more detail you include, the better. Include the effects of all the illnesses you may have, not just ME.

When writing the diary detailing your day-to-day experience, please refer to the summary list of the activities (following pages) that are part of the assessment for either the **Personal Capability Assessment** (Incapacity Benefit or Income Support on basis of being incapable of work) or **Disability Living Allowance / Attendance Allowance**. Having read the list please write the diary to include the following:-

- record clearly the activities that are very tiring and cannot be repeated within a relatively short interval of time because you will need to rest afterwards:

*for example you may be able to go out for a walk, for 250 metres, 2 days in the week, but the effort will mean that you have to rest for 2 hours when you get back and you are more limited in what you do for the rest of the day*

- record those activities which are more occasional, and which may be necessary for your well-being or comfort, but can cause so much fatigue that you need to rest and you may not be able to do much else that day or even longer.

*continued over*

*for example a bath may bring some relief to muscle or joint pains, but might only be possible when somebody is present to help you in and out of the bath, and to dry you down. The effort of the bath might mean that you cannot do much else that day.*

- note those activities that you usually avoid because you know that they would be too tiring, or because your concentration / cognitive capabilities make it difficult to complete, or maybe some other reason why you routinely can't do something;

*for example filling out benefit forms, or making a proper meal for yourself, because experience has shown how difficult it is for you to complete the task*

- the sort of pain you have, where it occurs in the body, how frequently, is it continuous, how severe it is;
- if you are unable to start or complete tasks by yourself, because of mental or physical illness, or both, state which activities are affected;
- describe your feelings if these affect what you are able to do, or feel able to do.

*for example if you are frequently tearful, this might make you less confident about meeting others; or if you know that when walking you will need to stop frequently for rest, you may be concerned about what others might think of you.*

Please remember that if you are not able to do something **without the physical support or encouragement** of another person, please record this. It is **very important** that you also write about the activities that **you don't do but could manage if somebody was to help you**.

Please write the diary to cover a week if possible, recording how you are day-to-day and include the difficulties you have at night.

If writing the diary is difficult, ask a friend or carer to compile one based on what they observe of your day-to-day life. Please show them this information.

When the diary is complete, make a copy before sending it in with any benefit application, or if possible ask the Rights for ME caseworker to look it over and make a copy.

Put your name and national insurance number on each sheet of the diary.

Appointments for the Rights for ME caseworker can be arranged through the:

**referral line:**

**01524 65842**

**info@bayme.org**

or

**Lancaster Citizens Advice Bureau**

**87 King Street, Lancaster, LA1 1RH**

**enquiries@lancastercab.org**

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