

# **Assessment for Employment and Support Allowance (ESA)**



## **Report on Feedback from Members 2012**

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## Introduction

The 25% ME Group is the UK charity supporting people who are severely affected by the neurological disorder myalgic encephalomyelitis. It is estimated that around 1 in 4 ME patients are severely affected.

We are a membership organisation committed to helping people with severe ME and their families access benefits and services to which they are entitled. To this end the Group employs an advocacy worker and through this aspect of our work we quickly became aware that people with severe ME are facing an exceedingly uphill struggle to access basic welfare benefits which are essential to achieving a minimum level of financial security. An emerging area where this is clearly exemplified lies in the introduction of Employment and Support Allowance (ESA) to replace Incapacity Benefit, Severe Disablement Allowance, and Income Support paid on grounds of disability. This process is taking place on a phased basis over a three year period, and is expected to be completed in 2014.

Many members had been exempt from the 'Work Capability Assessment' under the previous system, in view of their grave ill health and debility. Under the new system there are no exemptions.

Another change is that awards of ESA are time limited – there are no indefinite awards.

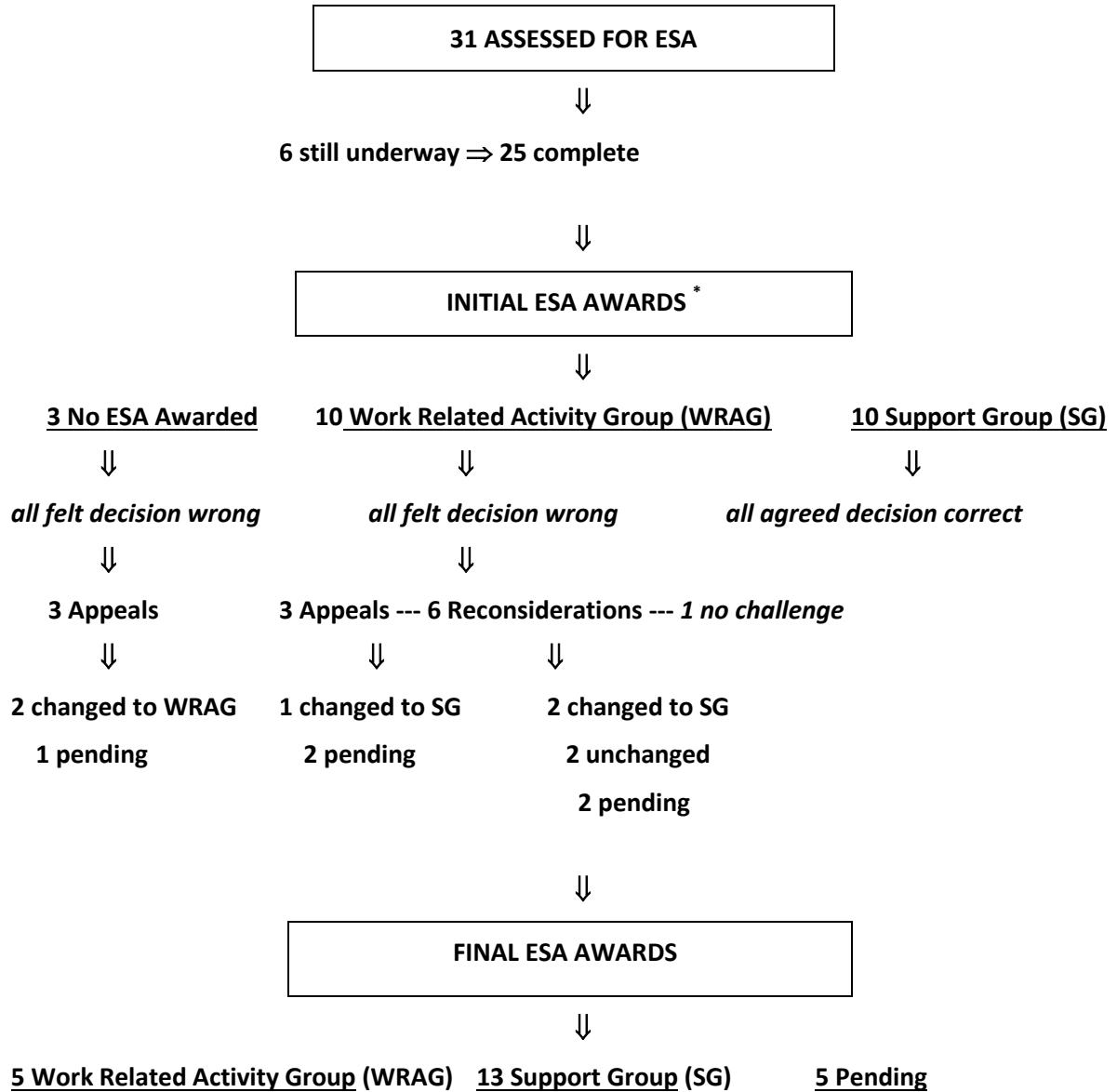
In the spring of 2012, as part of our annual ME Awareness Week activity we sent out a questionnaire about ESA assessment experiences to our membership. We hoped to learn more about how members were experiencing the new system, including finding out about the experiences of members who had not accessed the Group's advocacy service for support.

*"I have been in receipt of Severe Disablement Allowance and Disability Living Allowance since 1992. Most recent award was for an indefinite period, and I am exempt from the Personal Capability Assessment. But they had to put a 'notional review date' of 2012 on the system to satisfy the computer, so I'm guessing this will prompt an ESA Assessment – I await this with dread"*

***This is an illustrative exercise, giving an indication of the broad picture and highlighting problematic aspects of the system – of which there are many. It is not intended as a statistical survey.***

***We received responses from or on behalf of 64 working age members, 31 of whom had been through the ESA assessment process. This report considers their experiences.***

## Summary Overview Spring 2012



\* Figures are presented on 23 cases as two questionnaires were unclear on elements of the detail: one person had had an unspecified but unsatisfactory initial decision changed at tribunal; the other case appeared to be unresolved - the existing decision was clearly felt to be unsatisfactory.

## Question Area 1 – Claiming ESA?

Respondents were fairly evenly split between those who remained on one of the ‘old’ sickness benefits - *i.e.* Incapacity Benefit, Severe Disablement Allowance, or Income Support paid on the grounds of ill health or disability - and those who had begun the transfer to Employment and Support Allowance (ESA):

- 30 were on the old system and their ESA assessment had not begun;
- 31 had been or were being assessed for ESA – including 2 who had experienced ESA assessment and reassessment;
- 3 were not on a disability benefit and had not applied for ESA. For example:

*“Previously I was on Income Support but five years ago I sold my flat and have some capital as I now rent. I would like to move home into a part-owned, part-rented flat, which would fairly soon necessitate me claiming ESA. But I have heard such dispiriting news of ESA that I am at present still in inadequate accommodation.”*

***This report focuses on the experiences of the 31 respondents who had been involved in ESA assessment.***

## Question Area 2 – Stage of Assessment

Of the 31 respondents who had begun the ESA assessment process:

- 24 had completed an ESA assessment – including two respondents who were now being reassessed for a 2<sup>nd</sup> or 3<sup>rd</sup> time;
- 4 had returned an ESA50 ‘Limited Capability for Work’ Questionnaire but had not yet had a decision on their claim;
- 2 had received an ESA50 ‘Limited Capability for Work’ Questionnaire and were still completing it.

The remaining respondent returned a rather confused questionnaire: however it was clear that they were involved in an ESA assessment process and that this had been problematic. Their response did illustrate how a sick person can find themselves bewildered and confused and unclear as to what is to be done for the best – even with a carer available to assist:

*“Carer called the Department of Work and Pensions and was told that I should appeal and that I should not have been sent the forms. Awaiting reply. Then sent appointment. Carer filled ESA50 form in. Told I'd have to have a face to face assessment. For 3rd time in 6 months money stopped. Takes so long to talk to someone and they are so rude. I was told they don't have to inform me if they stop my money it was a mistake will get it next week. It causes problems. They have no idea. Cancelled for 3 months pending an appeal.”*

## Question Area 3 – ‘Limited Capability for Work’ Questionnaire (ESA50)

### FEASIBILITY OF TIMESCALE

When ESA assessments were first introduced claimants were allowed 6 weeks from date of posting out an ESA50 questionnaire to complete and return it. Ten respondents had been assessed at this early stage and were permitted the 6 weeks. Not surprisingly - given constraints of illness and vagaries of the postal system - half (5 of 10) had found that this was not long enough to adequately complete the form without stress or discomfort.

*“From Atos I met with complete bafflement as to why I would need one [an extension]. I submitted a completed form within the 4 week timescale, but I suffered a relapse from forcing myself to meet the deadline.”*

A larger number (n=16) had been assessed after the timescale for return was shortened to 4 weeks. Not surprisingly few had found this long enough for completion (n=5, including one carer).

Looking at responses from all 29\* who had completed an ESA50, the majority (n=17) had found that there was insufficient time allowed to complete the form. In response:

- Six had claimants approached the assessing authority to seek more time. Three did this directly on their own behalf and were denied so had kept to the timescale set. The other three had their cases taken up by the 25% ME Group advocacy service, which approached Atos and/or the DWP regarding timeframe. In these three cases the form was submitted when ready and the lateness caused no problem.\*\*
- One had not returned the ESA50 on time and had not contacted the DWP or Atos in advance. They had had their claim denied as a result.
- Two had submitted forms with some sections not completed at all, in order to meet the deadline.
- The others (n=20) had completed the form on time as best they could.

*“I was told no extension was available, and that people sending in forms late were getting their benefit stopped.”*

### OBTAINING ASSISTANCE WITH THE ESA50 FORM

Only seven claimants did not feel that some help with the ESA50 had been necessary or desirable. Two had been helped by carers who were comfortable completing the form.

*“Wanted face to face help but didn’t get it. Used Benefits Guides off Internet, but still found them very very long and confusing.”*

However in most cases (n= 22) a clear wish for further help was expressed by the claimant and/or

*“I can only talk for 15 minutes a day which makes accessing advice from the standard organisations e.g. CAB, even where they are prepared to make a home visit, impossible.”*

carer. Most had been able to access some form of help, from a variety of sources.

However this was not always the level or type of assistance that was required and some could access no help at all.

\* Five respondents could not recall exactly how long they had been given to complete and return the form.

\*\* Broadly speaking, the advice obtained was that no extensions are formally given, but if there is reason why the form cannot be completed within the time specified then one should (i) specify these in the ‘why this form is late’ section; (ii) inform Atos / the DWP – a note can be put on the system to the effect that the form is to be expected and likely timeframe; and (iii) take no more than an extra two weeks without further approach to the assessing authority.

## Question Area 4 – Obtaining Evidence

We asked members if they had attempted to obtain medical evidence to support their ESA claim. Eighteen said that they had; nine had not (four did not respond).

Medical evidence was not always readily available. Several of those who had not attempted to obtain medical evidence had been deterred from the effort because their experience of their doctor suggested that the doctor did not appreciate how debilitated they were and would not support. Several others, who had taken steps to submit medical evidence, had found that their best source was a private practitioner. Further barriers could take the form

*"I asked my GP to prepare a report to accompany my ESA form, but it took me 3 weeks to complete the form; allowing for time to post it and for it to get back to Atos, there just wasn't time for my GP to prepare a detailed report, he just had time to do a short covering letter."*

of a charge for this service, and time constraints. Regarding the latter, claimants may not appreciate that medical evidence can be submitted subsequent to submission of their ESA50, and that if Atos / the DWP are informed of this then they may well hold off making a decision until the expected medical evidence arrives. The attempt therefore was to obtain evidence within the very tight timeframe for sending back the

questionnaire, which was found to be a stressful and unsatisfactory timescale.

Most of those who had taken steps to obtain / submit medical evidence (n=10) found that it was supportive, although it was not always fully taken into account in decision making. Three found it of limited value and the other five were unclear/ did not respond.

*"My OT provides helpful reports but they are generally ignored. A letter from my consultant takes 8 weeks to type and often arrives too late. My GP is reluctant to write letters and the surgery has recently introduced a charge for letters to support benefit applications."*

It should be noted that the DWP seldom, in our experience, approach a GP for evidence in connection with ESA assessments. And that when they do the form used [ESA113] provides little or no guidance on nor indication of the specific parameters on which ESA is assessed / awarded, making it quite possible for a GP to provide what they feel is a relevant and supportive report that nonetheless fails to state relevant facts about their patient that could help secure an appropriate award of ESA.

Another issue is that the GP may not know the patient's case very well, and the DWP will tend to disregard evidence provided in such cases. This is a significant barrier for many people with severe ME, as we know from previous member surveys that reluctance to make home visits to people with severe ME is common, and if the patient cannot get to the surgery – which is also common – then this effectively leaves them with no medical care whatsoever: not even basic monitoring and awareness of their condition.\*

*"I have moved somewhere new. They don't know me and, although the doctor supported my claim, she said that on the forms. I asked to be referred to someone who could support my level of health, but she did not know where to send me. I had several doctor's appointments, and saw a specialist. The whole thing cost the government a lot of unnecessary money."*

As well as being relevant to decision making, where a claimant is unable to travel and attend an assessment centre for face to face assessment GP support can be vital in having this accepted. (More on this below.)

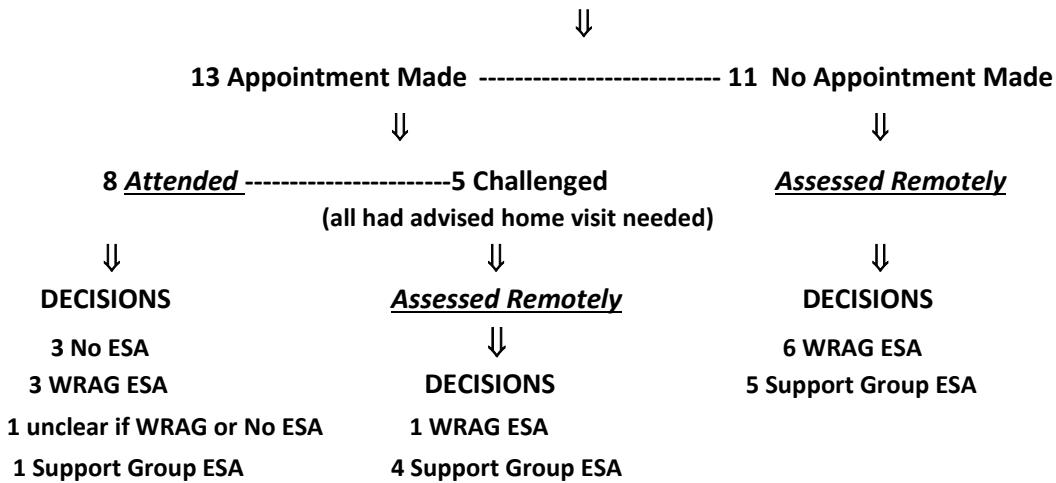
\* "Over half stated that they were completely unable to attend their GP's surgery (253 patients; 58%). Just over half of these patients (134 patients; 53%) never received a visit from their GP." REF: Report by 25% ME Group 'Severely Affected ME (myalgic encephalomyelitis) analysis report on questionnaire issued Jan 2004' (Mar 2004)

## Question Area 5 – Face to Face Assessment

A major issue for claimants with severe M.E. is that appointments for face to face assessment at an assessment centre can be generated once an ESA50 questionnaire has been submitted, even if the claimant has clearly stated that they are unable to travel. For many people with severe ME travelling to an assessment centre is quite impossible, and for those who may be able to manage ‘at a push’ with support to travel the after effects can be serious and long lasting.

Against this background we wanted to find out more about this part of the process. The experiences of 24 claimants\* with severe ME are summarised below:

### FACE TO FACE ASSESSMENT AT AN ASSESSMENT CENTRE?



Testimony from a medic was often the key to having the inability to travel for assessment accepted – though in some cases this had had to be submitted repeatedly before it was taken on board.

A home visit for face to face assessment had not taken place in any of these cases. Where it was accepted that a person could not reasonably be expected to travel to an assessment centre the consistent tendency was to have the relevant form completed remotely, by a practitioner who had never met the patient.

For the eight who attended an assessment centre, often with a huge struggle, the outcome was mostly bleak. Only one had been placed in the Support Group, and all of those who were awarded no ESA at all had attended an assessment centre for face to face assessment. A substantial proportion of these initial decisions were subsequently changed on reconsideration / appeal. (All but one challenged the decision and at time of feedback only one decision had been upheld.)

We also asked about what type of healthcare professional had completed the assessment. With so many assessments taking place remotely, quite a substantial proportion were unable to advise on this (11 of 24). Of the twelve who could answer this, only one had been assessed by a doctor. This is notable, given that the Government’s contract with Atos Healthcare requires that doctors are used to assess claimants with conditions that are likely to have complex central nervous system findings.

*“I was assessed by a doctor at an assessment centre. I was not aware that I could have an assessment at home. Attending the assessment caused me pain and fatigue. I was placed in the WRAG. I do not agree that this is the correct decision, but I didn’t challenge it as this would have been too tiring and made me more ill.”*

\* One questionnaire was unclear on the matter of face to face assessment.

## Question Area 6 – Decisions, Challenges & Outcomes

An overview of initial decisions, claimant challenges, and final decisions is presented in chart form on page 3. Summary figures are as follows:

- Initial Decision: 10 Support Group ESA (SG); 10 Work Related Activity Group ESA (WRAG); 3 No ESA; in 2 cases the specific decision was unclear but unsatisfactory [total n=25].
- Response to Decision: None of those awarded ESA in the WRAG or denied ESA altogether agreed with the decision made. All but one had requested reconsideration or lodged an appeal.
- Outcomes: Four decisions had been changed on reconsideration by the DWP decision maker; 3 decisions changed at Appeal Tribunal; 2 decisions were upheld; 5 cases pending. All changes of decision were in the claimant's favour.
- Resulting Awards of ESA: 13 Support Group: 5 WRAG; 5 Cases pending.

*"I found the process of being turned down, and the people I spoke to very demoralising. Detrimental to my health as I feared losing my house. I was living beyond my financial means until, thankfully, the decision was overturned at tribunal. I went to CAB who sent me to the Law Centre. My experience of them was OK but not great. I was told to attend the tribunal. On the day they rang and said I did not have to go in. They had decided on the basis of the paperwork."*

*Five weeks later I am still getting over the appeal process. I have been awarded basic ESA [i.e. WRAG]. Won't appeal this as too worried about losing it.*

*"I went to Welfare Rights. It was a long and tiring journey and experience. They were quite helpful. When I told her I wanted to appeal to be in Support Group she wasn't sure I should. She did say that all ME patients she knew were in WRAG and that some of the doctors didn't believe in ME at all. I did say it wasn't an opinion. She said that it was some Drs' opinion that it didn't exist & government would want to believe this." (Outcome: Decision changed on review by decision maker)*

### Placement in the WRAG and Work Focussed Interviews

Claimants who are placed in the Work Related Activity Group (WRAG) can be obliged to participate in 'Work Related Activity' as a condition of receipt of ESA, regardless of whether or not they are appealing the decision that they are fit to do so. We were previously aware this is an issue for many members, who receive an initial decision of WRAG despite severe ill health and grave debility, and we wanted to find out more about this.

Nine respondents placed in the WRAG disputed this decision. All but one had received an appointment to attend the Job Centre for a work related interview. However only one had actually managed to attend. The others had contacted the Job Centre, or had someone else make contact on their behalf, resulting in telephone interviews being arranged and/or discretionary power to defer the interview being applied. However it was not always straightforward to achieve this: reactions from Job Centre staff were

*"The first appointment was deferred for 3 months then a 2<sup>nd</sup> appointment sent. I ended up with one phone interview and adviser decided not to give me any more because of my illness and problems."*

*"A telephone interview was permitted but she informed me this would be 'one-off' so in future I would be expected to attend."*

mixed - some experienced a considerable amount of pressure to participate while others found significant understanding of their difficulties.

## OVERVIEW OF ASSESSMENT: THREE ILLUSTRATIVE EXPERIENCES

### (1) Support Group without face to face assessment

*"I am severely affected and have been for many years. In January I was contacted by the DWP to inform me that I was being reassessed for ESA. I returned the questionnaire in early March having struggled with it for a month. I had a phone call from the DWP to tell me I will be transferred onto the ESA in May and have been put into the Support Group. My next review date is set for 3 years. I was told that I had included enough detail for them to make a decision without me having to attend a face to face assessment.*

*I am very much relieved, as I have had this hanging over me since January. Whether it was because I included a copy of my Care Plan showing the help I receive in my home through social services and also typed out a 2 page snapshot of my day and how I'm affected (which took so much out of me having to do this); plus my GP's report, I don't know. I know there are so many going through hell and being declared 'fit for work' when they are anything but fit.*

*I would not have had to attach a 2 page letter to the form if the form had covered my difficulties – there is no emphasis on stamina; the inability to do tasks repeatedly and the worsening of symptoms due to sustaining a level of activity. I felt the whole experience took so much out of me both physically and mentally.*

*Of course anyone who is claiming a sickness benefit should be assessed but it should be a fair and just assessment, not one designed to exclude as many genuinely sick people from being eligible. You should not have to hope that your ESA form will fall into the hands of someone with a bit of common sense and understanding – that should be the norm. It is hard enough just getting through each day with this lousy illness without having had this terrible added burden as well."*

### (2) WRAG decision on appeal hearing

WRAG ESA in this case was a first award after many applications, secured after a long period awaiting appeal against refusal of benefit. They were not a new patient, having been ill since 1999. The feedback questionnaire was completed on their behalf by a carer.

*"Awarded ESA after 12 years + 6 mths. First award of many applications.*

*Two years ago I was awarded 6 points. The Atos rep did not listen to anything I had to say; copy of decision bore no resemblance to myself and included a number of untruths.*

*I didn't know that I could ask for an extension for the ESA50 form. I submitted a completed form, but late. However two days before the ESA50 was due back decision made, failed ESA claim (due to form late) and enclosed P45. I would have liked assistance with the form but had no access to this.*

*I applied for a home assessment for my appeal. This request was turned down. I was awarded a taxi to appeal. Amazed we got there (myself and partner). Five weeks later I am still getting over the appeal process. I have been awarded basic ESA [i.e. WRAG]. Won't appeal this as too worried about losing it.*

*Only after 12 years was I able to get evidence – persistent virus infections, at least ten years, inflammation, MRI etc.*

*I've now applied for DLA again, and presently having difficulty completing the application. I was last turned down because I'd been turned down for ESA!"*

### (3) WRAG following remote assessment; reconsideration requested; outcome pending.

Response from carer:

*"I am so glad to be able to share this information with you as it is making me ill. Every time I read the medical report I cannot believe what I am reading. It is quite disgusting that some Registered Nurse can write about someone, so ill, in this manner. (Report completed without a face to face assessment. WRAG decision.)*

*Fortunately our GP is very supportive and finds the situation as ludicrous as I do.*

*A is too ill to be told about any of this and I, as his mother / carer who has cared for him 24/7 bedbound for now 18 years without problems, has been made ill by this and have had to consult GP with stress / anxiety / chest pains and put on medication."*

## **Post Script: Reassessment**

Two respondents had experienced a further assessment, with their initial award of ESA reviewed after a relatively short time. One reported:

*"Was changed to ESA nearly a year ago and wrongly placed in the WRAG. Asked them to reconsider and place me in the Support Group. Reconsideration unsuccessful. Just returned my 2<sup>nd</sup> ESA50 questionnaire, hoping to be placed in Support Group, but doubt it."*

The other person had faced multiple problems. These had compounded one another and yielded poor decision making and considerable distress. Overall this case provides a very clear illustration of how problematic the ESA assessment process can be for a sick person when unable to access help and advice:

*"I am mainly bedbound, and I am noise sensitive. This will be the 3<sup>rd</sup> questionnaire. I have been assessed twice for ESA before. I was refused both times.*

*I submitted an incomplete ESA50 form because I didn't have time to complete it fully. I required assistance to complete the form but I was denied due to staff shortages from both the CAB and my two O.T.s. My sister helped me.*

*I was assessed at an assessment centre. I travelled an 80 mile round trip. I was treated with disrespect because I had managed to travel that distance. Both times I was refused ESA.*

*When I got the wrong decision I went to CAB for help. This was a 40 mile round trip. I was given the same attitude from them. The woman challenged that I was ill due to my 'tidy appearance'. She eventually agreed to represent me and appealed on my behalf. I was then awarded ESA in the WRAG.*

*I now have only a few days left to post my 3<sup>rd</sup> ESA50 form. My doctor's surgery is eight miles away. My family have been there to collect my medical evidence but still waiting. I will have to post the form without evidence."*