



Time for Action on the Work Capability Assessment



September 2012



Foreword

Myalgic Encephalomyelitis (M.E.) or Chronic Fatigue Syndrome (CFS), as it is often called by the medical profession, is a chronic disabling condition that affects 250,000 people in the UK

Earlier this year, Action for M.E. published *Ignorance, injustice and neglect: an investigation into NHS specialist service provision for people with M.E./CFS*, a damning report which used the NHS's own statistics to expose its neglect of this patient group.

This new report focuses on another crucial factor that seriously affects the quality of life of people with M.E., the Work Capability Assessment. It provides evidence that people disabled by M.E. are either not getting the welfare support to which they are entitled, or are at constant risk of losing their benefits.

The Department of Work and Pensions claims to have made big improvements to the assessment procedures and that the concerns of people with M.E. and other fluctuating conditions identified prior to, and again in response to, Prof Malcolm Harrington's *Independent review of the Work Capability Assessment* are being addressed.

However, Parliamentarians of all parties continue to hear from people with M.E. experiencing the same or similar problems. This is backed up by this report, which recounts the experiences of 461 people with M.E. who applied for Employment and Support Allowance during the 12 month period from June 2011 to May 2012.

This report, and Action for M.E.'s important Time for Action campaign, must not be ignored. I ask that all my fellow Peers, MPs and Ministers take urgent action to ensure that the failings of the existing Work Capability Assessment are addressed with immediate effect, to help end the injustice, neglect and ignorance faced by people with M.E.



Countess of Mar
Chair of Forward M.E.
Vice Chair of All-Party Group on M.E.

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About M.E.

M.E. (Myalgic Encephalomyelitis) is a chronic, fluctuating illness, also known as Chronic Fatigue Syndrome (CFS) and sometimes diagnosed as Post Viral Fatigue Syndrome (PVFS). It affects more than 250,000 men, women and children in the UK.

Common symptoms include persistent exhaustion, un-refreshing sleep, poor concentration and memory, headache, muscle pain and digestive problems.

It is of crucial relevance to this submission that this illness fluctuates over time, and that its characteristic symptoms are ones which the Department of Work and Pensions (DWP) do not routinely recognise.

Patient surveys indicate that up to 25% of people with the illness are so severely affected that they are unable to leave their homes or beds, some for many years. M.E. can affect anyone, at any age and from any ethnic group.

About Action for M.E.

Action for M.E. is the UK's leading charity dedicated to improving the lives of people with M.E. We have been at the forefront of the campaign for more research, better treatments and services since 1987. We provide information and support to people affected by M.E. and their carers.

Aims and introduction

The aim of this research is to carry out an empirically grounded study of people's experience of the Work Capability Assessment (WCA) during the 12 month period from June 2011 to May 2012.

From 27 October 2008 Employment and Support Allowance (ESA) replaced Incapacity Benefit (IB) for new claimants who cannot work due to their sickness or disability. The WCA is the test used to assess whether someone is eligible for ESA. It involves filling in the ESA50 form and attending a face-to-face medical (see Appendix 2).

Prof Malcolm Harrington, occupational health specialist and Professor Emeritus of Occupational Health at the University of Birmingham, carried out independent reviews of the WCA in 2010 and 2011.

In his second review, Prof Harrington¹ pointed out "fluctuating conditions descriptors" should be used to assess people with long-term conditions, such as M.E., in order to avoid a "snapshot" assessment.

People with M.E. suffer from debilitating physical and/or cognitive symptoms that fluctuate over time which cannot be easily assessed in a 40 minute face-to-face meeting.

However, the Department for Work and Pensions (DWP) has not identified a 'fluctuating condition.' There is neither an agreed medical definition nor a list of what constitutes such a condition.²

In its response to Prof Harrington's second review³, the DWP said, "Prof Harrington set up a similar group to assess whether there were specific improvements to the descriptors for individuals with fluctuating conditions. This group included representation from a number of disability groups [...] We will consider his recommendations carefully and respond in due course."

¹ Harrington, M., Nov 2011, *An independent review of the Work Capability Assessment: year two*, p 33

² MS Society, Arthritis Care, Parkinsons UK et al., Apr 2011, *Employment and Support Allowance Work Capability Assessment review: making it work for fluctuating conditions*, p 16

³ Secretary of State for Work and Pensions, Nov 2011, *Government's response to Professor Malcolm Harrington's second independent review of the Work Capability Assessment (Cm8229)*, p 12

In the House of Commons Stephen Timms MP asked about (a) new mental health descriptors and (b) new fluctuating conditions descriptors in the WCA. In a written answer⁴ on 24 May 2012, Chris Grayling, Secretary of State for Work and Pensions, said: "*We have been working to develop proposals for the evidence-based review since the publication of Prof Harrington's second independent review of the WCA.*"

"Departmental officials have been considering the best way to evaluate the proposed descriptors, and have been and continue to discuss these with the charities. Our aim is to carry out the evidence-based review for both the mental, intellectual and cognitive descriptors and the fluctuating conditions descriptors which have been proposed by the charities at the same time."

However, there has been no visible change so far for people with fluctuating conditions.

In 2010, 203 people who had been through the WCA process responded to an online consultation by Action for M.E. Respondents were given the opportunity to state their views on some of the commonly stated opinions of people with M.E. in relation to the benefits system, and these statements were found to be very widely supported as follows:

- More than 95% of respondents felt that people with genuine health problems such as M.E. are not believed in the current system.
- 97% felt that the current system excludes the most vulnerable (from support) by intentionally placing too many barriers before those who already face significant challenges.
- More than 98% of respondents felt that M.E. is not understood within the current benefits system.⁵

These findings illustrated a lack of confidence in the benefits system by just those people it is intended to help. Two years on, Action for M.E. continues to receive emails, letters and telephone calls from people with M.E. expressing their frustration and anxieties about their experience of WCA.

The charity therefore decided to investigate whether the WCA process has been improved or not by conducting another survey in May 2012, designed to gather contemporary evidence to submit to the third annual independent review conducted for the Government by Prof Harrington.

⁴ www.publications.parliament.uk/pa/cm201213/cmhansrd/cm120524/text/120524w0001.htm#12052476000248

⁵ Action for M.E., Nov 2010, *The Work Capability Assessment: a call for evidence. Action for M.E. consultation report*

The aim of the survey was to investigate how people with M.E. experienced the WCA, including:

- how easy or difficult they found the application process
- whether they think the WCA report reflects their answers properly
- how they feel about the result of the assessment
- whether things have improved, as the Government claims, since 2010 and Professor Harrington's two reviews
- what things could be done to improve the system for people with M.E.

In addition, Action for M.E. has conducted in-depth interviews with several people with M.E. to use as case studies. This report combines the survey results and the case studies in order to provide an accurate real-life picture of people with M.E.

Timing of this report is pertinent as Prof Harrington is collecting evidence⁶ for his third independent review to present to Parliament before the end of 2012.

He is particularly interested in seeing evidence of implementation of his year two recommendations⁷ and any changes claimants are experiencing in communications, face-to-face assessments and decision-making.

⁶ DWP, Jul 2012, *The Work Capability Assessment, a call for evidence: year three independent review*, p 83

⁷ Harrington, M., Nov 2011, *An independent review of the Work Capability Assessment: year two.*

Executive summary

In 2010, 203 people responded to Action for M.E.'s survey on ESA and WCA. This formed the basis of our response⁸ to Prof Harrington's year one call for evidence, in which we highlighted many concerns about the suitability of the WCA for assessing those with fluctuating conditions such as M.E.

Two years on, respondents to Action for M.E.'s latest consultation – all of whom had applied for ESA **within the past year (June 2011 to May 2012)** – raise concerns which will be familiar to anyone who has read our 2010 report.

Our main findings

The main findings of our consultation, from which we have analysed the responses of 461 people plus 10 case studies (written following in-depth interviews with 10 people with M.E.) are:

- 80% (329 people) of those responding said the ESA application form was difficult or very difficult to complete
- 90.2% of respondents (358 people) said the process had caused stress and anxiety that had made their condition worse
- more than a third of those responding (36.3%; 149 people) were not able to supply supporting evidence from a healthcare professional of their choice
- almost two thirds (63.7%; 261 people) of those who did obtain supporting documents were charged between £15 and £90 for them
- respondents felt their supporting evidence was ignored
- fewer than a third of respondents (28.7%; 71 people) thought the Atos healthcare professional asked about all the symptoms/aspects of their condition that affected their ability to work
- only 13.4% (33 people) thought the Atos healthcare professional understood their condition
- more than two thirds of respondents (68.6 %; 166 people) disagreed or strongly disagreed that the Atos healthcare professional took into account how their condition fluctuated
- fewer than a third of respondents (33.9%; 82 people) thought they were treated as an individual
- almost two thirds (60.3%; 146 people) felt the Atos healthcare professional had not taken time to communicate effectively with them
- fewer than one in five respondents (19%; 46 people) thought the assessment was long enough for the healthcare professional to learn about all the symptoms that affected their capability to work

⁸ Action for M.E., Nov 2010, *The work capability assessment: a call for evidence. Action for M.E. consultation report*

- only just more than a third of respondents (35.1%; 85 people) felt they were given all the information they needed about the assessment
- almost half of respondents (48.8%; 118 people) were not given an opportunity to see a copy of the report from their face-to-face assessment
- of those respondents who did see a copy of the report from their face-to-face assessment, 82.1% (87 people) said it was not an accurate reflection of the answers they gave
- fewer than a third of respondents (29.7%; 97 people) agreed with the outcome of their application for ESA
- only 11 of the 149 (7.4%) respondents placed in the Work-Related Activity Group following their assessment felt it was the right place for them
- many respondents said the support they were offered in the Work-Related Activity Group was 'pointless' and 'ineffective' and that the group advisors agreed that it was the wrong place for people with M.E.
- most people we contacted said they had received no communication or explanation from the DWP about how it came to its decision, even after they contacted it to specifically ask for this information
- more than half of our respondents (55.3 %; 182 people) said they had already appealed or were planning to appeal against the DWP's decision
- nearly half of those who knew the results of their appeal (43%; 34 people) had been moved to the Support Group.

Conclusions and recommendations

Our report concludes that:

- those applying for ESA should be clearly advised to present additional evidence in support of their claim and this should be given due consideration during the decision-making process
- the ESA application form needs to be made easier and simpler to complete by consulting with disability organisations
- all face-to-face interviewees should be automatically given a copy of the Atos medical report
- more efficient communication is needed between the DWP and Atos
- Atos healthcare professionals who carry out the face-to-face assessment should receive specialist training about fluctuating conditions, developed in consultation with organisations that support people with M.E. Training needs be as frequent as the staff turnover at Atos requires
- the WCA should incorporate an individual's fitness, history and needs
- the DWP should keep people regularly informed of the progress of their claim and/or appeal using the preferred method of communication indicated by the claimant
- the DWP should develop support offered to those in the Work-Related Activity Group so that people with fluctuating conditions have more suitable options.

Method

This report combined two research methods: quantitative for the survey and qualitative for the case studies.

The survey which was available to complete online and in hard copy, either in Action for M.E.'s membership magazine *InterAction* or by request.

Of the 489 people who had applied for ESA within the past year (June 2011 to May 2012) began the survey, 408 people (83.4%) completed it.

For the case studies, Action for M.E. interviewed 10 people with M.E. Due to the unpredictable nature of M.E., it was difficult to plan face-to-face meetings so interviews were conducted by telephone and email.

Background and 2010 survey

In 2010, 203 people responded to Action for M.E.'s survey on ESA and WCA. The resulting report⁹ reflected their concerns about:

- inadequate opportunity to reflect the impact of fluctuating symptoms
- Atos assessors and DWP decision makers' reluctance to accept evidence provided by GPs and/or consultants
- skepticism about M.E. among Atos assessors and DWP decision makers
- the DWP's assumption that all claimants are fraudsters until proven otherwise
- insufficient understanding among Atos assessors and DWP decision makers of M.E. and the barriers to work it presents
- unrealistic expectations of claimants with M.E. to find and sustain work.

More than 98% of respondents were concerned that M.E. was not understood within the current benefits system and 97% of respondents felt there were too many barriers in the system for people who already face significant challenges such as M.E.

Two years on, respondents to Action for M.E.'s latest survey raise concerns which are familiar to those who read the charity's response to Prof Harrington's year one review. In particular, it is apparent that each wave of welfare reform appears to hit the most vulnerable members of society even more disproportionately.

The rationale behind the WCA is not as clearly explained as the Government claims. In a letter to Neil Parish MP (see Appendix 3), Chris Grayling, Secretary of State for Work and Pensions, says that the function of the WCA is to "ensure that

⁹ Action for M.E., Nov 2010, *The work capability assessment: a call for evidence. Action for M.E. consultation report*

people receive the most appropriate support and are able, where feasible, to move towards suitable employment.”

However, Action for M.E. has repeatedly reported that the WCA is failing. Back-to-work support is inadequate for the complex needs of people with M.E., potentially leaving people facing poverty as they are found ineligible for benefits and yet cannot overcome the barriers they face to gaining employment.

The timing of this report is critical. Not only are thousands of disabled people dealing with IB reform and subsequently the WCA, but Disability Living Allowance will also be replaced by Personal Independence Payment for working-age disabled people¹⁰ and Universal Credit will replace several other benefits¹¹ from April 2013. Given the many changes to the benefit system, it is essential for the Government to demonstrate that they are working fairly – but the evidence we have gathered tells us otherwise.

In this report, Action for M.E. will reveal the remaining flaws of the current WCA, as illustrated by the experiences of people with M.E. who have undertaken the assessment in the past year. We will also make recommendations for the steps which still need to be taken in order to ensure that new descriptors will be fairly and effectively applied during the assessment and decision making process.

¹⁰ <http://www.dwp.gov.uk/policy/disability/personal-independence-payment/#wpi>

¹¹ <http://www.dwp.gov.uk/policy/welfare-reform/universal-credit/latest-on-universal-credit>

Results of Action for M.E.'s 2012 survey

Although 489 people took part in the survey, we only collected answers from the 461 people (94.3%) who had applied for ESA within the past year (June 2011 to May 2012).

We asked if respondents had been migrated onto ESA from IB, a process the Government began in 2008 (see Appendix 2). Of the 417 people who answered this question, 52.3% (218 people) said yes.

A Supporting Member of Action for M.E. who has not applied for ESA told us why: *"It took quite some time to diagnose M.E. but when that happened, I was told by the hospital occupational health doc[tor] and my GP that there was no use in me applying for ESA as due to fluctuations in this condition it was very unlikely that I would get anything."*

People with M.E.'s state of health

Our survey asked: "Which of the following best describes your state of health over the past six months?"

As you can see from the table below, of the 443 people that answered this question, 74.9% said they were moderately affected. However, many said it was hard to summarise their condition, since it fluctuates, and their true state of health is between moderately and severely affected.

	Response percent	Response count
Mildly affected: you are mobile, can care for yourself and can do light domestic tasks with difficulty. If still working or in education, you have had to stop all leisure and social pursuits, and often take days off.	10.6%	47
Moderately affected: you have reduced mobility and are restricted in all activities of daily living, although you may have peaks and troughs in your level of symptoms and ability to do activities. You have stopped work or education and need rest periods. Your sleep at night is of generally poor quality and disturbed.	74.9%	332
Severely affected: you are unable to do any activity for yourself, or can carry out minimal daily tasks only (such as face washing, cleaning teeth). You have severe cognitive difficulties and depend on a wheelchair for mobility. You are often unable to leave the house, or have a severe and prolonged after-effect if you do so. You may also spend most of your time in bed, and may be extremely sensitive to light and noise.	14.4%	64

Our survey asked: "Which of the following symptoms, if any, present a barrier to you being able to work?"

Of the 441 people that answered this question, almost everyone (99.3%; 438 people) identified fatigue/exhaustion as the biggest barrier. However, other symptoms represent multiple barriers to work such as:

- difficulty concentrating (93.4%; 412 people)
- pain (82.8%; 365 people)
- memory problems (81%; 357 people)
- malaise, ie. having 'flu-like symptoms (79.8%; 352 people)
- speech/communication problems (47.8%; 211 people)

Furthermore, 189 people said they experienced other symptoms including:

- hypersensitivity towards light and noise
- blackouts
- dizziness
- anxiety and depression
- muscular spasms
- blurred vision

A case study from Brighton said: *"Most people are familiar with the general symptoms [of M.E.], such as muscle pain and chronic fatigue. I want to emphasise that there are more subgroups of pain. For example, I cannot talk due to the muscle pain in my throat when it is cold, and I am very sensitive to high-pitched sound. It is vital for specialists, doctors and politicians to understand the various symptoms instead of generalising [the symptoms of] people with M.E."*

Completing the ESA50 application form

Our survey asked: "How easy did you find the ESA application form to complete?" Of the 411 people that answered the question, 80% (329 people) said it was very difficult or difficult to complete the application form

One of the survey respondents commented: *"The migration process from IB to ESA is naturally stressful for someone like me who is quite unable to deal with the long form, so I had no choice but to hand the whole thing over to my partner. It's just as well that my partner is largely able to deal with such things. And doubtless, such long forms/processes prove almost impossible for some people who have no assistance at all. There is almost certainly a significant drop-out rate caused by such a thing, and that in its own right cannot be correct."*

The unnecessarily complex form itself is putting off people who would otherwise apply for ESA. It should be made easier to understand and complete.

Providing supporting medical evidence

Our survey asked: "Were you able to supply information from a healthcare professional of your choice (eg. your GP) to support your application?"

Of the 410 people who answered this question, more than a third (36.3%; 149 people) said no. Many of the 261 people (63.7%) who obtained supporting documents said they were charged between £15 and £90 pounds for them, a significant amount of money for people on benefits.

Moreover, a number of people said they thought that their supporting evidence was disregarded by the DWP.

One respondent who was put in the Work-Related Activity Group for ESA (see Appendix 2) commented: *"As part of the appeal submission, I went to see the GP who provided a good letter, pointing out my many years of ill's and ailments (a large raft of them) and I included this with the appeal paper, along with a statement that I could not mobilize more than 50 metres without stopping with discomfort, and that I could certainly not repeat such an activity.*

"This should be enough to enable a person to be granted the Support Group. But another letter came back stating that the decision remained unchanged as 'there was no evidence' to the contrary. This is quite remarkable in the light of the GP's letter and one's qualification under the terms of the actual system in place."

One of our case studies based in Bristol received a letter (see Appendix 4) from Jobcentre Plus, regarding his unsuccessful application and subsequent appeal for ESA. It says: *"An opinion from a person's GP that he remains incapable of his work is not relevant to the determination of ESA with regard to the Limited Capability for Work assessment, which relies on the award of points."*

Action for M.E. emphatically disagrees that the opinion of a GP or other healthcare professional who knows and has been treating the patient for some time is not relevant when it comes to a decision about whether that patient is capable for work.

We strongly recommend that the DWP take such evidence into consideration, particularly in the light of Prof Harrington's year two review,¹² which criticised DWP decision makers for not taking into account medical evidence supplied by claimants' own GPs or healthcare professional.

¹² Harrington, M., Nov 2011, *An independent review of the Work Capability Assessment: year two*, p 33

Experience of the face-to-face assessment

The WCA is the test used to assess whether someone is eligible for ESA. It involves filling in the ESA50 form and attending a face-to-face assessment which explores their ability to work and carry out day-to-day activity.

Of the 413 survey respondents who answered the question on whether they had invited to or already attended a face-to-face assessment:

- 248 (60%) had already attended
- 125 (30.3%) had not been invited to attend
- 26 (6.3%) said they are invited at a date in the future.

We asked those who had already attended an assessment about the process and the attitude of the healthcare professionals from Atos Healthcare, the company contracted by the DWP to carry out the face-to-face assessment.

Our survey asked respondents to what extent they agreed with the statement: "The healthcare professional asked about all the symptoms/aspects of my condition that affects my ability to work."

Of the 247 people that answered this question, only 28.7% (71) agreed or strongly agreed.

One respondent, based in Glasgow, commented: *"The WCA seems to bear little relation to capability to work, focusing only on simple bodily movements, serious mental health difficulties and feeding and dressing yourself. No credence at all was given to the fact that, while I can move, repetition of any action soon becomes impossible; nor of the obvious fact that you have to feed, wash, dress yourself, travel and probably manage your house as well as working. For me those basics of life use all of my available energy."*

Our survey asked respondents to what extent they agreed with the statement: "The healthcare professional understood my condition."

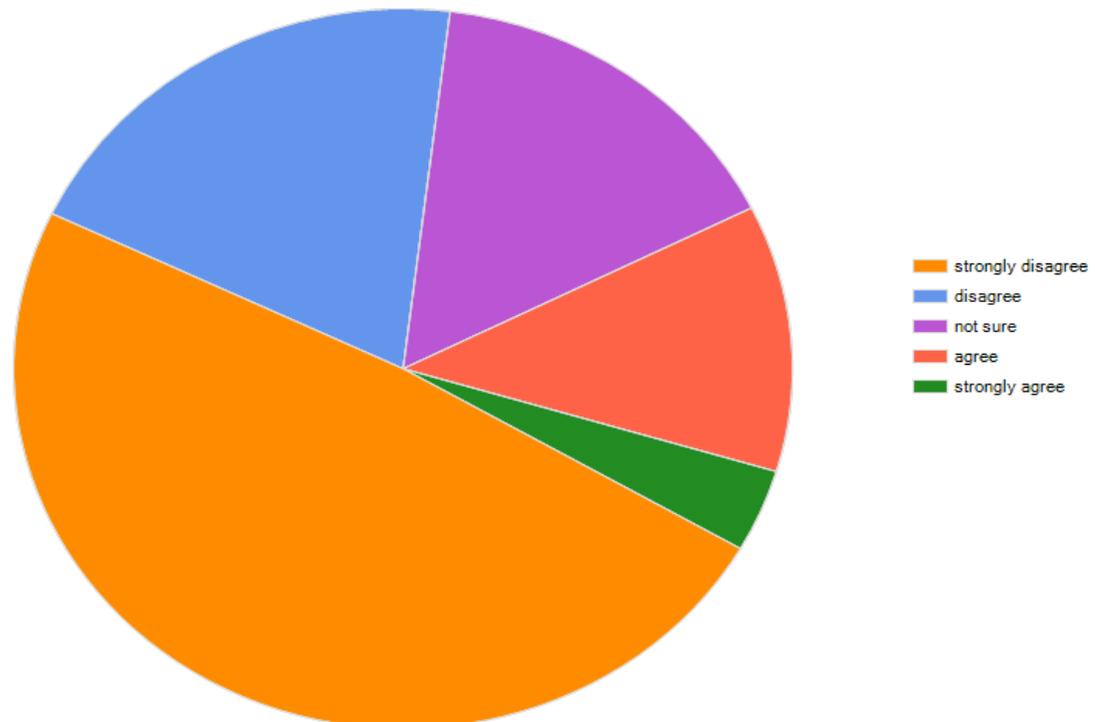
Of the 247 people that answered this question, 13.4% (33) said they agreed or strongly agreed.

One respondent, based in Somerset, commented: *"Some questions seemed ludicrous: I can spell 'world' backwards, I am a writer. And I can calculate change from a pound. The physical tests were meaningless. It is repetition, consistency and duration of activity that is relevant, not one lift of the arms. At the end of it she said, 'Well, I suppose you'll be wiped out for the rest of the day.' No - it will be months. I'm still recovering."*

Our survey asked respondents to what extent they agreed with the statement: "The healthcare professional took into account how my symptoms change/fluctuate."

Of the 242 people who answered the question, 68.6% (166) disagreed or strongly disagreed with this statement.

They took into account how my symptoms change/fluctuate (eg. how my symptoms affect me on a 'bad day' as well as a 'better day').



One respondent commented: " *Cognitive impairment has apparently been removed as a qualifying factor for medical points. I cannot phone or cope with Q&A in real time. Most of the time I have no voice. What do I need to say to them to get them to understand? I have told them the truth. What more is there?*"

Our survey asked respondents to what extent they agreed with the statement: "The healthcare professional treated me as an individual."

Of the 242 people that answered this question, only 33.9% (82) agreed or strongly agreed.

One respondent from Anglesey said, " *It's not tailored to individuals' problems. The one size fits all. There is no middle ground.*"

Our survey asked respondents to what extent they agreed with the statement: "The healthcare professional took the right amount of time to communicate effectively with me."

Of the 242 people that answered this question, 60.3% of them (146) disagreed or strongly disagreed.

A survey respondent from London said: *"The assessment itself took less than 20 minutes. The healthcare professional did not listen to me carefully and I was asked to do several irrelevant tests eg. eye sight tests, checking I could lift my arms (with M.E., it's the repetition and effect on energy of movement that is the problem, not the mobility of joints).*

"The healthcare professional did not talk much during the assessment. He just kept nodding and typing, which made me to think that I was not being assessed properly. He cut me short on many questions, did not allow me to finish sentences and moved on to the next before I'd had chance to fully think and answer him."

One of our case studies, also questioned awareness of M.E. among healthcare professionals employed by Atos: *"Compared to the Atos healthcare professionals, the GP who actually diagnosed my condition as M.E. and disability advisers were more understanding and familiar with M.E. I believe that the doctors from Atos could change through education from the Government. The Government needs to educate them the fluctuating character of M.E. and other neurological conditions."*

In a letter to Neil Parish MP (see Appendix 3), Chris Grayling, Secretary of State for Work and Pensions, says healthcare professionals employed by Atos *"receive training in accurately assessing fluctuating conditions and mental, intellectual and cognitive function."*

However, evidence from our survey suggest otherwise. Action for M.E. believes health professionals employed by Atos should be better informed about the fluctuating nature of M.E. and other neurological conditions.

Our survey asked respondents to what extent they agreed with the statement: "The assessment was long enough for the healthcare professional to learn about all the symptoms that affect my capability to work."

Of the 242 people who answered this question:

- 36.8% (89 people) strongly disagreed
- 25.2% (61 people) disagreed
- 19% (46 people) said they were not sure
- 14% (34 people) agreed
- 5% (12 people) strongly agreed

Our survey asked respondents to what extent they agreed with the statement: "The assessment was fully accessible and I was given all the information I needed in my preferred format."

Of the 242 people that answered this question:

- 23.1% (56 people) strongly disagreed
- 24% (58 people) disagreed
- 17.8% (43 people) said they were not sure
- 30.2% (73 people) agreed
- 5% (12 people) strongly agreed

Our survey asked if respondents were given the opportunity to see a copy of the report from their face-to-face assessment.

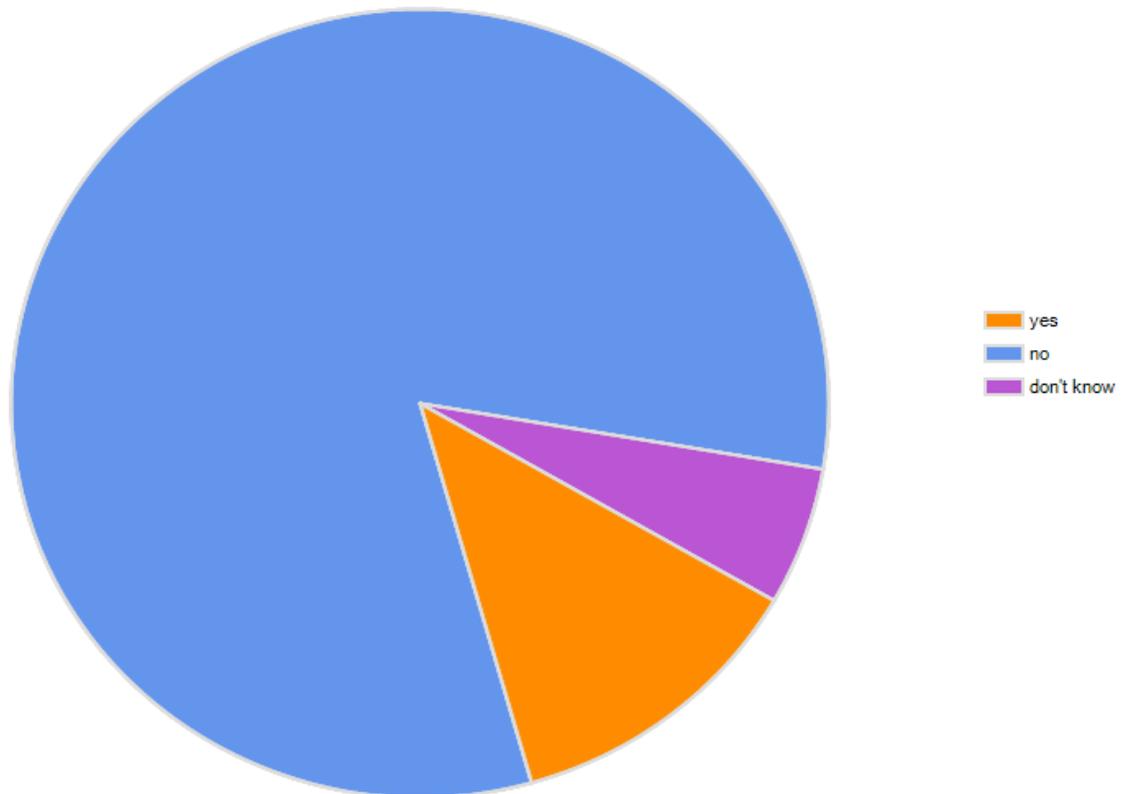
Of the 242 people that answered this question, almost half (48.8%; 118 people) said no.

Action for M.E. believes this inconsistency needs to be addressed with immediate attention. All applicants are entitled to see the copy of the report, but some only receive one if they request it.

Our survey asked if respondents felt that the report was an accurate reflection of the answers they gave in their face-to-face assessment.

Of the 106 people that answered this question, the majority of them (82.1%; 87 people) said no and only 12.3% (13 people) said yes.

Did you feel that the report was an accurate reflection of the answers you gave in your Work Capability Assessment?



One respondent from Glasgow said, *"The report was biased by omission. I did say everything they attributed to me, but the important points were missed out. For example, it simply said that I had done a course. I have, but only a maximum of two hours a week, and I still have to miss some weeks due to ill health. Similarly, I manage my housework, but only by resting in between activities and having complete flexibility as to when or whether I do anything. It was only stated that I do housework."*

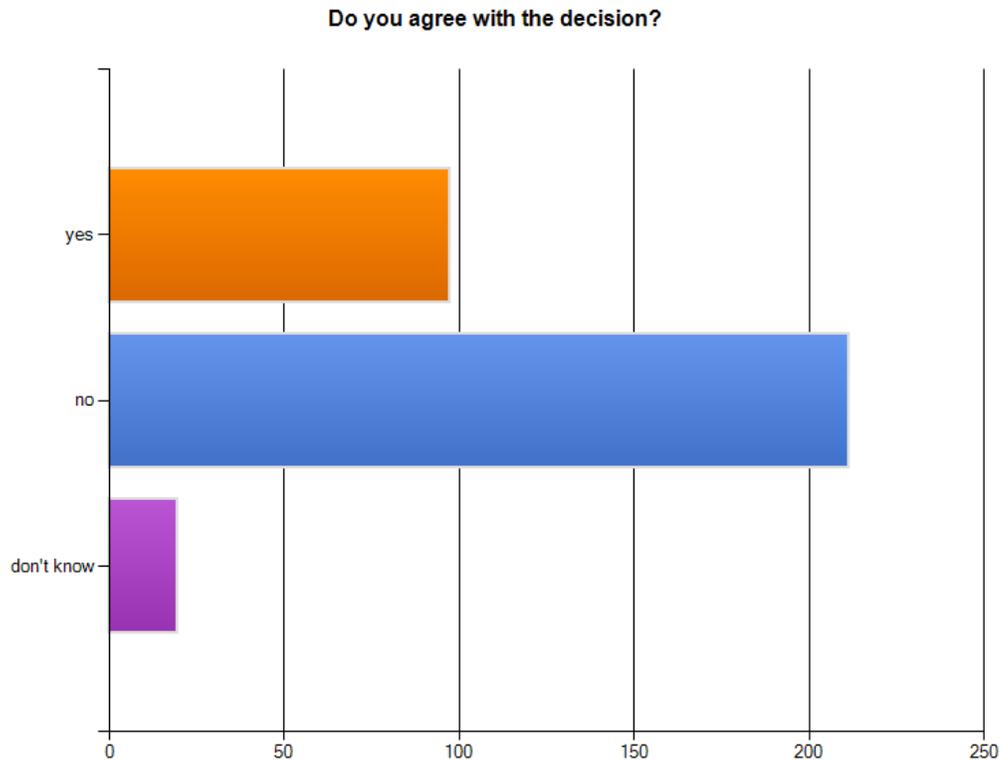
One of our case studies from Hampshire told us the assessment report simply said *"she looked tired."* This case study had explained to the assessor exactly what she had to go through living with M.E. and how her symptoms were fluctuating in nature. She said she believes that ticking boxes is not a suitable way to assess people with M.E.

Results of the WCA

Of the 380 people that answered the question "Have you had the results of your application for ESA?", 87.6% (333 people) said yes.

Our survey asked if respondents if they agreed with the decision.

Of the 327 people that answered this question, only 29.7% (97 people) said yes.



Our survey asked respondents which group they were placed in as a result of their WCA.

Of the 333 people that answered this question:

- 45% (150 people) were placed in the Work-Related Activity Group
- 31.2% (104 people) were denied ESA
- 17.7% (59 people) were placed in the Support Group.

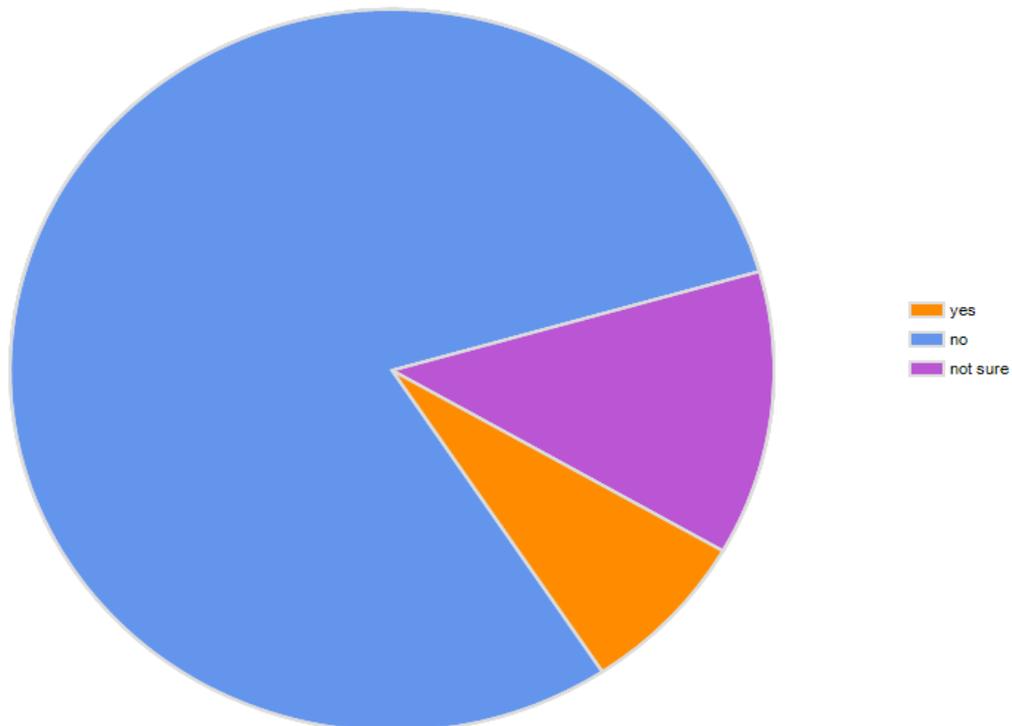
(See Appendix 2 for explanation of ESA groups.)

Our survey asked respondents who had been placed in the Work-Related Activity Group if they thought this was the right group for them.

Of the 149 people that answered this question:

- 7.4% (11 people) said yes
- 79.9% (119 people) said no
- 12.8% (19 people) said they weren't sure.

Did you think the Work-Related Activity Group was the right group for you?



Our survey asked respondents what support they have been offered in the Work-Related Activity Group.

We also asked them to comment on whether they found the support useful or relevant to them.

Many respondents said the support they were offered was pointless and ineffective and that the advisers who provide the support agree that people with M.E. are placed in the wrong group.

Some respondents said their work-focused interviews (which claimants are required to attend, though benefits advisers are given some discretion) were deferred and they were not expected to take part in further work-related activity as a result of this.

A survey respondent from Derbyshire said " *They couldn't even get me a voluntary post or unpaid placement. Even in large town/city 20 miles away they don't have a disability-specific Work Programme. It needs staffing by people who actually understand illness and their limitations, who know about the employment market in my area and can advise me as to what types of job I could do, that can cope with people who are capable of a little more than minimum wage working. I am a former senior finance professional, with lots of other high-level qualifications. Although I'm prepared to start again and do anything that I can do, they can't work out what I could do except my old job, which I can't do any more.*"

People with severe M.E.

Action for M.E. has serious concerns about the fairness of the assessment when it comes to assessing fluctuating conditions such as M.E.

Of the 64 respondents who said they were severely affected by M.E., 42 answered the question about which group they had been placed in. Of these 42 people:

- 38.1% (16 people) were placed in the Support Group
- 33.3% (14 people) were placed in the Work-Related Activity Group
- 19% (8 people) were told they were not eligible for ESA.

Severely affected means: you are unable to do any activity for yourself, or can carry out minimal daily tasks only (such as face washing, cleaning teeth). You have severe cognitive difficulties and depend on a wheelchair for mobility. You are often unable to leave the house, or have a severe and prolonged after-effect if you do so. You may also spend most of your time in bed, and may be extremely sensitive to light and noise.

A severely affected respondent from Kent, who was placed in the Support Group, commented: "*Even though I have been granted ESA, I do not know for how long that benefit is secure as there is no set date for re-application. In fact, I was re-applying for ESA this year because I was suddenly contacted and told that I needed to, even though I had only applied and been granted ESA (Support Group) in October 2010, about 18 months previously.*

"It's very unsettling to think that I may be contacted at any time to re-apply, not only because my benefit is in doubt again but also because the whole application process has been so draining and stressful and actually detrimental to my health in the past."

A severely affected respondent from West Yorkshire who was placed in the Work-Related Activity Group said, "*I was asked if I had seen a psychiatrist, so I presume that M.E. is still thought of as being 'all in the mind!'"*

One severely affected survey respondent from Warwickshire who was placed in the Work-Related Activity Group said: *"With regards to having to have a job-focused interview, it is very difficult to book and attend appointments. I was invited to attend an interview. I declined and explained that it would be better if they could give me an interview over the telephone. After a bit of wrangling they reluctantly agreed and we have since persuaded other members of our [local M.E. support] group that if this happens then to request the same. Some staff have been very good but others haven't."*

A severely affected respondent from Staffordshire who was told they were not eligible for ESA at all said: *"I have had two WCAs, despite being housebound and unable to care for myself. Both times I was declared fit for work. I won the first tribunal and was awarded ESA. The second WCA assessment was a year later. I have been on appeal for more than a year now awaiting a tribunal."*

Challenging the decision

The DWP's leaflet¹³ about ESA says claimants who don't agree with its decision can:

- *"ask us to explain our decision*
- *ask us to write to you with the reasons for our decision*
- *ask us to look at our decision again (you may think we have overlooked some facts or you may have more information to give us which affects our decision), or*
- *appeal against our decision to an independent tribunal (but you must do this in writing).*

"You, or someone else who has the authority to act on your behalf, can do any of these things, or you can do all of them"

However, most people that we contacted said that they received no communication or explanation from the DWP about how it came to its decision, even though they contacted the DWP specifically to ask them for this information.

One case study from London said: *"I want the Government to improve the whole process, which takes too long for people who need help. Staff at call centres need to be better informed, more empowered to answer questions; they need to work better between their own departments and Atos – they're clearly all working with little communication or connection."*

A case study from Brighton said: *"The DWP does not send out the result of their decisions. In order to find out whether I got the ESA, I had to keep ringing the*

¹³ DWP, Apr 2012, *Employment and Support Allowance: help if you're ill or disabled* (DWP015), p 10

DWP. How can you challenge a decision of the Government if you don't know the decision?"

Action for M.E. has found that some claimants are sent a copy of the WCA report without asking, while others must make a specific request. Claimants must also wait until the DWP has seen the report first¹⁴ and request it from them, rather than asking for a copy directly from Atos Healthcare.

Action for M.E. believes that every claimant be given a medical assessment should automatically be given a copy of the report without having to ask for it. We also recommend that it is sent to the claimant at the same time that it is sent to the DWP. Despite this being recommended in our first consultation report¹⁵ there has been no clear progress on this.

Our survey asked respondents if they would appeal or had already appealed the DWP's decision.

Of the 329 the people answered this question, 55.3% (182 people) said yes. We asked if they could tell us the reason why they will or have already appealed and 179 people answered this question:

- 57% (102 people) said it was because they were denied ESA
- 43% (77 people) said it was because they felt they were put in the wrong group.

When we asked about the result of their appeal (if known), 177 people answered the question:

- 55.4% (98 people) were still waiting for a decision
- 19.2% (34 people) were granted ESA in the Support Group
- 17.5% (31 people) were granted ESA in the Work-Related Activity Group
- 7.9% (14 people) were still denied the ESA.

Nearly half (43%; 34 people) of those who knew the result of their appeal had been moved into the Support Group, suggesting the initial computer-based assessments are neither efficient nor accurate. The DWP¹⁶ says that 45% of appeals against ESA decisions result in claimants being awarded ESA.

A survey respondent from Glasgow commented: *"I have mostly worked out for myself the best ways to manage my illness, with considerable success. I certainly didn't choose to spend the past 20 years ill. I have kept up to date with research, had intermittent contact with my GP and use aspects of CBT. However, I wanted*

¹⁴ Atos, frequently asked questions, www.atoshealthcare.com/claimants/faq

¹⁵ Action for M.E., Nov 2010, *The Work Capability Assessment: a call for evidence. Action for M.E. consultation report*, p 17

¹⁶ DWP, Jul 2012, *Employment and Support Allowance: outcomes of Work Capability Assessments, Great Britain – new claims (quarterly official statistics bulletin)*, p 2

to use my very limited energy to have the best quality of life I could, rather than a continuous round of doctors. Such independence went against me in the assessment, particularly at the appeal. The assessment is supposed to be judging my ability to work, not my compliance or outlook on life, or the decisions I have made, but that was how it felt I was being judged."

Further comments on the assessment

Action for M.E. is concerned that the ESA application process is detrimental to the health of people with M.E.

Our survey asked respondents if they agreed that applying for ESA and/or attending a WCA was stressful. Of the 397 people answered, 94.4% (375 people) agreed or strongly agreed.

A respondent from Somerset commented: *"When I got home I was exhausted, couldn't stop crying. The process does not inspire trust [...] it assumes I am dishonest, that my GP is not to be trusted. I worried about every answer. I am honest and tend to play down my problems, I forgot to mention a number of problems. The severe symptoms and very low mood lasted for months afterwards, and I am only now, June 2012, beginning to recover. Addressing it again for this [survey] brought it all back and I have been dizzy and trembling."*

Our survey asked respondents why the assessment process was stressful. The most common reasons given were:

- the WCA does not assess actual ability to work
- the healthcare professional conducting the face-to-face assessment does not understand fluctuating conditions such as M.E.

One survey respondent said: *"The assessment process was stressful because it is so spectacularly unrelated to assessing my actual ability to work. This was obvious at every stage. The assessors were polite enough, but their reports showed strong disbelief in what I said. I was telling the simple truth about my life, and the fact that, while greatly improved, I am not well enough to sustain working."*

One respondent from North Wales said: *"The assessment is done by a doctor who doesn't know you, where as your GP knows everything about your health."* Although letters from claimants' GPs are accepted in support of claims for ESA, many respondents thought the DWP do not make this sufficiently clear. The respondent from North Wales continues: *" They should request a supporting letter by your own GP and take note of the GPs' comments."*

Our survey asked respondents if the application process made their health worse because of stress/anxiety.

Of the 397 people that answered this question, 90.2% (358 people) agreed or strongly agreed.

One respondent who didn't tell us they were from said: *"My contribution-based Incapacity Benefit was stopped despite my struggling to produce clear letters explaining my true circumstances. They were all just ignored and more and more distressing demands were made for me to do something physically impossible."*

The one-month period in which claimants must make their appeal has been often pointed out by Action for M.E. members, survey respondents and case studies as being a source of stress.

The same respondent continued: *"I did express in writing my intention to appeal for reconsideration but got no response regarding that from the DWP office. They had relentlessly asked for medical evidence and their letters seemed to indicate they had not even read what I had striven to communicate to them. I was not able to meet the appeals deadline or supply the medical evidence which the DWP and Atos were demanding. I do not consider myself depressed or mentally ill, but this whole situation makes me wish at times that I was dead."*

Many survey respondents also told us that, having been granted ESA as a result of a successful appeal, they are due for re-assessment again only a matter of months later. This is because the periods between assessment are calculated from the original decision, rather than the appeal decision.

A case study from Bristol said: *"I had my first tribunal in August 2010 and I won the case. Upon winning, my benefits were reinstated. However, I had to reapply for ESA in April 2011, only eight months after my 15-month ordeal trying to get ESA the first time. Once again, my ESA amount was significantly reduced, pending the results of the application. I found having to re-apply so soon very stressful and it had a negative effect on my health. This time it took over a year – and I won again."*

Action for M.E. believes is unfair and unrealistic for people with a chronic, fluctuating condition such as M.E. to be frequently re-assessed, and to have to wait such a long period of time for decisions on appeal.

Communication issues

Many survey respondents commented on the lack of communication and cooperation between the DWP and Atos Healthcare.

A survey respondent told us: " In April 2012, I had the WCA. It took six months for me to get an appointment after submitting my application. I found this waiting one of the most unbearable parts of the whole process. The appointment only materialised after chasing the DWP on multiple occasions.

"However, the people from the DWP only answered the basic questions: they could tell you the rates of the benefit payments but could give no indications of how long the process will take, what to expect at the medical. Even simple questions such as 'Have you received X that I posted?' could not be answered. Other questions were referred to the Atos, who also could not provide the answers that I wanted.

"Atos call answering times are very slow – often the line would just ring and ring with no answer and I often found them to be rude and unhelpful. It seemed as if the official did not seem to know what was happening with the system. There is clearly poor communication between Atos and the DWP – they don't seem to share information and both parties simply refer you to the other, claiming the other is responsible for answering your question."

Survey respondents commented on the disregard paid to correspondence from their GPs, despite them having been treated by them for a number of years.

GPs themselves are also concerned that their professional opinions are being dismissed by the DWP. In June 2012, the British Medical Association's Annual Representative Meeting¹⁷ voted in favour of a motion that the WCA should be "ended with immediate effect and be replaced with a rigorous and safe system that does not cause unavoidable harm to some of the weakest and vulnerable in society."

Many survey respondents also said some communication after sending the completed ESA50 form in would be helpful. One based in Birmingham said: *" I found information and communication poor. The official timescale for the ESA assessment period is 13 weeks but when I phoned to say I had not been called for a medical, I was told that there were a lot of people waiting and there was a backlog because of people transferring from Incapacity Benefit to ESA. If we are not going to be called for medical within the timescale they state it would be helpful to be informed of this. "*

¹⁷ <http://bma.org.uk/news-views-analysis/news/2012/june/scrap-work-capability-assessment-doctors-demand>

Claimant journey

Some survey respondents and most of our ten case studies expressed concerns about the ESA and WCA documentation sent from the DWP, saying it is generic, rather than specific to an individual's circumstances, and confusingly worded.

They also told us that documentation is sometimes sent without any explanation. Most letters are anonymous so it is not possible to contact any particular individual with any queries.

A survey respondent from York commented: *"In general, DWP letters and correspondence could be made much clearer. For example, it wasn't clear that I'd been moved from the Work-Related Activity Group to the Support Group until I got part way down page three of a letter headed 'Your claim For ESA: a change in the ESA payable.'*

"It would have been useful to receive explanatory booklets, medical report, etc automatically, rather than having to request them; and to receive clear reasons for their decisions – in my case, why was I initially put in Work-Related Activity Group and then subsequently moved to the Support Group."

Some of the survey respondents said that, compared to the DWP and Atos Healthcare, Jobcentre Plus was quite helpful during the ESA application process and subsequent result.

A survey respondent from York said: *"Jobcentre Plus was helpful and reasonable. When I was initially put in the Work-Related Activity Group, Jobcentre Plus allowed me to postpone my interview with them while I queried the decision. Once I was placed in Support Group, Jobcentre Plus told me that while an interview with them was no longer 'compulsory,' I could contact them at any time for assistance. I dealt with the same person throughout by phone and in writing.*

"Compare this to the DWP where I was never sure who the reply would come from – information comes from several different addresses. It would be better if the DWP's ESA system provided you with one named person through whom all correspondence passed."

Conclusions and recommendations

Despite recommendations made by Prof Harrington's year one and year two reviews, Action for M.E. believes the ESA process is still putting people with M.E. through unnecessary stress and anxiety.

This report shows that the majority of people with M.E. who took part in our consultation or case study interviews – all of whom had applied for ESA within the last 12 months – found the application process for ESA stressful to the extent that it is detrimental to their health.

A vast majority of respondents said that the WCA does not give them the opportunity to adequately explain their fluctuating condition and how it might present a barrier to work. Many believe they are placed in the wrong group for ESA, or are found fit for work, as a result of this. The process of appeal is overly long and complex, causing additional stress.

We have also shown that difficulties communicating with the DWP and frustration at the lack of co-operation between the DWP and Atos Healthcare have a negative effect on the health of people with M.E.

Action for M.E. makes the following recommendations:

- Those applying for ESA should be clearly advised to present additional evidence in support of their claim such as letters from GPs, consultants and support workers. This evidence should be given due consideration during the decision-making process rather than being overlooked until tribunal.
- The ESA application form needs to be made easier and simpler for people to complete by consulting with disability organisations.
- Every person who has a face-to-face interview with Atos should be automatically given a copy of the medical report without having to ask for it.
- More efficient collaboration and better communication is needed between the DWP and Atos Healthcare.
- Healthcare professionals who carry out the face-to-face assessment should receive specialist training about fluctuating conditions in order to understand the nature and demands of M.E. This training should be developed in consultation with organisations that support people with M.E. In order to instigate a shift in attitudes the training needs to be carried out as frequently as the staff turnover at Atos requires.

- The WCA should be developed further to incorporate an individual's fitness, history and needs, rather than the initial one-size-fits-all approach. The DWP needs to question the purpose of this assessment more carefully and consider different approaches for different types of illness.
- The DWP should keep claimants regularly informed of the progress of their claim and/or appeal using the preferred method of communication indicated by the claimant.
- The DWP should develop support offered to those in the Work-Related Activity Group so that people with fluctuating conditions have more suitable options.

Appendix 1: Action for M.E.'s Time for Action campaign

Action for M.E. launched its Time for Action campaign in February 2012, asking people with M.E., their friends and family and the general public to support our aim of ending the ignorance, injustice and neglect of M.E., once and for all.

The Time for Action manifesto details the ignorance, injustice and neglect faced by people with M.E. To combat this, we are:

- campaigning relentlessly to expose the neglect of M.E. and the institutional discrimination against those who have it, until Government commits to putting this right
- driving the agenda on scientific research by investing in our own pilot studies to open up understanding of the biology of M.E.
- raising awareness of M.E. on social networking sites Facebook and Twitter and on Google, the internet's biggest search engine
- using case studies to show the reality of living M.E.
- meeting ministers, MPs and MSPs to ask them to support Time for Action.

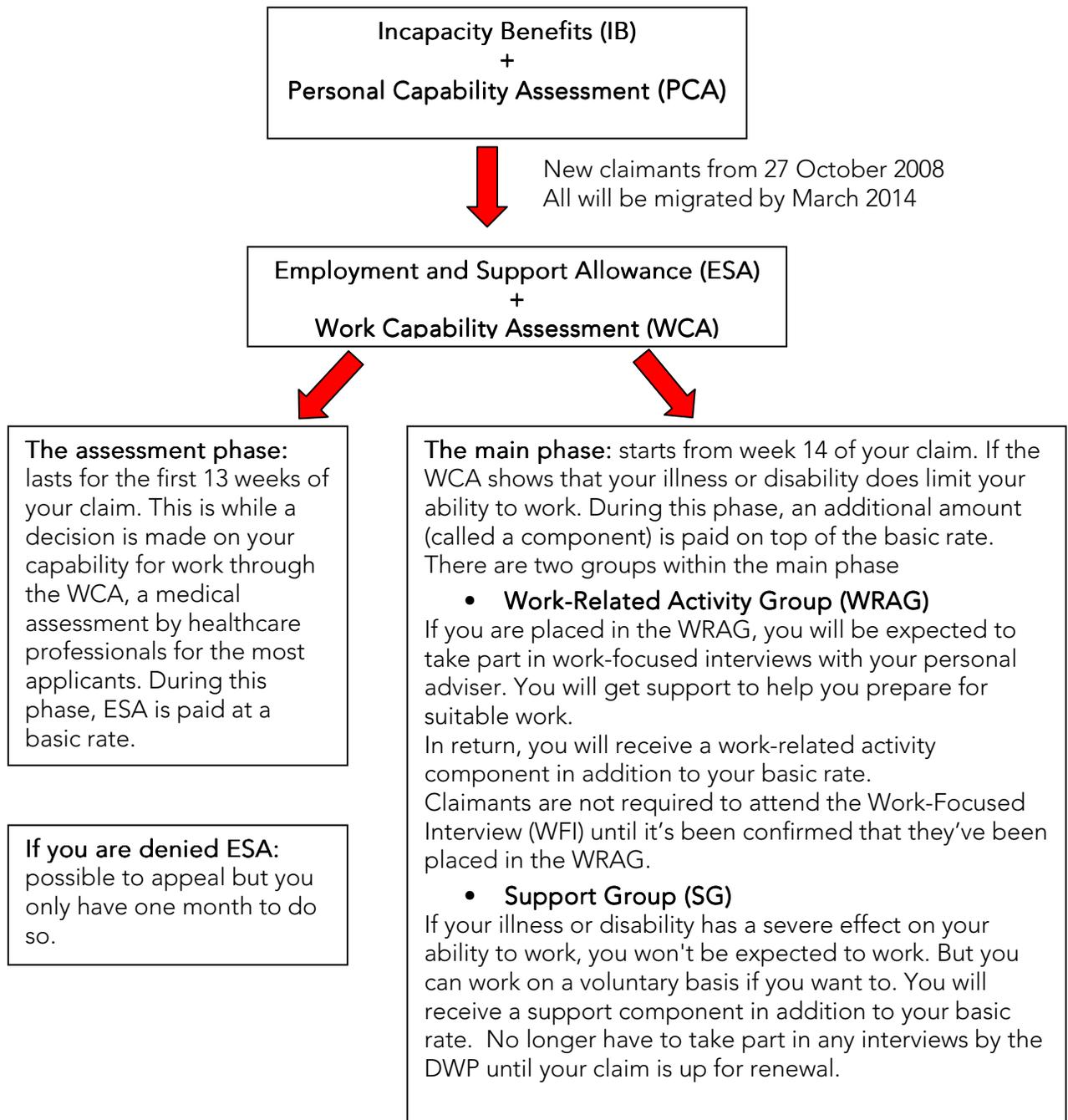
In March, Action for M.E. co-sponsored an employer's conference with KPMG to highlight the reasonable adjustments needed for people with fluctuating conditions such as M.E. to remain in or return to work.

In May, we published our report *Ignorance, injustice and neglect*, based on evidence sent to use by the NHS about services they provide for people with M.E. The report highlights the urgent need for better commissioning, more research and more consistency when it comes to diagnosing and treating people with M.E.

Now we will use this Action for M.E. report on the Work Capability Assessment not only to respond to Prof Harrington's year three review but also to lobby ministers and MPs as part of the Time for Action campaign.

Read more about Time for Action and sign up to support our campaign at www.actionforme.org.uk/time-for-action

Appendix 2: Employment and Support Allowance process



Source: modified from
www.direct.gov.uk/en/MoneyTaxAndBenefits/BenefitsTaxCreditsAndOtherSupport/Injured/DG_171894

Appendix 3: Letter from Chris Grayling, Secretary of State for Work and Pensions, to Neil Parish MP



Department of Work and Pensions

Caxton House
Tothill Street
London SW1H9DA
Telephone 020 7340 4000
Email ministers@dwp.gsi.gov.uk
www.dwp.gov.uk

Our ref: XXXX

Mr Neil Parish MP
neil.parish.mp@parliament.uk

1 February 2012

Dear Neil

Thank you for your letter of 26 January on behalf of Mrs XXXX regarding Employment and Support Allowance (ESA).

I understand the concerns that you have brought to my attention regarding the Work Capability Assessment (WCA), which determines entitlement to ESA, and Mrs XXXX is not alone in raising these concerns. We strongly support the principle of the WCA, but we have taken steps to address the reservations that we had upon taking office about the way the WCA was working. I would therefore like to take this opportunity to set out our aims and plans for this policy, and to explain the rationale behind certain features of the WCA.

There are currently 2.6 million people on incapacity benefits (some seven per cent of the working age population) at a cost to the taxpayer of around £13 billion a year. We know that many of these people, with the right support, could and indeed want to work but in many cases the current system does not give them that opportunity. Our policy in this area is supported by a large body of evidence showing that work is generally good for people. This is why we want to assess people as accurately as possible to ensure that they receive the most appropriate support and are able, where feasible, to move towards suitable employment.

The WCA was designed in close consultation with experts and disability organisations. It is a functional assessment which focuses on what an

individual can do, rather than assuming that their health condition or disability is automatically a barrier to work. We know that individuals claiming ESA can experience a very wide range of functional effects from one or more health conditions and we are determined to ensure that the WCA accurately reflects these.

The healthcare professionals who carry out the medical assessments are employed by Atos Healthcare, on behalf of the Department for Work and Pensions. They receive training in accurately assessing fluctuating conditions and mental, intellectual and cognitive function. They must have at least three years post-registration experience in a relevant field and be approved by the Chief Medical Advisor to the Department. Strict audit and quality control measures are in place to ensure that Atos delivers high-quality assessments.

However, Atos does not make decisions on benefit entitlement. Decision makers in the Department consider their advice, along with any other appropriate evidence, to make a decision. There are no targets to be met that relate to the number of people found fit for work.

Following the assessment, people who face the greatest barriers to employment will receive the extra support they need as part of the Support Group within ESA. They will not be expected to undertake any work-related activity, though they can do so on a voluntary basis if they wish. People who need more support to prepare for work will become part of the Work Related Activity Group, while receiving ESA if the normal conditions are met. Those who are found capable of work will be invited to claim Jobseeker's Allowance if they satisfy the conditions of entitlement for that benefit.

In order to ensure that the WCA is as fair and accurate as possible, we are committed to a process of ongoing review and improvement. As part of this, Professor Malcolm Harrington, a highly respected Occupational Physician, has now carried out two independent reviews of the WCA.

In his recently-published second review, Professor Harrington confirmed that the WCA remains the right process, and that the Department has taken forward all of the recommendations from his first review. He stressed that positive progress has been made to the assessment process, and expects this to be consolidated over the next year as new processes bed down.

Professor Harrington also made a series of further recommendations to build on the improvements already made. The Government endorses Professor Harrington's Review; we have fully accepted the majority of its recommendations, and are conducting work to assess the feasibility and implications of the remaining recommendations.

Both of Professor Harrington's reviews and the Government responses can be viewed at <http://www.dwp.gov.uk/policy/welfare-reform/employment-and-support/wca-independent-review/>.

We have now appointed Professor Harrington to conduct a third independent review of the WCA and provide further recommendations as appropriate.

I would like to assure Mrs XXXX that we will continue to review and refine the WCA to ensure that it is more effective; fairer for all claimants and as a result fairer for the taxpayer.

With best wishes,

A handwritten signature in blue ink, appearing to be 'C. Grayling', with a faint 'VIA' watermark visible behind the letters.

Rt Hon Chris Grayling MP Minister for Employment

Appendix 4: Extract from letter from Jobcentre Plus to one of our case studies



Department for
Work and Pensions

Jobcentre Plus
Freepost Plus RRJR-HCGX-SHYX
St Austell BC
Breakwater Road
PLYMOUTH
PL95 8BN

Fax: 01726 293126
www.direct.gov.uk
Ref: XXXX

31-Aug-2011

Dear Sir or Madam

About the appeal for Mr XXXX

I am writing because Mr XXXX has told us that you will be representing him at his appeal.

We have sent you a copy of the appeal papers with this letter. These papers give our reasons and evidence for the decision.

[...]

Secretary of State's Response, Section 4: The facts of the case

9. An opinion from a person's GP that he remains incapable of his work is not relevant to the determination of Employment and Support Allowance with regards to the limited Capability for Work assessment, which relies on the award of points.



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