



ME and the work capability assessment

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Contents

About this factsheet	1
What is the work capability assessment	1
Having limited capability for work	2
Having limited capability for work-related activity	4
The questionnaire	5
Pacing for the Capability for Work Questionnaire	
The assessment appointment	7
Challenging the Government's decision	8
Further information	8
Appendix I: assessing whether a claimant has limited capability for work	10
Appendix II: assessment of whether a claimant has limited capability for work-related activity	18

About this factsheet

At Action for ME we are not experts in welfare benefits. The aim of this factsheet therefore is to try to add to the high quality information for disabled people on the work capability assessment that already exists, and consider the topic specifically from a “ME perspective”. Sources of further information are available at the end of the factsheet.

What is the work capability assessment

The work capability assessment (WCA) forms part of the benefit rules for Employment and Support Allowance (ESA) and Universal Credit (UC). It is not a benefit in-and-of-itself.

The WCA is the assessment used by the Government to decide two things:

- Whether you are able to work or not; and
- If you’re not able to work, then whether you are able to take steps to get ready for looking for work (for example work on a CV, or attend a training course).

If you’re not able to work, the Government call this having *limited capability for work*.

If you’re also not able to take steps to prepare for work, the Government calls this having *limited capability for work-related activity*.

It is important to understand that these are specific legal definitions, and don’t necessary equate to a real-world test of whether you can hold down a particular job, or do any particular “work-related activity”.

Why is the work capability assessment important?

The WCA forms a key part of our benefits system in two important ways:

- It determines whether you are eligible for ESA, or for the health element of UC
- It determines what conditions, if any, you have to meet in order to keep getting the benefit (e.g. look for work, or complete tasks such as writing a CV, etc).

When might I need to have a work capability assessment?

You will need to have a WCA if you claim “new-style” ESA. You will also need to have a WCA if you claim Universal Credit and are not able to work. (However, if you claim UC after receiving a “migration notice” letter, you wouldn't usually need to have another WCA at the point at which you move off ESA and onto UC).

What does the assessment involve?

For most people the assessment has two key stages. The first is a large form called the Capability for Work Questionnaire. The second is an assessment appointment with a health professional. Ultimately, these are two parts of the same overall “assessment” process by which the Government makes a decision on your capability for work and/or work related activity. The Government is trying to gather the same information at both stages.

It's therefore really important to understand how the Government makes a decision. This enables you to give them all of the relevant information about your health, your ability to do the activities listed on the form, and the impact of doing these.

Having limited capability for work

If you have limited capability for work, you won't be expected to look for and take up work. However, you may be expected to do “work-related activity”, for example write a CV or do a training course.

There are two possible routes for being found to have limited capability for work. Remember that what the Government is looking at is the cumulative impact of all your health conditions, not just ME.

Route one: The “activities” and “descriptors”

You will be assessed on your ability to do 17 activities, and are awarded points based on how much you struggle with these activities. In relation to each of the 17 activities, the healthcare professional and the Government decision-maker look at certain specific phrases (called “descriptors”), and allocate you points based on which descriptor best describes your ability to do that activity. If you score 15 points or more, you are considered “not fit for work”.

The activities are laid out explicitly in the Capability for Work Questionnaire. When you are at your assessment appointment with a Health Professional you are being assessed against exactly the same activities, even if this is less explicit in that context. Therefore, it is very important to understand what these activities are.

You can find more information in **Appendix 1**.

Route two: exceptional circumstances

Even if you don’t score 15 points under the activities, you can be treated as not fit for work if certain exceptional circumstances apply.

The rule which will most likely be relevant for a person with ME is the rule around risks to your health (or anyone else’s).

The rules say that you should be treated as having limited capability for work (even without scoring 15 points) if you have a condition which means that there would be “a substantial risk to the physical or mental health of any person” if you were to be found fit for work.

Having limited capability for work-related activity

If you have limited capability for work-related activity you will likely get extra money as part of your ESA or UC claim. Additionally, there will be no requirements on you to undertake any work-related activity in order to continue to get your benefit.

There are two ways of demonstrating you have limited capability for work-related activity.

Route one: the descriptors

If one of a list of 16 phrases applies to you, you are considered to also be unfit for work-related activity. These are listed in **Appendix 2** of this factsheet.

If any one of these sentences applies to you, you will have “limited capability for work-related activity”.

Route two: exceptional circumstances

There is an alternative route to having limited capability for work related activity if “exceptional circumstances” apply.

Again, the exceptional circumstance that might be most relevant to most people with ME is about risk.

The rules say that you should be treated as having limited capability for work related activity (even without meeting one of the 16 phrases) if there would be “a substantial risk to the mental or physical health of any person” if you were found to be capable of work-related activity.

The questionnaire

Pacing for the Capability for Work Questionnaire

It's important to remember that the process of filling in this large form can take a lot of energy, so we suggest that you try to pace this as much as you can. This is true whether this is the first time you have gone through this process, or you are undergoing a review of your capability for work.

Completing the form is likely to take a significant amount of cognitive energy. It may well also take quite a lot of emotional energy: it requires you to be really honest with yourself about how much you might be struggling. Sometimes we are so used to just "making the best of things" that to be confronted with a reminder of how hard things are can be really difficult. However, it's important to give the full truth so that you can get the support you are entitled to.

There is a deadline for returning the questionnaire, so it's important to think about how you can best manage to complete it within the time that you have. This article from Citizens' Advice gives good information and advice about [how you can prepare in advance for receiving the form](#).

Filling in the questionnaire

Having to think about how your condition affects you can be distressing so if you can, have a friend or relative with you to support you through the process.

Regarding the questions on the form about your ability to do the specified activities, the form is explicit that you should "*[o]nly answer Yes to the following questions, if you can do the activity safely, to an acceptable standard, as often as you need to and in a reasonable length of time.*"

This is *really important* for people with fluctuating conditions like ME.

Therefore, when completing each question about one of the specified activities we suggest that you consider the following:

- Look at the descriptors sheet. What is the descriptor for this activity that best applies to you?
- Can you do this activity at all? Can you do it all the times that you attempt it? How many days in a week/in a month can you do it? Is there a time of day when you cannot do it? (A diary which tracks your activities and symptoms can be a useful way to demonstrate this).
- Can you do it safely? This means: if you do it, will it cause symptoms such as pain and fatigue to flare up? What will the impact on your health be of doing this activity as often as you need to? In some cases, if you do it, will you accidentally hurt yourself?
- Can you do this activity repeatedly? Can you do it as many times as you need to in the day? (For example, if you do it in the morning, will you be so exhausted you can't do it in the afternoon if you need to?)
- Can you do it in a reasonable amount of time? Will it take you more than twice the amount of time it would take someone without your health issues to do it?
- Can you do it to an acceptable standard?
- Can you link the above to your M.E., any other health conditions you have, or the cumulative impact of health conditions? What symptoms in particular get in the way? (For example pain, fatigue, difficulties with concentration, anxiety.)

We would strongly recommend that in your answer to each question you specifically address whether you can do the "safely, to an acceptable standard, as often as you need to and in a reasonable length of time".

There is a sample answer below to illustrate.

Sample answer

Question 1. Mobilising unaided by another person with or without a walking stick, manual wheelchair or other such aid if such aid is normally or could reasonably be worn or used:

Answer: I find it very difficult to mobilise effectively even with a mobility aid, in my case a walking stick. I cannot mount or descend two steps unaided by another person even with the support of a handrail. I cannot mobilise:

Safely: My mobility is affected by my condition. I cannot mobilise up and down steps safely due to the extreme exhaustion, pain and muscle weakness resulting from my condition. This is also true when I am mobilising on flat ground. I cannot mobilise 50m repeatedly within a reasonable timescale due to severe pain and discomfort.

Reliably: I cannot mount or descend two steps unaided by another person, even with the support of a handrail, as I find it very difficult to lift my feet to climb the steps. I also find descending two steps very difficult as I cannot judge the distance and the action involved increases my pain levels. I also cannot reliably walk 50m in a reasonable amount of time due to severe pain and discomfort.

Repeatedly: I cannot manage this activity repeatedly because I have to rest regularly due to muscle weakness, pain and exhaustion.

In a reasonable amount of time: I cannot manage this activity in a reasonable amount of time. It takes me more than twice as long as a non-disabled person to complete the activity. I can only manage this activity on average three days a week.

Access needs for an assessment

There is space on the form to give information about whether or not you are able to attend a face-to-face appointment. We would also encourage you to give information in this section of the form about any other access needs you might have. For example, if you were to have an assessment by phone, would you still need rest breaks?

The assessment appointment

After you have completed and returned your questionnaire, you will likely be contacted about an assessment appointment. The appointment might take place in person at an assessment centre, or over the phone or by video call.

While the assessor may not ask you the same questions that were on the form, it's important to remember that the information they are trying to get during the appointment is exactly the same as the information they are trying to get from the form. That is, which "descriptors" you meet, and any risks to your or others' health of being found fit for work or work-related activity.

It's still important to give a sense of the fluctuating nature of your symptoms and the impact of activity during the assessment. For example, if you are asked if you went to the shops yesterday, it's important you tell them whether this is something you can do every time you need to, and explain any fatigue and pain that you experience as a result.

We suggest that the appointment is recorded. You can find out more about the [recording of Work Capability Assessment appointments](#) on the Government website.

Challenging the Government's decision

If you're not happy with the outcome of the assessment, you can challenge the decision. There are deadlines by which this should be done, so it's important not to delay looking into how to do this.

You can get more information about challenging a decision from the [Citizens' Advice website](#).

Further information

Citizens Advice Bureau

Offers advice on a range of issues and may complete a benefits check for you. Citizens' Advice's website is also a good source of information about UC and ESA.

www.citizensadvice.org.uk

Benefits and Work

A website with lots of information on disability benefits, including the work capability assessment (you need to be a member to access some of the guides).

www.benefitsandwork.co.uk/

Disability Rights UK

Factsheets on benefits, tax credits and independent living

www.disabilityrightsuk.org

Local councils

Some local councils employ welfare rights workers and/or may also have information about other services in your area.

Scope

Have information about different disability benefits on their website, including ESA and UC.

<https://www.scope.org.uk/advice-and-support>

Appendix I: assessing whether a claimant has limited capability for work

Activity	Descriptors	Points
<p>1. Mobilising unaided by another person with or without a walking stick, manual wheelchair or other aid if such aid is normally or could reasonably be worn or used.</p>	<p>1(a) Cannot, unaided by another person, either:</p> <p>(i) mobilise more than 50 metres on level ground without stopping in order to avoid significant discomfort or exhaustion; or</p> <p>(ii) repeatedly mobilise 50 metres within a reasonable timescale because of significant discomfort or exhaustion.</p>	15
	<p>(b) Cannot, unaided by another person, mount or descend two steps even with the support of a handrail.</p>	9
	<p>(c) Cannot, unaided by another person, either:</p> <p>(i) mobilise more than 100 metres on level ground without stopping in order to avoid significant discomfort or exhaustion; or</p>	9
	<p>(ii) repeatedly mobilise 100 metres within a reasonable timescale because of significant discomfort or exhaustion.</p>	6
	<p>(d) Cannot, unaided by another person, either:</p> <p>(i) mobilise more than 200 metres on level ground without stopping in order to avoid significant discomfort or exhaustion; or</p> <p>(ii) repeatedly mobilise 200 metres within a reasonable timescale because of significant discomfort or exhaustion.</p> <p>(e) None of the above applies.</p>	0

<p>2. Standing and sitting.</p>	<p>2(a) Cannot move between one seated position and another seated position which are located next to one another without receiving physical assistance from another person.</p> <p>15</p> <p>(b) Cannot, for the majority of the time, remain at a work station:</p> <p>9</p> <p>(i) standing unassisted by another person (even if free to move around);</p> <p>(ii) sitting (even in an adjustable chair); or</p> <p>(iii) a combination of paragraphs (i) and (ii),</p> <p>for more than 30 minutes, before needing to move away in order to avoid significant discomfort or exhaustion.</p> <p>(c) Cannot, for the majority of the time, remain at a work station:</p> <p>6</p> <p>(i) standing unassisted by another person (even if free to move around);</p> <p>(ii) sitting (even in an adjustable chair); or</p> <p>(iii) a combination of paragraphs (i) and (ii),</p> <p>for more than an hour before needing to move away in order to avoid significant discomfort or exhaustion.</p> <p>0</p> <p>(d) None of the above applies.</p>	
<p>3. Reaching.</p>	<p>3(a) Cannot raise either arm as if to put something in the top pocket of a coat or jacket.</p> <p>15</p> <p>(b) Cannot raise either arm to top of head as if to put on a hat.</p> <p>9</p> <p>(c) Cannot raise either arm above head height as if to reach for something.</p> <p>6</p> <p>0</p> <p>(d) None of the above applies.</p>	

<p>4. Picking up and moving or transferring by the use of the upper body and arms.</p>	<p>4(a) Cannot pick up and move a 0.5 litre carton full of liquid.</p> <p>(b) Cannot pick up and move a one litre carton full of liquid.</p> <p>(c) Cannot transfer a light but bulky object such as an empty cardboard box.</p> <p>(d) None of the above applies.</p>	<p>15</p> <p>9</p> <p>6</p> <p>0</p>
<p>5. Manual dexterity.</p>	<p>5(a) Cannot press a button (such as a telephone keypad) with either hand or cannot turn the pages of a book with either hand.</p> <p>(b) Cannot pick up a £1 coin or equivalent with either hand.</p> <p>(c) Cannot use a pen or pencil to make a meaningful mark with either hand.</p> <p>(d) Cannot single-handedly use a suitable keyboard or mouse.</p> <p>(e) None of the above applies.</p>	<p>15</p> <p>15</p> <p>9</p> <p>9</p> <p>0</p>
<p>6. Making self understood through speaking, writing, typing, or other means which are normally or could reasonably be used, unaided by another person.</p>	<p>6(a) Cannot convey a simple message, such as the presence of a hazard.</p> <p>(b) Has significant difficulty conveying a simple message to strangers.</p> <p>(c) Has some difficulty conveying a simple message to strangers.</p> <p>(d) None of the above applies.</p>	<p>15</p> <p>15</p> <p>6</p> <p>0</p>
<p>7. Understanding communication by:</p> <p>(i) verbal means (such as hearing or lip reading) alone;</p> <p>(ii) non-verbal means (such as reading 16</p>	<p>7(a) Cannot understand a simple message, such as the location of a fire escape, due to sensory impairment.</p> <p>(b) Has significant difficulty understanding a simple message from a stranger due to sensory impairment.</p>	<p>15</p> <p>15</p> <p>6</p> <p>0</p>

<p>point print or Braille) alone; or</p> <p>(iii) a combination of sub-paragraphs (i) and (ii).</p> <p>using any aid that is normally or could reasonably be used, unaided by another person.</p>	<p>(c) Has some difficulty understanding a simple message from a stranger due to sensory impairment.</p> <p>(d) None of the above applies.</p>	
<p>8. Navigation and maintaining safety using a guide dog or other aid if either or both are normally used or could reasonably be used.</p>	<p>8(a) Unable to navigate around familiar surroundings, without being accompanied by another person, due to sensory impairment.</p> <p>(b) Cannot safely complete a potentially hazardous task such as crossing the road, without being accompanied by another person, due to sensory impairment.</p> <p>(c) Unable to navigate around unfamiliar surroundings, without being accompanied by another person, due to sensory impairment.</p> <p>(d) None of the above applies.</p>	<p>15</p> <p>15</p> <p>9</p> <p>0</p>
<p>9. Absence or loss of control whilst conscious leading to extensive evacuation of the bowel and/or bladder, other than enuresis (bed-wetting), despite the wearing or use of any aids or adaptations which are normally or could reasonably be worn or used.</p>	<p>9(a) At least once a month experiences:</p> <p>(i) loss of control leading to extensive evacuation of the bowel and/or voiding of the bladder; or</p> <p>(ii) substantial leakage of the contents of a collecting device, sufficient to require cleaning and a change in clothing.</p> <p>(b) The majority of the time is at risk of loss of control leading to extensive evacuation of the bowel and/or voiding of the bladder, sufficient to require cleaning and a change in clothing, if not able to reach a toilet quickly.</p> <p>(c) Neither of the above applies.</p>	<p>15</p> <p>6</p> <p>0</p>

<p>10. Consciousness during waking moments.</p>	<p>10(a) At least once a week, has an involuntary episode of lost or altered consciousness resulting in significantly disrupted awareness or concentration.</p> <p>(b) At least once a month, has an involuntary episode of lost or altered consciousness resulting in significantly disrupted awareness or concentration.</p> <p>(c) Neither of the above applies.</p>	<p>15</p> <p>6</p> <p>0</p>
<p>11. Learning tasks.</p>	<p>1(a) Cannot learn how to complete a simple task, such as setting an alarm clock.</p> <p>(b) Cannot learn anything beyond a simple task, such as setting an alarm clock.</p> <p>(c) Cannot learn anything beyond a moderately complex task, such as the steps involved in operating a washing machine to clean clothes.</p> <p>(d) None of the above applies.</p>	<p>15</p> <p>9</p> <p>6</p> <p>0</p>
<p>12. Awareness of everyday hazards (such as boiling water or sharp objects).</p>	<p>12(a) Reduced awareness of everyday hazards leads to a significant risk of:</p> <p>(i) injury to self or others; or</p> <p>(ii) damage to property or possessions,</p> <p>such that the claimant requires supervision for the majority of the time to maintain safety.</p> <p>(b) Reduced awareness of everyday hazards leads to a significant risk of:</p> <p>(i) injury to self or others; or</p> <p>(ii) damage to property or possessions,</p> <p>such that the claimant frequently requires supervision to maintain safety.</p>	<p>15</p> <p>9</p>

		0
15. Getting about.	15(a) Cannot get to any place outside the claimant's home with which the claimant is familiar.	15
	(b) Is unable to get to a specified place with which the claimant is familiar, without being accompanied by another person.	9
	(c) Is unable to get to a specified place with which the claimant is unfamiliar without being accompanied by another person.	6
	(d) None of the above applies.	0
16. Coping with social engagement due to cognitive impairment or mental disorder.	16(a) Engagement in social contact is always precluded due to difficulty relating to others or significant distress experienced by the claimant.	15
	(b) Engagement in social contact with someone unfamiliar to the claimant is always precluded due to difficulty relating to others or significant distress experienced by the claimant.	9
	(c) Engagement in social contact with someone unfamiliar to the claimant is not possible for the majority of the time due to difficulty relating to others or significant distress experienced by the claimant.	6
	(d) None of the above applies.	0
17. Appropriateness of behaviour with other people, due to cognitive impairment or mental disorder.	17(a) Has, on a daily basis, uncontrollable episodes of aggressive or disinhibited behaviour that would be unreasonable in any workplace.	15
	(b) Frequently has uncontrollable episodes of aggressive or disinhibited behaviour that would be unreasonable in any workplace.	15

	<p>(c) Occasionally has uncontrollable episodes of aggressive or disinhibited behaviour that would be unreasonable in any workplace.</p> <p>(d) None of the above applies.</p>	9
		0

Appendix II: assessment of whether a claimant has limited capability for work-related activity

<i>Activity</i>	<i>Descriptors</i>
1. Mobilising unaided by another person with or without a walking stick, manual wheelchair or other aid if such aid is normally or could reasonably be worn or used.	1. Cannot either: (a) mobilise more than 50 metres on level ground without stopping in order to avoid significant discomfort or exhaustion; or (b) repeatedly mobilise 50 metres within a reasonable timescale because of significant discomfort or exhaustion.
2. Transferring from one seated position to another.	2. Cannot move between one seated position and another seated position located next to one another without receiving physical assistance from another person.
3. Reaching.	3. Cannot raise either arm as if to put something in the top pocket of a coat or jacket.
4. Picking up and moving or transferring by the use of the upper body and arms (excluding standing, sitting, bending or kneeling and all other activities specified in this Schedule).	4. Cannot pick up and move a 0.5 litre carton full of liquid.
5. Manual dexterity.	5. Cannot press a button (such as a telephone keypad) with either hand or cannot turn the pages of a book with either hand.
6. Making self understood through speaking, writing, typing, or other means which are normally, or could reasonably be, used unaided by another person.	6. Cannot convey a simple message, such as the presence of a hazard.
7. Understanding communication by:	7. Cannot understand a simple message, such as the location of a fire escape, due to sensory impairment.

<p>(i) verbal means (such as hearing or lip reading) alone;</p> <p>(ii) non-verbal means (such as reading 16 point print or Braille) alone; or</p> <p>(iii) a combination of sub-paragraphs (i) and (ii),</p> <p>using any aid that is normally, or could reasonably, be used unaided by another person.</p>	
<p>8. Absence or loss of control whilst conscious leading to extensive evacuation of the bowel and/or voiding of the bladder, other than enuresis (bed-wetting), despite the wearing or use of any aids or adaptations which are normally or could reasonably be worn or used.</p>	<p>8. At least once a week experiences:</p> <p>(a) loss of control leading to extensive evacuation of the bowel and/or voiding of the bladder; or</p> <p>(b) substantial leakage of the contents of a collecting device sufficient to require the individual to clean themselves and change clothing.</p>
<p>9. Learning tasks.</p>	<p>9. Cannot learn how to complete a simple task, such as setting an alarm clock, due to cognitive impairment or mental disorder.</p>
<p>10. Awareness of hazard.</p>	<p>10. Reduced awareness of everyday hazards, due to cognitive impairment or mental disorder, leads to a significant risk of:</p> <p>(a) injury to self or others; or</p> <p>(b) damage to property or possessions,</p> <p>such that the claimant requires supervision for the majority of the time to maintain safety.</p>
<p>11. Initiating and completing personal action (which means planning, organisation, problem solving, prioritising or switching tasks).</p>	<p>11. Cannot, due to impaired mental function, reliably initiate or complete at least two sequential personal actions.</p>
<p>12. Coping with change.</p>	<p>12. Cannot cope with any change, due to cognitive impairment or mental disorder, to the extent that day to day life cannot be managed.</p>

13. Coping with social engagement, due to cognitive impairment or mental disorder.	13. Engagement in social contact is always precluded due to difficulty relating to others or significant distress experienced by the claimant.
14. Appropriateness of behaviour with other people, due to cognitive impairment or mental disorder.	14. Has, on a daily basis, uncontrollable episodes of aggressive or disinhibited behaviour that would be unreasonable in any workplace.
15. Conveying food or drink to the mouth.	<p>15. (a) Cannot convey food or drink to the claimant's own mouth without receiving physical assistance from someone else;</p> <p>(b) Cannot convey food or drink to the claimant's own mouth without repeatedly stopping or experiencing breathlessness or severe discomfort;</p> <p>(c) Cannot convey food or drink to the claimant's own mouth without receiving regular prompting given by someone else in the claimant's presence; or</p> <p>(d) Owing to a severe disorder of mood or behaviour, fails to convey food or drink to the claimant's own mouth without receiving:</p> <p>(i) physical assistance from someone else; or</p> <p>(ii) regular prompting given by someone else in the claimant's presence.</p>
16. Chewing or swallowing food or drink.	<p>16. (a) Cannot chew or swallow food or drink;</p> <p>(b) Cannot chew or swallow food or drink without repeatedly stopping or experiencing breathlessness or severe discomfort;</p> <p>(c) Cannot chew or swallow food or drink without repeatedly receiving regular prompting given by someone else in the claimant's presence; or</p> <p>(d) Owing to a severe disorder of mood or behaviour, fails to:</p> <p>(i) chew or swallow food or drink; or</p>

	(ii) chew or swallow food or drink without regular prompting given by someone else in the claimant's presence.
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Useful contacts:

C-App

Guides to applying for PIP and ESA

<https://c-app.org.uk>

Citizens Advice Bureau

Offers advice on a range of issues and may be complete a benefits check for you.

www.citizensadvice.org.uk

Disability Rights UK

Factsheets on benefits, tax credits and independent living.

www.disabilityrightsuk.org

PIP info

A guide to regulations and case law regarding PIP.

<http://pipinfo.net>

Registered office:

Action for ME

Unit 2.2 Streamline

436-441 Paintworks

Bristol, BS4 3AS

Telephone: 0117 927 9551

Info & Support: infosupport@actionforme.org.uk

Fundraising: fundraising@actionforme.org.uk

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