

# Employment and Support Allowance

Money, grants and benefits

Find out more about Employment and Support Allowance (ESA), and how to claim



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If you have Parkinson's, or care for someone who does, you may be worried about how you'll manage financially if you can't work, or if you need help with your day-to-day needs. But there is financial support available, so it's important to find out what benefits you're entitled to.

This sheet explains what Employment and Support Allowance (ESA) is, who qualifies and how to claim.

The information in this publication is correct as of June 2024, but is subject to change. Our most up-to-date information is on our website at **parkinsons.org.uk/benefits**. Our helpline can also give advice on benefits. Call **0808 800 0303** or email **hello@parkinsons.org.uk** 

### What is ESA?

You might be eligible for a benefit called Employment and Support Allowance (ESA) if your ability to work is limited because of ill health or a disability.

The benefit has two parts – contributory/new-style ESA and income-related ESA. Income-related ESA is currently being phased out and replaced by Universal Credit.

# Contributory/new-style ESA

Contributory ESA is now called 'new-style' ESA for new claims.

To be eligible for contributory/new-style ESA, you need to have paid enough in National Insurance contributions. If you have paid enough, you'll receive a flat-rate benefit.

Payment of contributory/new-style ESA is limited to 12 months, unless you're placed in the 'support group' (see 'The assessment phase and the Work Capability Assessment' section in this information).

#### **Income-related ESA**

Income-related ESA is a means-tested benefit. This means your needs (and those of your partner, if you have one) are compared with the existing money you have, such as income and savings. Whether you get income-related ESA, and how much you're paid, is worked out from this.

Income-related ESA has now been replaced by Universal Credit. It's no longer possible to make a new claim for means-tested ESA.

If you're already getting income-related ESA, you will at some point be moved over to Universal Credit.

**Find out more:** see our information on Universal Credit.

Income-related ESA can be paid on its own (if you're not entitled to contributory ESA) or as a top-up to contributory ESA if you are. Unlike contributory ESA, income-related ESA is not time-limited.

# Do I qualify for ESA?

There are common rules that apply to both types of ESA. You must:

- not be working (some limited work is permitted see the section on 'What work is permitted with ESA?' in this information)
- · be aged 16 or over
- be under State Pension age. You can find out your State Pension age online by visiting www.gov.uk/ state-pension-age
- · live in Great Britain
- not be entitled to Income Support, Jobseeker's Allowance or Statutory Sick Pay
- have a limited capability for work. This is tested under the Work Capability Assessment

For new-style ESA (only) you cannot be in receipt of Carer's Allowance, Retirement Pension or Maternity Allowance.

### How do I claim ESA?

You can claim contributory/new-style ESA by phone or you can claim online at www.gov.uk/employment-support-allowance/how-to-claim

To claim Universal Credit alongside your contributory ESA, you must claim online at www.gov.uk/universal-credit/how-to-claim

You'll be expected to provide a medical certificate from your doctor (commonly known as a 'fit note' or 'sick note') until you've undergone the Work Capability Assessment (see below for more information).

If you have a job but don't get Statutory Sick Pay, you'll need to send in form SSP1 as well as a medical certificate. You can get this form from your employer.

# The assessment phase and the Work Capability Assessment

An 'assessment phase' normally applies to all new ESA claimants. During the assessment phase, you should undergo the 'Work Capability Assessment'.

The assessment phase should last for 13 weeks, although it can be extended if there's a delay in carrying out the assessment (delays are common). During the assessment phase, you'll be paid just a basic allowance of ESA.

The Work Capability Assessment has two aims:

- to assess whether you have a limited capability for work. If you do, you're considered eligible for ESA
- to assess whether you have a limited capability for work-related activity. This is used to decide whether you're placed in the 'support group' or the 'workrelated activity group' (see pages 8-9)

#### **Universal Credit**

The Work Capability Assessment is also important for Universal Credit, the benefit that's currently replacing several existing means-tested benefits, including the income-related part of ESA.

The Work Capability Assessment works out whether you're entitled to the 'limited capability for work-related activity' element of Universal Credit and what if any work-related requirements you must meet to keep receiving the benefit in full.

**Find out more:** see our information on Universal Credit.

#### When will the assessment take place?

Your first Work Capability Assessment for both ESA and Universal Credit should take place during the 13-week assessment phase.

If it's decided that you're entitled, you may be asked to take part in further Work Capability Assessments in the future. This is to make sure you're still entitled to ESA or Universal Credit and to find out whether you should remain in the same group.

# The 'limited capability for work' assessment

The first part of the Work Capability Assessment finds out if you have a 'limited capability for work'. It looks at your physical, mental and cognitive health.

A points system is used to see how well you can carry out a range of activities, such as moving around, standing and sitting, reaching, communicating, manual dexterity (using your hands), behaving appropriately, socialising and keeping safe.

In some situations, you don't need to meet the 15 points required to pass the test. There's a long list of circumstances which mean you're exempt from the test, including being terminally ill, receiving cancer treatments (chemotherapy or radiotherapy), having an infectious disease, being in hospital, being pregnant, having a serious risk to your health, or receiving dialysis. In these kinds of circumstances you can be automatically treated as having a limited capability for work.

For more details contact the Parkinson's UK helpline on **0808 800 0303**. See Appendix 1 on page 22 of this information for a list of the 'limited capability for work' assessment descriptors.

If you don't qualify you'll need to claim benefits as a jobseeker instead, or challenge the decision.

If you're unsuccessful with your first claim and make a second claim, you'll have to show either a new disablement (disability or condition) or that your original condition(s) has significantly worsened before the new claim can proceed.

#### The work-related activity group

If you're put in the work-related activity group, it means the Department for Work and Pensions has decided that your disability or health condition does limit your ability to work at the moment, but there are things you can do to improve this situation.

You'll have to meet strict work-related conditions to continue receiving ESA or Universal Credit in full. This involves attending a series of work-focused interviews.

At these interviews, a work coach will discuss with you your work prospects, the steps you're willing to take to move into work and the support available to you. Your benefit can be reduced (or 'sanctioned') if you don't meet the work-related conditions.

If you're placed in the work-related activity group and are getting contributory ESA, your ESA payment will be limited to 12 months.

The work-related activity group is known as the 'limited capability for work group' for both ESA and Universal Credit.

# The 'limited capability for work-related activity' assessment

The second part of the assessment looks at whether you have a 'limited capability for work-related activity'. This decides whether you'll be placed in the 'support group' or classed as having 'limited capability for work-related activity'. This assessment also has a list of descriptors. If at least one of them applies to you, you'll be placed in the support group. See Appendix 2 on page 30 of this information for the list of descriptors.

#### The support group

If you're put in the support group, it means the Department for Work and Pensions has decided that you're unable to work and that it doesn't expect you to do anything to improve your chances of finding work. You'll get a higher rate of ESA or Universal Credit payment, and if you're awarded contributory/new-style ESA, it can be paid indefinitely (which means it's paid for as long as you continue to meet the conditions for it).

Under both new-style ESA and Universal Credit, you'll be placed in the support group/limited capability for work-related activity group if there's a 'substantial risk' to your mental or physical health if you're not found to have a limited capability for work-related activity. For more details on this, call the Parkinson's UK helpline on **0808 800 0303**.

If you're in the support group, you won't have to take part in work-related activities, but you can do paid work with strict limitations or voluntary work if you want to.

# How will I be assessed for ESA?

A Department for Work and Pensions decision-maker looks at the information you've provided with your claim for ESA or Universal Credit, to see if there's evidence that you have a limited capability for work or for work-related activity.

You'll be asked to complete a capability for work questionnaire (called ESA50 or UC50) unless you're terminally ill.

# Completing the capability for work questionnaire

This questionnaire asks about your ability to complete different tasks. The questions relate to the activities in the limited capability for work assessment.

The activities, and the points you get for each one, are listed in Appendix 1 on page 22 of this information.

If you're not sure how to complete this questionnaire, call our helpline on **0808 800 0303**, or get in touch with Citizens Advice or another local advice centre.

#### General advice

Things to note when filling out the questionnaire:

- The questionnaire asks whether you can do certain tasks without problems. You can answer 'yes', 'no' or 'it varies'. The last answer is helpful if your condition changes, which is highly likely to be the case with Parkinson's. You might find it useful to keep a diary over a few days of your day-to-day problems, to help answer this correctly.
- Each of your answers should take into account tiredness, pain and discomfort and whether you can repeat the activity. If you're not able to complete a task repeatedly, or without pain or discomfort, then you should be treated as being unable to do it.
- Remember that non-physical problems are just as important to the assessment as physical problems.
   So do include information about non physical difficulties such as depression, memory problems or hallucinations.

- Use the box provided in each section to give extra information about the problems you have with each task. For example, if a task causes discomfort, pain or tiredness, you should say so. If your condition varies, give an idea of how many days you would be able to do the task and how many you would not.
- You must be able to do each task safely, to an acceptable standard, as often as you need to, and in a reasonable time. Make a note whenever this is not the case. Think about whether you could do the task in a workplace setting. Include information about any injuries or accidents that have happened when you've tried to do a task. Explain how much rest or medication you need after doing a particular task.
- If a task would pose a risk to your health, enough to put off any reasonable person from doing it, then you should be treated as being unable to do it.
- If your doctor, physiotherapist or another health professional has told you to avoid an activity, make sure you put this on the form.
- A detailed statement can be attached to the questionnaire, setting out how Parkinson's (and any other health issues) affects you. This could be a diary, making clear what your difficulties are on a good day, a bad day and an average day. Comment generally, as well as specifically about actual work situations. Make several copies of your statement (one of which you could give to the healthcare professional at the assessment).

- If you have to appeal against a benefit decision, the questionnaire and your statement will make up part of the evidence put before the tribunal. It's important that you don't miss anything out and that you give as much information as you can.
- You should attach copies of any medical evidence to the questionnaire if possible.

Parkinson's affects people differently, and some people with the condition may also have other illnesses or disabilities. So, depending on the individual, any of the activities in the questionnaire might be important. Because of this it's crucial that you read the whole questionnaire very carefully.

For more detailed guidance, including explanations of each of the activity headings and example responses, please see Appendix 3 on page 35 of this information.

# The face-to-face assessment

Once you've sent in your capability for work questionnaire, you may be asked to attend an assessment carried out by a healthcare professional working for Maximus, the organisation delivering the assessment on behalf of the Department for Work and Pensions. At the moment most assessments are being completed on the phone or via video.

Maximus is also called the 'Health Assessment Advisory Service' or the 'Centre for Health and Disability Assessments'. If you have an assessment, the following tips might be useful:

- If you think you'll have problems getting to the venue for a face-to-face assessment, it's important to explain this and ask for an alternative arrangement, such as a home visit or phone assessment. Set out any risk to your health if you were to attempt to go to their venue. It may be necessary to get a letter from a healthcare professional to back this up.
- During the assessment, explain your physical abilities as well as you can. You shouldn't assume the professional assessing you knows you can only do a task with discomfort or that your ability to do it changes because of your condition. Tell them about any pain or discomfort the task causes and how you'd feel if you had to keep repeating it.
- Focus on the problems you have, rather than on how you manage them.
- The healthcare professional assessing you shouldn't base their opinion of your condition on the day they meet you, but on the effects of your condition over time. So if you're having a good day when you have your assessment, you'll need to tell them this, and explain how your condition affects you most of the time, and how you are at your worst.
- When they ask about your mental or other nonphysical difficulties, the healthcare professional assessing you should find out how your condition affects your day-to-day abilities. When you explain this, tell them how you are most of the time. If your condition changes day-today or over the course of a day, tell them how often it changes and for how long.

- You might find it helpful to have someone with you, such as a friend or relative, to fill in the gaps of what you tell the healthcare professional.
- If you've made a written statement or diary, give the healthcare professional a copy of it.

# Challenging the decision

# Asking for a reconsideration

If you're refused ESA or Universal Credit ('limited capability for work' or 'limited capability for work-related activities') after the assessment, and you disagree with the decision, you can ask the Department for Work and Pensions for a 'mandatory reconsideration' of the decision, or for ESA you can go straight to an appeal. This appeal option only applies for new claims, it is not available if you have previously claimed ESA.

You can also request a mandatory reconsideration or appeal if you're put into the work-related activity group and you think you should be in the support group (and therefore would not have new-style/contributory ESA limited to 12 months).

You must ask for the mandatory reconsideration or appeal within one month of the date on the decision letter. If you miss this deadline but are within 13 months of the decision you can still ask for a mandatory reconsideration or appeal, but will need to show a 'good' reason for being late.

You can ask for a mandatory reconsideration by phone, but it's best to put your request in writing and keep a copy of your letter.

You can use a CRMRI mandatory reconsideration form, but you're not obliged to do so. In any letter you send, include your National Insurance number, the date of the disputed decision (on your letter from the Department for Work and Pensions) and why you believe it's incorrect.

To challenge a decision about Universal Credit, you need to add an entry to your online journal asking for a mandatory reconsideration. For Universal Credit you can't go straight to appeal.

### Appealing the decision

If your mandatory reconsideration request is unsuccessful, you can decide to appeal all ESA decisions and Universal Credit decisions to an independent tribunal.

You should ask for the appeal within one month of the date on the decision letter, but if you have a good reason for being late, you have a maximum of 13 months to request the appeal. You should contact the Parkinson's UK helpline on **0808 800 0303** or at hello@parkinsons.org.uk for more information.

When you are told of the mandatory reconsideration decision you'll be sent two copies of the mandatory reconsideration notice. This is the Department for Work and Pensions' decision. To appeal, use form SSCS1 if you live in England, Wales or Scotland, or form NOA1(SS) in Northern Ireland. You can download the form from www.gov.uk (or from www.nidirect.gov.uk in Northern Ireland). Alternatively you can request the appeal online at www.appeal-benefit-decision.service.gov.uk/benefit-type

When you complete the appeal form attach the mandatory reconsideration decision and list all the descriptors you think apply to you (see Appendix 1 on page 22 and Appendix 2 on page 30 of this information). The form will also ask if you want to attend an appeal hearing. You stand a better chance of winning your case if you do.

Appeal papers will then be sent to you. These will contain the report from the face-to-face assessment that was used in making the decision. This will show you where you need to dispute the decision or identify where misunderstandings have occurred.

Try to get medical evidence to back up your case. For example, you could get a letter from your Parkinson's nurse confirming which descriptors they think apply to you. Send a copy of this evidence to the tribunal before your appeal hearing.

You might want to contact an advice centre, such as Citizens Advice, to see if they can give you advice and perhaps represent you at the tribunal.

For more information on rights and benefits call the Parkinson's UK helpline on **0808 800 0303** or email **hello@parkinsons.org.uk** 

# What if my condition gets worse before the appeal?

A tribunal can only look at how your condition was at the time of the decision that you are appealing.

If your condition has got significantly worse since then, you could consider making a new claim for ESA or requesting a new Universal Credit assessment.

However, this is a complex area and it's best to get advice first. Call our helpline on **0808 800 0303**, or get in touch with Citizens Advice or another local advice centre.

# How much is contributory ESA?

For the first 13 weeks of your claim (the 'assessment phase'), you're paid the basic allowance. This amount depends on your age:

Assessment phase	per week
Aged under 25 years	£71.70
Aged 25 years and over	£90.50

During the assessment phase, you should undergo the Work Capability Assessment. If you're found to have a limited capability for work at this assessment, then from the 14th week of your claim you will enter the 'main phase'.

Once in the main phase, for ESA the standard rate of the basic allowance will apply. If you're placed in the support group, you'll also get the 'support component'.

Main phase	per week
Basic allowance	£90.50 / £71.70
Support component	£47.70

If you have an occupational or personal pension that pays more than £85 a week, then for any amount over this limit, your contributory ESA payment will be reduced by half that amount. For example, a pension paying £100 per week will reduce your ESA payment by £7.50 per week (£100 - £85 = £15, half that = £7.50).

# What work is permitted with ESA?

The general rule is that, if you do any work, you're not entitled to ESA. You are, however, allowed to do 'permitted work'.

The rules allow you to:

- work for under 16 hours a week and earn up to £183.50 a week, or
- earn up to £183.50 a week if you're doing 'supported permitted work'

'Supported permitted work' is work that's supervised by an employee of a public or voluntary body, whose job it is to arrange job opportunities for disabled people.

It can also be work carried out as part of your treatment programme under medical supervision while you're a patient in hospital or a regular outpatient.

Earnings from permitted work will not affect your ESA amount.

You must inform the Department for Work and Pensions that you're due to start permitted work (you can call the helpline on **0800 169 0310**).

If you live in Northern Ireland, contact the Employment and Support Allowance Centre on **0800 587 1377**.

# Will ESA affect other benefits?

If you already get income-related ESA, you might already get full Housing Benefit. Please note no new Housing Benefit claims can now be made unless you live in certain types of accommodation (specified or temporary accommodation).

If you only get new-style/contributory ESA, you will now need to claim Universal Credit to get help with housing costs.

Income-related ESA can also provide access to Sure Start Maternity Grants and Funeral Payments. If you have a mortgage, income-related ESA can provide access to Support for Mortgage Interest Loans, which provide help through repayable loans towards the costs of the interest on your mortgage.

If you get income-related ESA, you qualify for help with NHS charges such as prescriptions, vouchers for glasses and help with hospital travel fares.

If you receive income-related ESA and were born before 22 September 1958, you'll automatically receive the Winter Fuel Payment in 2024. This is a one-off payment of £200 if you were born between 23 September 1944 and 22 September 1958. It's £300 if you were born before this.

If you only get contributory ESA, you can apply for help with NHS charges under the Low Income Scheme, but this will be means-tested.

The rules for Disability Living Allowance and Personal Independence Payment are different from ESA, so they're not affected by an ESA claim.

### The benefit cap

A 'benefit cap' limits the total amount of out-of-work and children's benefits that you can receive.

The cap varies according to your circumstances, and whether or not you live in Greater London.

- In Greater London, the cap is £326.29 a week for single people and £486.98 a week for single parents and couples (with or without children).
- Outside Greater London, the cap is £283.71 a week for single people and £423.46 a week for single parents and couples (with or without children).'

You'll be exempt from the benefit cap if you (or anyone in your household) are getting ESA with the support component or Universal Credit with 'limited capability for work-related activity'.

# What can I do if ESA is time-limited?

If your contributory ESA is terminated after the 12-month payment period, you have several options.

There are no time limits on means-tested ESA.

In all the following situations, you'll need to show that you still have a limited capability for work. You'll probably need to complete a new 'capability for work' questionnaire and take part in a new Work Capability Assessment where necessary.

#### 1. Reclaim ESA

At the end of the first 12 months, you can reclaim ESA after a gap of 12 weeks if you can use a different tax year for your new second claim.

So if the first claim used your National Insurance contributions in the tax years 2019/20 and 2020/21 and the second uses your National Insurance contributions in the tax years 2021/22 and 2022/23 (because of the date of the new claim), you can claim ESA for an additional 365 days.

#### 2. Claim National Insurance credits

If you can't be paid income-related ESA, you can still be given National Insurance credits as long as your circumstances don't change. National Insurance credits can help you satisfy the conditions for State Pension.

#### 3. If your condition gets worse in the future

If you can't get income-related ESA, you may be able to claim contributory ESA again in the future if your condition gets worse – as long as the Department for Work and Pensions considers that you have continuously had a limited capability for work since your new-style/contributory ESA stopped being paid.

To make sure this happens, you should ask the Department for Work and Pensions to continue to assess you as having limited capability for work once your contributory ESA ends. Then, if your condition does get worse, you can make a new claim for new-style ESA.

You'll probably be referred for a Work Capability
Assessment. If it's accepted at this assessment that
you have limited capability for work-related activity
(and so can be moved into the support group) you can
be awarded contributory ESA again. It will last as long
as you stay in the support group.

# APPENDIX 1. The limited capability for work assessment: the points

To be assessed as having a limited capability for work, you need to score 15 points or more. Add together the highest scores from each of the activity headings that apply to you. If any of the tasks marked in bold apply, you'll also satisfy the limited capability for work-related activity assessment (in which case any contributory ESA payable will not be limited to just 12 months).

The assessment takes into account your abilities when using any aid or appliance you would normally or could reasonably use.

- 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
- A. Cannot, unaided by another person, either: (i) mobilise more than 50 metres on level ground without stopping in order to avoid significant discomfort or exhaustion, or (ii) repeatedly mobilise 50 metres within a reasonable timescale because of significant discomfort or exhaustion.
- B. Cannot, unaided by another person, mount or descend two steps even with the support of a handrail.9 points
- C. Cannot, unaided by another person, either: (i) mobilise more than 100 metres on level ground without stopping in order to avoid significant discomfort or exhaustion, or (ii) repeatedly mobilise 100 metres within a reasonable timescale because of significant discomfort or exhaustion.
  9 points

- D. Cannot, unaided by another person, either: (i) mobilise more than 200 metres on level ground without stopping in order to avoid significant discomfort or exhaustion, or (ii) repeatedly mobilise 200 metres within a reasonable timescale because of significant discomfort or exhaustion.
   6 points
- E. None of the above applies.

**0** points

#### 2. Standing and sitting

- 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.
- B. Cannot, for the majority of the time, remain at a work station either: (i) standing unassisted by another person (even if free to move around), or (ii) sitting (even in an adjustable chair), or (iii) a combination of paragraphs (i) and (ii) for more than 30 minutes, before needing to move away in order to avoid significant discomfort or exhaustion.
  9 points
- C. Cannot, for the majority of the time, remain at a work station either: (i) standing unassisted by another person (even if free to move around), **or** (ii) sitting (even in an adjustable chair), **or** (iii) a combination of paragraphs (i) and (ii) for more than an hour before needing to move away in order to avoid significant discomfort or exhaustion.

  6 points
- D. None of the above applies.

0 points

#### 3. Reaching

- A. Cannot raise either arm as if to put something in the top pocket of a jacket.

  15 points
- B. Cannot raise either arm to top of head as if to put on a hat.9 points
- C. Cannot raise either arm above head height as if to reach for something.6 points
- D. None of the above applies. **0 points**
- 4. Picking up and moving or transferring by the use of the upper body and arms
- A. Cannot pick up and move a 0.5 litre carton full of liquid.15 points
- B. Cannot pick up and move a one litre carton full of liquid.9 points
- C. Cannot transfer a light but bulky object such as an empty cardboard box.6 points
- D. None of the above applies. **0 points**

#### 5. Manual dexterity

- A. Cannot press a button (such as a telephone keypad) with either hand or cannot turn the pages of a book with either hand.

  15 points
- B. Cannot pick up a £1 coin or equivalent with either hand.

  15 points
- C. Cannot use a pen or pencil to make a meaningful mark with either hand.9 points
- D. Cannot single-handedly use a suitable keyboard or mouse.9 points
- E. None of the above applies. **0 points**

- 6. Making self understood through speaking, writing, typing, or other means which are normally or could reasonably be used, unaided by another person
- A. Cannot convey a simple message, such as the presence of a hazard.

  15 points
- B. Has significant difficulty conveying a simple message to strangers.

  15 points
- C. Has some difficulty conveying a simple message to strangers. **6 points**
- D. None of the above applies. **0 points**
- 7. Understanding communication by: (i) verbal means (such as hearing or lip reading) alone, (ii) non-verbal means (such as reading 16-point print or Braille) alone, or (iii) a combination of (i) and (ii) using any aid that is normally or could reasonably be used, unaided by another person
- A. Cannot understand a simple message, such as the location of a fire escape, due to sensory impairment.

  15 points
- B. Has significant difficulty understanding a simple message from a stranger due to sensory impairment.

  15 points
- C. Has some difficulty understanding a simple message from a stranger due to sensory impairment.6 points
- D. None of the above applies. **0 points**

- 8. Navigation and maintaining safety, using a guide dog or other aid if either or both are normally used or could reasonably be used
- A. Unable to navigate around familiar surroundings,
   without being accompanied by another person, due
   to sensory impairment.
- B. Cannot safely complete a potentially hazardous task such as crossing the road, without being accompanied by another person, due to sensory impairment.
  15 points
- C. Unable to navigate around unfamiliar surroundings, without being accompanied by another person, due to sensory impairment.9 points
- D. None of the above applies. **0 points**
- 9. Absence or loss of control while conscious leading to extensive evacuation of the bowel and/or bladder, other than enuresis (bedwetting), despite the wearing or use of any aids or adaptations which are normally or could reasonably be worn or used
- A. At least once a month experiences: (i) loss of control leading to extensive evacuation of the bowel and/ or voiding of the bladder, or (ii) substantial leakage of the contents of a collecting device, sufficient to require cleaning and a change in clothing. 15 points
- 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.
  6 points
- C. None of the above applies. **0 points**

#### 10. Consciousness during waking moments

A. At least once a week, has an involuntary episode of lost or altered consciousness resulting in significantly disrupted awareness or concentration.

15 points

- B. At least once a month, has an involuntary episode of lost or altered consciousness resulting in significantly disrupted awareness or concentration.
  6 points
- C. None of the above applies. **0 points**

#### 11. Learning tasks

- A. Cannot learn how to complete a simple task, such as setting an alarm clock.

  15 points
- B. Cannot learn anything beyond a simple task, such as setting an alarm clock.9 points
- C. Cannot learn anything beyond a moderately complex task, such as the steps involved in operating a washing machine to clean clothes.6 points
- D. None of the above applies. **0 points**
- 12. Awareness of everyday hazards (such as boiling water or sharp objects)
- A. Reduced awareness of everyday hazards leads to a significant risk of: (i) injury to self or others, or (ii) damage to property or possessions such that the claimant requires supervision for the majority of the time to maintain safety.

  15 points

- B. Reduced awareness of everyday hazards leads to a significant risk of: (i) injury to self or others, or (ii) damage to property or possessions such that the claimant frequently requires supervision to maintain safety.

  9 points
- C. Reduced awareness of everyday hazards leads to a significant risk of: (i) injury to self or others, or (ii) damage to property or possessions such that the claimant occasionally requires supervision to maintain safety.
  6 points
- D. None of the above applies. **0 points**
- 13. Initiating and completing personal action (which means planning, organisation, problem solving, prioritising or switching tasks)
- A. Cannot, due to impaired mental function, reliably initiate or complete at least two sequential personal actions.

  15 points
- B. Cannot, due to impaired mental function, reliably initiate or complete at least two sequential personal actions for the majority of the time.9 points
- C. Frequently cannot, due to impaired mental function, reliably initiate or complete at least two sequential personal actions.6 points
- D. None of the above applies. **0 points**

### 14. Coping with change

- A. Cannot cope with any change to the extent that day-to-day life cannot be managed. 15 points
- B. Cannot cope with minor planned change (such as a pre-arranged change to the routine time scheduled for a lunch break), to the extent that, overall, day-to-day life is made significantly more difficult.
  9 points
- C. Cannot cope with minor unplanned change (such as the timing of an appointment on the day it is due to happen), to the extent that, overall, day-to-day life is made significantly more difficult.
  6 points
- D. None of the above applies.

#### 0 points

0 points

#### 15. Getting about

- A. Cannot get to any place outside of the claimant's home with which the claimant is familiar. 15 points
- B. Is unable to get to a specified place with which the claimant is familiar, without being accompanied by another person.9 points
- C. Is unable to get to a specified place with which the claimant is unfamiliar without being accompanied by another person.6 points
- D. None of the above applies.

# 16. Coping with social engagement due to cognitive impairment or mental disorder

A. Engagement in social contact is always precluded due to difficulty relating to others or significant distress experienced by the claimant.
 15 points

- 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 points
- 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 points

D. None of the above applies.

0 points

- 17. Appropriateness of behaviour with other people due to cognitive impairment or mental disorder
- A. Has, on a daily basis, uncontrollable episodes of aggressive or disinhibited behaviour that would be unreasonable in any workplace.
- B. Frequently has uncontrollable episodes of aggressive or disinhibited behaviour that would be unreasonable in any workplace.

  15 points
- C. Occasionally has uncontrollable episodes of aggressive or disinhibited behaviour that would be unreasonable in any workplace.
   9 points
- D. None of the above applies.

0 points

# APPENDIX 2. The limited capability for work-related activity assessment

If one or more of the following descriptors applies, you'll be assessed as having a limited capability for work-related activity, and you'll be placed in the support group.

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

#### 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 Cannot move between one seated position and another seated position located next to one another without receiving physical assistance from another person.

#### 3. Reaching

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 Appendix)

Cannot pick up and move a 0.5 litre carton full of liquid.

#### 5. Manual dexterity

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 Cannot convey a simple message, such as the presence of a hazard.

7. Understanding communication by: (i) verbal means (such as hearing or lip reading) alone, (ii) non-verbal means (such as reading 16-point print or Braille) alone, or (iii) a combination of (i) and (ii) using any aid that could normally, or could reasonably be used, unaided by another person

Cannot understand a simple message, such as the location of a fire escape, due to sensory impairment.

8. Absence or loss of control while 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

At least once a week experiences:

- A. loss of control leading to extensive evacuation of the bowel and/or voiding of the bladder, **or**
- B. substantial leakage of contents of a collecting device, sufficient to require the individual to clean themselves and change clothing.

#### 9. Learning tasks

Cannot learn how to complete a simple task, such as setting an alarm clock, due to cognitive impairment or mental disorder.

#### 10. Awareness of hazards

Reduced awareness of everyday hazards, due to cognitive impairment or mental disorder, leads to a significant risk of:

- A. injury to self or others, or
- B. damage to property or possessions such that the claimant requires supervision for the majority of the time to maintain safety.
- II. Initiating and completing personal action (which means planning, organisation, problem solving, prioritising or switching tasks)

Cannot, due to impaired mental function, reliably initiate or complete at least two sequential personal actions.

#### 12. Coping with change

Cannot cope with any change, due to cognitive impairment or mental disorder, to the extent that day-to-day life cannot be managed.

13. Coping with social engagement, due to cognitive impairment or mental disorder

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

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

- A. Cannot convey food or drink to the claimant's own mouth without receiving physical assistance from someone else, **or**
- B. Cannot convey food or drink to the claimant's own mouth without repeatedly stopping or experiencing breathlessness or severe discomfort, **or**
- C. Cannot convey food or drink to the claimant's own mouth without receiving regular prompting given by someone else in the claimant's physical presence, or
- D. Owing to a severe disorder of mood or behaviour, fails to convey food or drink to the claimant's own mouth without receiving: (i) physical assistance from someone else, or (ii) regular prompting given by someone else in the claimant's presence.

### 16. Chewing or swallowing food or drink

- A. Cannot chew or swallow food or drink, or
- B. Cannot chew or swallow food or drink without repeatedly stopping, experiencing breathlessness or severe discomfort, **or**
- C. Cannot chew or swallow food or drink without repeatedly receiving regular prompting given by someone else in the claimant's presence, or
- D. Owing to a severe disorder of mood or behaviour, fails to: (i) chew or swallow food or drink, or (ii) chew or swallow food or drink without regular prompting given by someone else in the claimant's presence.

# APPENDIX 3. Capability for work questionnaire: advice and examples

Here we look at some of the activity headings in the questionnaire in more detail and provide some example responses. The headings used here are sometimes worded differently to those in Appendices 1 and 2, where we give the exact wording of the law.

#### Activities 1–10 cover physical functions.

# Moving around and using steps (Activity 1 in Appendix 1)

This includes using aids like crutches, a walking stick or a manual wheelchair (but not an electric wheelchair), if you normally or could reasonably use them. So if, for example, you can't use crutches or a stick because it would be too painful or difficult, or if you don't use a manual wheelchair because it wouldn't make getting around any easier, then you should explain why.

Most people with Parkinson's experience problems with moving around. You may not be able to physically move, or may feel so tired from doing so that you need to stabilise yourself by leaning on furniture. You may feel so sick, exhausted and 'off' that you often have to lie down.

#### **Example response:**

"On most days, I can stand and move using walking sticks and manage about 20 to 30 metres, before I need to stop due to tiredness. I then need to sit down for five to 10 minutes. My condition changes from day to day, and sometimes I can't move very well at all. I fall often if I don't use my walking sticks, and my balance is badly affected."

# Picking up and moving things (Activity 4 in Appendix 1)

This looks at your ability to pick up and move light objects (such as a carton of liquid or an empty cardboard box). You may have a tendency to drop such things, due to poor grip or tremor. If you have dropped items like this in the past, write down what happened. This way, you may be able to show that you can't do the task in question reliably.

#### **Example response:**

"My grip in both hands is poor, and on most days I have tremor. Trying to drink a glass of juice at mealtimes can be very difficult and I often end up spilling most of it."

### Manual dexterity (Activity 5 in Appendix 1)

This test is assessing whether you can manage the tasks with either hand. Some people with Parkinson's may have problems with their grip and fine finger movements. Tremor can also cause problems with manual dexterity.

### **Example response:**

"Because of my tremor I can't use my computer anymore. I press the wrong keys and end up typing nonsense. I can't use the mouse, and keep managing to delete anything I have typed. My daughter tells me she can't read my handwriting."

# Communicating – speaking, writing and typing (Activity 6 in Appendix 1)

This may be relevant if your condition affects your speech and you also have difficulties in writing or typing.

It asks if you can convey a simple message through any of these means. So, if you think this applies, you should give details of all your difficulties with speech, writing, typing and any other means (for example, texting on a mobile phone), explaining why this is difficult. Even if you've already mentioned dexterity problems in Activity 5, you should mention them here too, as each stage of the test is assessed separately.

#### **Example response:**

"I find verbal communication very difficult. My voice is very quiet and sometimes my speech is slurred. I also find it hard to type or write because of a physical tremor."

# Controlling your bowels or bladder and using a collecting device (Activity 9 in Appendix 1)

Some people with Parkinson's will develop problems with their bladder and bowels, such as incontinence. Some people may also have problems reaching the toilet in time, due to difficulties with movement. Some people with Parkinson's may need to use continence pads, or need someone to help them go to the toilet.

### **Example response:**

"I have a lot of difficulty with bladder and bowel problems. I have to visit the toilet several times during the night. This can be incredibly difficult, because sometimes I can't move quickly enough to get to the toilet on time and I have an accident. My daughter needs to clean up afterwards. She needs to do this about once a week."

# Activities 11–17 cover mental, cognitive and intellectual functions.

Learning how to do tasks (Activity 11 in Appendix 1)

This might apply if you have memory problems.

### **Example response:**

"Parkinson's has caused me to have memory problems, so I have difficulty remembering instructions I have just been given. Even if someone tells me how to do something two or three times, I tend to forget. I need visual prompts, such as notices around the house to remind me to do everyday tasks. Learning anything beyond a simple task is now beyond me."

# Awareness of hazards or danger (Activity 12 in Appendix 1)

This may apply if your concentration has been affected, so you're less aware of potential risks. Mention any accidents you've had because of this and list any injuries you sustained as a result. Also, if you don't try certain activities because of the risks, then say so and explain why.

#### **Example response:**

"My mind tends to wander and I can forget that I have started doing something. I left a pan of beans on the hob last month and it burnt dry. Fortunately a neighbour noticed before fire took hold. Three weeks ago I turned on the bath taps and flooded the bathroom. My daughter comes round several times a week now, to ensure I am safe."

# Coping with social situations (Activity 16 in Appendix 1)

Some people with Parkinson's may get extremely anxious or distressed meeting people and may need constant support to engage. This may be due to cognitive issues, such as dementia.

#### **Example response:**

"Anxiety is a symptom of Parkinson's and I experience this quite often, especially when in crowds of people.

Because I often 'freeze' this makes anxiety a lot worse, so social situations are difficult for me. I have difficulty making facial expressions because of rigid facial muscles. This makes it difficult to express my emotions, and I am often misunderstood. I am no longer able to mix with people I don't know."

#### Eating and drinking (Activities 15 and 16 in Appendix 2)

This relates to your ability to get food and drink to your mouth without help and also your ability to chew and swallow food. It may be difficult to put food or drink to your mouth because of tremor or weakness. Some people with Parkinson's will need help to eat food or drink, because of swallowing problems, which can cause choking. They may also need prompting because of memory problems.

# **Example response:**

"I have problems eating because I have swallowing problems. This causes a fear of choking, so I don't eat unless I have help, this has led to weight loss. I need prompting and encouragement to help me eat and often need help to cut up food, as I find it difficult to grip cutlery."

# More information and support

#### Parkinson's nurses

Parkinson's nurses have specialist experience and knowledge of Parkinson's. They can:

- support people coming to terms with their Parkinson's diagnosis
- help people to manage their medication, so they get the best results and fewer side effects
- make referrals to other professionals such as speech and language therapists and physiotherapists

Some nurses are based in the community, such as your GP surgery. Others are based in hospital settings and clinics.

Talk to your GP or specialist for more details on speaking to a Parkinson's nurse.

# Parkinson's UK information and support

Whatever your journey with Parkinson's, you're not alone.

From the moment you or someone you care about is diagnosed, we have information and support for you.

Speak to one of our friendly expert advisers, including specialist Parkinson's nurses, care advisers, and benefits and employment advisers. We've got information and advice on all aspects of living with Parkinson's.

**Get help managing your diagnosis**. Our information packs, webinars, courses and support groups can help you and your loved ones understand your Parkinson's diagnosis and better manage your symptoms.

Read our up to date, reliable health information. Our website, booklets and magazines can help you better understand Parkinson's. They're full of tips and advice on managing your condition and supporting a loved one.

Find ways to get active, stay active and live well with Parkinson's. Whatever your fitness level, we'll help you find the right activities for you.

Connect with other people with Parkinson's, families, friends and carers. Across the UK, in your local area or online. We'll help you meet others who understand what you're going through, because they're going through it too.

#### Find out more

- Call our helpline on 0808 800 0303 or email hello@ parkinsons.org.uk to speak to an expert adviser.
- Visit parkinsons.org.uk/information-and-support to read our information or find support that's local to you.
- Call 0330 124 3250 or visit parkinsons.org.uk/orderprint-booklets to order free printed information.

# Thank you

Thank you very much to everyone who contributed to or reviewed this information.

Thanks also to our information review group and other people affected by Parkinson's who provided feedback.

**Feedback** 

If you have any comments or feedback about our information, please call **0800 138 6593**, email **feedback @parkinsons.org.uk**, or write to us at Parkinson's UK, 50 Broadway, London, SW1H 0BL.

If you'd like to find out more about how we put our information together, or be part of the team that reviews our health content, please contact us at healthcontent@parkinsons.org.uk or visit our website at parkinsons.org.uk/health-content.

### Can you help?

At Parkinson's UK, we are totally dependent on donations from individuals and organisations to fund the work that we do. There are many ways that you can help us to support people with Parkinson's.

If you would like to get involved, please contact our Supporter Care team on **0800 138 6593** or visit our website at **parkinsons.org.uk/donate**.

Thank you.

These pages have been left intentionally blank.



We're Parkinson's UK, the charity that's here to support every Parkinson's journey. Every step of the way.

Free confidential helpline 0808 800 0303 Monday to Friday 9am to 6pm, Saturday 10am to 2pm (interpreting available) Relay UK 18001 0808 800 0303 (for textphone users only) hello@parkinsons.org.uk | parkinsons.org.uk

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