

Attendance Allowance

If you have Parkinson's, you may have some concerns about how you'll manage financially. If you need help with your day-to-day needs, this can lead to extra costs. But there is some financial support available, so it's important to find out what benefits you're entitled to.

This sheet explains what Attendance Allowance is, who qualifies, how to claim and what information you need to supply when you claim.

What is Attendance Allowance?

If you're aged 65 or over and have an illness or disability, and you need help with personal care or someone to watch over you to make sure you are safe, you may be able to claim Attendance Allowance.

This benefit is for you, not for a carer (if you have one) and you don't need to have someone looking after you to qualify. If you have a carer, they may be able to claim Carer's Allowance or National Insurance contribution credits.

Find out more: see our information sheet *Carer's Allowance*.

Attendance Allowance is based on what help you need – not on the help you currently get. It doesn't matter whether you live alone, with other people or if you get a lot of help or a little.

The Attendance Allowance claim form is quite long, and can be difficult to complete because it deals with personal care issues. But it is worth taking the time to do it, because getting Attendance Allowance can significantly increase your weekly income.

If you need help filling out the form, you can call our free confidential helpline on **0808 800 0303** to be put in touch with your Parkinson's local adviser.

Do I qualify for Attendance Allowance?

You are eligible for Attendance Allowance if :

- you are aged 65 or over
- you have had care or supervision needs for the last six months (the 'waiting period')
- you have been living in the UK for two of the last three years and your immigration status doesn't prevent you claiming
- you are 'habitually resident' in the UK, **and**
- you satisfy one of the disability tests

What are the disability tests?

To get Attendance Allowance, you must show that you are so severely disabled physically or mentally (or both) that you need:

- care from another person several times throughout the day to help you with your 'bodily functions'. This can include matters such as getting in and out of bed, getting dressed and undressed, washing and other personal hygiene needs, going to the toilet, taking medication, eating, cutting up food, drinking and communicating with other people
- supervision (ie to be checked on or watched regularly – but not non-stop) throughout the day to ensure that you are safe and/or not a danger to other people
- care from another person at least twice each night, or for 20 minutes or more, to help you with your bodily functions (as described above), **or**
- another person to be awake and watch over you to make sure that you are safe or not a danger to other people, at least three times each night, or for 20 minutes or more each night

How much will I get from Attendance Allowance?

Attendance Allowance is paid at one of two weekly rates, depending on the amount of help you need:

- The lower rate is £55.10 and applies if you need the above care or supervision throughout the day or the night.
- The higher rate is £82.30 and applies if you need care or supervision throughout the day and the night.

Special rules

If you are terminally ill, you can get the higher rate under 'special rules'. In this case, your doctor will need to confirm that you have a terminal illness and you are unlikely to live more than six months (they can do this using a DS1500 form, which they should keep at the surgery). There is no six-month waiting period for terminal illness. Under the special rules, someone else can apply on your behalf. Special rules claims are reviewed every three years.

If I apply for Attendance Allowance, will this affect other benefits I receive?

Attendance Allowance is not means-tested and may increase the amount of any means-tested benefits (such as Pension Credit) you receive. It can be paid in addition to any other social security benefits. However, although it is often ignored, your local authority may take Attendance Allowance into account when considering whether you need to contribute towards the cost of any care and support services you receive from them.

Attendance Allowance is not taxable. It is not based on National Insurance contributions and any income or savings you may have do not affect it.

Can I claim Attendance Allowance alongside Disability Living Allowance?

No. If you already get Disability Living Allowance or Personal Independence Payment, you will continue to receive that benefit and you won't be able to claim Attendance Allowance.

How will my Attendance Allowance be paid to me?

Attendance Allowance is normally paid every four weeks directly into a bank, building society or Post Office card account.

Find out more: if you don't have a bank account, see our information sheet *General information about benefits*. This explains how to get a bank account.

What if I go into hospital?

If you go into hospital, your Attendance Allowance will stop when you have been there for a total of four weeks (either in one stay, or several stays, where the gaps between stays are no more than four weeks each time). It can restart when you return home.

What if I go into a care home?

If you pay your own fees for the care home without help from the local authority or health service, your Attendance Allowance can continue to be paid. If the local authority helps with the fees, or a nursing home is paid for by the health service, your Attendance Allowance will stop after a total of four weeks (either in one stay, or several stays, where the gaps between stays are no more than four weeks each time). It can restart when or if you are able to return home.

How long is Attendance Allowance awarded for?

Attendance Allowance may be awarded to you for an indefinite period or for a fixed period of time. If it is for a fixed amount of time, then you will normally be sent a renewal claim form four months before your existing claim runs out.

How do I claim Attendance Allowance?

You will need the claim form AA1A. If you live in England, Scotland or Wales, you can request the form by calling the Attendance Allowance helpline on **0345 605 6055** (Textphone **0345 604 5312**) or by downloading one from **www.gov.uk/attendance-allowance/how-to-claim**

In Northern Ireland call **028 9090 6178** (Textphone **028 9031 1092**) or visit **www.nidirect.gov.uk/attendance-allowance-eligibility**

If the Attendance Allowance helpline sends you the claim form, it will be stamped with the date you asked for it. If Attendance Allowance is awarded to you, it will be paid from this date as long as you return the claim form within six weeks.

Once you have sent off the claim form, the Department for Work and Pensions may contact your GP, specialist or Parkinson's nurse (if you have one) for further information, or it may send one of its doctors to your home to assess you before they approve your claim.

When can I make a claim?

You must have been in need of care or supervision for six months before you can start getting Attendance Allowance. You can make your claim during this six-month waiting period, but the benefit will not be paid until it has ended. If you apply under the special rules for terminal illness, there is no six-month waiting period.

Tips for making a claim

- Use an up-to-date claim form.
- Make a photocopy of the claim form once you have completed it. Keep this safe.
- You normally have six weeks, so take your time filling in the claim form – try to get help if you need it (see page 7 for details of how to contact your Parkinson's local adviser).
- Don't be afraid to write too much and add extra pages if you need to – just remember to write your name and National Insurance number on each of them.
- Don't underestimate your needs. If you have a carer, think about what it would be like without them. If you manage on your own, don't be afraid to make it clear how difficult it is for you.
- If a doctor visits you, try not to feel uncomfortable or be rushed into making hasty comments, such as, "I can manage by myself". Keep in mind why you are applying for this benefit. If you live by yourself, you may not have the choice but to manage by yourself – but if you had help you may be able to do things more effectively, or quicker, or without risk or pain. Let the doctor know if this is the case.
- Your condition may change through the day. It is important that you record this information when you complete the claim form.
- If your condition changes from day to day, explain what you are like on an average or typical day, but also include what you are like on both a good and bad day too. Write down how often both good and bad days occur (for instance, "I have bad days around four days each week").

Take some time to think about how Parkinson's affects you. It may be helpful to ask yourself the following questions:

- Is dressing a problem?
- Is bathing or showering difficult?
- Do you need help cutting toe or fingernails?
- How do you get out of bed?
- Do you find it difficult to start moving?
- Do you fall or stumble sometimes? If so, is it difficult to get up again?
- Do you need someone with you when you go outside?
- Does your condition change through the day?
- Do you have times during the day when you go 'off'?
- What is your handwriting like?
- What is your speech like? Do people find it difficult to understand you?

It may also help to keep a daily diary of your care needs.

Find out more: see our information sheet *Keeping a diary: people with Parkinson's*.

Write down in the claim form any changes you've had to make to your routine because of your condition. For example, you may have difficulty putting on make-up, wearing jewellery or tying a tie.

If a woman wears lipstick and has problems applying it, she may give up wearing it. But why should she if that is part of her appearance? This needs to be mentioned in the claim form.

A man may want to wear a tie every day because he does not feel properly dressed without one. The problem is doing up the tie. He may need help because he struggles to do it himself. This also needs to be mentioned.

You may now wear a different style of clothing. This may be because you find it easier to cope with. If this is the case, always say so in the claim form and explain why you now wear a particular garment. For example, you may wear a sweatshirt without buttons rather than a cardigan because it is easier to manage.

What if I am refused Attendance Allowance?

If you feel that you have wrongly been refused Attendance Allowance, it is worth asking the Department for Work and Pensions for a 'mandatory reconsideration' of its decision. You have one month from the date of the decision to do this. You can ask for a mandatory reconsideration over the phone but it is best to confirm your request in writing.

It would help if you were to get a letter from your GP, specialist or Parkinson's nurse, pointing out what your care needs are. The letter may simply state that they have read your diary of your care needs and they agree that your condition creates those needs.

If you have asked for a mandatory reconsideration and the Department for Work and Pensions doesn't change its decision, you have another month to lodge an appeal to an independent tribunal. To do this, fill in form SSCS1, available at www.gov.uk/social-security-child-support-tribunal/appeal-tribunal. If you can't download the online form, you can get a paper copy from Citizens Advice or another advice agency.

Try to get help with your appeal. There are some organisations that can offer help and advice (some for free) with your appeal, such as Citizens Advice, local welfare rights groups or local solicitors.

What if there is a change in my condition?

If you receive the lower rate of Attendance Allowance and your condition progresses, you can ask the Department for Work and Pensions to look at your claim again and consider the higher rate – if, for example, you need help during both the day and the night or if you develop a terminal illness.

Before putting in your request, try to get some advice and information about the process. If the Department for Work and Pensions receives information that shows your care needs have reduced, then your benefit may be withdrawn.

Before asking for a review, you should consider how your needs have increased on a daily basis. What extra support and help do you need now that you did not need when you first claimed Attendance Allowance? As mentioned before, keeping a diary of your care needs may help you with this.

It is important to get medical support before you ask for a review. A letter from your GP, specialist or Parkinson's nurse, that points out what your current care needs are, will help. The letter may simply say that they have read the diary of your care needs and they agree that your condition would create those needs.

When you ask for a review, you need to contact:

Attendance Allowance Unit (for England, Scotland and Wales)

0345 605 6055

Textphone **0345 604 5312**

Disability and Carers Service – Attendance Allowance (for Northern Ireland)
028 9090 6178

You will normally be sent a review form to complete.

If your condition improves, you also need to get in touch with the Department for Work and Pensions (on one of the above numbers) as soon as you can. They will normally send you a review form to complete, so they can re-assess your award.

It is always important to provide full, accurate information to the Department for Work and Pensions, and to let them know if your circumstances change.

More information and support

For more information on rights and benefits, you can contact the Parkinson's UK helpline on **0808 800 0303** (calls are free from UK landlines and most mobile networks) or email **hello@parkinsons.org.uk**

We also have information sheets on other benefits you may be entitled to. You can download these from our website at **parkinsons.org.uk/publications** or call our helpline.

We run a peer support service if you'd like to talk on the phone with someone affected by Parkinson's who has faced similar issues to you. The service is free and confidential – ring the helpline to talk to someone about being matched with a volunteer.

Our helpline can also put you in touch with one of our Parkinson's local advisers, who give one-to-one information and support to anyone affected by Parkinson's. They can also provide links to local groups and services.

We also have a self-management programme for people with Parkinson's, partners and carers. It is an opportunity to reflect on life with the condition, learn about self-management and think about the future. To find out if there is a group near you visit **parkinsons.org.uk/selfmanagement**

Our website **parkinsons.org.uk** has a lot of information about Parkinson's and everyday life with the condition. You can also find details of your local support team and your nearest local group meeting at **parkinsons.org.uk/localtoyou**

You can also visit **parkinsons.org.uk/forum** to speak with other people in a similar situation on our online discussion forum.

Parkinson's nurses

Parkinson's nurses provide expert advice and support to people with Parkinson's and those who care for them. They can also make contact with other health and social care professionals to make sure your needs are met.

The role of the Parkinson's nurse varies. Each will offer different services, aiming to meet local needs. Some nurses are based in the community, whereas others are based in hospital settings.

Many Parkinson's nurses are independent prescribers. This means they can prescribe and make adjustments to medication, so someone with Parkinson's doesn't always need to see their specialist for changes to or queries about their Parkinson's drugs.

Parkinson's nurses may not be available in every area, but your GP or specialist can give you more details on local services.

You can find out more at **parkinsons.org.uk/nurses**

Thank you

Thank you to Disability Rights UK for updating this information sheet. Disability Rights UK also have a wide range of online factsheets relating to disability-related issues including Access to Work, education, the Blue Badge scheme, independent living and disabled facilities grants.

Visit their website: www.disabilityrightsuk.org



Attendance Allowance (2016)

If you have comments or suggestions about this information sheet, we'd love to hear from you. This will help us ensure that we are providing as good a service as possible. We'd be very grateful if you could complete this form and return it to **Editorial and Creative Services, Parkinson's UK, 215 Vauxhall Bridge Road, London SW1V 1EJ**. Or you can email us at publications@parkinsons.org.uk. Thanks!

Please tick...

- ☐ I have Parkinson's. When were you diagnosed?
- ☐ I'm family/a friend/a carer of someone with Parkinson's
- ☐ I'm a professional working with people with Parkinson's

Where did you get this information sheet from?

- | | |
|--|--|
| <input type="checkbox"/> GP, specialist or Parkinson's nurse | <input type="checkbox"/> Parkinson's local adviser |
| <input type="checkbox"/> Parkinson's UK local group or event | <input type="checkbox"/> Ordered from us directly |
| <input type="checkbox"/> Our website | <input type="checkbox"/> Other |

How useful have you found the information sheet? (1 is not useful, 4 is very useful) ☐ 1 ☐ 2 ☐ 3 ☐ 4

Have you found the publication easy to read/use? ☐ Yes ☐ No

What aspects did you find most helpful?

Were you looking for any information that wasn't covered?

Do you have any other comments?

If you would like to become a member of Parkinson's UK, or are interested in joining our information review group, please complete the details below and we'll be in touch.

- ☐ Membership ☐ Information review group (who give us feedback on new and updated resources)

Name

Address

Telephone Email

What is your ethnic background? ☐ Asian/Asian British ☐ Black/Black British ☐ White

☐ Mixed/multiple ethnic backgrounds ☐ Other (please specify)

**We're the Parkinson's charity that drives better care, treatments and quality of life.
Together we can bring forward the day when no one fears Parkinson's.**

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 Services team on **020 7932 1303** or visit our website at **parkinsons.org.uk/support**. Thank you.

Parkinson's UK

Free confidential helpline **0808 800 0303**

Monday to Friday 9am–7pm, Saturday

10am–2pm. Interpreting available.

Text Relay **18001 0808 800 0303**

(for textphone users only)

hello@parkinsons.org.uk

parkinsons.org.uk

How to order our resources

0845 121 2354

resources@parkinsons.org.uk

Download them from our website

at **parkinsons.org.uk/publications**

We make every effort to make sure that our services provide up-to-date, unbiased and accurate information. We hope that this will add to any professional advice you receive and will help you to make any decisions you may face. Please do continue to talk to your health and social care team if you are worried about any aspect of living with Parkinson's.

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