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Pulmonary fibrosis and benefits

A short guide to UK social security benefits for
people with pulmonary fibrosis



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Introduction

Living with pulmonary fibrosis (PF) can bring extra costs and challenges. But there is support available to help you. This guide explains the different benefits you may be able to get, depending on your circumstances. You'll also find details of where to get further information and support.



Here to help...

If you need this information in a different format such as large print, easy read or another language, please contact us.



Contact our support team:

✉ support@actionpf.org 📞 Support Line: 01223 785725

Personal independence payment

About the benefit

Personal independence payment (PIP) is a benefit you can get if you are:

- between the age of 16 and pension age, **and**
- need help taking part in everyday life or find it difficult to get around.

PIP applies in England, Northern Ireland and Wales.

PIP is tax-free, and you do not need to have paid National Insurance contributions to get it. PIP is not affected by any earnings or other income you get. Nor is it affected by any capital or savings you have. You can get PIP whether you are in or out of work.

It is almost always paid in full, in addition to any other benefits that you get.

PIP is not paid simply because you have PF. It's paid because of the effect that your PF symptoms have on your everyday life.

PIP acts as a 'passport' for other types of help, such as the Motability scheme if you get the enhanced rate of the mobility component.

PIP comes in two parts:

- a daily living component – for help taking part in everyday life, and
- a mobility component – for help with getting around.

Each component has two rates: a 'standard rate' and an 'enhanced rate'. Whether you are paid either component, and at which rate, is tested under the PIP assessment.

Personal independence payment (continued)

The PIP assessment

The PIP assessment works on a points system. It looks at how well you can complete everyday tasks. These tasks come under 12 'activity headings' related to your daily living needs and your mobility.

Each activity heading has a list of examples (called 'descriptors'). The descriptors explain related tasks with different levels of difficulty, and different types of help you may need to complete a task. These descriptors have scores ranging from 0 to 12 points. You score points when you are not able to complete a task:

- safely
- to an acceptable standard
- repeatedly, and
- in a reasonable time.

So, the more help you need, the more points you get.

Points scored	PIP rate entitlement (of either component)
8 to 11	Standard rate
12 or more	Enhanced rate

How do you claim

In England, Scotland and Wales:

📞 Call **0800 917 2222**

In Northern Ireland:

📞 Call **0800 012 1573**

Find out more

To find out more about PIP, read **Personal Independence Payment: A Guide to Making a Claim.**

It's free to download at

📄 www.disabilityrightsuk.org/resources/personal-independence-payment-pip

The guide gives details of all the activities in the PIP assessment and the points that you can get for each 'descriptor'.

Turn2us have made a free PIP Helper tool: 📄 www.pip.turn2us.org.uk



Adult disability payment

About the benefit

Adult disability payment (ADP) is a benefit you can get if you:

- live in Scotland
- are between the age of 16 and pension age, **and**
- need help taking part in everyday life or find it difficult to get around.

It has replaced PIP in Scotland, and is a similar benefit.

How do you claim

📄 Claim online at www.mygov.scot/adult-disability-payment/how-to-apply

📞 Call Social Security Scotland **0800 182 2222**

Find out more

To find out more about ADP, read **Adult Disability Payment: A guide to the benefit.**

It's free to download at

📄 www.disabilityrightsuk.org/resources/adult-disability-payment-scotland

Attendance allowance

About the benefit

Attendance allowance is a benefit you can get if:

- you have reached pension age (currently 66), **and**
- because of your condition, you need help with personal care or supervision to keep safe.

It applies in England, Northern Ireland and Wales.

Attendance allowance is tax-free, and you don't need to have paid National Insurance contributions to get it.

Attendance allowance is not affected by any earnings or other income you get. Nor is it affected by any capital or savings you have. It's almost always paid in full, in addition to any other benefits that you get.

Attendance allowance is for you, not for a carer. You can get attendance allowance whether or not you have someone helping you. What matters is the effect your condition has on you and the help you need, not whether you actually get that help. You can spend your attendance allowance on anything you like.

Find out more

To find out more about attendance allowance, see the Disability Rights UK resource: www.disabilityrightsuk.org/resources/attendance-allowance

Attendance allowance has two rates:

- A lower rate - you get the lower rate if your needs are limited to just the day or just the night.
- A higher rate – you get this if your needs are spread throughout the day and the night.

How do you claim

To get an attendance allowance claim form:

In **England, Scotland and Wales:**

- ☎ Call **0800 731 0122**
- 📄 Download a form or apply online at www.gov.uk/attendance-allowance/how-to-claim

In **Northern Ireland:**

- ☎ Call **0800 587 0912**
- 📄 Download a form or apply online at www.nidirect.gov.uk/articles/attendance-allowance

Keeping a diary

Writing a short diary of your day-to-day needs can help support your claim for attendance allowance. The diary can be a reminder of the help you need. It can be easy to forget the help you need because it's a part of your everyday life.

The diary can also be important when trying to explain needs that change either during a single day or over a longer period. The simplest form of diary would be a record of your needs in a typical day.

Start from the time you get up in the morning and record what happens for 24 hours. End with the time you get up the following morning. List all the times when you need help from someone or you have difficulties doing something because there is no one around to help.

When you write something down, try to answer the following questions:

- what help do you need?
- why do you need the help?
- at what time do you need help?
- how long do you need the help for?



If your needs vary from day to day, keep the diary over a few days to get a clearer picture of your needs.

Once you have finished the diary, write your name and National Insurance number on it and make several copies of it.

Attach a copy to the claim form and keep a copy for yourself. You should send copies of the diary to anyone else listed on the claim form, such as your respiratory doctor, nurse or GP.

Pension age disability payment

About the benefit

Pension age disability payment is a benefit you can get if you:

- live in Scotland,
- have reached pension age, **and**
- because of your condition, you need help with personal care or supervision to keep safe.

It has replaced attendance allowance in Scotland and is a similar benefit.

How do you claim

📄 Claim online at www.mygov.scot/pension-age-disability-payment/how-to-apply

☎ Call Social Security Scotland
0800 182 2222

If you are nearing the end of your life

If you are nearing the end of your life because of your condition, 'special rules' can apply to your disability benefit claim. This can ensure your claim is processed quickly.

For personal independence payment (PIP) and attendance allowance, you can apply under the special rules if you:

- have a progressive disease, and
- as a result, your death can reasonably be expected within 12 months.

Ask your doctor, consultant or specialist nurse to complete an SR1 form. This form will provide the evidence that you are eligible to apply under the special rules.

If the Department for Work and Pensions accepts that you are nearing the end of your life, you will automatically get either:

- the enhanced rate of the PIP daily living component, or
- the higher rate of attendance allowance.

For adult disability payment (ADP) and pension age disability payment (PADP), you can apply under the special rules if you are terminally ill. You are considered to be terminally ill if, in the judgment of a doctor, consultant or nurse who is involved in your care, you have a progressive disease which can reasonably be expected to cause your death. Ask your doctor, consultant or nurse to complete a BASRiS form.

For ADP, if Social Security Scotland accepts that you are terminally ill, you will automatically qualify for the enhanced rate of the daily living component. If you have not reached pension age, you will also get the enhanced rate of the mobility component. For PADP, you will automatically get the higher rate of that benefit.



Carer's allowance

The person caring for you may be able to claim carer's allowance if:

- you get the daily living component of personal independence payment or, adult disability payment, or you get attendance allowance, or, pension age disability payment **and**
- they regularly spend at least 35 hours a week caring for you.

They don't need to be living with you or related to you.

Carer's allowance applies in England, Northern Ireland and Wales.

To apply for carer's allowance in **England and Wales:**

📄 Apply online at www.gov.uk/carers-allowance/how-to-claim

📄 Download a claim form from www.gov.uk/government/publications/carers-allowance-claim-form

☎ Request a claim form by calling
0800 731 0297

To apply for carer's allowance in **Northern Ireland:**

📄 Apply online at www.nidirect.gov.uk/services/apply-carers-allowance-online

☎ Request a claim form by calling
0800 587 0912

Find out more

To find out more about carer's allowance, see the Disability Rights UK resource: 📄 www.disabilityrightsuk.org/resources/carers-allowance

Carer support payment

Carer support payment has replaced carer's allowance in Scotland. It's a similar benefit.

To claim carer support payment:

📄 Apply online or download a claim form at www.mygov.scot/carers-support-payment/how-to-apply

☎ Call Social Security Scotland on **0800 182 2222**

Find out more

To find out more about carer support payment, see the Disability Rights UK resource:

📄 www.disabilityrightsuk.org/resources/carers-support-payment-scotland



Unable to work?

Statutory sick pay

If you work for an employer and have to take time off because of your condition, you may be entitled to statutory sick pay (SSP). This is paid by your employer. It's a set rate that is paid for up to 28 weeks.

You don't need to have paid National Insurance contributions to get it, but you must earn at least £125 a week (from April 2025). You may be able to top up SSP with universal credit if your income is low (see page 15).



Employment and support allowance

About the benefit

If your ability to work is limited by your condition, you may be able to get employment and support allowance (ESA). You must have paid enough National Insurance contributions over recent years to be entitled to it.

How do you claim

In **England, Scotland and Wales:**

🔗 Online at www.gov.uk/employment-support-allowance/how-to-claim

☎ Call **0800 055 6688**

In **Northern Ireland:**

🔗 Online at www.nidirect.gov.uk/services/claim-new-style-employment-and-support-allowance

☎ Call **0800 085 6318**

If you find ESA is not enough to live on, you may be able to get it topped-up with universal credit (see page 15).

Find out more

To find out more about ESA and the work capability assessment, see the Disability Rights UK resource: 🔗 www.disabilityrightsuk.org/resources/new-style-employment-and-support-allowance

The work capability assessment

Once you have claimed ESA, you will need to take part in a ‘work capability assessment’. This assessment will decide:

- what level of ESA you get,
- whether it will be paid indefinitely (in other words, it will continue until further notice) or for just 12 months, **and**
- whether or not you need to take part in activities to help you get back into work.

The assessment involves completing the ‘capability for work questionnaire’ form. You may also be asked to take part in an assessment with a health worker.

The work capability assessment also applies to universal credit, the benefit we look at on page 15.

Universal credit

About the benefit

Universal credit is a benefit paid to people of working age who are on a low income. You may be able to claim universal credit if you are:

- looking for work
- unable to work because of your condition
- a lone parent
- caring for someone, or
- working and your wages are low.

Universal credit provides for your basic living expenses. If you are a single person, you can claim it to cover just your needs. If you have a family, you can claim to also cover their needs. It can be paid on its own if you have no other income, or it can top-up other benefits or earnings.

How do you claim

You are expected to claim universal credit online if you can, at 🔗 www.gov.uk/universal-credit/how-to-claim

When you do so, you will set up an online account. You can use this to keep in touch with the officer dealing with your universal credit claim: your ‘work coach’.

If you need help with your claim

If you need help with the claim, or need to make a telephone claim instead, you can call the universal credit helpline (**0800 328 5644**). This can be difficult to get through to.

You can also use the Citizens Advice ‘Help to Claim’ service

🔗 www.citizensadvice.org.uk/helptoclam

☎ England: **0800 144 8444**

☎ Wales: **08000 241 220**

☎ Scotland: **0800 023 2581**

If your condition means that your ability to work is limited, you will need to get a ‘fit note’. You can get this from:

- your GP, or
- another healthcare professional treating you

You will need to give the fit note to the Department for Work and Pensions. You will then be asked to take part in a ‘work capability assessment’ (see page 14). This assessment will decide:

- if you can get an extra amount paid in your universal credit award, and
- what work-related responsibilities, if any, you must meet to keep getting the full benefit.

Universal credit (continued)

Once you have claimed universal credit, you will need to book an interview with your work coach. This is to discuss the work available to you and the support you need.

Claiming universal credit if you are nearing the end of your life

If your doctor or another medical professional says you might have 12 months or less to live, you can tell the Department for Work and Pensions (DWP) when you apply for universal credit. Ask your GP, consultant or specialist nurse for an SR1 form. Send this completed form to the DWP. It allows them to process your claim more quickly.

If the DWP accepts that you are nearing the end of your life:

- you will not have to do any work-related activities to continue getting universal credit in full, and
- you will get an extra amount paid in your universal credit award



Payments

Universal credit is normally paid once a month into a bank, building society or credit union account. If you are waiting for your first payment and cannot afford the things you need, you can ask for an advance payment. This will have to be repaid.

If you owe money to the Department for Work and Pensions (DWP) money can be taken from your universal credit award to repay the debt. Money can also be taken if you owe money elsewhere, e.g. rent to your landlord. If this leaves you without enough money, you can ask the DWP to take less.

If you need help paying for one-off costs, such as household items, you can ask the DWP for a 'budgeting advance'. This also must be repaid.

Help with your rent

If you have to pay rent, an amount can be included in your universal credit award to help cover this. This amount may be reduced if it is decided that your home has more bedrooms than you need (sometimes known as the 'bedroom tax').

Find out more

To find out more about universal credit, read **Universal Credit: A Guide for Disabled Claimants**, free to download at:

www.disabilityrightsuk.org/resources/universal-credit

Retirement

State pension

You can claim State Pension at pension age (currently 66), whether or not you continue working. It's based on the National Insurance contributions that you have paid over the years.

Find out more

To find out more about the state pension, go to:

www.gov.uk/new-state-pension



Pension credit

If you are on a low income, you may be able to get your state pension topped-up with 'pension credit'. To claim, you must have reached pension age. If you have a partner, you must both have reached pension age.

Pension credit acts as a 'passport' for other types of help, such as:

- housing benefit towards your rent (contact your local authority for details),
- council tax reduction towards your council tax (contact your local authority), and
- budgeting loans from the social fund to cover one-off costs (see www.gov.uk/budgeting-help-benefits).

How to claim pension credit

To make a claim over the phone or get a claim form sent to you, call 0800 99 1234.

You can apply online if you have already claimed state pension. To apply online, go to: apply-for-pension-credit.dwp.gov.uk/start

Find out more

To find out more about pension credit, go to:

www.gov.uk/pension-credit

If your condition was caused by your job

Industrial injuries disablement benefit

If your condition was caused by your job, you may be entitled to industrial injuries disablement benefit (IIDB). This may be paid if your diagnosis is on a list of diseases that are linked to a certain working environment that you worked in. For example:

- if it has been diagnosed that your pulmonary fibrosis is a result of pneumoconiosis, **and**
- this was caused by you working in a dusty environment

IIDB is tax-free. You don't need to have paid National Insurance contributions to get it. IIDB is not affected by any earnings or other income you get. Nor is it affected by any capital or savings you have. You can get IIDB whether you are in or out of work.

How to claim IIDB

📞 Call **0800 121 8379**

🔗 Visit www.gov.uk/industrial-injuries-disablement-benefit/how-to-claim

Find out more

To find out more about IIDB, go to:

🔗 www.gov.uk/industrial-injuries-disablement-benefit

Lump sum payments

If you get IIDB for a listed disease, you may also be entitled to a government lump sum payment. These are paid under the Pneumoconiosis etc. (Workers' Compensation) Act.

Find out more

To find out more about the lump sum payments, go to:

🔗 www.gov.uk/industrial-injuries-disablement-benefit/further-information

Further help and information

The Motability scheme

The scheme allows you to exchange the mobility component of your benefit (personal independence payment or adult disability payment) to lease a car, powered wheelchair or scooter.

The Blue Badge scheme

The Blue Badge scheme allows people with severe mobility problems and those with certain other conditions or disabilities to park close to places they wish to visit. Contact your local authority for details.

Disabled Person's Railcard

You can buy a Disabled Person's Railcard which entitles you and a companion to one-third off the cost of most train journeys.

📞 **0345 605 0525**

🔗 www.disabledpersons-railcard.co.uk

Health benefits

The NHS generally aims to provide free health care. Charges are made, however, for things like prescriptions (in England), dental treatment and dentures, sight tests and vouchers for glasses.

In some circumstances, you may be exempt from these charges, including if you get universal credit (if you work, there are earnings limits) and the guarantee credit of pension credit. Charges may also be fully or partially reduced if you are on a low income.

🔗 www.nhsbsa.nhs.uk/nhs-help-health-costs

The Department for Work and Pensions

🔗 www.gov.uk/government/organisations/department-for-work-pensions

Social Security Scotland

📞 **0800 182 2222**

🔗 www.mygov.scot/browse/benefits/social-security-scotland

Finding a local advice centre

If you need help making a claim for a benefit or with appealing against a decision, you can contact a local advice centre. There may be times when seeing someone locally will be the best option to ensure you get good advice. You may want to use 🔗 www.advicelocal.uk to get advice in your area.

Action for Pulmonary Fibrosis
is a patient-driven charity.

Our vision is to **stop** pulmonary
fibrosis so that everyone
affected has **a better future.**



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