



**Action for
Pulmonary
Fibrosis**

Pulmonary fibrosis and benefits

A short guide to social security benefits
for people affected by pulmonary fibrosis

www.actionpf.org



Contents

This guide is for people who have a diagnosis of pulmonary fibrosis, or who care for someone with a diagnosis, living in England, Scotland, Wales or Northern Ireland.

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Here to help...

The APF support line is here for anyone affected by pulmonary fibrosis, whether you have a diagnosis yourself or know someone who does. The support line is answered by a team of staff and volunteers with a range of different skills and experiences. We're here to offer information, signposting, or a friendly ear when you need one.

You can also find information on our website. We have a growing library of resources on different aspects of life with pulmonary fibrosis, from carer's assessments to cough management.

Contact our support team:
support@actionpf.org



Support line:
01223 785725

Follow us on socials:



Introduction

If you are affected by pulmonary fibrosis, there are a number of different benefits that you can claim.

Whether you are in or out of work, you may be able to claim personal independence payment to cover the extra costs that result from your condition; in Scotland, you can claim adult disability payment. If you have reached pension age, then attendance allowance may be claimed instead. If you have a carer, they could consider claiming carer's allowance. These benefits are described on page 6 and 7.

The benefits that you can claim if you are not able to work because of your condition are described on page 10. Page 12 explains universal credit, the benefit paid to people of working age who are on a low income. Finally, on page 14, we look at the benefits that you can claim once you have reached pension age.

At the end of this guide, we give details of where to go if you need further help or information.

Disability benefits

Personal independence payment

ABOUT THE BENEFIT

Personal independence payment (PIP) is a benefit for people in England, Northern Ireland and Wales between the age of 16 and pension age who need help taking part in everyday life or who find it difficult to get around.

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 acts as a 'passport' for other types of help, such as the Motability scheme.

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.

HOW DO YOU CLAIM?

To start a claim for PIP, phone 0800 917 2222 or, in Northern Ireland, phone 0800 012 1573.

Find out more

To find out more about PIP, read *Personal Independence Payment: A Guide to Making a Claim*, free to download at: www.disabilityrightsuk.org/resources/personal-independence-payment-pip

Adult disability payment

ABOUT THE BENEFIT

Adult disability payment (ADP) is a benefit for people in Scotland between the age of 16 and pension age who need help taking part in everyday life or who find it difficult to get around. It is replacing PIP in Scotland, and is a similar benefit.

HOW DO YOU CLAIM?

You can claim online at: www.mygov.scot/adult-disability-payment/how-to-apply. Alternatively, 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*, free to download at www.disabilityrightsuk.org/resources/adult-disability-payment-scotland

Carer's allowance

If you get the daily living component of personal independence payment or adult disability payment or you get attendance allowance, and someone is caring for you, that person may be able to claim 'carer's allowance'. They must regularly spend at least 35 hours a week caring for you. They do not need to be living with you, or be related to you.

You can apply for carer's allowance online at: www.gov.uk/carers-allowance/how-to-claim (or in Northern Ireland at: www.nidirect.gov.uk/services/apply-carers-allowance-online).

If someone gets carer's allowance for looking after you, this could affect your benefit. This will happen if you are

getting a means-tested benefit such as income-related employment and support allowance, and are getting a 'severe disability premium' as part of that benefit. You will lose the premium if someone is paid carer's allowance for looking after you. If you are getting universal credit, however, this is not affected by someone claiming carer's allowance. If you are in any doubt about whether your carer should claim carer's allowance, seek advice.

You get a claim-form by calling 0800 731 0297 (or 0800 587 0912 in Northern Ireland) or by downloading one from: www.gov.uk/government/publications/carers-allowance-claim-form

Find out more

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

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.

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 is 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. Attendance allowance has two rates: a lower rate and a higher rate.

HOW DO YOU CLAIM?

To get an attendance allowance claim-form, ring 0800 731 0122 or download one from the website (www.gov.uk/attendance-allowance/how-to-claim). To get a claim-form in Northern Ireland, ring 0800 587 0912 or download one from the website (www.nidirect.gov.uk/articles/attendance-allowance).

KEEPING A DIARY

Writing a short diary of your day-to-day needs can lend support to your claim for attendance allowance. The diary can be a reminder of the help you need, which you might otherwise forget because it is so much a part of your everyday life. It can also be important when trying to explain needs that fluctuate either during a single day or over a longer period. The simplest form of diary would be an account of your needs over a typical day.

Start from the time you get up in the morning, through a 24-hour period, ending 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 who you have listed on the claim-form, such as your respiratory consultant or nurse or your GP.

Find out more

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

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 to ensure that it is dealt with swiftly.

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.

If the Department for Work & 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)**, 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.

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



Unable to work?

Statutory sick pay

If you are working for an employer and you have to take time off work because of your condition, you may be entitled to Statutory Sick Pay. This is paid by your employer at a flat rate for up to 28 weeks. You do not need to have paid National Insurance contributions to get it, but you must earn at least £123 a week (from April 2023).

Employment and support allowance

ABOUT THE BENEFIT

If your ability to work is limited because of 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?

You can claim ESA online at: www.gov.uk/employment-support-allowance/how-to-claim. If you cannot claim online, you can call 0800 055 6688.

In Northern Ireland, you can claim ESA online at: www.nidirect.gov.uk/services/claim-new-style-employment-and-support-allowance. If you cannot claim online, you can 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 the next chapter.

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 or for just 12 months, and whether or not you need to take part in activities to help you move back into work. The assessment involves completing a form, the '*capability for work questionnaire*', and possibly taking part in an assessment with a health worker.

The work capability assessment also applies to universal credit, the benefit we look at in the next chapter.

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



Universal credit

ABOUT THE BENEFIT

Universal credit is a benefit paid to people of working age who are on a low income. You can claim it if you are looking for work, if you are unable to work because of your condition, if you are a lone parent, if you are caring for someone or if you are working and your wages are low.

Universal credit provides for your basic living expenses. You can claim it to cover just your needs if you are a single person, or those of your partner and/or children if you have a family. It can be paid on its own if you have no other income, or it can top up other benefits or earnings.

IF YOU NEED HELP WITH YOUR CLAIM

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

You can also use the Citizens Advice 'Help to Claim' service (www.citizensadvice.org.uk/help-toclaim – England: 0800 144 8444; Wales: 08000 241 220; Scotland: 0800 023 2581).

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 who is dealing with your universal credit claim: your 'work coach'.

If your condition means that your ability to work is limited, you will need to get a 'fit note' from your GP or from someone else who is treating you. Once you have given the fit note to the Department of Work & Pensions, you will be asked to take part in a 'work capability assessment' (see the previous chapter for details). The assessment will decide if you can get an extra amount paid in your universal credit award and what work-related responsibilities, if any, you need to meet to keep getting the benefit paid in full.

Once you have claimed universal credit, you will need to book an interview with your work coach so that you can discuss your work prospects and the support you need.



CLAIMING UNIVERSAL CREDIT IF YOU ARE NEARING THE END OF YOUR LIFE

If your doctor or another medical professional has told you that you might have 12 months or less to live, you can let the Department for Work & Pensions (DWP) know this when you apply for universal credit. Ask your GP, consultant or specialist nurse for an SR1 form, which you should send to the DWP so that they can deal with your claim more quickly.

If it is accepted that you are nearing the end of your life, you will not be expected to meet any work-related conditions 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 have difficulty budgeting at the start of your claim, you can ask for an advance payment, which you will have to repay.

If you owe money to the Department for Work & Pensions (DWP), deductions can be made from your universal credit award to recover the debt. Such deductions can also be made if you owe money elsewhere, eg rent to your landlord. If you are struggling because of these deductions, you can ask the DWP to reduce them.

If you have to pay for something that you need and would have difficulty budgeting for it, you can ask the DWP for a 'budgeting advance'.

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, the so-called '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 go on working. It is based on the National Insurance contributions that you have paid over the years.

Find out more

To find out more about state pension, go to www.gov.uk/new-state-pension

Pension credit

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

Find out more

To find out more about pension credit, go to www.gov.uk/pension-credit

To make a claim over the phone or get a form sent to you, call 0800 99 1234. You can apply online if you have already claimed state pension and there are no children or young people in your claim. To apply online, go to: www.apply-for-pension-credit.dwp.gov.uk/start

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).



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.

Telephone: 0300 456 4566
www.motability.co.uk

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.

Telephone: 0345 605 0525
www.disabledpersons-railcard.co.uk

Health benefits

The NHS generally aims to provide free health care. Charges are made, however, for such things as 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. A full or partial reduction of charges can also be made on the grounds of low income.

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

The Department for Work and Pensions

www.gov.uk/government/organisations/departments/departments-for-work-pensions

Social Security Scotland

Telephone: 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. Use advice.local 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.****

Here to help...

Email our support team:
support@actionpf.org



Support line:
01223 785725

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

General enquiries:

01733 839642
info@actionpf.org

www.actionpf.org

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Pulmonary
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