

**CROHN'S &
COLITIS UK**

**CLAIMING PERSONAL
INDEPENDENCE
PAYMENT**

A GUIDE
FOR ADULTS WITH
CROHN'S DISEASE OR
ULCERATIVE COLITIS

ABOUT THIS GUIDE

This guide is for people aged 16 to 64 with Inflammatory Bowel Disease - Ulcerative Colitis or Crohn's Disease - who are thinking about applying for Personal Independence Payment (PIP).

The guide explains what PIP is, who can qualify and how to apply. It includes information on how to increase your chance of a successful claim.

You may find this information helpful even if you do not think you will qualify for PIP. People sometimes miss out on benefits for years because they don't realise they are entitled to claim or don't think their claim will be successful. If you aren't sure whether you qualify for PIP, you could contact one of the organisations listed on page 38.

This guide does not include information on benefits for people younger than 16, or older than 64. If you would like to claim for someone younger, you may like to read our guide **Claiming Disability Living Allowance: A guide for children under 16 with Ulcerative Colitis and Crohn's Disease**. If you are 65 or over, you can apply for Attendance Allowance. You can find out more from the organisations listed at the end of this guide.

PLEASE NOTE: PIP is subject to change. This guide is not a full and authoritative statement of the law. The information in this guide is intended as general information only and is not intended to be relied upon by any individual in relation to their specific circumstances. It is not intended as a replacement for appropriate professional advice.

ABOUT CROHN'S AND COLITIS UK

We are Crohn's & Colitis UK, a national charity fighting for improved lives today – and a world free from Crohn's and Colitis tomorrow. To improve diagnosis and treatment, and to fund research into a cure; to raise awareness and to give people hope, comfort and confidence to live freer, fuller lives. We're here for everyone affected by Crohn's and Colitis.

This publication is available for free thanks to the generosity of our supporters and members. Find out how you can join the fight against Crohn's and Colitis: call 01727 734465 or visit crohnsandcolitis.org.uk.

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WHAT IS PERSONAL INDEPENDENCE PAYMENT?

PIP is a welfare benefit for adults with a disability or long-term condition, such as Inflammatory Bowel Disease (IBD). PIP helps to cover the extra costs you may face if your IBD makes it hard for you to get around or cope with daily living.

PIP has two parts, called the **daily living component** and the **mobility component**. You may qualify for one or both.

Your claim will be assessed using a points system. You can score points if you have difficulty carrying out certain activities, such as using the toilet or walking. You cannot score points just for having IBD - you need to show how your IBD affects your life. Whether you qualify for PIP, and how much you get, depends on the total number of points you score for all of the listed activities. You can read more about the points system on page 10.

How much could I get?

Whether you qualify for the daily living component, the mobility component or both depends on how your IBD affects you. Each component has two rates – a standard rate and an enhanced rate. The rate you get depends on how badly your IBD impacts your daily life. Your rate will be reviewed regularly to make sure you are receiving the right amount of help.

As of April 2018, the weekly rate for the daily living component of PIP is:

- Standard rate - £57.30
- Enhanced rate - £85.60

The weekly rate for the mobility component is:

- Standard rate - £22.65
- Enhanced rate - £59.75

These rates may be subject to change. You can find the current weekly rates for PIP on the DWP and DfC websites.

PIP is usually paid every four weeks into your bank, building society or credit union account. It is tax-free and you can get it whether or not you are working. You can claim PIP even if you have a high income or a high level of savings. It is paid on top of any other benefits you may be receiving, and it may mean you qualify for a top-up on some of your other benefits. You can read more about other benefits on page 34.

Who provides PIP?

The Department for Work and Pensions (DWP) is responsible for PIP in England, Wales and Scotland. Scotland is introducing a new Social Security System, which includes PIP, so there may be some changes to PIP in the future.

In Northern Ireland, the Department for Communities (DfC) is responsible for PIP. You can find contact details for the DWP and DfC at the end of this guide.

What happens if I am claiming Disability Living Allowance?

PIP is replacing Disability Living Allowance (DLA) for everyone aged 16 to 64.



If you get DLA, even if you have been awarded indefinite or lifetime DLA, you will need to transfer to PIP.

The DWP or DfC intends to write to you by mid-2019 to invite you to make a PIP claim. They will ask you to transfer from DLA to PIP if you were born after 8 April 1948 (20 June 1951 in Northern Ireland) and you are aged 16 or over. If you were born before this date, you will be able to carry on receiving DLA.

If you do not respond to the DWP or DfC when they invite you to claim PIP, your existing award of DLA will stop.

PIP and DLA have different qualifying conditions. This means that some people who currently get DLA will not qualify for PIP, and some who did not qualify for DLA may be able to get PIP. If you currently get DLA, you may get more money, the same amount or less money when you apply for PIP.

You cannot receive PIP and DLA at the same time.

COULD I QUALIFY FOR PIP?

To qualify for PIP, you will need to meet the conditions listed below. Many people tell us that they have struggled to get PIP or that their claims have not been successful. There is information on page 32 about what to do if your claim is turned down.

Age

You must be aged between 16 and 64 at the start of your claim. If you receive PIP before your 65th birthday, you can continue to receive it after you turn 65.

Children under the age of 16 may be able to apply for Disability Living Allowance. If you are aged 65 or over and you do not already get PIP or DLA, you may qualify for Attendance Allowance.

Residency and presence

You must:

- be living in England, Wales, Scotland or Northern Ireland when you apply for PIP **and**
- have lived in one of these countries for at least two of the last three years.

There are some exceptions to these rules, for example, if you are an Armed Forces member or family member.

If you have not spent two out of the last three years in the UK, it may be possible for time spent in another EU or EEA country, or Switzerland, to be taken into account.

If you are not a British citizen, you may be able to apply for PIP if you usually live in, or plan to settle in, the United Kingdom, the Republic of Ireland, the Isle of Man or the Channel Islands. You must not be subject to immigration control, unless you are a sponsored immigrant.

If you are not sure how your immigration status affects you or if you have recently spent a long time abroad, you may want to get advice from one of the organisations listed at the end of this guide.

IMPACT OF YOUR IBD

You will need to show that your IBD affects your daily life. To claim PIP, you must:

- have had problems with daily living activities and/or mobility difficulties for at least three months **and**
- expect these problems to last for at least another nine months.

You can apply for PIP sooner than this, but you will not receive any payment until after the three-month qualifying period.

You may qualify for the **daily living component** if you have difficulty with any of the following activities.

1. Preparing food
2. Eating and drinking
3. Managing treatments
4. Washing and bathing
5. Managing toilet needs
6. Dressing and undressing
7. Communicating
8. Reading
9. Mixing with other people
10. Making decisions about money



Here are some questions to help you decide whether you are likely to qualify for the daily living component (continues on next page). Think about the times when you do each of the activities listed above and ask yourself:

- Does it take me a long time?
- Am I in pain or discomfort?
- Is it difficult for me to do?
- Do I need prompting or help from another person?
- Do I need any aids or appliances to help me?
- Have I had any accidents, such as falls, while doing this activity?



- Do I avoid this activity?
- Does it make me feel tired?
- Is it harder to do at certain times of the day or night, or when my IBD flares?
- Do I have to pay for help, aids or appliances to help me do this activity?

If you have answered yes to some of these questions, you may want to consider applying for PIP.

You may qualify for the mobility component if you have difficulty with any of the following activities:

- Planning and following journeys
- Moving around

To help you decide whether you qualify for the mobility component, think about the activities listed above and ask yourself:

- Do I walk slowly or find it difficult to walk?
- Am I in pain or discomfort?
- Could it make my IBD worse?
- Do I need prompting or help from another person?
- Do I need a walking aid, such as a walking stick?
- Does it make me tired?
- Do I feel anxious or panicky when I go out?
- Do I avoid leaving the house?
- Is walking harder at certain times of the day or night, or when my IBD flares up?

If you have answered yes to some of these questions, you may want to think about applying for PIP.

TERMINAL ILLNESS

If you have any medical condition that means you're expected to live six months or less, your claim will be dealt with more quickly. You will automatically qualify for the enhanced rate of the daily living component of PIP. But you will need to show that you have problems moving around or going out, to qualify for the mobility component of PIP.

You will be able to claim PIP straight away - you do not have to wait for the three-month qualifying period. You or someone else can call the PIP claim line to start your claim. You do not need to fill in any forms, but your doctor or consultant will need to send a DS1500 form to the DWP or DfC.

The organisations listed at the end of this guide can give you more information on applying for PIP if you have a terminal illness.

HOW DO I APPLY FOR PIP?

There are four stages to applying for PIP.

1. Registering your claim
2. Completing the form, 'How your disability affects you'
3. The face-to-face consultation
4. Receiving a written decision telling you whether you have been awarded PIP, at what rate and how long for.

1 REGISTERING YOUR CLAIM

To register a new claim in **England, Wales or Scotland**, telephone the DWP on **0800 917 2222** (textphone **0800 917 7777**).

If you are registering your claim in **Northern Ireland**, telephone the DfC on **0800 012 1573** (textphone **0800 012 1574**).

Lines are open Monday to Friday, 8am to 6pm, except public holidays.

Your claim normally starts from the date you register and cannot be backdated.

Before you call

To help you answer the questions when you call to register your claim, make sure you have the following information with you.

- Full name
- National Insurance Number – you can find this on a payslip or on letters about tax or benefits
- Full address and postcode
- Date of birth
- Bank or building society account number and sort code – for you to receive payments if you qualify for PIP
- Daytime telephone number
- GP and other health professionals' contact details
- Details of any recent stays in a hospital, care home or hospice
- Nationality or immigration status
- Details of any time spent abroad – for stays of more than four weeks at a time over the last three years
- Details of pensions or benefits that you or your family get from another EEA country or Switzerland.

You will also be asked whether you give permission for the DWP or DfC to contact your GP or other organisations for further information about your IBD. You will not be asked for detailed information about your IBD in this telephone call.

If you find it difficult to speak on the telephone, someone else can make the call for you but you will need to be there to confirm that you want to register a claim. If your first language is not English, you can ask to use the DWP or DfC's interpreting service. If you are not able to use the telephone and there is nobody to help you, you may be able to ask for a paper form to register your claim.

WHAT HAPPENS NEXT?

The person you speak to on the telephone will use your answers to decide whether you meet the basic conditions to apply for PIP. If you do meet the conditions, they will send you a form to fill out, which is called 'How your disability affects you' (PIP2).

If they decide you do not meet the conditions, they will write to you to explain why. You can challenge this decision by writing to the DWP or DfC.

2 COMPLETING THE FORM 'HOW YOUR DISABILITY AFFECTS YOU'

The form you are sent will have your name and National Insurance number printed on it. It cannot be copied for anyone else to use. You will also be sent an information booklet to help you fill in the form.

The form is long, and it can take an hour or more to fill in. It is important to give yourself plenty of time to think about the questions and answer them fully.

You may want to practice filling in a photocopy of the form first. Or you could complete the form in pencil before going over your answers in pen when you are happy with them.

If you run out of space, you can add more information in question 15. Or you can staple extra sheets of paper to the form. Make sure you write your name and National Insurance number at the top of each extra page and clearly mark which question they refer to.

You must return your completed form within one month, otherwise your claim may be turned down. If you are not able to return the form on time, contact the DWP or DfC before the deadline. They will usually give you a further two weeks to return your form if you have a good reason, such as illness or bereavement.

GETTING HELP WITH THE FORM

You may want to ask someone who knows you well to help you fill in the form. They can help you explain the difficulties your IBD causes you.

You can also get help from an advice service, such as Citizens Advice. You can find contact details at the end of this guide. There may also be local advice services available where you live. You may want to contact your local authority or local council to find out what is available in your area.

COMPLETING THE FORM: QUESTIONS 1 AND 2

Q1 PROFESSIONALS

The form asks for contact details for up to three professional people who can give information about your IBD and how it affects you.

This does not have to be your GP. It could be another health professional who knows you well and knows about your condition, such as a gastroenterologist or an IBD nurse, or a professional who knows how your condition affects your life, such as a psychologist.

You may want to make an appointment with this health professional to talk about your PIP application. There is a checklist in Appendix 2 at the back of this guide that you may want to fill in at home and take with you to your appointment. You could take photocopies of the checklist to share with any health professionals who may help with your PIP application. The checklist gives you space to write how your IBD affects your ability to do the activities that you will be assessed on. You could talk through the problems you have with each activity at your appointment. This will help your health professional to give full and accurate information on their PIP report.

Q2a HEALTH CONDITIONS AND DISABILITIES

This question asks you to list your health conditions or disabilities and when they started. Make sure you list all your ongoing health conditions as well as any IBD-related problems, such as arthritis, anaemia or skin problems. Also include any diagnosed mental health conditions, such as depression or anxiety.

Give the date that you started having symptoms of IBD, even if you did not get a formal diagnosis until months or years later. Don't worry if you can't remember the exact date. For example, you could say 'summer 2011' or 'about five years ago' and the DWP or DfC will ask for more information if they need it.

Q2b TREATMENTS

This question asks for details of your medicines, therapies or other treatments, such as enemas, stoma checks, colonoscopies or regular appointments with a therapist, nutritionist or psychologist. Remember to describe any side effects and how they affect you.

If you have tried a treatment that did not work, you may want to explain this on the form. You can also say whether there are any standard IBD treatments that you cannot take, for example, due to the side effects or because you cannot take them with your other medicines.

If you are taking a lot of medicines, you may find it easier to attach your prescription list to the form.

COMPLETING THE FORM: QUESTIONS 3 TO 15

These questions ask about how your IBD affects your daily life. Remember to include information about any other health problems you have, as well as IBD.

The form lists 10 daily living activities and two mobility activities. For each activity, there are questions with tick boxes, followed by a larger box where you can give more information.

The PIP assessment is based on whether you are able to complete the activities reliably. Ask yourself if you can complete each activity:

- **safely** – is there a risk that you could injure yourself or make your IBD worse?
- **to an acceptable standard** – does your IBD make it hard for you to do it properly?
- **repeatedly** – can you repeat the activity as many times as you need, or do you need to rest for a long time in between?
- **in a timely manner** – does it take you much longer than someone who does not have IBD?

Descriptors and points

Each activity has a list of descriptors. These are statements that describe increasing levels of difficulty in carrying out the activity. Each descriptor has a score attached to it.

The PIP form does not tell you what the descriptors are for each activity, but we list them on the following pages. Some of the descriptors use medical or technical words – you can find out what these mean in Appendix 3 at the back of this guide.

For each activity, the person who assesses your ability (the assessor) will choose the one descriptor that fits you best. You will score the points attached to that descriptor. If more than one descriptor applies to you, the assessor will choose the one with the most points.

You can score points for a descriptor if it applies to you at any time during the day or night. For example, if you feel very tired in the morning and need help to wash, but then feel better later in the day and need less help, you should still score points based on how you are in the morning.



If your symptoms vary over time

The impact of your IBD on your daily life may vary over time. When you are filling in the form, think about how your IBD affects you over a 12-month period. Your assessor will pick the descriptor that applied to you for more than half the days in the last three months and is likely to apply over the next nine months. If more than one descriptor applies, they will pick the one with the most points.

If you are waiting for treatment that could improve your IBD, you should be assessed on how you are now, not how you are expected to be after you have had the treatment.

If your IBD varies a lot over time or if you are not sure if you qualify for PIP, you can contact the Crohn's and Colitis UK Disability Benefit Service, Citizens Advice or a local advice centre. You can find contact details at the end of this guide.

Your scores from the 10 daily living activities are added together to give a total score for daily living. Your scores from the two mobility activities are added together to give a total score for mobility.

This table shows the minimum number of points you must score to qualify for each of the PIP components.

Component	Points needed to qualify for:	
	Standard rate	Enhanced rate
Daily living	8	12
Mobility	8	12

Aids and appliances

The assessment will take into account any aids or appliances you normally use.

Aids are devices that help you perform a function. For example, a walking stick to help you walk or a bath seat to help you wash.

Appliances are devices that provide or replace a missing function. For example, a stoma bag.

When you fill in the PIP form, say whether you need help from another person when you use an aid or appliance. You might need someone to help you use it, to remind you to use it or to help you clean the aid or appliance. You can score more points if you need help from another person.

Include details of any aids or appliances that people with IBD commonly use, but that would not be helpful for you. Explain why you can't use them and whether this makes your daily life more difficult. This will help the assessor understand how IBD affects you personally.

Tips for completing questions 3 to 15

- **Give as much extra information as you can.** The person assessing your claim may have very little knowledge of IBD and will not know your personal circumstances or history.
- **You can repeat the same information.** For example, if bending causes you pain, this may affect more than one activity, such as bathing, using the toilet and getting dressed.
- **Do not be embarrassed about describing the problems you are having.** You may need to describe the problems you have using the toilet, or explain symptoms such as explosive, runny stools (diarrhoea). Many people with IBD have other problems or conditions, such as depression or incontinence. Describing fully how these affect you will help you to get the right amount of PIP.
- **Give examples to help explain the problems you have.** Instead of saying 'I am at risk of falls when getting out of the bath', you could say 'Two weeks ago I lost my balance, slipped and fell when getting out of the bath. I hit my hand on the radiator and cut it. I lay there for a few minutes before I could try to stand up. It took me a few attempts before I could get up, because my arms and legs felt weak.'
- **Do not underplay the problems you have.** Many people cope with their IBD by keeping positive and accepting that there are some things they cannot do.

When you are filling in the PIP form, you will need to focus on the things you cannot do or that you find difficult or painful. Make sure you do not leave out any details of how your IBD affects your life.

- **Be clear about how bad your IBD is.** If your IBD has become worse, or if a doctor has told you it is likely to get worse, you should make this clear on the form and attach medical evidence if you can.
- **It is okay to tick the box to say you need help** with an activity if you find it difficult but do not actually receive any help. You do not need to have a carer to qualify for PIP. Explain what kind of help you need, for example, verbal prompting, physical help or supervision.
- **Think about the descriptors for each activity.** Remember that the assessor will choose the descriptor that applied to you for more than half the days over the last three months, and is likely to apply to you over the next nine months. Try to give a detailed picture of how often your IBD affects your daily life. For example, 'On 10 days out of 12 I get diarrhoea after eating. This makes it hard for me to make myself eat'.
- **Explain how fatigue (tiredness) affects you.** Many people with IBD have fatigue. If it affects your daily life, explain on the form whether it means you avoid certain activities or whether you ever have to stop an activity after you have started. Do you need to take naps or rests during the day? Could some activities, such as cooking, be dangerous when you are very tired?
- **Think about the different steps involved in each activity.** Even if you can do most of the activity, there may be an important part of it that you find difficult. For example, maybe you can put on most of your clothes without too much difficulty, but you struggle to put on socks and shoes because it is painful for you to bend over to reach your feet.

DAILY LIVING ACTIVITIES AND DESCRIPTORS

Q3 PREPARING FOOD

This question asks about your ability to prepare and cook a simple meal.

'A simple meal' means a cooked one-course meal for one person, using fresh ingredients. 'Cooking' means 'heating food at or above waist height', so the assessor will not take into account any difficulty you may have with bending to put things into the oven or to get things out of low cupboards.

Activity: Preparing food

Descriptor	Score
a Can prepare and cook a simple meal unaided	0 points
b Needs to use an aid or appliance to either prepare or cook a simple meal	2 points
c Cannot cook a simple meal using a conventional cooker but is able to do so using a microwave	2 points
d Needs prompting to be able to either prepare or cook a simple meal	2 points
e Needs supervision or assistance to either prepare or cook a simple meal	4 points
f Cannot prepare and cook food	8 points

Things you could write about:

- If another person helps you to cook, because of your IBD or another medical problem, explain what they do to help you.
- If you skip meals, explain why. For example, feeling sick, pain, tiredness.
- Do you eat 'ready meals' or snacks because you find it difficult to prepare a meal or because you lack motivation to do so?
- Describe any aids or appliances you use during cooking. They do not have to be medical appliances. They could be kitchen appliances that make it easier for you to prepare meals.
- Do you find it hard to watch over a meal while it is cooking? For example, this may happen if you urgently need to use the toilet several times and for long periods of time. This could make it difficult for you to make sure the food is cooked properly and not burnt. It could be dangerous to leave food cooking unattended.
- Do you have to follow a special diet or avoid certain foods? You will not score points just for this, but you may get points if it means you find it harder to prepare a meal. It may mean that preparing meals takes longer or involves extra tasks, such as mashing food or chopping it more finely. Or you may need prompting, help or supervision from another person to help you follow the right diet.

Example:

'When my IBD flares up (two months out of the last three months), I need to go to the toilet urgently two or three times while I am cooking. This makes it hard to cook safely. I have burnt my dinner twice because I have been in the toilet and have not been able to turn the oven off in time.'

Q4 EATING AND DRINKING

Activity: Eating and drinking

Descriptor	Score
a Can take nutrition unaided	0 points
b Needs either: <ul style="list-style-type: none">• to use an aid or appliance to take nutrition, or• supervision to be able to take nutrition, or• assistance to cut up food	2 points
c Needs a therapeutic source to take nutrition	2 points
d Needs prompting to take nutrition	4 points
e Needs assistance to manage a therapeutic source to take nutrition	6 points
f Cannot convey food and drink to their mouth and needs another person to do so	10 points

Things you could write about:

- Do you find it difficult to make yourself eat because you know it is likely to make you feel sick or cause loose and runny stools (diarrhoea)?
- The symptoms of IBD are likely to be affected by what you eat – you could explain the importance of eating regular, healthy meals and snacks to manage your condition.
- Do you find it hard to keep to a healthy weight? If your IBD has caused you to lose weight, you may want to give details of how much weight you have lost. You will not score points for being underweight, but it gives the assessor an idea of the problems you are having with getting enough nutrition.
- Do you need liquid food, taken through a tube into the stomach or small intestine or TPN? Two of the descriptors – c and e, above - describe these as 'therapeutic sources'.
- Do you have mouth ulcers? Do they make eating painful or uncomfortable?
- Do you find it difficult to use cutlery? For example, you may have joint pain that makes this difficult.

Example:

'When I eat, I need to go to the toilet straight afterwards to open my bowels. Because of this, I cannot eat if I need to leave the house. My partner has to push me to eat and, if she is not there, I skip meals because eating makes me feel sick and gives me diarrhoea.'

Q5 MANAGING TREATMENTS

Activity: Managing treatments

Descriptor	Score
a Either: <ul style="list-style-type: none"> does not receive medication, therapy or need to monitor a health condition, or can manage medication, therapy or monitor a health condition unaided 	0 points
b Needs either: <ul style="list-style-type: none"> to use an aid or appliance to be able to manage medication, or supervision, prompting or assistance to be able to manage medication or monitor a health condition 	1 point
c Needs supervision, prompting or assistance to manage therapy that takes up to 3.5 hours a week	2 points
d Needs supervision, prompting or assistance to manage therapy that takes between 3.5 and 7 hours a week	4 points
e Needs supervision, prompting or assistance to manage therapy takes between 7 and 14 hours a week	6 points
f Needs supervision, prompting or assistance to manage therapy that that takes more than 14 hours a week	8 points

Things you could write about:

- Do you need help from another person with things like taking medicine to empty your bowels (enema), applying cream or changing dressings?
- Do you need help from another person with monitoring the effect of your IBD and its treatment? For example, you may need help with checking the condition of the area around your back passage (anus).
- Do you need someone to remind you to take your medicines? For example, if you have depression, you may forget to take medicines on time.
- Do the side effects of your IBD or other health problems make it difficult for you to take your medicines?
- Do you need to use an aid or appliance? Examples include an alert on your phone or an alarm to remind you when to take your medicines. If you have a lot of different medicines, do you need a dosette box to help you organise your tablets?

Example:

'I take several medicines at different times of the day (my prescription list is attached to this application). I find it hard to remember what medicine to take at what time. I use a dosette box to organise my medicines and an alarm on my mobile phone to tell me when to take them.'

Q6 WASHING AND BATHING

Activity: Washing and bathing

Descriptor	Score
a Can bathe unaided	0 points
b Needs to use an aid or appliance to be able to wash or bathe	2 points
c Needs supervision or prompting to wash or bathe	2 points
d Needs assistance to be able to wash either their hair or body below the waist	2 points
e Needs assistance to be able to get in or out of a bath or shower	3 points
f Needs assistance to be able to wash their body between the shoulders and waist	4 points
g Cannot wash and bathe at all and needs another person to wash their entire body	8 points

Things you could write about:

- Do you need help from another person? Explain what they do to help you, for example, helping you in and out of the bath.
- Do you need any equipment, such as handrails, a long-handled brush or a shower seat?
- Do you need to use a bidet to clean yourself after using the toilet?
- Do you need to wash or shower more often because of leakage, incontinence, infections or fistulas?
- Do you find it difficult or painful to reach any areas of your body when you are washing?
- Do you sometimes feel too tired or depressed to wash, bathe or shower?
- Do you feel tired or drained after washing or bathing?
- Can you wash or bathe reliably and safely without pain? Have you had any falls, or nearly fallen, while having a bath or shower?
- Do you only take a bath or shower if there is someone close by in case you fall?

Example:

'I find it hard to wash by myself because it is so tiring. If my husband is not there to help me, I usually do not feel like washing and do not bother to have a shower or bath. Last week, I had a shower and I slipped when I was getting out. Luckily my husband was there and he stopped me from falling.'

Q7 MANAGING TOILET NEEDS

This includes using a toilet and managing incontinence.

Using a toilet means getting on and off a normal (not adapted) toilet and cleaning yourself afterwards. Managing incontinence means coping with not being able to control your bladder or bowel, and cleaning yourself afterwards. This may include using an aid, such as incontinence pads, a stoma bag or a catheter.

The assessment does not look at needing to get from another room to the toilet, finding a toilet in a public place or cleaning the toilet or surrounding area.

Activity: Managing toilet needs

Descriptor	Score
a Can manage toilet needs or incontinence unaided	0 points
b Needs to use an aid or appliance to manage toilet needs or incontinence	2 points
c Needs supervision or prompting to manage toilet needs	2 points
d Needs assistance to manage toilet needs	4 points
e Needs assistance to manage incontinence of either bladder or bowel	6 points
f Needs assistance to manage incontinence of both bladder and bowel	8 points

Things you could write about:

- Do you have difficulty getting on or off the toilet? Do you feel weak or unsteady when you get up from the toilet?
- How long do you spend sitting on the toilet each time you go?
- Do you use any aids or appliances, such as a commode, raised toilet seat, bottom wiper, bed or seat pad or waterproof sheet? If you use incontinence pads, how often do you need to change them? Do you need any help from another person, for example with emptying a commode?
- If you use a stoma bag, explain how you use it, how often you need to empty it and how you clean the stoma site. Describe any problems with bags leaking or bursting. If you need help from another person, explain what they do to help you.
- Do you find it difficult to clean yourself after using the toilet or following an episode of incontinence? Does it take you a long time to clean yourself properly? Do you need help with changing bed sheets or washing clothes?
- Do you face extra costs for any aids or appliances that help you use the toilet or manage any episodes of incontinence?

Example:

'I cannot control when I empty my bowels, so I need to be near a toilet all the time. I wear incontinence pads and I use waterproof sheets on my bed. My IBD makes me feel very tired, so I need help to change the bed sheets during the night.'

Q8 DRESSING AND UNDRRESSING

Activity: Dressing and undressing

Descriptor	Score
a Can dress and undress unaided	0 points
b Needs to use an aid or appliance to dress or undress	2 points
c Needs either: <ul style="list-style-type: none"> • prompting to dress, undress or determine appropriate circumstances for remaining clothed, or • assistance or prompting to select appropriate clothing 	2 points
d Needs assistance to dress or undress lower body	2 points
e Needs assistance to dress or undress upper body	4 points
f Cannot dress or undress at all	8 points

Things you could write about:

- Do you find it difficult or painful to bend down? Does this make it hard for you to put on or take off socks, shoes or clothes on your lower body?
- Do you need to wear clothes that are easy to undo if you need the toilet urgently, for example, clothes with elasticated waists or Velcro fastenings?
- Do you have joint pain that makes it hard to use zips or buttons on clothes?
- Do you need to use any aids, such as elasticated shoelaces or a shoe horn? Do you need to wear clothes or support garments that give extra support to a stoma or hernia?
- If you sometimes need to change your underwear or clothes because of incontinence or leakage, say how often this happens.
- Do you lack the motivation or energy to get dressed or change your clothes? This may be because you are depressed or tired, or because dressing is painful or difficult. Do you sometimes stay in night clothes during the day or go to bed in the clothes you have worn all day?
- If another person helps you to get dressed, explain how they help you.

Example:

'I find it painful to bend down, so I cannot put my socks or shoes on myself. My partner helps me get dressed every day. If she is not there, I cannot get dressed to go outside by myself, so I have to stay at home.'

Q9 COMMUNICATING

This question asks about how well you can speak, hear and understand your native language.

If your IBD makes you feel very tired, then you may have problems understanding what people are saying. But for most people with IBD, communication is unlikely to be a problem, unless they have other health problems. For example, if you are hard of hearing or have a learning disability, you may score points for this activity.

If anxiety or depression makes it hard for you to speak to people, you can explain this later in question 11.

Activity: Communicating

Descriptor	Score
a Can express and understand verbal information unaided	0 points
b Needs to use an aid or appliance to be able to speak or hear	2 points
c Needs communication support to be able to express or understand complex verbal information	4 points
d Needs communication support to be able to express or understand basic verbal information	8 points
e Cannot express or understand verbal information at all even with communication support	12 points

Q10 READING

This question asks about how well you can read and understand signs, symbols and words.

This is unlikely to be relevant for you if your only health condition is IBD. If you have another health condition that affects your ability to see or understand written information, explain what difficulties you have.

Activity: Reading

Descriptor	Score
a Can read and understand basic and complex written information either unaided or using spectacles or contact lenses	0 points
b Needs to use an aid or appliance, other than spectacles or contact lenses, to be able to read or understand either basic or complex written information	2 points
c Needs prompting to be able to read or understand complex written information	2 points

d Needs prompting to be able to read or understand basic written information 4 points

e Cannot read, or understand signs, symbols or words at all 8 points

Q11 MIXING WITH OTHER PEOPLE

This question asks about how well you engage with people face-to-face. This includes people you know well and people you do not know.

If mixing with other people causes you extreme worry or stress, you will need to show that this is linked to a mental health condition, such as anxiety or depression. Sometimes, the stress of living with IBD can affect your mental health.

If you need prompting or support, this can come from a family member or friend. It does not have to be professional support. You will need to show that the family member or friend has experience of supporting you – state how long they have been helping you and how often.

Activity: Engaging with people face-to-face

Descriptor	Score
a Can engage with other people unaided	0 points
b Needs prompting to engage with other people	2 points
c Needs social support to engage with other people	4 points
d Cannot engage with other people, due to such engagement causing either: <ul style="list-style-type: none"> overwhelming psychological distress to the claimant, or the claimant to exhibit behaviour which would result in a substantial risk of harm to the claimant or another person 	8 points

Things you could write about:

- Do you have a mental health condition that makes it hard for you to mix with other people?
- Do you have panic attacks?
- Have you avoided mixing with other people because of your IBD? Explain the reasons for this. For example, you may be worried about needing the toilet, incontinence or passing wind.

- Do you feel isolated? For example, do you avoid going out in case you cannot find a toilet easily?
- When you mix with other people, do you take someone you know well with you? How does this person reassure or support you?
- Do you avoid social activities or meeting new people? Have you given up any activities that you enjoyed in the past?
- Do you find it very tiring to mix with other people? Do you need to rest afterwards?
- Do you sometimes become irritable or lose your temper around other people?

Example:

'I used to go to a weekly exercise class, but I have stopped going because I am worried that my stoma will leak or make loud noises. I worry a lot about it and so I avoid being around other people and now spend a lot of time by myself at home. My GP has diagnosed me with anxiety.'

Q12 MAKING DECISIONS ABOUT MONEY

This question asks about how well you understand money and prices, and whether you can work out a household budget and pay bills. It does not cover your ability to walk around shops, get cash out of a purse or carry shopping.

This question may not be relevant to you if your only health condition is IBD, unless you have severe tiredness that makes it hard for you to manage money or plan what you want to buy.

If you have another health condition that affects your ability to understand money and prices, explain the difficulties you have.

Activity: Making budgeting decisions

Descriptor	Score
a Can manage complex budgeting decisions unaided	0 points
b Needs prompting or assistance to make complex budgeting decisions	2 points
c Needs prompting or assistance to make simple budgeting decisions	4 points
d Cannot make any budgeting decisions at all	6 points

MOBILITY ACTIVITIES AND DESCRIPTORS

To qualify for the standard rate of PIP mobility component, you need to score at least 8 points in total from the two mobility activities. They are 'going out – planning and following journeys' and 'moving around'. To get the enhanced rate, you need to score at least 12 points. If your difficulties are mainly physical, you may score zero for 'planning and following journeys'.

Q13 GOING OUT

This question is about planning and following journeys. It could be relevant to you if you have a learning disability or a condition such as anxiety, depression, agoraphobia or sight problems.

This activity includes journeys you make using public transport for an unfamiliar journey. It does not take into account any physical difficulties involved in using public transport (such as lack of toilets or difficulty getting on and off a bus).

This question does not look at your physical ability to get around, which is covered in question 14.

Activity: Planning and following journeys

Descriptor	Score
a Can plan and follow the route of a journey unaided	0 points
b Needs prompting to undertake any journey to avoid overwhelming psychological distress	4 points
c Cannot plan the route of a journey	8 points
d Cannot follow the route of an unfamiliar journey without another person, assistance dog or orientation aid	10 points
e Cannot undertake any journey because it would cause overwhelming psychological distress	10 points
f Cannot follow the route of a familiar journey without another person, assistance dog or orientation aid	12 points

Things you could write about:

- Does going out make you feel anxious, panicky or distressed? You are more likely to score points if you can show that this is linked to a diagnosed mental health condition. Provide evidence where you can, for example, by attaching a letter from a doctor or counsellor, or a prescription list showing the medicines you have been given for a mental health condition.
- Do you need someone to talk you into going out?
- Is it helpful to have someone with you when you go out, to help you find your way around or to calm and reassure you?
- If you have panic attacks, describe how you feel when they happen. Do you feel short of breath or dizzy?
- Have you ever had to stop your journey and go home because you were too upset to continue?
- Do you find it hard to concentrate on following an unfamiliar route? For example, due to feeling very tired or anxious. You may be distracted because you are worrying about needing a toilet.
- Do you find it difficult to understand timetables or to plan a route using public transport?

Example:

'I cannot go on any journeys by myself because I am worried about not being able to get to a toilet quickly. I have to take someone I trust with me, otherwise I get very worried and upset. My friend helps me work out where the nearest toilets are along the route and helps to calm me down when I panic.'

Q14 MOVING AROUND

This question asks about your physical ability to stand and move around without severe discomfort, such as breathlessness, pain or fatigue. The assessment looks at your ability to move around outdoors on normal outdoor surfaces - this includes pavements and kerbs but not flights of stairs or rough ground.

Question 14a is one of the most important questions on the whole form. Your answer will help the assessor decide whether you qualify for the PIP mobility component. You need to tick a box to say how far you can walk. Your choices are:

- less than 20 metres
- between 20 and 50 metres
- between 50 and 200 metres
- 200 metres or more
- it varies.

To give you an idea of how far these distances are, a bus is about 10 metres long and a full-size football pitch is usually about 100 metres long.

It is important to give an honest picture and not overstate the effects of your IBD. But this question is not just asking whether you can physically walk each distance if you have to. It is asking whether you can walk that distance **reliably, repeatedly and safely**.

Think about whether you can walk that distance:

- in a reasonable manner – or would you be unsteady, shuffling, limping or bent over?
- without pain or discomfort – either while walking or afterwards
- in a reasonable time - would you be much slower than a person with no disability or health condition?
- without needing to pause or stop
- without falling
- without making your IBD worse in any way
- without feeling so tired afterwards that you cannot do other activities
- a second time after a short break - or would you need to rest and be unable to walk that far again for a long time?
- at almost any time, or only at certain times of day or on 'good days'

Do not say that you can walk a certain distance unless you are sure that you can walk it safely, in an acceptable manner, repeatedly and in a reasonable time.

Activity: Moving around

Descriptor	Score
a Can stand and then move more than 200 metres, either aided or unaided	0 points
b Can stand and then move more than 50 metres but no more than 200 metres either aided or unaided	4 points
c Can stand and then move unaided more than 20 metres but no more than 50 metres	8 points
d Can stand and then move using an aid or appliance more than 20 metres but no more than 50 metres	10 points
e Can stand and then move more than one metre but no more than 20 metres – either aided or unaided	12 points
f Cannot, either aided or unaided: <ul style="list-style-type: none">• stand, or• move more than one metre	12 points

Things you could write about:

- Do you have any pain when you walk? Do you have this pain as soon as you start to walk? If not, how far can you walk before the pain starts? Describe where the pain is and how it feels – for example, cramping, shooting, stinging, burning or aching.
- Does walking cause you to feel sick, dizzy or breathless? How far can you walk before this starts?
- Give details of any aids or appliances you use, such as a walking stick or wheelchair, even if you only use it sometimes. If you use a wheelchair, do you need someone to push it for you?
- Have you tried using a walking aid but found it unhelpful?
- Do you need to take someone's arm or lean on them when you walk?
- If you need to stop and rest, how long do you stop for and do you need to sit down or hold on to something?
- Does walking increase your risk of leaking or incontinence?
- Are there times of the day when you cannot go outdoors because you need to stay close to a toilet?
- If you walk slowly, you could give an example like, 'I take twice as long as my partner to walk to the corner shop, which is 150 metres away'.
- Give examples of how this affects your daily life. Does your GP visit you at home because it is a struggle to get to the surgery? Do you have your food shopping delivered because you find it too difficult to walk to the shop?

- This activity looks at your ability to walk outdoors. But if you have difficulty moving around indoors, particularly in your own home, this could help to show that you are likely to have difficulty walking outdoors as well. Guidance from the Department for Work and Pensions and Department for Communities says that anyone who has difficulty walking less than 200 metres outdoors is likely to have difficulty walking within their own home as well.

Example:

‘I can walk to the corner shop, which is 150 metres away. But it makes me feel very tired and I need to sit down and rest before I can walk home. This makes it hard for me to get around and to do my shopping. My neighbour gets my food shopping for me and gives me a lift to the GP surgery or anywhere else I need to go.’

Q15 ADDITIONAL INFORMATION

This is where you can give any relevant information that you have not already mentioned.

Things you could write about:

- How your IBD has affected your life – for example, if you have had to give up work, if you are housebound or if you sometimes feel like harming yourself.
- If you have a paid or unpaid carer, you could say how much time they spend looking after you.
- You could give more information about how your IBD varies over time. You can read more about how this is assessed on page 28.
- If your IBD is getting worse, you could describe how it is causing you more difficulty.

Before you send off the form

The final section of the form asks about any help you need for a face-to-face assessment. For example, you may need accessible toilets or you may have difficulty using stairs. Your assessment should be held in a room that is either on the ground floor or that you can access by a lift. If you cannot use the stairs in an emergency, the room should be on the ground floor.

You can ask for a sign-language interpreter or language interpreter if you need one.

You can ask for a home visit if it would be too difficult for you to get to an assessment centre. Most people need to go to an assessment centre for a face-to-face consultation, but you may be more likely to get a home visit if you normally receive home visits from your GP. You may be asked for a letter from a medical professional, explaining why you need a home visit, particularly if Independent Assessment Services (previously called Atos Healthcare) are assessing you. If you feel you need a home visit but are turned down, you can get advice from the organisations listed at the end of this guide.

Keep a copy of the form

It is important to keep a copy of your completed PIP form and any supporting evidence that you send. There are several reasons for this.

- In case your form gets lost after you send it – make sure your copy shows the barcode.
- There can be a delay of several weeks or even months between you sending your form and going to the assessment consultation. Keeping a copy of the form means you can remind yourself of what you wrote.
- If you are not happy with the outcome of your claim, you may want a copy of the form to help you challenge the decision.
- If you are awarded PIP, this will probably be for a limited amount of time. When you come to renew your award, you may find it helpful to look at your original form.

Attach as much evidence as you can

It is very important to attach photocopies of evidence to support your claim. Remember to keep a copy as well. Here are some examples of the type of evidence that could be useful.

- Reports or letters from your GP, hospital doctor, specialist nurse or other medical professional.
- Reports or letters from other people who help you, such as a social worker, support worker or counsellor.
- Information about extra support that you get at work or college because of your IBD.
- A letter or statement from someone who gives you support, such as a friend, family member or neighbour.
- A diary kept by you or your carer – see page 40 for more information about keeping a diary.

More recent evidence, from the last year or so, may be more helpful than older evidence.

Send any evidence that you already have. Do not wait for extra evidence if it means you will miss the deadline for returning your form. **If you are waiting for new evidence, you can mention this in question 15 and send it later.**

Check that the evidence you are sending is helpful to your claim and is likely to help you score points in the PIP assessment. You may choose not to include something that is misleading, for example, if a report states you can do an activity but does not mention that it causes you pain.

You do not have to include evidence with your claim if you do not have it. Make sure you put plenty of detail on the form and explain at your face-to-face consultation about how your disability affects your daily living and mobility.

KEEPING A DIARY

It can be very useful to keep a diary to record your difficulties with daily living and mobility. You may want to keep a diary for two to three weeks, to show how your IBD varies over time.

The diary can help to show the impact of your IBD on your daily life, how often you have difficulties and how long it takes you to do things. Your diary can be in note form and can include things like:

- what you do during the day
- the symptoms you have and how they affect you
- how other people help you – whether they give you physical help, prompt you to do things or stay close by in case you need help
- what you do for yourself but find difficult because of your disability
- how long it takes you to do things like taking a shower or getting dressed
- what you do not do because there is no one to help, because it would be too difficult or because you are in too much pain or too tired
- any difficult situations, such as episodes of incontinence, falls or injuries, or being unable to complete an activity you have started
- how often you need to use the toilet
- your moods and whether you have a mental health condition

If you keep a diary for a few days or weeks before completing the form, you may find that it helps you to notice or remember difficulties that would have slipped your mind otherwise.

A diary may also be very useful if you have to challenge the decision you are given. If you need to attend a tribunal, it will be valuable evidence of the difficulties you faced on a day-to-day basis at the time of your application.

You can see a sample diary entry in Appendix 1 at the back of this guide.

WHAT HAPPENS AFTER I RETURN THE FORM?

An assessor will consider your claim. They will look at your PIP form and any other evidence you have sent and decide whether to invite you to a face-to-face consultation.

The assessor may want to get more evidence from one of the professionals you named on your form. They may also telephone you to ask for more information.

PIP assessments are done by people with medical training who work for one of two organisations:

- **Independent Assessment Services (IAS)** – used to be called Atos Healthcare. They assess claims in Scotland, North East and North West England, London and Southern England.
- **Capita Health and Wellbeing** assesses claims in the rest of the UK (Wales, Central England and Northern Ireland).

The person doing your assessment may be an occupational therapist, nurse, physiotherapist, paramedic or doctor. They will be fully registered and have had a Disclosure and Barring Service (DBS) check.

3 THE FACE-TO-FACE CONSULTATION

You should get seven days' notice of the time, date and location of your face-to-face assessment. Appointment times will be between 8am and 8pm on weekdays and 9am and 5pm on Saturdays. If your appointment time clashes with a medical appointment or if there is a good reason why you cannot go, like difficulty in travelling in the morning due to your IBD, you can ask for it to be changed. Telephone as soon as possible to rearrange the appointment.

Your claim is likely to be refused if you do not go to your appointment, unless you can show that you had 'good cause' for not going.

If you need an interpreter, contact either IAS or Capita to check there will be one available.

If you have a complaint about any part of your consultation, you can contact either IAS or Capita.

GETTING READY FOR THE CONSULTATION

You may want to ask someone to go with you to your consultation. They can support you or help you understand what is being said. You could ask a family member, friend or support worker.

Do not feel that you have to dress more smartly than you normally would, or 'put on a brave face'. If another person has helped you to dress, let the health professional know that you have had help.

On the day of your assessment you may need to get up extra early to eat before leaving the house. Or you may need to take anti-diarrhoeal medication if your doctor or IBD team has recommended it. It is worth mentioning if you have had to do this.

You can take written evidence to the face-to-face consultation. For example, you may have new evidence, or your medical team may not have sent evidence in time for you to include with your form. The assessor will take a copy of your evidence and take it into account when completing their report. You should also send a copy of your medical evidence to the DWP or DfC.

TRAVELLING TO THE CONSULTATION

Face-to-face consultations are carried out at a range of locations, including specialist assessment centres, local healthcare centres or in your own home. When you fill in the PIP form, you can ask for the consultation to be in your home if you would find it too difficult to travel to the assessment centre. If your assessment provider is IAS, you will probably need evidence from your doctor to support your request for a home visit. Capita aims to offer home visits to more than half the people who ask for them.

You may want to ask a family member or friend to give you a lift to the assessment centre. If you travel by public transport or drive yourself, the assessor may draw conclusions about your ability to walk or do other activities.

You can claim travel expenses for getting to the consultation if it is not at your home. The DWP and DfC expect people to travel by private car or public transport where possible. If you need to travel by taxi, telephone the assessment provider (IAS or Capita) in advance to let them know that you need to do this and will be claiming expenses. They may ask you to provide a letter from a medical professional explaining why your condition means that you cannot travel by public transport. If you travel by car or public transport, you can ask to claim your expenses on the day of the consultation.

If free parking is not available at the assessment centre, you can claim for parking costs.

Keep your tickets or receipts for public transport, parking or taxi fares, and be ready to provide your bank or building society details so your travel expenses can be paid into your account.

WHAT HAPPENS AT THE FACE-TO-FACE CONSULTATION?

You will be asked for proof of your identity before the consultation begins.

The assessor will make a note of how well you are able to walk into the assessment centre or room. They may ask how you travelled to the assessment centre, to find out how well you can walk and plan a journey. It is important to mention any difficulties that you had on the journey. For example, if you walked from your home to the bus stop, mention if the walk was slow or painful. Or you may have needed a lift and been dropped off right outside the centre. You may have struggled with the walk from the car park or with any stairs in the assessment centre.

The assessor will ask questions about your health condition(s) or disability and what treatment, therapies or medicines you are using. They will ask about how your IBD affects your daily life. They may ask you to describe a typical day and explain how your IBD varies over time. Make sure you describe how your IBD affects you when your symptoms are at their worst. Your assessor may ask how many 'good' or 'bad' days you have and what help you need over a 12-month period. We suggest you use the term 'better days', rather than 'good days', otherwise the assessor may think you don't have any problems at all on those days.

They will also ask what type of home you live in and whether you live with other people. They will probably ask you about activities that are not directly included in the assessment, such as whether you work, do housework, go shopping, take part in hobbies or look after children or pets. Your answers to these questions may reveal evidence about whether or not you have difficulty with things like bending, walking or using your hands. This can help to show whether you are likely to have difficulty with the other activities included in the assessment. If you have had to give up hobbies or activities you previously enjoyed, or if you can only take part in social and leisure activities occasionally because of your health condition, make sure you explain this.



When you are answering the questions, remember to explain whether you have difficulties with performing activities reliably. In other words, can you do them safely, to an acceptable standard, repeatedly and in a timely manner?

Do not give an overly optimistic picture of what you can do. This can be easy to do if you are being asked leading questions, such as 'You don't have any trouble with...do you?' Try not to be pressured into giving an incorrect or inaccurate answer.

WILL I HAVE A PHYSICAL EXAMINATION?

The health professional may carry out a physical examination or do non-invasive tests, such as testing your blood pressure. They may ask you to perform certain tasks or movements, such as raising a leg or bending over. They should not force you to do anything that would cause you pain, embarrassment or discomfort. They will not ask you to do a formal walking test, but they are likely to watch how you walk from the waiting room to the consultation room and how you move around during the consultation. They are not allowed to ask you to remove your underwear and they cannot carry out intimate examinations such as breast, rectal or genital examinations.

Throughout the consultation the health professional will also look at how you cope with activities such as removing your coat, handling your bag and holding a conversation. If you are having a consultation at your home, they will notice the home environment and any aids and adaptations. If they are in your home, they should not look into rooms that they have not been invited to enter.

RECORDING AND TAKING NOTES

You, or someone with you, can take notes of what was said during the consultation for your personal use. If you feel that the consultation was rushed or you did not get a chance to explain your difficulties fully, you may want to make notes about what happened. This could help you challenge the decision if you are not happy with the result of your claim.

You can make an audio recording of the consultation but there are some rules that you will need to follow.

- You will need to tell the organisation (IAS or Capita) in advance that you want to record the consultation.
- They will ask you to sign an agreement, which states what you can and cannot do with the recording.
- You will need to use your own recording equipment – the equipment must make two identical recordings at the same time, on audio cassette or CD. You keep one copy and the assessor keeps the other. **You cannot use a mobile phone or laptop to make the recordings.**

4 RECEIVING A WRITTEN DECISION

After the face-to-face consultation, the assessor will complete a report. They will recommend which descriptors they think should apply to you, and why. They should choose the descriptor that fits you best for each activity, without thinking about how many points you might score or whether your total score will mean you qualify for PIP.

They will send their report to the DWP or DfC. The DWP or DfC makes the final decision about which descriptors apply to you and whether you qualify for PIP.

THE DECISION

A case manager at the DWP or DfC will look at the report, along with your claim form and any other evidence. They will work out how many points you score and decide whether to award you PIP, at what rate and for how long.

They will send you a letter with their decision. If your claim is turned down or if your benefit is being reduced, a DWP or DfC case manager will phone you to explain the decision. They will try to phone you a week after the decision is sent out.

If you are not happy with the decision you may be able to challenge it – see page 32.

PIP is normally paid every four weeks. If you are terminally ill, you are paid weekly in advance.

HOW LONG WILL I GET PIP FOR?

Most PIP awards will be for a fixed amount of time. The length of your award will depend on whether your condition is likely to change and/or whether you are likely to need less support in the future. For example, you could be awarded PIP for two years, three years or five years. If your IBD is unlikely to change, you may be given an indefinite award.

However long you are awarded PIP for, the DWP or DfC may contact you at any time to see if your needs have changed or to invite you to another face-to-face consultation.

You must report changes in your condition, for example, if your health improves and you have less difficulty with daily living. If you fail to report a change that would result in your payment reducing, you may have to pay a fine.

If your difficulties with daily living and/or mobility increase, you may be able to get a higher rate of PIP by asking for your claim to be reconsidered. Think carefully before doing this to make sure that you have a chance of getting an increase and that you do not risk losing your existing payment. Even if you report that your condition is worse, the DWP or DfC may not agree and they have the right to look at your whole claim again. They could decide to reduce or remove your award. On the other hand, if you think that you have a good case for getting a higher rate because your IBD is worse, and you have new medical evidence, it could be worth having your claim looked at again. If you are not sure what to do, you could get advice from one of the organisations listed at the end of this guide.

If you are awarded PIP for a fixed term, you will be invited to renew your claim several months before it runs out. You will need to complete a PIP review form and will probably need to attend another face-to-face consultation.

WHAT HAPPENS IF I GO INTO HOSPITAL?

If you start a claim for PIP while you are in hospital, you usually will not get payment until you leave. If you are already getting PIP and then go into hospital, both components of PIP will normally be stopped after you have been in hospital for 28 days. It can start to be paid again as soon as you leave hospital, as long as you still meet all the other qualifying conditions. You should tell the office that pays your benefit whenever you go into or leave hospital or residential care. Try to do this as soon as you can.

Neither the day you go in, nor the day you leave, count as days in hospital.

If you use PIP mobility component to pay for a vehicle through the Motability scheme, you will have to return the vehicle 28 days after you stop receiving the mobility component of PIP. Motability may allow you to keep the vehicle for longer, for example if you are due to leave hospital soon.

Separate spells in hospital that are less than 28 days apart will be linked together and payment of PIP will stop after a total of 28 days.

You can get PIP while in hospital if you are a private patient with no funding from the NHS.

WHAT HAPPENS IF I GO ABROAD?

You can continue getting PIP if you go abroad for up to 13 weeks, or for up to 26 weeks if you are getting medical treatment abroad. If you are in an EEA country or Switzerland, you may be able to get PIP daily living component for longer.

WHAT HAPPENS IF I AM NOT HAPPY WITH THE OUTCOME OF MY CLAIM?

If your claim is turned down, or if you are unhappy with the rate or the length of time it has been awarded for, you can challenge the decision.

If you have been awarded PIP, but you are not happy with the award, be aware that challenging the decision may result in your award being stopped or reduced. The organisations listed at the end of this guide have information and advice to help you decide what to do.

Mandatory reconsideration

The first step is to ask the DWP or DfC to look at their decision again. This is called a **mandatory reconsideration**. You usually need to do this within one calendar month of the date on the decision letter. You can ask the DWP or DfC for a copy of the assessor's report, so you can comment on it.

Write a letter explaining why you disagree with the decision, listing the descriptors or scores that you disagree with and explaining how you think you meet the criteria. Send any new evidence or information to support your claim, if you can.

The DWP or DfC will look at your claim again. They will write to you to respond to the points you have raised and to tell you their decision. The letter (called a mandatory reconsideration notice) will include details of how to appeal to a tribunal, if you are still unhappy with the decision.



PIP-trained volunteers from the **Crohn's and Colitis UK Disability Benefit Service** can help you understand how to ask for a mandatory reconsideration. Call our Information Line on **0300 222 5700** to make an appointment with one of our volunteers. Appointments are arranged in advance and can last for up to 30 mins.

TRIBUNAL APPEAL

If you are still not happy with the result of your claim, you can appeal to an independent tribunal. You must do this within one month of the date on your mandatory reconsideration letter.

There is a risk that your existing award could be reduced or ended instead of being increased.

Contact details for organisations that give information and advice about tribunal appeals are listed at the end of this guide. Citizens Advice has detailed information on how to appeal at a tribunal. Advice Now has a guide called How to Win a PIP Appeal.

You can appeal by letter but you may find it easier to use the official form, which tells you what information to include. In England, Scotland and Wales, use the SSCS1 appeal form, which you can get from www.gov.uk. For Northern Ireland, use the NOA1 (SS) appeal form, which you can get from www.nidirect.gov.uk. Use the form to explain why you think the decision is wrong and include any evidence you have. Send the form and a copy of your mandatory reconsideration notice to the address on the form.

The form asks you whether you want to go to a tribunal hearing or not. The tribunal will be informal, with only the judge, two independent people and possibly one person from the DWP or DfC. You may want to represent yourself if you feel you are the best person to explain your situation. You can ask someone to represent you, but make sure they fully understand IBD and the problems you face in your daily life.

Going to the tribunal hearing gives you the chance to explain how your IBD affects you and why you think you should get PIP. From the calls we receive on our helpline, it seems that tribunal appeals may be more successful when people go to the hearing. If you do not go to a hearing, the decision will be based on your application form and supporting evidence.

If you want to go to a tribunal hearing, you need to state on the form if:

- someone will be representing you at the hearing, such as a family member, friend or lawyer
- you need an interpreter
- you need any special arrangements, for example, because you have health or mobility problems
- there are any dates you cannot attend the hearing.

The tribunal will send your application to the DWP or DfC for their response. If you are attending a hearing, you will need to take all of the documents related to your appeal, as well as any evidence you have.

At the hearing, you may be asked questions about your appeal. Do not be embarrassed to describe how your IBD affects your daily life. You could take a list of the important things you want to say, so that you do not forget anything.

A decision may be made at the hearing or you may be sent a letter afterwards. The DWP and DfC almost always accept the tribunal's decision but, on rare occasions, they may challenge it. If this happens, they will write to you. If your appeal is successful, you will start to receive the new rate of PIP as well as the money you should have been paid from the date you started to claim PIP. You may be able to claim expenses for attending the tribunal, for example travel costs, meals, loss of earnings and care expenses. Take any receipts or a letter from your employer with you to the hearing.

IF YOU ARE UNHAPPY WITH THE DECISION MADE AT THE TRIBUNAL

You can appeal if you think there is a legal reason why the decision is wrong. Citizens Advice can give you more information about this.

You may want to contact your local MP if you think you have been treated unfairly or if you have had to wait a long time to get a response. Your MP may be able to help you get an apology or help you get a decision more quickly. They may be able to help get the law changed. There is information on how to find your local MP on page 38.

HOW WILL PIP AFFECT MY OTHER BENEFITS?

PIP is paid on top of any other benefits you may be getting. It may increase the amount of benefit that you, your family or your carer can get. If you have previously been told that your income is too high for you to qualify for means-tested benefits, an award of PIP may change this. We recommend seeking advice to check whether there is anything else you can claim. Online benefits checkers are available on the Turn2us and Citizens Advice websites.

If you (or your partner or a dependant young person included in your benefit claim) are awarded PIP, you should tell the offices that pay your other benefits. If you stop getting PIP, or if the rate you get changes, you will need to tell the offices that pay your other benefits as well.

You could also qualify for:

- extra support with council tax - ask your local authority
- a blue badge for parking
- exemption from Vehicle Excise Duty (road tax) if you receive the enhanced rate of PIP mobility component
- 50 per cent discount on road tax if you receive the standard rate mobility component
- discounted travel on public transport.

If you are awarded the enhanced rate of PIP mobility component for 12 months or more, you can use it to pay for a car or powered wheelchair under the Motability scheme. Be aware that if you currently have a Motability car and you transfer from DLA to PIP, you will lose your car if you are not awarded the enhanced rate of PIP. For more information, phone **Motability** on **0300 456 4566** or go to www.motability.co.uk

Citizens Advice has information on getting extra money and help, including information on the Motability scheme.

If you have a carer, they may qualify for extra benefits. The carer could be your partner, grown child or another relative or friend who regularly helps you.

- Your carer may be able to claim carer's allowance if you get either the standard or enhanced rate of PIP daily living component. To qualify, they need to spend at least 35 hours a week helping you. Carers allowance overlaps with some other benefits and cannot normally be paid if the carer is earning more than £116 per week (after taxes, care costs while at work and 50% of pension contributions). This figure may be subject to change – you can find the latest figures on the DWP and DfC websites. If you are entitled to means-tested benefits, these may be affected if a carer receives carers allowance for looking after you. You may want to get advice before they apply.
- If your carer looks after you for at least 20 hours a week, they can claim national insurance credits to help them to qualify for the state retirement pension. If they claim carers allowance, they will automatically get national insurance credits.

Carers may qualify for increases in means-tested benefits, such as housing benefit or universal credit.

QUICK GUIDE TO APPLYING FOR PIP

Here are the key stages that you need to follow when you are applying for PIP.

Check you qualify

- Age 16-64.
- Living in the UK, with some exceptions – see page 4.
- Inflammatory Bowel Disease or another health condition has caused problems with daily living and/or mobility for at least 3 months.
- These problems are expected to last for at least another 9 months.

Find out more on pages 4 to 5

REGISTER YOUR CLAIM

Telephone:

- England, Wales, Scotland: **0800 917 2222** (textphone **0800 917 7777**).
- Northern Ireland: **0800 012 1573** (textphone **0800 012 1574**).

Find out more on page 7

Complete the form 'How your disability affects you'

- Return your completed form within one month, or your claim may be turned down.
- Explain the **impact** of your IBD on your daily life and your ability to get around – it is not enough to just say you have IBD.

- Ask yourself whether you can do the listed activities **reliably** – this means safely, to an acceptable standard, repeatedly and in a timely manner. Use the text boxes to give as much information as you can about the help you need – do you use any aids or appliances, or do you need another person to prompt, help or supervise you?
- Describe how your IBD affects you on a typical day and on your worst days - state how your symptoms vary over time.
- Attach photocopies of evidence to show how your IBD affects you, such as medical reports, diary entries, letters from employers or carers, prescription lists of medicines you take.
- Give details of any help you need at the face-to-face assessment.
- Keep a copy of your completed form and any supporting evidence.

Find out more on pages 9 to 27

PREPARE FOR THE FACE-TO-FACE CONSULTATION

- You should get seven days' notice of your appointment date and location.
- If possible, ask someone to give you a lift to the assessment centre.
- Keep tickets and receipts to claim travel expenses and parking costs.
- You can take someone with you to give you support and help you understand what is said.
- Do not put on a brave face – give full details of the problems you have and describe what help you need.
- Describe how your IBD affects you when your symptoms are at their worst and how this can vary over time.
- Take copies of evidence to the consultation to support your claim.
- You can take notes at the consultation. You can record the consultation, as long as you meet the conditions listed on page 31.

Find out more on pages 29 to 30

GETTING A DECISION

- You will get a letter to say whether you have been awarded PIP, at what rate and for how long.
- You are normally paid every four weeks.
- Once you are receiving PIP, report any changes in your health that may lead to your payment being reduced, to avoid a fine.
- You may need to tell the DWP or DfC if you go into hospital or abroad – see page 32.
- If your claim is turned down, you can challenge the decision.

Find out more on pages 30 to 32

CHALLENGING THE DECISION

- Ask the DWP or DfC for a mandatory reconsideration within one month of the date on the decision letter – see page 32.
- If you are not happy with the outcome, you can appeal to an independent tribunal within one month of the date on the revised decision letter – see page 33.
- Remember that any award can be reduced as well as increased, if you challenge it.

HOW WE CAN HELP YOU

We produce about 50 information sheets, booklets and guides about all aspects. We're here for you whenever you need us. Our award-winning publications on Crohn's Disease, Ulcerative Colitis, and other forms of Inflammatory Bowel Disease have the information you need to help you manage your condition.

We have information on a wide range of topics, from individual medicines to coping with symptoms and concerns about relationships, school and employment. We'll help you find answers, access support and take control.

Our helpline is a confidential service providing information and support to anyone affected by Crohn's or Colitis. You may be interested in the following services:

Crohn's and Colitis Support

Many people find the process of applying for PIP emotionally demanding. If you do find the application process stressful, you may like to telephone our emotional support line. Our specially trained volunteers all have personal experience of living with Crohn's or Colitis. They are unable to give any information about PIP, but they can offer you confidential support.

Contact us by telephone on **0300 222 5700**
or email helpline@crohnsandcolitis.org.uk

OTHER USEFUL ORGANISATIONS

Making a claim

Department for Work and Pensions (DWP)

www.gov.uk/pip

For claims in England, Wales and Scotland

PIP claims (to start a claim) **0800 917 2222** (textphone **0800 917 7777**)

Disability Service Centre (for advice about a claim you have already made)

0345 850 3322 (textphone **0345 601 6677**)

Department for Communities (DfC)

www.nidirect.gov.uk/articles/personal-independence-payment

For claims in Northern Ireland

PIP claims (to start a claim) **0800 012 1573** (textphone **0800 012 1574**)

PIP enquiry line **0300 123 9221** (textphone **0300 123 1008**)

Your assessment

Capita

www.capita-pip.co.uk

England **0808 1788 114**

Northern Ireland **0808 1788 116**

Wales **0808 1788 115**

Independent Assessment Services (IAS)

www.mypipassessment.co.uk

North of England & Scotland **0300 3300 120**

Southern England **0300 3300 121**

Getting support and advice

Advice Now

www.advicenow.org.uk

Citizens Advice

www.citizensadvice.org.uk

England **03444 111 444**

(the telephone advice service is being rolled out across England. If it is not available in your area, contact your local Citizens Advice)

Scotland **0808 800 9060**

Northern Ireland – Contact your local Citizens Advice

Wales **03444 77 20 20**

Motability www.motability.co.uk

Turn2us www.turn2us.org.uk

Your MP

You can find contact details for your local MP from your local library or from

www.parliament.uk/mps-lords-and-offices/mps

APPENDIX 1: SAMPLE DIARY

Saturday Morning

Bad day today. Woke up feeling totally exhausted - had a bad night, woke up lots, needed to go down to toilet, couldn't get back to sleep for a long time each time.

My neck is stiff and painful and my hands and shoulders hurt. My hands are not very flexible. Feel extremely depressed. I can't think straight, I can't find the strength to communicate with my partner except 'Yes', 'No' and 'Please don't talk to me now'.

Get out of bed to go to the loo. My body is very stiff and tired. My feet hurt. Get down to the loo slowly. Sit for ages but just wind and pain in stomach. Go back upstairs, getting pains in my thighs by the time I get to the top of the stairs. I need to lie down. Go back to bed. Partner brings me cup of tea. Drink it, doze off for a while. 10.30, get up again. Partner reminds me to take medication - I hadn't remembered.

Have a bath. Takes a long time, as I feel very sluggish and slow. Try to get out, feel faint and light-headed. Pull plug out immediately, call to partner to come and help me. Dry myself, feel totally exhausted, need to lay down for 15 minutes. Get dressed. Hands are still stiff, need some help with buttons and laces. Partner helps to dry my hair as my arms become tired and painful holding hairdryer and trying to brush.

Have breakfast, feel very bloated and uncomfortable, have to change clothes to something looser.

Partner takes me shopping in car. By the time we get to town I need to get to the loo fast - explosive diarrhoea. No disabled loo with sink inside in the covered market so I can't clean myself up properly. Need to change underwear. No soap in loos, I'm feeling very dirty and not able to get clean. Ask partner to take me home, am very depressed. Partner is very reassuring, calms me down. We go home. Need to lie down, am upset and very tired.

Afternoon

Partner makes lunch, but I can't eat much. Back in the toilet soon after. Have to clean the toilet and myself. This leaves me feeling very tired and more depressed.

Watch TV in the afternoon till 5.30 on couch with feet up. Take dogs for walk up lane. Come back too tired to cook dinner. Sit in kitchen and tell partner how to do it. Too tired to sit up to table so meal brought to me laying on couch.

Evening

Watch TV till 10ish, get up to go to bed very tired and stiff, partner helps me upstairs, helps me undress and into bed. Checks I've remembered my medication. Helps me put on skin treatment to upper arms neck and shoulders as my arms hurt too much to stretch to these places.

During the night

Stomach is feeling bloated, uncomfortable and painful. My neck is also very stiff and painful. Can't get to sleep. Partner has to get up for medication for my tummy pain. Also makes me a hot water bottle and rubs some Ralgex into my neck for me.

APPENDIX 2: HEALTH PROFESSIONALS' SHEET

Information for healthcare professionals providing evidence about a Personal Independence Payment (PIP) claim

The DWP or DfC needs very specific evidence from health professionals, so that they can make a fair decision about a claim.

The DWP/DfC wishes to know:

- how long the patient has been receiving treatment
- details of the diagnosis for all medical conditions, not just IBD
- likely future clinical course.

The most important information is a description of the **consequences** of symptoms and their causes. For example:

Symptom:

Weakness and lethargy due to anaemia resulting from chronic disease and blood loss.

Effect:

Breathless and unsteady, even when walking a short distance or using stairs. Poor concentration, very slow performing daily activities, needs reminding to take medication and safely carry out activities of daily living such as locking doors and turning off appliances.'

Tips:

- The checklist of daily living activities on the following pages may help you gather evidence. The patient may have already completed this form. You may want to go through it with them.
- Patients may not have told their health professional how much their IBD affects their daily life. One possible reason for this may be that living a restricted life has become the norm, and thinking about it and telling others can be distressing.
- It is important to bear in mind that Ulcerative Colitis and Crohn's Disease are largely 'hidden' conditions. The disabilities they cause are not usually obvious. The evidence you give to the DWP or DfC can help make it clear that this does not reduce the importance of the disabilities.

COMPONENTS AND RATES OF PIP

PIP has two parts (components):

1. **Daily living component**
2. **Mobility component**

Patients may qualify for either or both parts, depending on how their disability or health condition affects them. Each component has two rates:

1. **Standard rate**
2. **Enhanced rate**

PIP claims are assessed using a point-scoring system.

Patients may qualify for PIP **daily living component** if they have difficulty with any of the following activities.

1. Preparing food
2. Eating and drinking
3. Managing treatments
4. Washing and bathing
5. Managing toilet needs
6. Dressing and undressing
7. Communicating
8. Reading
9. Mixing with other people
10. Making decisions about money.

They may qualify for PIP **mobility component** if they have difficulty with either or both of the following activities.

1. Planning and following journeys
2. Moving around.

CHECKLIST

ACTIVITY	✓	Very brief details of the problems you have with this activity. For example 'I am in pain and unsteady when I use the stairs. It helps to have someone to lean on'.
Preparing food		
Eating and drinking		
Managing treatments		
Washing and bathing		
Managing toilet needs		
Dressing and undressing		
Communicating		
Reading		
Mixing with other people		
Making decisions about money		
Planning and following journeys		
Moving around		

APPENDIX 3:

WORDS USED IN THE ACTIVITIES AND DESCRIPTORS

Aided	with help from an aid or appliance, or with supervision, prompting or help from another person
Assistance	physical help from another person with part of, or the whole of, an activity
Basic verbal information	information in your native language spoken in a simple sentence
Basic written information	signs, symbols and dates written or printed in standard-size text in your native language
Bathe	includes getting into or out of a standard bath or shower
Communication support	support from a person trained or experienced in communicating with people with communication needs, including interpreting spoken information into written form and vice versa
Complex budgeting decisions	decisions involving: <ul style="list-style-type: none">• calculating household and personal budgets• managing and paying bills• planning future purchases
Complex verbal information	information in your native language spoken in either more than one sentence or in one complicated sentence
Complex written information	more than one sentence of written or printed standard-size text in your native language
Cook	to heat food at or above waist height
Dress and undress	includes putting on and taking off socks and shoes
Engage socially	includes: <ul style="list-style-type: none">• interacting with other people in an acceptable way• understanding body language• building relationships
Manage incontinence	managing involuntary emptying of the bowel or bladder, including using a collecting device or self-catheterisation, and cleaning yourself afterwards
Manage medication or therapy	taking medicines or having therapies, when failing to do so is likely to make your IBD worse
Medication	medicines you take at home that are prescribed or recommended by a registered doctor, nurse or pharmacist
Monitor health	you are able to: <ul style="list-style-type: none">• notice significant changes in your health that may mean your IBD is getting worse, and• follow the advice of a registered doctor, nurse or health professional, without which your health is likely to get worse

Orientation aid	a specialist aid designed to help disabled people to follow a route safely
Prepare	(when talking about food) making food ready for cooking or eating
Prompting	reminding, encouraging or explaining by another person to help you complete part of, or the whole of, an activity
Psychological distress	distress related to an ongoing mental health condition or an intellectual or cognitive impairment
Read	reading signs, symbols and words - does not include reading Braille
Reliably	safely, to an acceptable standard, repeatedly and in a timely manner
Simple budgeting decisions	making decisions based on calculating the cost of goods and calculating how much change you should get when you pay
Simple meal	a cooked one-course meal for one person using fresh ingredients
Social support	support from a person trained or experienced in helping people to engage in social situations. This may be a family member or friend who has experience of providing support to you
Stand	stand upright with at least one biological foot on the ground
Supervision	the presence of another person throughout the whole of an activity, for your safety
Take nutrition	either: <ul style="list-style-type: none">• cutting food into pieces, passing food and drink to your mouth, chewing and swallowing food and drink, or• taking nutrition through a therapeutic source
Therapeutic source	parenteral (into a vein) or enteral (into the stomach or small intestine) tube feeding, using a rate-limiting device, such as a delivery system or feed pump
Therapy	treatment at home that is prescribed or recommended by a registered doctor, nurse, pharmacist or health professional regulated by the Health and Care Professions Council
Toilet needs	includes: <ul style="list-style-type: none">• getting on and off an unadapted toilet• emptying your bladder and bowel• cleaning yourself afterwards
Unaided	without using an aid or appliance or being supervised, prompted or helped by another person

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We hope that you have found this leaflet helpful and relevant. If you would like more information about the sources of evidence on which it is based, or details of any conflicts of interest, or if you have any comments or suggestions for improvements, please email the Publications Team at publications@crohnsandcolitis.org.uk. You can also write to us at Crohn's & Colitis UK, 1 Bishops Square, Hatfield, Hertfordshire, AL10 9NE, or contact us through the **Helpline: 0300 222 5700**.

ABOUT CROHN'S & COLITIS UK

We are Crohn's & Colitis UK, a national charity fighting for improved lives today – and a world free from Crohn's and Colitis tomorrow. To improve diagnosis and treatment, and to fund research into a cure; to raise awareness and to give people hope, comfort and confidence to live freer, fuller lives. We're here for everyone affected by Crohn's and Colitis.

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