Claiming Personal Independence Payment (PIP)

This guide is for people with Crohn's or Colitis who are thinking about applying for Personal Independence Payment (PIP).

This information is for people living in England or Wales.

If you live in Northern Ireland

PIP rules are the same as in England and Wales so you may still find this guide useful when applying for PIP. There may be some slight differences between your application form and the information in this guide. The relevant government department in Northern Ireland is called the Department for Communities (DFC).
To find out more about PIP in Northern Ireland, visit the Nidirect website.

If you live in Scotland

You will need to apply for Adult Disability Payment (ADP) instead. Find out more about ADP in our disability benefits quick guide.

This guide explains what PIP is, who may be eligible 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 under getting support and advice.

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This guide does not include information on other benefits. 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

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Key facts about PIP

- **PIP is a payment to help with extra living costs if you have a disability or long-term condition and difficulty in doing everyday tasks or getting around because of your condition.**
- **You can get PIP whether you are working or not. It doesn't depend on income, savings or who you live with.**
- **PIP doesn't have a negative effect on any other benefit you claim. If you have a carer, they may be able to claim extra money too.**
- **To claim PIP, you will need to fill in a form about how your condition affects you. You may then be invited to have an assessment with a health professional. Your claim will be assessed using a points system.**
- **Whether you qualify for the daily living component, the mobility component or both depends on how much help you need because of how your condition affects you.**
- **You will get a letter to say whether you have been awarded PIP, at what rate and for how long. You can challenge this decision.**

What is personal independence payment (PIP)?

PIP is a payment to help with extra living costs if you have both:

- A disability or long-term condition
- Difficulty in doing everyday tasks or getting around because of your condition

If your Crohn's or Colitis makes it hard for you to get around or cope with daily living, you may be eligible to receive PIP.

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

To claim PIP, you will need to fill in a form about how your condition affects you. You may then be invited to have an assessment with a health professional.

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 Crohn's or Colitis or any other condition - you need to show how your Crohn's or Colitis affects your life based on the listed activities. 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.

How much could I get?

Whether you qualify for the daily living component, the mobility component or both depends on how much help you need because of how your condition affects you.

Each component has two rates – a lower (standard) rate and a higher (enhanced) rate. The Department for Work and Pensions (DWP) will decide whether you are entitled to PIP, and which rate you will get, depending on how your condition affects your ability to carry out the listed daily living activities and mobility activities.

Your rate will be reviewed regularly to make sure you are receiving the right amount of help.

Check the GOV.UK website to check the current rates for PIP.

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.

Who provides PIP?

The Department for Work and Pensions (DWP) is responsible for PIP in England and Wales.

What happens if I am claiming Disability Living Allowance?

Disability Living Allowance (DLA) is being replaced by PIP, except if you are aged under 16 years old. Read more on the GOV.UK website.

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Quick guide to applying for PIP

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

Check you are eligible

- Aged between 16 and State Pension age at the start of your claim
- Living in the UK, with some exceptions – see Eligibility
- Crohn's or Colitis 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. (unless you are terminally ill)

Starting your claim

Telephone:

Call the 'PIP new claims' phone line:

- Telephone: 0800 917 2222
  Textphone: 0800 917 7777
- Relay UK (if you cannot hear or speak on the phone): 18001 then 0800 917 2222
  British Sign Language (BSL) video relay service if you're on a computer - find out how to use the service on mobile or tablet
- Calling from abroad: +44 191 218 7766

Complete the form 'How your disability affects you'

- This form will be posted or emailed to you after you start your claim.
- Return your completed form within one month. If you need extra time to complete the form, ring the DWP and they can extend that deadline.
- Explain the **impact** of your Crohn's or Colitis on your daily life and your ability to get around. You cannot score points just for having Crohn's or Colitis - you need to show how your Crohn's or Colitis affects your life based on the listed activities.

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- 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 Crohn's or Colitis affects you on a typical day and on your worst days - state how your symptoms vary day-to-day.
- Attach photocopies of evidence to show how your Crohn's or Colitis affects you, such as medical reports, diary entries, letters from employers or carers, prescription lists of medicines you take.
- Keep a copy of your completed form and any supporting evidence.

Prepare for the assessment with a health professional

- Most assessments are now done through phone or video call.
- You may be invited to a face-to-face assessment if the DWP cannot assess you over the phone or by video call.
- You, or someone with you, can take notes of what was said during the consultation for your personal use.
- You can make an audio recording of the assessment if it is over the phone or face-to-face. There are some rules you need to follow. See **Recording and taking notes.**
- Give full details of the problems you have and describe what help you need. Don’t be embarrassed to describe particular problems.
- Describe how your Crohn's or Colitis affects you when your symptoms are at their worst and how this can vary day-to-day.

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.

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- Once you are receiving PIP, report any improvement in your health that may lead to your payment being reduced, to avoid overpayment and even a fine.
- You should also report if your needs increase, if you are not already on the enhanced rates.
- You may need to tell the DWP if you go into hospital or abroad.
- If your claim is turned down, you can challenge the decision.

Challenging the decision

- Ask the DWP for a mandatory reconsideration within one month of the date on the decision letter.
- 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.
- Remember that any award can be reduced as well as increased, if you challenge it.

Eligibility

To be eligible for PIP, you will need to meet the conditions listed below. There is information further down about what to do if your claim is turned down.

Age

You must be aged between 16 and State Pension age at the start of your claim.

Citizens Advice have more information on getting PIP after you've reached State Pension age.

Children under the age of 16 may be able to apply for Disability Living Allowance. If you have reached State Pension age and you do not already get PIP or DLA, you may qualify for Attendance Allowance. Read more about Attendance Allowance at Citizens Advice or Age UK.

Residency and presence

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You must:

- be living in England or Wales when you apply for PIP, **and**
- have lived in either 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 to claim if you have spent time in the EU, Norway, Switzerland, Iceland or Liechtenstein.

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 Crohn's or Colitis

You will need to show that your Crohn's or Colitis 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 (unless you are terminally ill)

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:

- Preparing food
- Eating and drinking
- Washing or bathing
- Using the toilet
- Dressing and undressing
- Reading and communicating
- Managing your medicines or treatments
- Making decisions about money
- Socialising and being around other people

Tip:

Here are some questions to help you decide whether you are likely to qualify for the daily living component. 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 Crohn's or Colitis flares?
- Do I have to pay for help, aids or appliances to help me do this activity?

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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 a route and following it
- Moving around
- Leaving your home

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 Crohn's or Colitis 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 Crohn's or Colitis 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 might have 12 months or less to live, your claim will be dealt with more quickly. You will automatically qualify for the enhanced

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rate of the daily living component of PIP. But you will still 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 can get an SR1 medical report from your doctor.

The GOV.UK website has information on how to claim if you might have 12 months or less to live.

Starting your claim

The GOV.UK website has information on how to start your claim, and the information you will need to give.

You will be asked whether you give permission for the DWP to contact your GP or other organisations for further information about your Crohn's or Colitis. You will not be asked for detailed information about your Crohn's or Colitis 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 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.

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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 need more time to complete your form, contact the PIP enquiry line. They will usually give you an extension to return your form if you have a good reason, such as illness or bereavement. Read about asking for more time to send your PIP form on the Citizens Advice website.

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 Crohn's or Colitis causes you.

You can get help from an advice service, such as Citizens Advice. There may also be local advice services available where you live. You may want to contact your local council to find out what is available in your area.

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Completing the form: Section 1 – About your health condition or disability

Q1a. Health conditions or disability

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 Crohn's or Colitis 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 Crohn's or Colitis, 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 will ask for more information if they need it.

Q1b. Tablets or other medicines

This question asks for details about any medicine you are taking, these might be prescribed to treat your Crohn's or Colitis, or other medicines such as painkillers. Write down how often you take each medicine, and the dosage if you know it.

Include information on any side effects you experience, especially if they affect your ability to do daily living or mobility activities.

If you have tried a medicine that did not work, you may want to explain this on the form. You can also say whether there are any standard Crohn's or Colitis medicines 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.

Q1c. Treatments

This question asks for details of treatments you have had, are currently having or have planned for the future.

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Include details of treatments or therapies 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.

Completing the form: Section 2– About your health professionals

Q2. Professionals

The form asks for contact details for up to three professional people who can give information about your Crohn's or Colitis 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 end 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 Crohn's or Colitis 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.

Tips for section 3 - How your health condition or disability affects your day-to-day life

Some of the questions in section 3 use medical or technical words – you can find out what these mean in Appendix 3 at the end of this guide. Have a look at this appendix before answering the questions.

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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.

Questions 3 to 15 ask about how your Crohn's or Colitis affects your ability to complete the listed daily living activities and mobility activities. Remember to include information about any other health problems you have, as well as Crohn's or Colitis.

PIP is assessed 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 Crohn's or Colitis worse?
- **To an acceptable standard** – does your Crohn's or Colitis 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 Crohn's or Colitis?

You should add as much detail as you can to each question. It is not enough to say you just find an activity hard, you should explain why you find it hard and include any examples or evidence.

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. Make sure you consider the descriptors and points when thinking about each question.

Activity and descriptors example

Activity: Preparing food

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Descriptors and points:

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**)

The PIP form does not tell you what the descriptors are for each activity, but we list them on the following pages.

For each activity, the person who assesses your ability (the assessor) will choose the one descriptor that fits you best **based on what you have said on your form and at your assessment.** 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.

TIP: If your symptoms vary over time

The impact of your Crohn's or Colitis on your daily life may vary on a day-to-day basis. When you are filling in the form, think about how your Crohn's or Colitis 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 Crohn's or Colitis, you should be assessed on how you are now, not how you are expected to be after you have had the treatment.

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

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Scoring

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.

These are the number of points you must score to qualify for each of the PIP components:

Lower weekly (standard) rate

Daily living – 8 to 11 points
Mobility – 8 to 11 points

Higher weekly (enhanced) rate

Daily living – 12 or more points
Mobility - 12 or more points

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 Crohn's or Colitis 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 Crohn's or Colitis 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 Crohn's or Colitis 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 poo (diarrhoea). Many people with Crohn's or Colitis 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 falling 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 Crohn's or Colitis 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 Crohn's or Colitis affects your life.
- **Be clear about how bad your Crohn's or Colitis is.** If your Crohn's or Colitis 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.

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- **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 Crohn's or Colitis affects your daily life. Explain how often you need help doing the listed activities – for example "3 weeks out of 4 in a month" or "6 days out of 7 in the week".
  Example: "On 10 days out of 12 I get diarrhoea after eating. This makes it hard for me to make myself eat. My family check that I eat most meals, but if they're not home then I don't bother.'
- **Explain how fatigue (tiredness) affects you.** Many people with Crohn's or Colitis 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? Do you have to lean on furniture when moving around the house or the wall of the shower because of your fatigue?
- **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.

Getting support

It can be challenging to list all the negative ways your Crohn's or Colitis affects you. You might feel that you need to complete a little bit of the form each day and take rests. You may find it helpful to have someone with you when you complete the form to talk about each question and your answers. This could be a friend or family member, or a benefits advisor. You can find a benefits advisor at Citizens Advice or Turn2Us.

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Completing the form: Questions 3 to 15 - 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.

Preparing food descriptors and points
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 Crohn's or Colitis 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. Give examples of what these appliances are, such as lightweight saucepans, electric tin openers or needing a stool or chair while cooking.

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- 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 Crohn's or Colitis 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

Eating and drinking descriptors and points

a) Can take nutrition unaided **(0 points)**
b) Needs either (i) to use an aid or appliance to take nutrition; (ii) supervision to be able to take nutrition; or (iii) 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 be able 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 poo (diarrhoea)?
- The symptoms of Crohn's or Colitis 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 Crohn's or Colitis 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 bowel 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 poo (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 your treatments

Managing treatments descriptors and points

a) Either (i) does not receive medication, therapy or need to monitor a health condition; or (ii) can manage medication, therapy or monitor a health condition unaided **(0 points)**

b) Needs any one or more of the following – (i) to use an aid or appliance to be able to manage medication; (ii) supervision, prompting or assistance to be able to manage medication; (iii) supervision, prompting or assistance to be able to monitor a health condition **(1 point)**

c) Needs supervision, prompting or assistance to manage therapy that takes no more than 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 that takes between 7 and 14 hours a week **(6 points)**

f) Needs supervision, prompting or assistance to manage therapy 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 Crohn's or Colitis and its treatment? For example, you may need help with checking the condition of the area around your bottom (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 Crohn's or Colitis 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

Washing and bathing descriptors and points

a) Can wash and 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 be able 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

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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. Using the 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 wiper, 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.

Using the toilet and managing incontinence descriptors and points

a) Can manage toilet needs or incontinence unaided **(0 points)**
b) Needs to use an aid or appliance to be able to manage toilet needs or incontinence **(2 points)**
c) Needs supervision or prompting to manage toilet needs **(2 points)**
d) Needs assistance to be able to manage toilet needs **(4 points)**
e) Needs assistance to be able to manage incontinence of either bladder or bowel **(6 points)**
f) Needs assistance to be able 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?

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- 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 to shower or bathe? 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?
- Is there a risk of slipping or falling when getting on or off the toilet, sickness, or infection due to an inability to maintain personal hygiene).

One of the solutions that the assessor may suggest as reducing the need for assistance is the use of a commode. That is not always a practical suggestion, for reasons of space, privacy and the difficulty in emptying and cleaning it so you may find it helpful to have some reasons to explain why it wouldn't be suitable for you.

Example of a supporting statement:
'I cannot control when I poo (empty my bowels). The need is both urgent and unpredictable. A commode is not practical option. I wear incontinence pads and use waterproof sheets on my bed. My Crohn's or Colitis makes me feel very tired, so I need help to change the bed sheets during the night and have someone nearby for safety if I need to shower or bathe.'

Q8. Dressing and undressing

Dressing and undressing descriptors and points

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 (i) prompting to dress, undress or determine appropriate circumstances for remaining clothed or (ii) prompting or assistance to select appropriate clothing **(2 points)**

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d) Needs assistance to be able to dress or undress their lower body **(2 points)**
e) Needs assistance to be able to dress or undress their 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. Talking, listening and understanding

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

If your Crohn's or Colitis makes you feel very tired, then you may have problems understanding what people are saying. But for most people with Crohn's or

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Colitis, 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.

Talking, listening and understanding descriptors and points

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 Crohn's or Colitis. If you have another health condition that affects your ability to see or understand written information, explain what difficulties you have.

Reading descriptors and points

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)**

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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 Crohn's or Colitis 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.

Mixing with other people descriptors and points

a) Can engage with other people unaided **(0 points)**
b) Needs prompting to be able to engage with other people **(2 points)**
c) Needs social support to be able to engage with other people **(4 points)**
d) Cannot engage with other people due to such engagement causing either (i) overwhelming psychological distress to the claimant or (ii) the claimant to exhibit behaviour which would result in a substantial risk of harm to the claimant or another person **(8 points)**

Things you can 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?

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- Have you avoided mixing with other people because of your Crohn's or Colitis? 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 need to have someone 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. Managing 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 Crohn's or Colitis, 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.

Managing money descriptors and points

a) Can manage complex budgeting decisions unaided **(0 points)**
b) Needs prompting or assistance to be able to make complex budgeting decisions **(2 points)**

c) Needs prompting or assistance to be able 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 'planning and following a journey' 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 a journey'.

Q13. Planning and following a journey

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.

Planning and following a journey descriptors and points

a) Can plan and follow the route of a journey unaided **(0 points)**

b) Needs prompting to be able to undertake any journey to avoid overwhelming psychological distress to the claimant **(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 to the claimant **(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 the severe consequences of 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 important as 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 Crohn's or Colitis. But this question is not just asking whether you can physically walk each distance if you absolutely have to. It is asking whether you can walk that distance **reliably, repeatedly, safely and in a reasonable time.**

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 Crohn's or Colitis worse in any way
- Without feeling so tired that you cannot repeat it or do other activities for some time afterwards.

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- 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.

Moving around descriptors and points

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 1 metre but no more than 20 metres, either aided or unaided **(12 points)**
f) Cannot, either aided or unaided, (i) stand or (ii) move more than 1 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?

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- 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, or around, the shop? If you do shop, do you have to hold on to a trolley and do you only use shops that have accessible customer toilets?
- 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.

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 Crohn's or Colitis 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.

- Have you stopped or reduced seeing your friends and family or going to leisure activities such as cinema, sporting events, the library or bingo because of the risk of incontinence?
- 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 Crohn's or Colitis varies day to day.
- If your Crohn's or Colitis is getting worse, you could describe how it is causing you more difficulty.

Section 4 – What happens next

The final section of the form asks about any help you may need if you are invited to an assessment with a health professional. Most people have telephone or video assessments, rather than face-to-face.

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

You can also note down any help you would need if you have to go for a 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.

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 your assessment. 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 fixed 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 Crohn's or Colitis.
- 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 further down 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 the assessment about how your disability affects your daily living and mobility.

Sending evidence after you have completed your claim form

You may get additional evidence or information after you have already sent in your PIP form. The Citizens Advice website has information and a letter template to use to send evidence after your PIP claim form.

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 Crohn's or Colitis varies over time.

The diary can help to show the impact of your Crohn's or Colitis 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 end of this guide.

What happens after I return the form?

The DWP 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 an assessment with a health professional. It may take a long time to hear from the DWP. You can call the PIP enquiry line to check they have got your form.

The assessment

If more information is needed, you will be invited to an assessment with a health professional. The assessment will usually be done by phone or video call. You may be invited to a face-to-face assessment if the DWP cannot assess you over the phone or by video call.

The assessment usually takes about an hour.

Your claim is likely to be refused if you do not attend your assessment, 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.

Who carries out the assessment?

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

- **Independent Assessment Services (IAS)** – previously called Atos Healthcare. They assess claims in the 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. If you want an assessor of a particular gender, you can request this.

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

Getting ready for your assessment

To help prepare for your assessment, you may want to:

- Read through a copy of your completed PIP form
- Make notes on how your Crohn's or Colitis affects your ability to do day-to-day tasks and move around.
- Think about whether you need someone to attend your appointment with you. You can have someone aged 16 or over join your phone or video call or go with you if you have a face-to-face appointment. You could ask a family member, friend or support worker.
- If you have a phone or video call, think about where you are going to take this. It is a good idea to have the phone or video call in a quiet room where you will not be interrupted. Make sure your phone or device is charged.

What happens during the assessment?

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 Crohn's or Colitis affects your daily life. They may ask you to describe a typical day and explain how your Crohn's or Colitis varies over time. Make sure you describe how your Crohn's or Colitis 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 terms 'better days' or 'not quite so bad days', rather than 'good

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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.

TIP: 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.

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 assessment if it is over the phone or face-to-face. 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 assessment.
- They will ask you to sign or verbally consent to an agreement, which states what you can and cannot do with the recording.
- Video recordings of assessments are not allowed, to ensure privacy and safety of you and the assessor.

Face-to-face assessments

Face-to-face assessments 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, which could be up to 90 minutes away by public transport. 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 can claim travel expenses for getting to the assessment if it is not at your home. The DWP 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 assessment.

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.

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.

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 medicine if your doctor or Crohn's or Colitis team has recommended it. It is worth mentioning if you have had to do this.

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.

You can take written evidence to the face-to-face assessment. 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.

Will I have a physical examination?

During a face-to face assessment, 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 assessment. 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 assessment 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 an assessment at your home, they will notice the home environment and

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any aids and adaptations. If they are in your home, they should not look into rooms that they have not been invited to enter.

Receiving a written decision

After the assessment, 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. The DWP makes the final decision about which descriptors apply to you and whether you qualify for PIP.

The decision

A case manager at the DWP 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.

You will probably have to wait at least a month before you hear from them, but it may take more or less time than this. Unless you are claiming under ‘special rules’ due to terminal illness, in which case you will get a decision usually within 5-10 days.

You will receive a letter telling you whether you have been awarded PIP and at what rate. You may even get a payment into your bank account before you get the letter. You can try to call the PIP enquiry line (0800 121 4433) to chase progress. The DWP are unlikely to update you on your decision over the phone.

While you are waiting for a decision from the DWP, you can use this calculator to work out how much PIP you might get.

If you are not happy with the decision you may be able to challenge it.

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, five years or longer. If you are still getting PIP after you've reached State Pension age, the reviews are likely to be at least 10 years apart unless you request one sooner due to your health getting worse.

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

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.

If your claim was not successful, you can apply for PIP again straight away. But you may find it easier to challenge the decision through mandatory consideration or tribunal.

Mandatory reconsideration

The first step is to ask the DWP 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 for a copy of the assessor's report, so you can comment on it.
You can fill in and return a form asking for mandatory reconsideration. Complete the questions, explaining why you disagree with the decision. List the descriptors or scores that you disagree with and explain how you think you meet the criteria. Send any new evidence or information to support your claim if you can.

The DWP 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.

Citizens Advice have more information on challenging a PIP decision – mandatory reconsideration.

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.

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.

Visit the GOV.UK website for details of how to submit your appeal. 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. 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 Crohn's and Colitis and the problems you face in your daily life.

It is also possible that the DWP will contact you after you've appealed and offer a new decision. If it is what you think you should have, then you can accept it, and the appeal won't take place. If it isn't, you can ask for the appeal to go ahead.

Going to the tribunal hearing gives you the chance to explain how your Crohn's or Colitis 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 for their response. You will get a large set of papers called the appeal bundle, by post or email, containing copies of your claim forms, assessor's reports, copies of evidence and documents you have supplied. You need to take it with you. If you have new evidence, try to send it to the Appeal Service (not the DWP) seven days beforehand. If not, take it on the day but have 5 copies (one for each of the Tribunal; the clerk and the DWP official if there is one).

At the hearing, you may be asked questions about your appeal. Do not be embarrassed to describe how your Crohn's or Colitis 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 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.

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Reporting changes that affect your PIP

You must report changes in your condition, for example, if your health improves and you have less difficulty with daily living. This could be because of a change in medicine, medical care or treatment. 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. Even if you report that your condition is worse, the DWP 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 Crohn's or Colitis 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 up to a year before it runs out. You will need to complete a PIP review form and may need to attend another assessment.

Visit the GOV.UK website for information on how to report a change of circumstances.

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.

Speak to a Citizens Advice advisor for more information on benefits and being in hospital.

What happens if I go abroad?

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You can continue getting PIP if you leave Great Britain (England, Wales and Scotland) for up to 13 weeks, or for up to 26 weeks if you are getting medical treatment abroad. If you are in the EU, Norway, Switzerland, Iceland or Liechtenstein, you may be able to get PIP daily living component for longer.

How will PIP affect my other benefits?

You can get PIP at the same time as all other benefits, except Armed Forces Independence Payment. 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 and discounted travel on local buses - ask your local council
- A blue badge for parking
- Exemption from vehicle excise duty (road tax) if you receive the enhanced rate of PIP mobility component or a 50 per cent discount on road tax if you receive the standard rate mobility component

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.

For more information, phone **Motability** on **0300 456 4566** or go to motability.co.uk

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

If someone helps to care for you, they may be able to get Carer's Allowance or Carer's Credit.

Other organisations

Making a claim

Department for Work and Pensions (DWP): www.gov.uk/pip

PIP new claims

Telephone: 0800 917 2222
Textphone: 0800 917 7777
Relay UK (if you cannot hear or speak on the phone): 18001 then 0800 917 2222
British Sign Language (BSL) video relay service if you're on a computer - find out how to use the service on mobile or tablet
Calling from abroad: +44 191 218 7766
Monday to Friday, 8am to 5pm

Your assessment

Capita: www.capita-pip.co.uk
England 0808 1788 114
Wales 0808 1788 115

Independent Assessment Services (IAS): www.mypipassessment.co.uk

North of England 0800 188 4880
Southern England 0800 188 488

Getting support and advice

Advice Now: www.advicenow.org.uk

Citizens Advice: www.citizensadvice.org.uk

Motability: www.motability.org.uk

Turn2us: www.turn2us.org.uk

Your MP

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

Help and support from Crohn's & Colitis UK

We're here for you whenever you need us. Our award-winning information 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 and employment. We'll help you find answers, access support and take control.

All information is available on our website: crohnsandcolitis.org.uk/information

Our Helpline is a confidential service providing information and support to anyone affected by Crohn's or Colitis.

Our team can:

- Help you understand more about Crohn's and Colitis, diagnosis and treatment options
- Provide information to help you live well with your condition
- Help you understand and access disability benefits
- Be there to listen if you need someone to talk to
- Help you to find support from others living with the condition

Call us on **0300 222 5700** or email helpline@crohnsandcolitis.org.uk.

See our website for LiveChat: crohnsandcolitis.org.uk/livechat.

Crohn's & Colitis UK Forum

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This closed-group community on Facebook is for everyone affected by Crohn’s or Colitis. You can share your experiences and receive support from others at: facebook.com/groups/CCUKforum.

Help with toilet access when out

Members of Crohn’s & Colitis UK get benefits including a Can’t Wait Card and a RADAR key to unlock accessible toilets. This card shows that you have a medical condition, and will help when you need urgent access to the toilet when you are out. See crohnsandcolitis.org.uk/membership for more information, or call the Membership Team on **01727 734465.**

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.

This information 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.

About our information

Crohn’s & Colitis UK information is research-based and produced with patients, medical advisers and other professionals. They are prepared as general information and are not intended to replace advice from your own doctor or other professional. We do not endorse any products mentioned.

We hope that you’ve found this information helpful. You can email the Knowledge and Information Team at evidence@crohnsandcolitis.org.uk if:

- You have any comments or suggestions for improvements

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- You would like more information about the research on which the information is based
- You would like details of any conflicts of interest

You can also write to us at **Crohn's & Colitis UK, 1 Bishops Square, Hatfield, Herts, AL10 9NE** or contact us through the **Helpline: 0300 222 5700**.

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Claiming PIP, edition 4a

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Last review: June 2023

Next review: June 2026

Trusted
Information
Creator

Patient Information Forum

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 medicine - 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 medicine. 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 medicine for my tummy pain. Also makes me a hot water bottle.

Claiming PIP, ed 4
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Appendix 2: Health professionals' sheet

Information for healthcare professionals providing evidence about a Personal Independence Payment (PIP) claim.
The DWP needs very specific evidence from health professionals, so that they can make a fair decision about a claim.

The DWP wishes to know:

- How long the patient has been receiving treatment
- Details of the diagnosis for all medical conditions, not just Crohn's or Colitis
- 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 Crohn's or Colitis 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.

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- 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 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):

- Daily living component
- 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:

- Standard rate
- 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.

- Preparing food
- Eating and drinking
- Washing or bathing
- Using the toilet
- Dressing and undressing
- Reading and communicating
- Managing your medicines or treatments
- Making decisions about money
- Socialising and being around other people

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

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- Planning and following journeys
- Moving around.

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Checklist

Activity	✓	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		
Washing or bathing		
Using the toilet		
Dressing and undressing		
Reading and communicating		
Managing your medicines or treatments		
Making decisions about money		
Socialising and being around other people		
Planning and following journeys		
Moving around		

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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:

- 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:

- 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 Crohn's or Colitis 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:

- Notice significant changes in your health that may mean your Crohn's or Colitis 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

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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:

- 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:

- 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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