

MONEY WITH CROHN'S & COLITIS: BENEFITS



GARY VAUX

**Former Head of Money Advice Unit at
Hertfordshire County Council**

RAISING OF THE STATE PENSION AGE

- The state pension age was 66, but from 6 May 2026 it has started increasing to 67 for anyone born on or after 6 April 1960
- This has implications for other benefit claims – not just pensions
- Check your state pension age: www.gov.uk/state-pension-age

What are you doing for your 70th?

Probably the night shift



EMPLOYEES' BENEFITS

Statutory Sick Pay (SSP)

Statutory Maternity Pay

Statutory Paternity Pay

Statutory Adoption Pay

Occupational pensions

 = all four nations

 = England, Wales & Northern Ireland

 = Scotland

 = disappeared to be replaced by Universal Credit

CONTRIBUTORY

Contributory (new style) Jobseeker's Allowance (JSA)

Retirement and State Pensions

Bereavement benefits (Bereavement Support Payment and Widowed Parent's Allowance)

Contributory (new style) Employment and Support Allowance (ESA)

NON-CONTRIBUTORY

Child Benefit /  Scottish Child Payment

Personal Independence Payment (PIP) /  Adult Disability Payment (ADP)

Disability Living Allowance (DLA) /  Child Disability Payment

Attendance Allowance /  Pension Age Disability Payment (PADP)

Carer's Allowance / ( Carer Support Payment, plus  Scottish Carer Supplement, Additional Person Payment and  Young Carer Grant)

MEANS-TESTED

 Income Support

 Income-based Jobseeker's Allowance (JSA)

Pension Credit

 Housing and Council Tax  Benefit

 Child Tax Credit and  Working Tax Credit

 Income-related  Employment and Support Allowance (ESA)

Universal Credit



**TAX
CREDITS**

**INCOME
SUPPORT**

**INCOME
BASED
JSA**

**INCOME-
RELATED
ESA**

**MAINSTREAM
HOUSING
BENEFIT**

**LIVING WITH
CROHN'S OR COLITIS,
UNDER STATE PENSION AGE**

UNFIT FOR WORK OR NOT?

THE WORK CAPABILITY ASSESSMENT (WCA)

- Claim starts with a 'fit note', then claimant completes an ESA/Universal Credit claim
- Then issued with a WCA 50 questionnaire, where the claimant describes their health – almost identical test for ESA and Universal Credit
- WCA done by one of four assessment companies, based on postcode

Three possible outcomes:

1. **Fit for work** – need to look for work; claim Universal Credit and/or JSA
2. **Limited Capability for Work (LCW)** – no need to look for work, but need to try work-related activity. Extra benefit only paid if claimant has been unfit since before April 2017 and almost continuously since.
3. **Limited Capability for Work and Work-Related Activity (LCWRA)** – extra benefit paid but now at one of two rates if on Universal Credit

<u>NEW STYLE EMPLOYMENT AND SUPPORT ALLOWANCE (ESA)</u>	UNIVERSAL CREDIT
Based on National Insurance contributions – partner's work, income and capital not relevant	Based on a means test involving claimant and partner. £16,000 upper savings limit.
Not a 'passport' to other types of financial help	Does act as a 'passport', e.g. free prescriptions if no or low wages
Occupational pension – no deductions up to £85 per week	Occupational pension counts as income in full
Unlimited duration in Support Group, but limited to one year otherwise	No time limit, as long as claimant remains unfit for work
Permitted to work (£203.50 per week maximum, and below 16 hours per week)	Work Allowance if disabled – if you go over the Work Allowance limit, 55p is deducted for every £1 earned
Extra amount for Support Group (and Work-Related Activity Group in small number of cases)	Extra amounts for LCWRA (and LCW in small number of cases)

<u>INCOME-RELATED EMPLOYMENT AND SUPPORT ALLOWANCE (ESA)</u>	UNIVERSAL CREDIT
Less than 600 claimants still on income-related ESA - DWP hoping to move them all by October	Based on a means test involving claimant and partner. £16,000 upper savings limit.
	Does act as a 'passport', e.g. free prescriptions if no or low wages
	Occupational pension counts as income in full
	No time limit, as long as claimant remains unfit for work
	Work Allowance if disabled – if you go over the Work Allowance limit, 55p is deducted for every £1 earned
	Extra amounts for LCWRA (and LCW in small number of cases)

UNIVERSAL CREDIT / NEW STYLE ESA HEALTH CRITERIA

You need to score a total of 15 points or more, across one or more activities, to be classed as having 'Limited Capability for Work'

entitledto
independent | accurate | reliable

has information about the Work Capability Assessment and the criteria for LCW/LCWRA and ESA, as well as a free online benefits calculator: entitledto.co.uk/benefits-calculator

- Online self-testers, e.g. from benefitsandwork.co.uk

UNIVERSAL CREDIT / NEW STYLE ESA POINT-SCORING (17 ACTIVITIES)

1. Mobilising
2. Standing and sitting
3. Reaching
4. Picking up and moving objects
5. Manual dexterity
6. Making yourself understood
7. Understanding communication
8. Navigation and getting around
9. Continence
10. Remaining conscious

11. Learning tasks
12. Awareness of hazards
13. Initiating and completing personal actions
14. Coping with change
15. Coping with social engagement
16. Appropriateness of behaviour with other people
17. Coping with work-related stress

(and for ESA only, "conveying food or drink to the mouth, or chewing and swallowing")

ESA / UNIVERSAL CREDIT – EXAMPLE OF ONE ACTIVITY

9. Continence

Descriptor:

- (a) At least once a month experiences:
(i) loss of control leading to extensive evacuation of the bowel and/or voiding of the bladder; or (ii) substantial leakage of the contents of a collecting device sufficient to require cleaning and a change in clothing.
= 15 points (so, LCW [and LCWRA by default])
- (b) At risk of loss of control leading to extensive evacuation of the bowel and/or voiding of the bladder, sufficient to require cleaning and a change in clothing, if not able to reach a toilet quickly. **= 6 points (i.e. would need to score 9 more points elsewhere in the assessment to have LCW)**
- (c) None of the above apply. **= 0 points (i.e. would need 15 points elsewhere)**

GROUNDS FOR ESA SUPPORT GROUP, OR UNIVERSAL CREDIT LCWRA

- ☐ **Having a severe functional disability which meets one of the relevant descriptors (usually 15 point ones)**
- ☐ Awaiting, undergoing or recovering from certain types of cancer treatment
- ☐ Having a pregnancy-related risk
- ☐ Being terminally ill, with a reasonable chance that life expectancy is 12 months or less
- ☐ **Deemed to have mental or physical health risk if found not to have LCWRA**

CHILDREN UNDER 16 WITH CROHN'S OR COLITIS

DISABILITY LIVING ALLOWANCE (DLA) / CHILD DISABILITY PAYMENT (CDP)

- Two components – Care and Mobility
- Higher rate for Care if needed day **and** night
- Middle rate for Care if needed day **or** night
- Lower rate if occasional daytime care
- Mobility at higher rate from age 3, or at lower rate from age 5
- Lower rate Mobility is about supervision, safety, and support; Higher rate is about physical restriction or serious risk to health
- No claims after 16th birthday (PIP/ADP instead)
- **Need is 'substantially in excess of normal requirements' or is "what needs a younger person in normal health may have but which a person of their age in normal health would not have"**

STUDENTS WITH CROHN'S OR COLITIS

SUPPORT FOR STUDENTS

Disabled Students' Allowance (DSA)

- DSA isn't part of the benefits system – it forms part of a student finance package
- DSA helps with study-related costs, for example, if you need specialist computer software. It can also cover travel costs if you're unable to use public transport.
- It is not based on your household income (i.e. not means-tested)
- Available across the UK, but the process of applying varies per nation
- For more information, visit the  [Money and finding financial support resource](#)
- Students could get [extra money from their university or college](#) if experiencing financial hardship
- As a student, you may also qualify for disability related benefits, such as [PIP/ADP](#). If your disability started before your course starts, you could claim new-style ESA if recently working. Means-tested Universal Credit is also a possibility, although some of the maintenance loan gets taken into account as income.

 Information for [England and Wales](#), [Northern Ireland](#) and [Scotland](#)



PERSONAL INDEPENDENCE PAYMENT (PIP) / ADULT DISABILITY PAYMENT (ADP)

**WHO IS MISSING
FROM THIS DWP
LEAFLET LINE-UP?**

Personal Independence Payment - PIP

DWP

Department for
Work and Pensions



PIP points-scoring system

DLA, PIP/ADP & ATTENDANCE ALLOWANCE / PENSION AGE DISABILITY PAYMENT (PADP)

- DLA claimants **who were already 65 or older on 8 April 2013** stay on DLA and will not be migrated to PIP/ADP, providing they still meet the criteria
- DLA claimants **who turned pension age after 8 April 2013** will be invited to apply for PIP/ADP
- PIP/ADP claimants (aged 16 to 66/67) stay on after reaching pension age
- Attendance Allowance/PADP is for **people first claiming help when pension age or over**

PIP/ADP ACTIVITY ASSESSMENTS

Daily living	Activity 1:	Preparing food
	Activity 2:	Eating and drinking
	Activity 3:	Managing your treatments
	Activity 4:	Washing and bathing
	Activity 5:	Using the toilet and managing incontinence
	Activity 6:	Dressing and undressing
	Activity 7:	Talking, listening and understanding
	Activity 8:	Reading
	Activity 9:	Mixing with other people
	Activity 10:	Managing money
Mobility	Activity 11:	Planning and following a journey
	Activity 12:	Moving around

Read the full details in section 2.3 and 2.4 of the [PIP assessment guide](#).

PIP/ADP ENTITLEMENT THRESHOLDS

The scores for the activities are added together to give a total score for each component.

DAILY LIVING

MOBILITY

ENHANCED

ENHANCED

12+ points

STANDARD

STANDARD

8-11 points

NOT ENTITLED

NOT ENTITLED

0-7 points

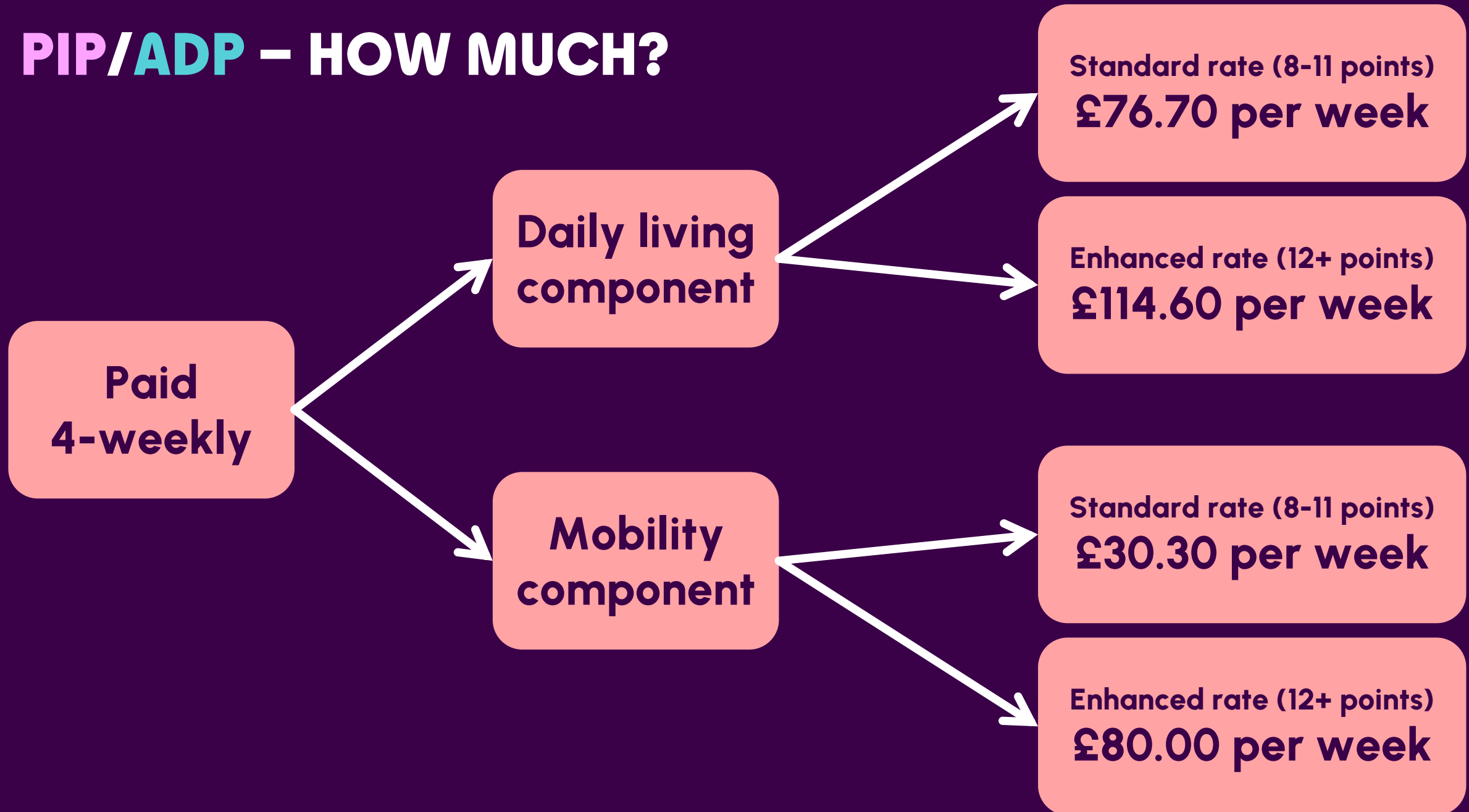
PIP/ADP – MANAGING TOILET NEEDS OR INCONTINENCE

- (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)**



Case law examples regarding incontinence: pipinfo.net/conditions/incontinence

PIP/ADP – HOW MUCH?



WHY MEDICAL EVIDENCE ALONE DOES NOT WIN PIP/ADP

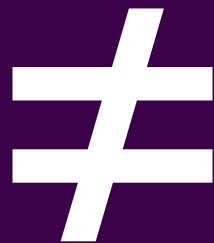


Diagnosis

Medical evidence
proves...

WHICH CONDITION YOU HAVE

- Crohn's Disease
- Ulcerative Colitis
- Microscopic Colitis
- IBD-U



Function

...but points are awarded based on...

HOW YOUR CONDITION AFFECTS YOUR LIFE

- Do you skip meals because you feel too tired or unwell to cook?
- Do you need to wash or shower more often because of leakage, incontinence, infections or fistulas?
- Do you use any aids or appliances, such as a commode, raised toilet seat, bottom wiper, bed or seat pad or waterproof sheet?
- Do you have joint pain that makes it hard to use zips or buttons on clothes?
- Does going out make you feel anxious, panicky or distressed?
- Are there times of the day when you cannot go out because you need to stay close to a toilet?

A STAR IS BORN!

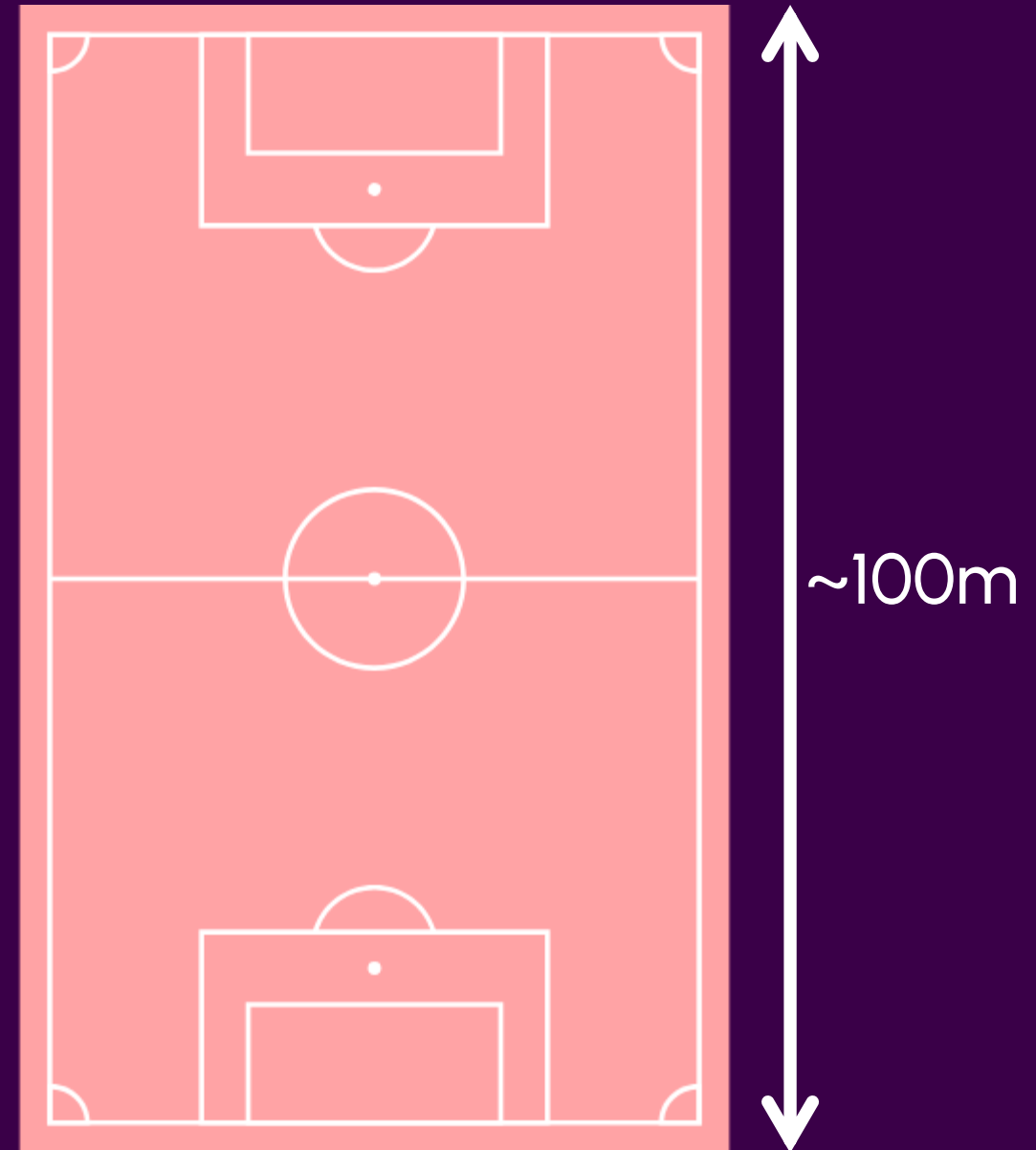
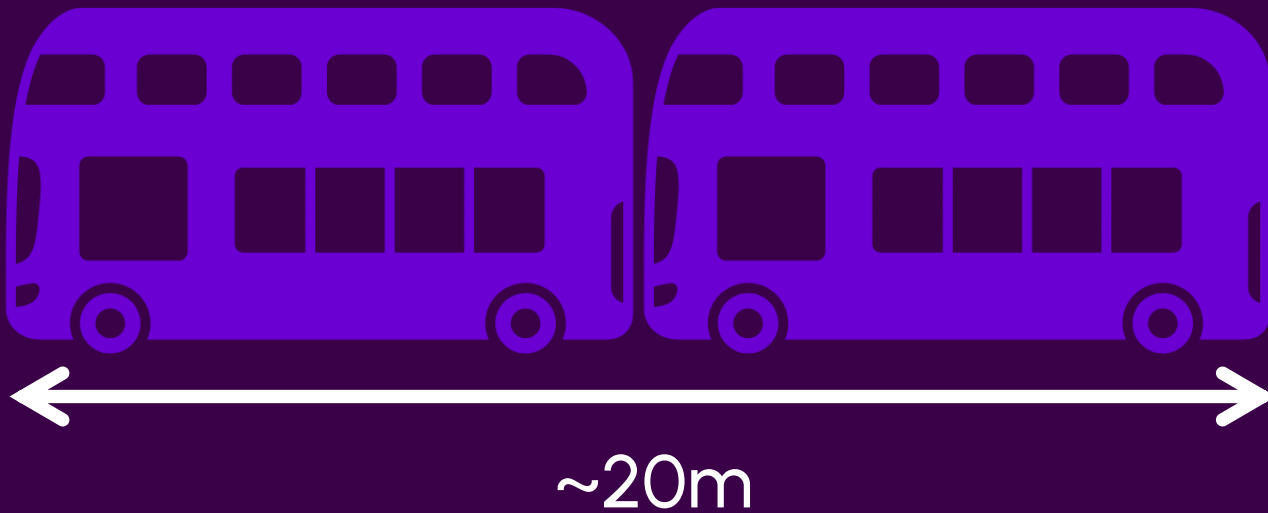
To be assessed as capable of doing an activity, you must be able to do it '**reliably**'. That means:



- **SAFELY** – in a manner unlikely to cause harm to the claimant or others during or after the activity;
- **TIMELY** – in no more than twice the maximum time someone with no disability takes to do the activity.
- to an **ACCCEPTABLE** standard;
- **REPEATEDLY** – as often as is reasonably required for the activity in question.

MOBILITY ACTIVITIES

1. Planning and following journeys
2. Moving around



TOP TIPS FOR PIP/ADP

- **Try not to talk about good days or bad days.** PIP/ADP is assessed on how you are *most of the time* (over 50% of days). If your condition fluctuates or is unpredictable, make it clear there are no days when you don't have Crohn's or Colitis!
- **Use the 'STAR' test:** safely, timely, to an acceptable standard, repeatedly
- **Be specific** – link your answers to the wording used in the activities
- **Include all aids, appliances, and adaptations**
- **Explain the help you need – even if you don't currently receive it.** PIP/ADP is about need, not whether someone is available to help. Prompting, supervision, and assistance all count. If you do get help, explain when and how.
- **Keep a short diary for 1–2 weeks.** Record pain levels, fatigue, accidents, time taken, and tasks you couldn't, or found it hard to, complete unaided.
- **Don't downplay your difficulties.** People often minimise their struggles out of habit or pride. As this can often mean your most intimate activities, it can feel difficult to reveal so much about yourself. Be fully honest about the impact on daily life.
- **Use extra pages – and keep copies of everything**
- **Get help with the form if you need it** – that can include written statements from people who know you best, not just professionals. Never rush the form – request an extension if needed.

MORE SUPPORT AROUND PIP/ADP

 Claiming Personal Independence Payment (PIP) resource. This offers example answers for each activity, to help communicate the impact of common problems experienced by people with Crohn's and Colitis. If you live in Scotland you may still find this helpful. Citizens Advice offer advice on ADP.



19 mins



Turn2us PIP tool

– doesn't currently cover ADP in Scotland

**FOR PEOPLE OVER
STATE PENSION AGE**

ATTENDANCE ALLOWANCE / PENSION AGE DISABILITY PAYMENT (PADP)

- If you are over State Pension age and **not** already on PIP/ADP, the primary option for additional disability support is Attendance Allowance/PADP
- "Help with bodily functions" or "danger to self or others"
- Day **and** night = higher rate (£114.60 per week)
- Day **or** night = lower rate (£76.70 per week)
- Non-taxable; positive impact on other benefits; not paid if in public-funded care (NHS or council)
- Can lead to higher rate of pension credit, housing benefit and council tax support
- You don't have to be in dire straits to get it - savings and income don't matter



More information: moneysavingexpert.com/family/attendance-allowance

ATTENDANCE ALLOWANCE / PADP

“HELP WITH BODILY FUNCTIONS”

- Eating and drinking
- Washing and bathing
- Dressing/undressing
- Going to bed and sleeping
- Going to the toilet
- Incontinence
- Moving about indoors
- Medication and therapy
- Laundry (in presence of disabled person)
- Seeing
- Communication
- Cognitive function

ATTENDANCE ALLOWANCE / PADP

Support must be **frequent**, **continual**, or **repeated**, depending on whether it's day or night

TYPE OF NEED	MINIMUM FREQUENCY	EVIDENCE STANDARD
Daytime attention	Several times across the day	Help with bodily functions
Daytime supervision	Ongoing, with short breaks allowed	Safety risk
Night attention (prolonged)	1 spell ≥ 20 minutes	Help with bodily functions
Night attention (repeated)	2+ spells	Help with bodily functions
Night supervision	Awake 20+ minutes OR awake 3+ times	Safety risk



Age UK factsheet
– England & Wales



Age NI
info



CARING FOR SOMEONE WITH CROHN'S OR COLITIS

CARER'S ALLOWANCE

- **£86.45** per week

Claimants must:

- Be aged 16 or over (no upper age limit)
- Care for someone who receives the **PIP** daily living component (either rate), the middle/highest care component for **DLA**, or **Attendance Allowance (or Scottish equivalents)**
- Care for at least 35 hours per week
- Earn under the limit of £204 per week ('cliff-edge' at present – may change in future to a taper)
- Not be in full-time education

N.B. **Carer's Allowance** overlaps with some other benefits, e.g. pension – and counts against Universal Credit and Pension Credit, but leads to additional benefit overall (a carer element)



SCOTTISH CARERS' BENEFITS

Carer Support Payment is the equivalent to Carer's Allowance, but there are three additional potential benefits only available in Scotland.



BENEFIT	AMOUNT	FREQUENCY	WHO GETS IT?
Carer Support Payment (CSP)	£86.45 per week	Weekly	Adult carers (35+ hours care per week)
Scottish Carer Supplement	£11.70 per week	Auto top-up	Anyone on CSP
Carer Additional Person Payment	£10.40 per week per extra person	Weekly	CSP recipients caring for >1 person
Young Carer Grant	£405.10 per year	Annual	Young carers (16-19/21)

**UNHAPPY WITH, OR UNSURE
ABOUT, A BENEFIT DECISION?**

CHALLENGING A DECISION

- It can be difficult to hear that you did not get the benefit decision you were hoping for. You may feel disheartened by this, but **you can challenge a benefit decision that you do not agree with**. This means someone will look at your whole benefit claim again. Going through the appeal process may feel like a lot. But there is support available.
- Independent advice agencies can help you with the paperwork and preparing your case: advice.local.gov.uk/find-an-adviser
- You can find out more information about how to challenge a decision from government sites: [England and Wales](#); [Northern Ireland](#); [Scotland](#)

Advicenow has [information on benefit appeals](#) in England and Wales

TAKEAWAYS

- Applying for benefits may feel confusing or daunting. If you have never claimed benefits before, you may not know where to start, but information and support is out there – good places to start are:
 -  **Crohn's & Colitis UK information on disability and sickness benefits, claiming PIP, claiming DLA for children, as well as money and finding financial support**
 - **Citizens Advice in England, Northern Ireland, Scotland and Wales**
 - **Benefit calculators: entitledto.co.uk/benefits-calculator and benefits-calculator.turn2us.org.uk**
- Worrying about money is stressful and may make you feel anxious. If your mental or emotional wellbeing is affected, please reach out for help. This may be asking for support from family or friends, or asking your healthcare professional for help. You can find **information about looking after your mental health** on the Crohn's & Colitis UK website.