

**CROHN'S &
COLITIS UK**

**CLAIMING
DISABILITY
LIVING
ALLOWANCE**

A GUIDE
FOR CHILDREN
UNDER 16 WITH
CROHN'S OR COLITIS

ABOUT THIS GUIDE

CLAIMING DLA FOR CHILDREN UNDER 16 – 2018

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PLEASE NOTE: DLA for Children is a benefit and 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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Claiming DLA for Children Under 16 Edition 5a Amended
2021

Last review: March 2018

Next planned review: 2021

WHAT IS DLA?

Disability Living Allowance (DLA) is a benefit for children under 16 that can help with any additional costs related to a disability, illness or health condition.

WHY CLAIM DLA?

Even if you don't consider your child to be disabled, if they have Inflammatory Bowel Disease (IBD), you may have extra expenses. For example, higher heating bills, special diets, taxi fares and more laundry costs. DLA can help to meet these extra costs, but you can spend DLA on anything you wish, not just the extra expense caused by illness. Some people use their child's DLA to provide treats and holidays and others put it away in a savings account for their child to use when they are older.

Making a claim for DLA on behalf of a child can take many months and some people can find the process emotionally draining. This guide will take you through the process step-by-step, from getting a copy of the claim form through to getting the result of your application.

We strongly recommend that you read the **Help, Support and Information** section and think about what support you can arrange before you start your claim.

APPENDICES

At the end of this guide, we've included four appendices with the following information to help support your claim:

Two-minute DLA test for children. A quick and easy way for you to decide whether to fill out a claim form on behalf of your child.

Claim file record sheet. This is for noting details of any letters and phone calls to and from the Department for Work and Pensions (DWP). It is intended to form part of your claim file, which we strongly recommend you keep. See **Before you begin**, on page 6, for further details.

Medical visit record sheet. This is for you to fill out if your child has a DWP medical. For more about this, see **Preparing for a medical** on page 38.

Health professional's sheet. Read this through carefully, along with the section, **The importance of supporting evidence** on page 37, before contacting your child's healthcare professionals for letters of support.

IS MY CHILD ELIGIBLE?

WHAT MATTERS?

Health problem: Your child must have had a long-term health problem, such as Crohn's Disease or Ulcerative Colitis, for at least three months, and be expected to have it for at least another six months. The health problem must result in your child needing much more care or supervision than other children of the same age.

Age: If your child is under 16 you can make a claim for DLA on their behalf. If they are 16 or over, they can claim Personal Independence Payment (PIP) themselves.

You can claim DLA for your child at any time, but there are some age restrictions regarding what can be paid. See **How is DLA worked out?** on the next page.

Residence and presence: Your child must satisfy certain residence and presence qualifications to qualify for DLA. They must be living in Great Britain, Northern Ireland, the Channel Islands or the Isle of Man at the time of claiming DLA and have been there for a set period of time. How long will depend on your child's age:

- children under six months must have been resident for at least 13 weeks
- children aged six months to three years, for at least 26 weeks
- children over three, for at least two out of the previous three years.

If you are subject to immigration restrictions, you should seek advice before making a claim for DLA, or any other benefits. The **Help, Support and Information** section gives details of organisations that may be able to help with this.

WHAT DOESN'T MATTER?

About your child: It doesn't matter if you don't consider your child to be 'disabled'. For the purposes of DLA, 'disabled' means that your child has a long-term chronic illness that adversely affects their everyday activities.

It also doesn't matter if you've been told by anyone (including the DWP, your GP, a nurse, social worker), other than a professional welfare rights worker, not to make a claim because your child is not ill enough. If in doubt, make a claim. Your child will not be 'registered disabled' if they receive DLA and it will not make it more difficult for them to get a job when they become an adult.

About you (and your family): When considering whether to award DLA, the Decision Maker is only interested in your child and the way their health problems affect them. Decision Makers are DWP staff who make decisions about claims. Your circumstances are not taken into account in any way.

So, it doesn't matter if:

- you're working
- you're unemployed
- your partner works
- you don't have a partner
- you've never paid National Insurance contributions

- you, or anyone else in your family, is claiming any other benefits (such as Employment and Support Allowance, Universal Credit, PIP, DLA, Income Support or Jobseekers Allowance)
- you have savings of any amount.

If you're still unsure whether to make a claim, try our Two-minute **DLA test for children** (Appendix 1) which can be found at the back of this guide.

HOW IS DLA WORKED OUT?

DLA has two components – the care component and the mobility component. A child may be awarded one or both at the same time. If your child is awarded DLA, you may be entitled to more money from other benefits that you claim. The **Help, Support and Information** section on page 41 lists organisations that may be able to offer advice.

CARE COMPONENT

The care component is paid if your child is at least three months old and needs looking after or help with their personal care, more than a child of the same age without a disability (even if they're not getting this help at the moment).

The care component can be paid at one of three weekly rates, depending on the amount of extra help your child needs:

Lowest	£22.65	Your child needs help with personal care for at least an hour, on most days. This help can be spread out throughout the day.
Middle	£57.30	Your child needs: <ul style="list-style-type: none"> • help with personal care several times throughout the day, or • frequent or regular supervision throughout the day to avoid danger, or • needs help with personal care at least twice a night, or once for at least 20 minutes, or • someone to be awake to watch over them at least twice a night, or once for at least 20 minutes.
Highest	£85.60	Your child has care needs (as described for the middle rate) during the day and during the night.

Please note these are the proposed rates for 2018/19. For the latest rates, see www.gov.uk/disability-living-allowance-children/rates

The main carer of a child awarded the middle or higher rate of the care component of DLA may be able to claim Carer's Allowance. Seek specialist advice from the organisations listed on pages 41–42.

MOBILITY COMPONENT

The mobility component is paid if your child needs extra help or supervision getting around, more than a child of the same age without a disability. The mobility component can be paid at one of two weekly rates, depending on the amount of extra help your child needs:

Lower	£22.65	Your child is aged 5 or over , can walk but needs someone to either supervise or guide them in places they are unfamiliar with.
Higher	£59.75	Your child is aged 3 or over , and is unable to walk or 'virtually unable to walk'. This is often taken to mean children who cannot walk more than 50 yards at a reasonable pace without pain, fatigue or breathlessness.

Please note these are the proposed rates for 2018/19. For the latest rates, see www.gov.uk/disability-living-allowance-children/rates

A parent or guardian of a child awarded the higher rate mobility component of DLA may be entitled to a Blue Badge, or a car under the Motability Scheme. Seek specialist advice from the organisations listed on pages 41–42.

GLOSSARY

Here are some of the terms used in the claim form and what they mean:

Aids and adaptations: Any device that is used by your child to improve or help an impaired mental or physical function.

- Aids include incontinence pads, commodes, buggies and learning aids such as computer programmes.
- Adaptations include rails and other alterations to the home.

Danger: A situation where your child has a serious risk of harming themselves or others. This situation may arise infrequently or be a one-off.

Extra help: When your child needs more help or support than a child of the same age without a disability.

Guide: Someone present to physically lead or verbally direct your child to prevent any accidents or harm.

Night: Begins when everyone in the house goes to bed (including the adults) and ends when everyone gets up.

Personal care: is anything carried out in connection with bodily functions – which includes dressing, washing, bathing, toileting, eating, drinking, taking medicines and getting in and out of bed.

Supervise: Someone continuously present with your child to prevent any accidents or harm, and/or provide encouragement or prompting.

BEFORE YOU BEGIN

Before you begin your claim, we strongly recommend you do two things:

1. KEEP A CLAIM FILE

A claim file is simply a folder in which you keep notes and copies of everything to do with your DLA claim.

What to put in your claim file:

A photocopy of everything you send to the DWP

Most importantly, keep a photocopy of your completed claim form. It may be difficult and expensive, but is important because:

The DWP may lose the claim form – it does happen.

If your child's claim is successful, the award will either be for a limited period, for example three years, or it will be awarded up to your child's sixteenth birthday. When you reapply for DLA (or PIP if you child turns 16) you'll have to fill out another claim form. If you don't give as much detail as you did in the original, the DWP may decide your child is getting better and stop the award.

If you're not happy with the result of the claim, you will have difficulty challenging the decision effectively without a copy of your original form.

Keep every letter you receive from the DWP

File the letters in date order, along with copies of any letters you've sent to DWP. This may help if there is an issue and you need to request that your DLA payment be backdated to the beginning of your claim.

Keep a note of any phone calls to or from the DWP

Ask for the name of anyone you speak to and keep a note of it, along with the date and the subject. For example:

16.11.18 – Spoke to Gemma Watson at the DLA Unit. She said they have received my consultant's letter.

Don't feel embarrassed about this. In the very unlikely event that anyone refuses to give you their first name and the section they work on, insist on speaking to their supervisor. You can use the **Claim file record sheet** (Appendix 2) to record your interactions with DWP.

2. ARRANGE SUPPORT

Making a claim for DLA can be hard work mentally and emotionally. It may all go smoothly for you, or you may find it a difficult and drawn out process. We recommend you use the **Help, Support and Information** section before you start your claim.

START YOUR CLAIM

The first step in making a claim is to get a claim form. The best way to do this is:

For England, Scotland and Wales:

Call the **Disability Living Allowance** Helpline on **0800 121 4600** (8am to 6pm, Monday to Friday).

Textphone: **0800 121 4523**.

For Northern Ireland:

Call the **Disability** and **Carers Service** on **0800 587 0912** (9am to 5pm, Monday to Friday, except Bank Holidays).

Textphone: **028 9031 1092**.

Note: The Scottish government is introducing a new social security system so DLA may change for those in Scotland in the future.

When you make the call, ask them to send you a DLA claim form for a child under 16. If, after asking you a few questions, the operator suggests you won't be eligible to claim DLA for your child, insist that they send you a form anyway.

Ask for the full name, or first name and department, of the person you speak to. Make a note of it, along with the date, in your claim file. If you don't receive a claim form, you should be able to get one backdated to the day of your original call.

You should receive a claim form with two dates stamped on it. The first is the date you asked for the form, the second is six weeks later. Your claim will start from the first date as long as the DWP receive the form by the second date. Remember to allow several days for the form to reach DWP by post. If they receive it after the six weeks, your claim is still valid, but it only starts from the date the DWP receive your completed form, instead of the date you first asked for the form.

The form should arrive in 7–10 days. In the meantime, you may wish to:

- keep a diary – see **The importance of supporting evidence** on page 37
- write a list of people who can provide supporting evidence – see **The importance of supporting evidence** on page 37
- make appointments to see your child's health professionals. Work out when you are likely to have completed the form, and ask for an appointment to take place soon afterwards.

You can also get a claim form online at www.gov.uk/disability-living-allowance-children/how-to-claim (for England, Scotland and Wales) or www.nidirect.gov.uk/articles/disability-living-allowance-dla (for Northern Ireland). You may wish to download a copy and begin drafting rough answers to the questions.

If you download a claim form or get one from elsewhere, for example from an advice agency, it won't be date-stamped and your claim will start when the DWP receives your completed form.

WHEN THE FORM ARRIVES

Please don't be put off by the size of the claim form – we will help you every step of the way. If you have received a date-stamped form, you've got over a month to complete it, depending on how long the DWP took to post it out to you. Before you start, please read the next section.

GENERAL TIPS FOR COMPLETING THE CLAIM FORM

The decision about whether to award DLA is based on evidence. The form you are about to complete is evidence, and so are your diary and any letters from doctors, carers or relatives.

An effective claim includes evidence that is as clear and as detailed as possible. This is particularly important for Crohn's Disease and Ulcerative Colitis, because they are not widely understood conditions. Please take the time to fill in the form in as much detail as you possibly can. If you don't know where to write something, write it under any question that appears relevant, even if it means writing it on the form several times.

Many claims are rejected because there wasn't enough evidence for the benefit to be awarded. If you don't fill in the claim form fully and have to appeal, you will have to explain to the tribunal why you are now saying that your child has problems that you didn't mention in your claim form.

When you're filling out the DLA form you don't need to worry about spelling, punctuation, grammar or staying inside the boxes. Do whatever works best for you, including any, or all, of the following:

- write in note form
- write in bullet points
- write outside the boxes and up the side of the page if you can't fit everything inside the boxes
- write on additional sheets of your own paper. If you do, always write your child's name (and National Insurance number if you know it) across the top of each extra sheet, give the page numbers of the questions you're answering and fasten the sheet securely to the last page of the section you're completing.

We strongly recommend keeping a diary for at least a week, or 2–3 weeks if your child experiences fluctuating symptoms, before you fill in the form. This will help you determine how long, how often and how many times your child needs help. This is particularly important if the amount of help your child needs varies – see **How to explain fluctuating conditions** below. You can send the diary as evidence with your claim form. You'll find an example of a diary in the claim form.

HOW TO EXPLAIN FLUCTUATING CONDITIONS

Explaining the fluctuating nature of Crohn's Disease or Ulcerative Colitis is a challenge when claiming DLA. Some agencies may advise you to complete the claim form thinking only of how your child is on bad days. However, Crohn's and Colitis are known to be fluctuating conditions, so if you present your child's condition as unvarying this may make your evidence less believable. If, on the other hand, their condition actually doesn't vary, then go out of your way to explain this on the claim form.

If your child is not awarded DLA and you choose to appear before a tribunal, they are likely to ask you to go back through the last week, day-by-day, explaining in detail the difficulties your child had. If the previous week was one of your child's better weeks, it may be harder to convince the tribunal of the difficulties your child faces and the appeal may fail.

So what do we advise you do?

We suggest that you explain how your child is on their bad days and then how they are on their 'better days'. If you use expressions like 'good days' or 'normal days' it will be assumed that these are days on which your child has no problems whatsoever.

For example:

On bad days Simon cannot get out of bed at all because of fatigue and pain in his large joints and back. On better days he can get out of bed, but only slowly and painfully, resting several times. The pain is in his ... (etc.)

If your child has very few (or no) days when they can get out of bed easily and without pain then you can reasonably say that they need help seven days a week.

Be careful not to underestimate your child's condition. Are their 'better days' actually free of pain and discomfort, or just relatively so by their standards? It may be that, for the purposes of claiming DLA, you have to accept that your child doesn't have any 'good days' at all – they have just learnt to deal positively with their condition. Having to think about this may be upsetting, so please make sure there is someone available to offer you support if you need it.

If your child has periods when they are symptom-free, then average them out as follows:

If your child's condition varies from day to day, decide on average how many symptom-free days a week they have. If it's only one or two, then they need help five or six days a week. If they need help for fewer than four or five days a week, it is less likely they will be awarded DLA.

If your child's condition varies from week to week, again average it out. If they have about one good week a month, that's a bit less than a quarter of the time, so they still need help, on average, every five to six days a week.

If your child's condition varies from month to month and they have long periods of remission then you should decide whether they have no problems during the periods of remission, or whether they still suffer from symptoms such as pain, discomfort or fatigue.

In order to qualify for the first time, your child's condition needs to have lasted for three months and be likely to last at least another six months. After that, if your child has a period of remission and their claim is stopped, then, as long as they claim again within two years, they don't have to serve another three month qualifying period and can claim as soon as their condition deteriorates.

COMPLETING THE CLAIM FORM

Some people prefer to fill in the claim form with a pencil first, whereas other people will just get stuck in – it's up to you. You may wish to photocopy the claim form and practice filling it in first. We will take you through each part of the DLA claim form page-by-page, so you will need the form open in front of you. It might be helpful to read the form all the way through before you begin.

Please note that the questions in the claim form for Northern Ireland are different. The NI Direct website has more detail at www.nidirect.gov.uk/publications/disability-living-allowance-dla-adult-and-child-claim-forms-and-guidance-notes-dla-1a

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QUESTIONS 1–18: ABOUT THE CHILD

These are straightforward factual questions, some just needing a simple yes or no answer.

Q1 Surname or family name, other names in full

Q2 Child reference number (if you know it)

This is your child's National Insurance number. Don't worry if you don't know it, or your child doesn't have one yet. Their National Insurance number will be found, or assigned, as part of the claim process and printed on any letters relating to the claim.

Q3 Date of birth

Q4 Sex

Q5 Full address where the child lives

Q6 Are you claiming for the child under special rules?

These special rules are for children who are terminally ill and not expected to live longer than six months.

Q7 What is the child's nationality?

Q8 Does the child normally live in Great Britain?

If your child does not normally live in Great Britain, or if they have been abroad for a long period, this may affect their entitlement to benefits. If this proves to be a problem, get advice from one of the agencies listed in the **Help, Support and Information** section.

Q9 Has the child been abroad for more than 4 weeks at a time in the last 3 years?

Q10 Entitlement to other benefits from another European Economic Area (EEA) State or Switzerland

Q11 Entitlement to other benefits from another EEA State or Switzerland

Q12 Is the child in a hospital or hospice now, or have they been admitted in the past 12 months?

Q13 Is the child in a residential college or similar place now, or have they been in the past 12 months?

Q14 In the last 12 months, has the child seen anyone apart from their GP about their illnesses or disabilities?

It is important to give the names and addresses of all the professionals your child has seen in the past 12 months. If there is more than one, make sure you add the extra information in question 70.

Q15 Name of the child's GP

Try to include the full address of your child's GP. You should let your child's GP know you are making a claim as the DWP may write to them for further information.

Q16 Has the child had or are they waiting for tests to help diagnose, treat or monitor their illnesses or disabilities?

If you do not know the exact date of any test, put an approximate date.

Q17 Do you have any reports, letters or assessments about the child's illnesses or disabilities?

If you have any helpful letters or reports about your child's condition that will support the claim, send a copy with the claim form.

Assessment reports may provide very useful information about the difficulties your child has with everyday activities. Please bear in mind that you are not obliged to submit these reports. Read through any letter or report you are considering submitting. If you decide that, for example, your child's care plan sets out an unreasonably optimistic assessment of how well they are likely to progress, then you may decide you do not wish to submit it. You should also be aware that the DWP may obtain a copy of the assessment directly from whichever organisation carried it out.

Q18 Name of the child's school or nursery

The 'person we can contact' should be the person who knows the most about how your child is affected by IBD.

Q19 Does the child have or are they waiting to hear about an Individual Education Plan (IEP), Individual Behaviour Plan (IBP) or a statement of Special Educational Needs (a statement)? In Scotland the statement is called a Co-ordinated Support Plan (CSP).

Make sure you tick a box if it is relevant as this kind of information can often be helpful in supporting a claim for DLA.

Q20 Statement from someone who knows the child

If possible the person who completes this statement should be a professional involved in your child's care, for example, their specialist doctor, nurse or GP.

Photocopy the sheet to give to the person you want to complete it. Make an appointment to see the person so you can answer any questions they might have and take the completed **Health professional's sheet** (Appendix 4) at the back of this guide with you. Ask them to complete the statement there and then if possible. If they can't, or wish to write a longer report, ask them to send it to you and tell them when you need to have it by. If you are happy with what they write, attach the sheet to your form. If not, give them another blank copy and ask if it would be possible to change what they have written. If this is not possible, get someone else to fill in the statement instead. Don't delay returning the claim form if you don't receive a statement in time, send any additional evidence afterwards if necessary.

Q21 Consent

Don't forget to sign and date the consent. You should give consent to the DWP to contact the people named on the form unless you have a very good reason not to.

Please make sure you also sign and date the declaration at question 71.

QUESTIONS 22–24: ABOUT THE CHILD'S ILLNESSES OR DISABILITIES

Q22 List the child's illnesses or disabilities in the table below

List **all** your child's health problems, not just Crohn's or Colitis, including any related problems such as arthritis, anaemia and skin problems. Also list any conditions that may not be related, such as asthma. Include any emotional or mental health problems, such as depression or anxiety. Your child's entitlement to DLA is based on the combined effects of ALL their health problems, so make sure you write them all down.

What treatment do they have? How often do they have treatment?

If you have a copy of a prescription, include it with the claim form. Although the question only refers to prescribed medication and treatments, you may also wish to list any alternative, complementary or non-prescription medication or treatments your child takes. Continue on a separate sheet if necessary.

Q23 Does the child use, or have they been assessed for, any aids or adaptations?

If your child uses any specialist equipment, write this in the table and explain what help they need to use the equipment.

Q24 When the child needs help

Only tick 'varies' if your child's needs clearly vary, and explain why they vary. It may be helpful to read the section **How to explain fluctuating conditions** on page 9 of this guide before completing this question. We recommend you use the terms 'better days' and 'bad days'. As a general guide, if they need help less often than four or five days/nights a week they will be less likely to qualify for DLA.

QUESTIONS 25–36: MOBILITY QUESTIONS

Q25 Can they physically walk?

If your child is unable to walk, tick 'no' and go to question 36.

Q26 Do they have physical difficulties walking?

If you tick 'yes', move on to question 27.

Q27 Please tick the boxes that best describe how far they can walk without severe discomfort and how long it takes them

Try timing your child rather than just guessing. Remember this is an average, so take into account your child's bad days.

There is no definition of severe discomfort except that the law says it is less than severe pain. Can your child walk at all on their bad days? Are they in severe discomfort all the time when they walk, or does it begin after a certain distance? If possible, measure how far they can walk, rather than trying to estimate. If you find it difficult and cannot tick a box, explain the reason why in question 31.

Q28 Please tick the box that best describes their walking speed

If this varies, explain why in question 31.

Q29 Please tick the box that best describes the way they walk

Q30 Does the effort of walking seriously affect their health?

If the answer is 'yes' explain why. For example, walking causes extreme fatigue and your child is unable to do anything else for the rest of the day.

Q31 Anything else you want to tell us

Does your child have difficulties with walking because of joint pain and stiffness, abdominal pain, fistulas, soreness around the anus, extreme fatigue, breathlessness, increased likelihood of incontinence, or any other physical problem? Is your child confined to bed for most of the time and seldom able to walk outdoors? Does your child walk much more slowly than other children of the same age? Does your child use a buggy although other children of the same age do not?

Give as much information as you can. For example, how can you tell when your child is becoming exhausted or is in severe discomfort or pain?

If you run out of space, write your extra information in question 35 or on a sheet and attach to the claim form.

Q32 Do they need guidance or supervision most of the time when they walk outdoors?

If your child needs guidance or supervision outdoors, tick **Yes** at the top of the page and then tick the boxes that apply to your child. You can explain why they need this help in questions 34 and 35.

Even if your child is so young that you would not allow them to walk outdoors in unfamiliar places on their own, if they need much more help and support than another child of the same age they may be eligible for lower rate mobility.

Only tick 'no' if you have read the examples on the form and read the box below and decided your child doesn't have any such problems.

Q33 Do they fall due to their disability?

Q34 & Q35 If you want to tell us why you have ticked the boxes, how their needs vary or anything else you think we should know, use the box below. If you want to tell us anything else about their mobility, use the box below.

Explain why your child needs guidance and/or supervision when walking outdoors. Remember, this is about when your child is in an unfamiliar place, not places that they know well. If you run out of space, use an extra piece of paper and attach it to the claim form.

Step 1 Say what problems your child has with this activity, giving examples if you can.

Does your child:

- run out of energy, often quite suddenly
- carry on walking even though they are exhausted
- experience pain when walking, perhaps because of arthritic symptoms, a sore anus, fistulas or abdominal pains?

If your child doesn't walk outdoors alone in unfamiliar places because of 'fear or anxiety' related to their physical (rather than mental) health, this will not entitle them to an award of lower rate mobility. For example, if your child doesn't go to unfamiliar places alone because they are afraid of having an episode of incontinence, this won't count. If, however, their fear or anxiety is so severe that their doctor diagnoses a mental health problem, such as agoraphobia, then they may be eligible for lower rate mobility on the basis of fear or anxiety related to their mental health. But if this is not the case, then it's best to avoid using words like frightened or anxious on this page.

Step 2 Say what help your child gets, or would benefit from.

Does your child:

- sometimes need carrying, or help to find somewhere to stop and rest
- need someone to make sure they do not over-exert themselves
- need comfort and reassurance because of discomfort or pain
- need someone to help them find a toilet, carry a change of clothing and a washing kit, offer comfort and reassurance if they have an episode of incontinence?

Step 3 Say why your child should not be expected to manage on their own.

For example, would your child:

- simply avoid walking in unfamiliar places if they were expected to do so on their own
- find it a distressing experience
- risk making themselves ill through over-exertion?

Step 4 Say how your child's needs are different from those of other children of the same age.

Would another child of the same age be more likely to walk outdoors in unfamiliar places on their own?

Even if your child is so young that you would not allow them to walk outdoors in unfamiliar places on their own, do they need much more help and support than another child of the same age?

Q36 When did the child's mobility needs start?

If you do not know the exact date, put in an approximate date/month.

QUESTIONS 37–53: CARE QUESTIONS

Q37 Do they need encouragement, prompting, or physical help to get into or out of or settle in bed during the day?

Tick **Yes**, fill in how often and for how long each time and write an explanation in the box at the bottom of the page if:

- your child takes longer than other children of the same age, or it causes them pain, discomfort or distress
- you have to provide more help, or help of a different kind, than for other children of the same age, or if your child has to be watched over more closely than other children of the same age.

Only tick **No** if:

- your child does not have any difficulty with these activities compared to other children of the same age
- you have read the examples on the form and in the main box below and decided that none of them apply.

How often each day?

If your child is often at home because they are ill, you may need to wake them, get them up and put them back to bed several times during the day.

For lower rate care, it doesn't matter how many times a day your child needs help, but for the middle rate you have to show that your child needs help several times throughout the day across all personal care activities. For example, in the morning, during the day and at night.

How long each time?

Roughly how long does it take your child to get out of bed or into bed to wake up or to settle?

In the morning, this should include the time from when your child wakes, or is woken, to the time when they are actually up and out of bed. At bedtime, if it takes a long time and repeated visits to settle your child, include the whole period until they are settled.

If you want to tell us why they need help, how their needs vary or anything you think we should know, use the box below.

Step 1 Say what problems your child has, giving specific examples if you can.

For example, does your child:

- have such disturbed nights that they are too tired to wake or get up in the morning
- get very depressed about their condition and so lack the motivation to get up
- experience severe exhaustion, joint pain, stiffness or abdominal pain in the morning, making getting up a slow and painful experience
- resist getting up in the morning because they are worried about being bullied at school because of their condition
- resist going to bed because they suffer from anxiety or nightmares
- get out of bed repeatedly during the night because of anxiety caused by their condition
- often have to stay in bed for most of the day because of their condition?

Step 2 Say what help your child gets, or would benefit from.

For example:

- do you bring them medication or a drink to help them wake up or get up
- do you encourage them to wake up or get up, perhaps having to return repeatedly
- do you offer them encouragement, support or reassurance in connection with getting up or going to bed
- do you have to watch over them to make sure they are safe when they get up or go to bed
- do they need physical help getting up or going to bed
- do you need to spend time settling them in bed before they are able to sleep?

Step 3 Say why your child should not be expected to manage without this help.

For example:

- would they be physically unable to wake up, get up or go to bed without it
- would they become emotionally distressed if they did not receive it

- might they come to harm if they did not receive it?
- If it is help that they don't currently receive, in what ways would they benefit from it?

Step 4 Say how your child's needs are different from those of other children of the same age.

- For example, can other children of the same age do these things:
 - with less help or with no help at all
 - more quickly
 - without pain, discomfort or becoming distressed
 - with less encouragement or with no encouragement at all
 - with less supervision or without being supervised at all?
- If your child uses any equipment to help with this activity, give details.

If you run out of space, write your extra information in questions 54 or 70, or on a sheet of paper attached to the claim form.

Q38 Do they need encouragement, prompting or physical help to go to or use the toilet during the day? Does the child have difficulties coping with their toilet needs?

If your child has a stoma, use this page to explain any difficulties they have or help they need with it.

Tick **Yes** at the top of the page and any other boxes on the page that apply to your child.

Give details in the main box below if, in connection with toilet needs:

- your child takes longer than other children of the same age, or it causes them pain, discomfort or distress
- you have to provide more help, or help of a different kind, than for other children of the same age
- your child has to be watched over more closely than other children of the same age
- your child needs more telling or encouragement in a different way to other children.

Only tick **No** if your child does not have any difficulty with these activities compared to other children of the same age, and you have read the examples on the form and in the main box below and decided that none of them apply.

If you want to tell us why you have ticked the boxes, how their needs vary or anything else you think we should know, use the box below.

Step 1 Say what problems your child has with their toilet needs, giving specific examples if you can.

For example, does your child:

- have difficulty getting to and from the toilet because of pain or fatigue
- have episodes of incontinence
- experience pain or distress in connection with bowel movements
- have more frequent bowel movements than other children of the same age
- become exhausted by the frequency of their bowel movements
- have particularly noisy, smelly or explosive bowel movements
- sometimes need to wash, shower or bathe after bowel movements
- need to apply cream or change pads after bowel movements
- need help in connection with leakage from a stoma appliance or with changing the bag?

Decision Makers may argue that a child who needs help getting to and from the toilet should use a potty or commode instead. Are there reasons why you do not think your child should be expected to do this? If there are, you need to make your case as strongly as possible. For example,

- they would still have to get to the bathroom to wash after a bowel movement
- their bowel movements have a very strong odour and the potty or commode would have to be emptied immediately and would leave the room unpleasant to use
- they are old enough that using a potty or commode would add painfully and unnecessarily to the emotional distress their condition causes them.

Step 2 Say what help your child gets, or would benefit from.

For example, do you:

- help them bathe and change after episodes of incontinence
- offer them comfort, support or reassurance because of distress caused by pain, discomfort or episodes of incontinence
- apply cream or change pads
- check stools for blood or excessive mucus
- clean the toilet
- help them change their stoma appliance
- empty a potty or commode?

Step 3 Say why your child should not be expected to manage without this help.

For example:

- would they be physically unable to attend to their toilet needs without it
- would they become emotionally distressed if they did not receive it
- might they come to harm if they did not receive it?

Step 4 Say how your child's needs are different from those of other children of the same age.

For example, can other children of the same age do these things:

- with less help or with no help at all
- more quickly
- without pain or discomfort
- without becoming distressed
- with less encouragement or with no encouragement at all
- with less supervision or without being supervised at all?

If you run out of space, write your extra information in questions 54 or 70, or on a sheet and attach to the claim form.

Q39 Do they need encouragement, prompting, or physical help to move around indoors, use stairs or get into or out of a chair during the day?

- Tick **Yes** at the top of the page and tick any other boxes on this page that apply to your child. Give details in the main box if, in connection with moving about indoors:
 - your child takes longer than other children of the same age, or it causes them pain, discomfort or distress
 - you have to provide more help, or help of a different kind, than for other children of the same age
 - your child has to be watched over more closely than other children of the same age
 - if your child needs more prompting or reminding than other children of the same age.

Only tick **No** if your child does not have any difficulty with these activities compared to other children of the same age, and you have read the examples on the form and in the box below and decide that none of them apply.

If you want to tell us why you have ticked the boxes, how their needs vary or anything else you think we should know about, use the box below.

Step 1 Say what problems your child has, giving specific examples if you can.

For example:

Moving around

- Does your child have to hang onto furniture to steady themselves?
- Do they suffer discomfort or pain if they stand for any length of time?
- Does standing make their bowel urgency worse?

Stairs

- Is it difficult/painful/exhausting going up or down stairs?
- Do they become dizzy or unsteady?
- Do they have to go very slowly, one step at a time?
- Do they need to hold on to the handrail?

Getting out of chairs and off sofas (and in and out of bed if they have periods when they stay in bed for a large part of the time)

- Do they take a long time to get in or out of chairs?
- Do they stiffen up if they sit or lay too long?
- Do they need someone to help them off chairs and sofas?
- Have they developed special techniques such as rolling off sofas onto their knees?
- Do they have to hold onto things to get upright?
- Are they sometimes too exhausted to get up?
- Is rising from sitting painful?
- Do they have to get up and down a lot because of pain and soreness around the anus or because of frequent trips to the toilet?

Step 2 Say what help your child gets, or would benefit from.

For example:

- do you give them physical help with moving around? If so, explain in detail what it is you do
- do you provide them with encouragement, comfort, reassurance or support in connection with moving around?

Step 3 Say why your child should not be expected to manage without this help.

For example:

- would they be physically unable to move around without it
- would they be in pain, or more pain, without it
- would they become emotionally distressed if they did not receive it
- might they come to harm if they did not receive it?

Step 4 Say how your child's needs are different from those of other children of the same age.

For example, can other children of the same age do these things with less help or with no help at all:

- more quickly
- without pain or discomfort

- without becoming distressed
- with less encouragement or with no encouragement at all
- with less supervision or without being supervised at all?

If your child uses any equipment to help with this activity, give details here.

If you run out of space, write your extra information in questions 54 or 70, or on a sheet and attach to the claim form.

Q40 Do they need encouragement, prompting or physical help to wash, bath, shower and check their appearance during the day?

Tick **Yes** at the top of the page if, in connection with washing or having a bath or shower:

- your child takes longer than other children of the same age, or it causes them pain, discomfort or distress
- you have to provide more help, or help of a different kind, than for other children of the same age
- your child has to be watched over more closely than other children of the same age
- your child needs more telling or encouragement or needs to be told or encouraged in a different way to other children.

Only tick **No** if your child does not have any difficulty with these activities compared to other children of the same age, and you have read the examples on the form and in the main box below and decided that none of them apply.

How often each day?

If your child has to wash or bathe after using the toilet or following episodes of incontinence, remember to include all these times. If their condition varies, give an average or a range.

For lower rate care it doesn't matter how many times a day your child needs help, but for the middle rate it needs to be several times a day across all personal care activities, for example, in the morning, during the day and at night.

How long each time?

Remember this includes the time to get undressed, bathe, dry and dress again and includes any time spent resting in-between.

If you want to tell us why they need help, how their needs vary or anything you think we should know, use the box below.

Step 1 Say what problems your child has, giving examples if you can.

For example, does your child:

- have problems, or suffer pain, getting in and out of the bath
- get too fatigued to wash, bathe or have a shower
- have problems or pain washing or drying their feet, hair or back

- have problems because they have dressings, a line into a vein, or a stoma appliance that needs to be kept dry or sterile
- need help replacing pads or applying cream after bathing
- have problems or pain standing to wash
- have to wash more often than other children
- tend to wash too often or for too long because of concerns about personal hygiene?

Step 2 Say what help your child gets, or would benefit from.

For example, do you:

- encourage them to wash or bathe
- help them with washing or bathing
- watch over them to make sure they are safe whilst they wash or bathe
- offer them support or reassurance if they are in pain or become distressed whilst washing or bathing?

Step 3 Say why your child should not be expected to manage on their own.

For example:

- would they be physically unable to wash or bathe without it
- would they become emotionally distressed if they did not receive it
- might they come to harm if they did not receive it?

Step 4 Say how your child's needs are different from those of other children of the same age.

For example, can other children of the same age do these things:

- with less help or with no help at all
- more quickly
- without pain or discomfort
- without becoming distressed
- with less encouragement or with no encouragement at all
- with less supervision or without being supervised at all?

Write down any special equipment that the child has to use, such as a shower seat or rail.

If you run out of space, write your extra information in questions 54 or 70, or on a sheet and attach to the claim form.

Q41 Do they need encouragement, prompting or physical help to dress and undress during the day?

Tick Yes at the top of the page and fill in 'how often' and 'how long each time'. Give details in the main box below if, in connection with getting dressed or undressed:

- your child takes longer than other children of the same age, or it causes them pain, discomfort or distress
- you have to provide more help, or help of a different kind, than for other children of the same age
- your child has to be watched over more closely than other children of the same age
- your child needs more telling or encouragement or needs to be told or encouraged in a different way to other children.

Only tick No if your child does not have any difficulty with these activities compared to other children of the same age, and you have read the examples on the form and in the box below and decide that none of them apply.

How often each day?

If your child has to change during the day due to episodes of incontinence, remember to include all these times as well. If your child's condition varies give an average or a range.

For lower rate care it doesn't matter how many times a day your child needs help, but for the middle rate it needs to be several times a day across all personal care activities, for example, in the morning, during the day and at night.

How long each time?

Remember to include any time your child spends resting, if they need to.

If you want to tell us why they need help, how their needs vary or anything else you think we should know about, use the box below.

Step 1 Say what problems your child has, giving specific examples if you can.

For example, does your child:

- have problems or pain reaching down to put on underwear, socks or shoes
- have to wear loose fitting clothes or ones that are easy to get on and off, such as ones with Velcro or elasticated waists
- sometimes have to get changed because of episodes of incontinence or leaks from a stoma appliance
- find it distressing if they have to get dressed or undressed in front of other children, perhaps because they have a stoma appliance, because they are embarrassed at being physically less developed than other children, or because medication has caused them to put on weight?

Step 2 Say what help your child gets, or would benefit from.

For example:

- do you encourage them to dress or undress
- do they need physical help getting dressed or undressed
- do they need watching over to ensure they are not bullied by other children when dressing or undressing
- do they need emotional support to deal with distress caused by other children (or adults) in connection with dressing and undressing?

Step 3 Say why your child should not be expected to manage without this help.

For example:

- would they be physically unable to dress or undress without it
- would they become emotionally distressed if they did not receive it
- might they come to harm if they did not receive it?

If there is help that they don't currently receive, in what ways would they benefit from it? For example, would more support and supervision in changing rooms from teachers make them less likely to be picked on?

Step 4 Say how your child's needs are different from those of other children of the same age.

For example, can other children of the same age dress and undress:

- with less help or with no help at all
- more quickly
- without pain or discomfort
- without becoming distressed
- with less encouragement or with no encouragement at all
- with less supervision or without being supervised at all?

If you run out of space, write your extra information in questions 54 or 70, or on a sheet and attach to the claim form.

Q42 Do they need encouragement, prompting, or physical help to eat and drink during the day?

Tick **Yes** at the top of the page if, in connection with eating or drinking:

- your child takes longer than other children of the same age, or it causes them pain, discomfort or distress
- you have to provide more help, or help of a different kind, than for other children of the same age
- your child needs more telling or encouragement, or needs to be told or encouraged in a different way to other children
- your child has to be watched over more closely than other children of the same age.

Only tick **No** if your child does not have any difficulty with these activities compared to other children of the same age, and you have read the examples on the form and in the main box below and decide that none of them apply.

How often each day?

If their condition varies give an average or a range. For lower rate care it doesn't matter how many times a day your child needs help, but for the middle rate it needs to be several times a day across all personal care activities.

How long each time?

Include any time spent preparing special diets and cleaning or maintaining special equipment.

If you want to tell us why they need help, how their needs vary or anything else you think we should know, use the box below.

Step 1 Say what problems your child has, giving specific examples if you can.

For example:

- do they have a very small appetite
- do they associate eating with abdominal pain
- do they feel sick when they eat
- does their medication affect their appetite
- have they suffered from malnutrition or weight loss as a result of not eating
- do they have to eat smaller amounts but more often than other children
- do they have to stick to a special diet or avoid certain foods
- do they suffer from joint pains which make holding cutlery or cutting up food painful
- are they on parenteral nutrition or tube feeding?

Step 2 Say what help your child gets, or would benefit from.

For example:

- do you have to remind or encourage them to eat or drink
- do you have to prepare special food or drinks for them
- do you offer support, comfort and reassurance in connection with pain or discomfort caused by eating
- do they need reminding or encouraging to avoid certain foods
- if they are on parenteral nutrition or tube feeding, describe in detail what this involves, including keeping the equipment sterile and clearing blockages.

Step 3 Say why your child should not be expected to manage without this help.

For example:

- would they be physically unable to eat or drink without it
- would they become emotionally distressed if they did not receive it
- might they come to harm if they did not receive it? For example, might they become very weak, malnourished, underweight or not develop physically at the proper rate?

If there is help they don't currently receive, in what ways would they benefit from it? For example, would their health benefit if they received more supervision and encouragement around eating at school?

Step 4 Say how your child's needs are different from those of other children of the same age.

For example, can other children of the same age do these things:

- with less help or with no help at all
- more quickly
- without pain or discomfort
- without becoming distressed
- with less encouragement or with no encouragement at all
- with less supervision or without being supervised at all?

Q43 Do they need encouragement, prompting or physical help to take medication or have therapy during the day?

Tick **Yes** if your child needs any help with medication. Tick **Yes** if your child receives any therapy at all. Don't worry about whether they need more or less help than other children of the same age.

Only tick **No** if your child does not have any difficulty with taking medication, and you have read the examples on the form and in the box below and decide that none of them apply.

How often each day?

If your child's condition varies give an average or a range.

For lower rate care it doesn't matter how many times a day your child needs help, but for the middle rate it needs to be several times a day across all personal care activities.

How long each time?

Remember to include any time spent making medication more palatable. State how long they spend with the therapist and how long you spend helping them.

If you want to tell us why you have ticked the boxes, how their needs vary or anything else you think we should know, use the box below.

If your child attends therapy and/or has to follow a programme of therapy at home, write down what they have to do, why they have to do it and what help they need.

Explain what therapy your child has, such as:

- physiotherapy
- hydrotherapy
- counselling
- psychiatric treatment.

If you are involved in the therapy in any way, such as helping or encouraging your child to do exercises, give details here.

If your child takes medication and they are too young to take it without help, explain everything you have to do related to this, including any ways that you try to make medication more palatable and any comfort or reassurance you provide.

If your child takes medication, and children of the same age might be able to take medication themselves during the day, then follow the usual four steps:

Step 1 Say what problems your child has, giving specific examples if you can.

For example, does your child:

- forget to take their medication
- try to avoid taking their medication because of the side effects it has
- become angry or distressed about a life which involves having to take so much medication
- become upset when they have to do physiotherapy exercises at home?

Step 2 Say what help your child gets, or would benefit from.

For example, do you:

- remind or encourage them to take their medication or do their therapy tasks
- offer them comfort or reassurance in connection with the effects of their medication
- find ways to make their medication more palatable?

Step 3 Say why your child should not be expected to manage without this help.

For example:

- would they be physically unable to take their medication without it
- would they become emotionally distressed if they did not receive it
- might they come to harm if they did not receive it?

Step 4 Say how your child's needs are different from those of other children of the same age.

For example, can other children of the same age take medication:

- with less help or with no help at all
- more quickly
- without pain or discomfort
- without becoming distressed
- with less encouragement or with no encouragement at all
- with less supervision or without being supervised at all?

Q44 Do they have difficulty seeing?

This may not be relevant to your child, but if it is, tick the boxes and describe the difficulties your child has with seeing.

Q45 Do they have difficulty hearing?

This may not be relevant to your child, but if it is, tick the boxes and describe the difficulties your child has with hearing.

Q46 Do they have difficulty speaking?

This may not be relevant to your child, but if it is, tick the boxes and describe the difficulties your child has with speaking. If your child has difficulty speaking to people they do not know or if they find it difficult to speak to people involved with their care such as doctors, write this in the box at the bottom of the page.

Q47 Do they have difficulty and need help communicating?

This may not be a section that is relevant to your child. However, if your child does have difficulties in this area, tick **Yes** and the relevant boxes.

Only tick **No** if your child does not have any difficulty with communicating with other people compared to other children of the same age, and you have read the examples on the form and in the box below and decided that none of them apply.

If you want to tell us why they need help, how their needs vary or anything you think we should know, use the box below.

Step 1 Say what problems your child has with, giving specific examples if you can.

For example:

- have they become solitary, shy or withdrawn because of their condition or the effects of their medication on their appearance
- do they struggle to talk about their symptoms or difficulties due to embarrassment

- do they find it easier to talk to adults than children their own age
- are they teased or bullied by other children as a result of their condition
- do they sometimes become anxious or aggressive when talking to other children or adults because of emotional difficulties caused by their condition or medication?

Step 2 Say what help your child gets, or would benefit from.

For example:

- do you spend more time talking with your child than you would with another child of the same age
- do you spend time trying to boost your child's self-confidence and self-image in order to help them feel able to talk to other children
- do you spend time encouraging your child to talk to other children
- do you offer your child support and reassurance if they are upset as a result of being teased or bullied by other children
- does your child need help explaining their needs to other people?

Step 3 Say why your child should not be expected to manage without this help.

For example:

- might they become more withdrawn or isolated without it?

Step 4 Say how your child's needs are different from those of other children of the same age.

For example, can other children of the same age communicate:

- with less help or with no help at all
- without becoming distressed
- with less encouragement or with no encouragement at all
- with less supervision or without being supervised at all?

Q48 Do they have fits, blackouts, seizures or something similar?

This may not be relevant to your child but if your child does have such difficulties, tick **Yes** and the other relevant boxes and describe their difficulties in detail in the box at the bottom of the page.

Q49 Do they need to be supervised during the day to keep safe?

Tick **Yes** at the top of the page and all the boxes that apply to your child if your child needs more supervision, or supervision of a different kind to other children of the same age, to keep them safe.

Only tick **No** if you have read the examples on the form and read the boxes below and decided your child doesn't have any such problems.

If you want to tell us why you have ticked the boxes, how their needs vary or anything else you think we should know, use the box below.

To be awarded DLA for supervision during the day, you need to show that your child needs continual supervision, which means that it must be frequent or regular throughout the day. You also need to show that there would be a risk of harm to your child if they did not receive this supervision.

Step 1 Say why your child needs supervision, giving examples if you can.

For example, does your child need someone to keep an eye on them because:

- they may become overtired
- they need someone to monitor their food and liquid intake
- they are on a nasal feeding tube or something similar throughout the day
- they may harm themselves?

Step 2 Say how your child's needs are different from those of other children of the same age.

- Would other children of the same age need supervising less closely, less frequently or not at all?

Q50 Do they need extra help with their development?

This may not be a section that is relevant to your child. If they have difficulty interacting with other children and the world around them, tick Yes at the top of the page and in all the boxes that apply to your child.

If you want to tell us why you have ticked the boxes, how their needs vary or anything else you think we should know, use the box below.

Step 1 Say what problems your child has with the activities listed on the page, giving specific instances if you can.

For example does your child:

- have difficulty getting on with other children of the same age, for instance because of embarrassment about their illness or because they're not physically able to play the same games as other children their age
- tend to be much more shy or aggressive than other children of the same age
- have difficulty playing with other children because they missed out on a lot of play opportunities due to illness
- have difficulty trusting other children
- relate much better to adults than other children
- spend most of their time alone?

Step 2 Say what help your child gets, or would benefit from.

For example:

- encouragement to spend time with other children
- careful supervision when with other children.

Step 3 Say why your child should not be expected to manage without this help.

For example:

- will it become harder to learn social skills as they get older
- will they become even more isolated as time passes by
- are they likely to become depressed?

Step 4 Say how your child's needs are different from those of other children of the same age.

- Would other children of the same age require the same amount of support or encouragement in connection with development?

Q51 Do they need encouragement, prompting or physical help at school or nursery?

Tick **Yes** and all relevant boxes if your child needs more help at school or nursery, and give details in the boxes below. If your child has behavioural issues since becoming unwell, write that information in the box.

Step 1 Say what problems your child has with the activities listed on the page, giving specific instances if you can.

For example, as a result of missing school and, whilst at school, often being unwell or frequently having to leave the room to go to the toilet, does your child:

- need help to change a stoma during the school day
- have problems with basic literacy or numeracy
- find it hard to concentrate, for example because of fatigue or side effects of medicines like steroids
- have difficulties keeping up with other children in their class
- have difficulty changing for PE or cannot take part in PE due to ill health
- need help to take medication
- need encouragement to eat or drink?

Step 2 Say what help your child gets, or would benefit from.

For example:

- more one-to-one help at school from a teacher or teaching assistant
- extra tuition at home
- extra help, support or encouragement from you with their school work.

Step 3 Say why your child should not be expected to manage without this help.

For example:

- would they become emotionally distressed if they did not receive it
- would it seriously affect their self-esteem
- would they become more isolated at school
- would they fall behind with their school work?

Step 4 Say how your child's needs are different from those of other children of the same age.

- Would other children of the same age require less help with school work?

Q52 Do they need encouragement, prompting or physical help to take part in hobbies, interests, social or religious activities?

Answering these questions can be very important if your child needs support and encouragement with play, socialising or other leisure activities. Don't hesitate to use separate sheets. If this applies to your child, tick **Yes**.

At home

This can be any activities that your child needs more help or encouragement with than other children of the same age. For example, this could be:

- help with school work, because they have missed a lot of school through illness
- encouragement to undertake any activities, because depression about their condition or physical pain make it difficult for them to motivate themselves
- physical help with setting up or playing games.

When they go out

Does your child need more help or encouragement to go out than other children of the same age? Anywhere your child might go to is relevant. For example, playing outdoors, going to the doctor, hospital, physiotherapist, counsellor, library, going shopping for pleasure (rather than for necessities), holidays, cinema, church, evening classes, local park, clubs, day-trips, visiting friends and relatives, swimming, gym, sports centre.

Help needed

Describe what help they get or would need in order to carry out this activity. Do they need someone to encourage them to undertake the activity? Do they need someone to drive them to and from places? Do they need someone to carry things for them, to lean on, to help them find a toilet, to help them get to and from the toilet? Do they need someone to offer them support and reassurance because of the possibility of an episode of incontinence? Do they need someone with them in case they have a dizzy spell or a fall?

How often?

Is this something they would do more than once a day?

For lower rate care it doesn't matter how many times a day your child needs help, but for the middle rate it needs to be several times a day across all activities.

How long each time?

Include, if relevant, the time needed to encourage them to undertake the activity, accompany them there, stay with them, throughout the activity and accompany them back.

Q53 Do they wake and need help at night or need someone to be awake to watch over them at night?

If you have to get up during the night to help your child, then tick **Yes**.

This is a very important page. Even a small amount of help at night may be sufficient for your child to be awarded the middle rate of the care component. If they need help during the day and at night they may get the higher rate care component.

Remember, night means the time when the adults in your house normally go to bed.

Only tick **No** if you have read the examples on the form and the box below and decided that none of them apply.

How often each night?

If this varies, give an average or a range. To qualify for middle rate care your child has to need help for at least 20 minutes a night, or at least twice a night.

How long each time?

If this varies, give an average or a range. To qualify for middle rate care your child has to need help for at least 20 minutes a night, or at least twice a night.

If you want to tell us why they need help or watching over, how their needs vary or anything else you think we should know, use the box below.

Explain why the child needs someone awake with them during the night.

Step 1 Say what problems your child has, giving specific examples if you can.

For example, do they:

- get hungry or thirsty
- have episodes of incontinence
- have bad dreams
- suffer pain?

Step 2 Say what help your child gets, or would benefit from.

For example, do you:

- bring them medication, drinks or anything else during the night. If so, explain at Step 3 why these can't just be left within reach for them, in case they need them
- help them with changing position or rearranging the bedding
- strip the bed, put on fresh bedding and put the soiled bedding on to soak or wash after an episode of incontinence
- make a hot water bottle for them to put on a painful joint or on their abdomen
- massage painful areas of their body
- give them comfort and reassurance to help them go back to sleep?

Step 3 Say why your child should not be expected to manage without this help.

Would they:

- be unable to sleep without it
- become emotionally distressed if they did not receive it
- come to harm if they did not receive it?

Step 4 Say how your child's needs are different from those of other children of the same age.

For example, can other children of the same age get through the night:

- with less help or with no help at all
- without pain or discomfort
- without becoming distressed
- with less supervision or without being supervised at all?

If your child uses any equipment to help them during the night, give details here.

QUESTIONS 54–55: EXTRA INFORMATION ABOUT CARE

Q54 If you want to tell us anything else about their care needs, use the box below.

Use this space to write down any extra information you think is relevant or any information that you couldn't fit on a previous page.

Use this space to tell the Decision Maker anything else that will help to give a clearer picture of the impact IBD has had on your child's life. For example:

- have they had to give up sports or other pursuits that used to mean a great deal to them
- have they changed from being outgoing and friendly to withdrawn, self-conscious and wary of other children or adults
- have they become very thin or has their medication made them put on a lot of weight?

Is their condition very unpredictable and difficult to manage?

Do they miss out on a lot of things, such as school trips and holidays, because of their condition?

If they have had hospital admissions or surgery you can give more details here.

If they have a stoma, or have special treatments such as total parenteral nutrition that you have not already covered fully, give details here.

Middle rate care

Although the claim form asks lots of questions about how often your child needs help and how long for, it doesn't ask you about when in the day they need help. However, this information can be very important. If your child needs help for at least an hour a day, but only in one chunk, or only at the beginning and end of the day – perhaps help with washing, dressing and undressing – they are likely to qualify only for the lower rate of the care component. For example, if your child needs help and encouragement for 40 minutes in the morning with getting up, washing and dressing and 20 minutes in the evening to get them to bed, this may be enough for them to get lower rate care.

To get the middle rate you have to show that your child needs help 'frequently throughout the day', so they have to need help in the morning, during the day and in the evening.

'Frequently' has been defined for benefits purposes as meaning 'several times – not once or twice', but there is no clear definition of what 'frequently throughout the day' means. The Decision Maker has to decide each case on the facts, so it may be helpful if you make those facts as clear as possible. You can use this page to list when they need help on an average day.

For example:

Help my child needs throughout an average day

7.30am	Help with getting out of bed washing and dressing
8.30am	Encouragement to eat and help taking medication
12.30pm	Encouragement to eat and help taking medication
4.00pm	Encouragement to spend time with other children outside school hours, because my child has become quite withdrawn and isolated due to their condition.
5.00pm	Additional help with school work because my child has missed so much due to time off when unwell.
6.00pm	Encouragement to eat and help taking medication.
8.30pm	Help with washing, undressing and getting into bed.

Q55 When did the child’s care needs you have told us about start?

If your child had care needs before they were diagnosed with IBD, write the date the care needs first started.

QUESTIONS 56–68: ABOUT YOU

These questions are about the adult who is making the claim on behalf of the child. Please remember to add your National Insurance number (question 58) and a daytime phone number (question 61) as the DWP may phone you and ask you a few questions.

Q69 How we pay you

The DWP need your bank details even before they make a decision whether or not to award DLA to your child.

Q70 Extra information

Tell us anything else you think we should know about the child’s claim

Write down any additional information about the claim that you want the DWP to know.

Q71 Declaration

Sign and date the declaration.

**Congratulations! You’ve done it. The claim form is complete.
Remember to photocopy the form before you send it.**

.....

THE IMPORTANCE OF SUPPORTING EVIDENCE

As well as your claim form, the Decision Maker has to take into account any other evidence you provide. This includes additional evidence from you and evidence from other people.

MEDICAL EVIDENCE

This can make an enormous difference to whether your child’s claim succeeds. Detailed evidence from health professionals, such as your child’s nurse, GP or other specialists involved in your child’s care, may mean that your child’s claim is dealt with more quickly and that you are less likely to have a home visit from the DWP. Always inform your GP that you are making a claim for DLA as it is likely the DWP will contact him or her without telling you first, even if he or she has very little to do with dealing with your child’s condition.

Ask the health professionals most involved in your child’s care if they will write a letter supporting the claim. Make an appointment to see them so you can answer any questions they have and take the **Health professional’s sheet** (Appendix 4) at the back of this guide with you. Ask them to send the letter to you so you can keep a copy, and if necessary, ask them to change anything you think is inaccurate or unhelpful. It is up to you to decide what evidence you submit. Do not feel obliged to use a letter that may not be helpful or might actually harm your case.

NON-MEDICAL EVIDENCE

Carers, teachers, friends or relatives who help to look after your child can also submit letters as supporting evidence, but they should give them to you to submit so that you can keep a copy. If the letter says things that you think are unhelpful then ask the writer to change them or simply do not submit it. Don’t feel obliged to submit a letter just because someone has been kind enough to write it. A letter that says the wrong things can be damaging to your claim.

It is important, if possible, to submit evidence from your child’s nursery, school or college. Families have told us that their claims have been turned down because they didn’t provide enough evidence from their child’s school. You could ask your child’s teacher to explain what help the school provides to overcome problems with absence, exams, school trips and toilet urgency.

KEEPING A DIARY

It is very useful to keep a diary for about seven days to detail all the difficulties your child experiences and all the help they receive. If you keep a diary before you fill in the claim form, it can make filling in the claim form a lot easier. You can send a copy of the diary in with your child’s claim form as additional evidence. If your child has a fluctuating condition it may be helpful to keep a diary for a longer period of 2–3 weeks, to better reflect their condition.

A diary may also prove invaluable if you need to attend a tribunal, as it will be evidence of what problems your child had at the time you made the claim. Tribunals are generally very keen on hearing a day-by-day account of the things your child finds difficult and the help you provide.

Don't forget

You must send your claim form before the deadline. You can send other evidence later if necessary. Enclose a letter with your claim form telling the DWP that you intend to send further evidence, and when you hope to send it to them.

WHAT HAPPENS NEXT

You should receive an acknowledgement within five working days of the DWP receiving your claim form. Your claim will then be looked at by a Decision Maker, who may make a decision on the information you have sent or may decide they require more information. The Decision Maker may contact your child's GP, or more rarely your child's specialist, for further information and/or they may ask the DWP to send a health professional to visit your child for a medical.

PREPARING FOR A MEDICAL

There's no way of knowing whether your child will have to have a medical or not when you make your claim. The first you will hear about it is when you receive a letter, or possibly a phone call, telling you that the DWP wish to send a health professional to your home. If you refuse to allow your child to be examined, your child's claim for DLA will automatically be turned down. The health professional may be a doctor, but they could be another health professional, such as a physiotherapist, occupational therapist or nurse.

You can tell the DWP that you want to have a friend or relative present and make sure that the visit is arranged for a time when they can be there. **We strongly advise you to do this – details why are given below.**

Some people will be visited at home by a polite and interested health professional who takes the time to listen and writes an accurate report of their visit. Sadly, we know from Crohn's and Colitis UK members that this isn't always the case. Some people have reported that the visiting health professional seemed in a rush, stayed only a very short time and wasn't interested in what they had to say. Some found the health professional rude. Others reported that although the health professional seemed sympathetic and encouraging, they later discovered that the medical report was very dismissive of their child's needs. Having a friend or relative with you can make it much easier to deal with these situations.

Having someone else present not only provides moral support, it can also provide you with a witness to what happened at the medical. Please also use the **Medical visit record sheet** (Appendix 3) at the end of this guide to record what happens, as this can be used as evidence at an appeal. Look through the sheet before the medical and fill it in afterwards if you want to have a record of what happened. Remember to make a note of the time the health professional arrived and left. If they only stayed a short time you can use this as evidence that their report is less likely to be reliable.

THE MEDICAL AND THE MEDICAL REPORT ARE DIVIDED INTO TWO PARTS:

PART ONE OF THE EXAMINATION

This should be a statement of your child's needs in your own words. The health professional should ask you about most of the activities in the claim form, what difficulties your child has with them, and what attention or supervision your child requires.

Read through your photocopy of your child's DLA claim form and refresh your memory on all these points before the health professional arrives. Beware of leading questions like 'They don't have any trouble with ... do they?' or 'They can manage ... can't they?' Try not to be persuaded or feel pressured into giving an answer that isn't correct. The health professional should write down what you say and then either read the statement back to you or give it to you to read. You then sign to say that you agree with what has been written.

Do not sign unless you are completely happy with what is written.

This is a signed statement saying what you consider your child's problems to be. If it differs from what you've written in your claim form it may be used by the DWP as grounds for refusing your claim.

If you need to read the statement, or have it read to you, two or three times in order to check it fully, then do so. Don't be hurried. The health professional is being paid by the DWP. If there is anything you disagree with, ask the health professional to change it. If there is anything missing, ask the health professional to put it in. Carry on until you are completely happy with the statement. If the health professional won't write what you ask, then politely refuse to sign, but still co-operate in every other respect with the medical. If the health professional tells you that you must sign or the claim will fail, tell them politely that they are mistaken and show them this page if you wish. This guide was written by a barrister. If the health professional says they are running out of time and have to be somewhere else, politely suggest that they arrange a further appointment to come back and finish the medical. But, whatever you do, don't sign until you're satisfied.

We do understand how difficult disagreeing with a health professional can be. That is why we strongly recommend you consider having another adult with you to give you support.

PART TWO OF THE EXAMINATION

In the second part of the medical, the health professional may ask you or your child more questions, carry out a brief physical examination and ask your child to carry out simple activities such as standing up and walking across the room. If you know that something they ask will cause your child pain, you should tell the health professional you do not wish your child to do it and explain why.

While the health professional examines your child they will fill out their own report stating what, in their opinion, your child's needs are. This is the health professional's part of the report, they are entirely free to disagree with everything you have said and they will not show you what is written. You will receive a copy of the whole report at a later date if you appeal against the decision.

While it's important to be prepared for a medical visit from a DWP health professional, try not to worry about it. Many people say they had no idea what to expect before they had their medical and that they were very disappointed with how quick and irrelevant the whole thing seemed to be. We also know that many DLA claims are turned down because of the visiting healthcare professional's report. By being properly prepared for the medical you can reduce the chances of this happening to you.

THE DECISION

You will receive a decision letter telling you whether your child has been awarded DLA. If your claim has been successful the letter will tell you which components – care and/or mobility – your child has been awarded and at what rates. It will also tell you whether your child's award is for a fixed number of years or whether it will continue until your child reaches the age of 16, when they will have to apply for PIP.

For information on claiming PIP, see our guide **Claiming Personal Independence Payments (PIP)**. If you are happy with the award then you don't need to do anything else, except check whether you qualify for other benefits, or increased amounts of other benefits. Citizens Advice may be able to advise you on this (see **Help, Information and Support** on page 41).

If the award is for a fixed number of years, you should be sent another claim form to complete several months before it runs out. If the award is until the age of 16, you may still receive claim forms to fill in every few years and the award can still be reduced or stopped depending on what you write in the claim forms. You should always keep your child's original claim form for reference, whatever length of award you receive.

If your child's circumstances change – their condition improves or deteriorates – you should tell the DWP as it may mean that their DLA should be reduced or increased.

CHALLENGING THE DECISION

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

Firstly, you can ask the DWP to look at their decision again. This is called a **Mandatory Reconsideration**. You must do this within one calendar month of the date on the decision letter, although the time limit can be extended in some circumstances. Tell them why you disagree with their decision, bearing in mind the criteria for DLA. There is a template form you can use for this at:

www.gov.uk/government/publications/challenge-a-decision-made-by-the-department-for-work-and-pensions-dwp

You don't have to use this form – you could write your own letter instead if you prefer.

It may be helpful to provide additional information or evidence in support of your claim – see the section **The importance of supporting evidence** on page 37, to find out what kind of evidence may best support your claim.

The DWP will look at your claim again and let you know whether they can change their previous decision.

After the reconsideration if you are still not satisfied, you can **appeal** to an independent tribunal. You'll have one month to appeal – the month starts from the date on the decision letter stating that, following the mandatory reconsideration, the decision is unchanged, but this can be extended in some circumstances. The decision letter will tell you where to send your appeal. You should use the form SSCS1 which is available from independent advice agencies, or online from

www.gov.uk/government/publications/appeal-a-social-security-benefits-decision-form-sscs1

For Northern Ireland, use form NOA1 (SS) and send to The Appeals Service (TAS) directly. You can find the NOA1 (SS) form at

www.nidirect.gov.uk/publications/appeal-form-noa1ss

We suggest that you seek advice if you are considering making an appeal.

If you have been awarded DLA but are considering challenging the decision to try to get your award increased, do bear in mind that there is some risk that your existing award could be reduced or ended, instead of being increased. If you are unsure what to do, seek advice from the organisations listed at the end of this guide.

HELP, SUPPORT AND INFORMATION

ADVICE AGENCIES AND ADVICE WORKERS

These organisations may be able to help with filling forms and challenging the decision if you're unhappy with it. However, advice agencies may be very difficult to get through to on the phone, have no appointment system, long queues and no public toilets. If you can't get through to your local agency on the phone, try writing to them explaining your child's health problems and asking if they do home visits, or see if they can phone you to offer advice. You can search online for advice agencies by using search terms such as 'disability information and services' or 'social service and welfare organisations' plus your local area.

Please note: you may have to try repeatedly before you can get through to advice agencies on the telephone. You should also be aware that help from advice agencies is very much in demand, so the sooner you seek help the better.

Citizens Advice

www.citizensadvice.org.uk

There are Citizens Advice offices across the UK. You can find details of your nearest office on their website.

Civil Legal Advice (CLA)

0345 345 4345

www.gov.uk/civil-legal-advice

Get free and confidential legal advice in England and Wales if you're eligible for legal aid.

AdviceUK

www.adviceuk.org.uk

Over 700 advice agencies are members of AdviceUK. Details of your nearest ones are available from AdviceUK's website.

Advice NI (Northern Ireland)

0800 988 2377 (Freephone)

Advice NI is the umbrella body for independent advice centres in Northern Ireland. You can get details of your local independent advice centre in Northern Ireland from their website: www.adviceni.net

Housing Associations

Some housing associations employ a welfare rights worker. If you live in a housing association property, contact your local office.

Doctors' surgeries

An increasing number of surgeries and health centres have a welfare rights worker on the premises, part-time or full-time. Check with the receptionist at your surgery.

Local Authority

Your local council may employ welfare rights workers who can help you with your claim. Start by asking your council's main switchboard if they can put you through to a welfare rights worker. If the operator doesn't know of one, ask to be put through to the Social Services Department.

Government websites

Government in England, Scotland and Wales

www.gov.uk

Government in Northern Ireland

www.nidirect.gov.uk

APPENDIX 1. TWO-MINUTE DLA TEST FOR CHILDREN

Step 1 Look through this list of some (but not all) of the activities that are relevant to DLA:

- walking outdoors (especially in unfamiliar places)
- getting into or out of bed or settling in bed
- going to or using the toilet
- washing, bathing, showering and checking their appearance
- dressing and undressing
- eating and drinking
- talking to other people
- being left alone
- taking medication or doing therapy
- someone keeping an eye on them
- help with their development – play, behaviour
- extra help at school or nursery
- social and leisure activities
- help during the night – toilet, someone to watch over them

Step 2 Choose one of the activities above that your child has difficulties with. For example, your child may have difficulties with walking because of fatigue; talking to other people because they have become very withdrawn; going to the toilet because of soreness around the anus.

Step 3 With your chosen activity in mind, answer the following true or false questions:

My child can do it,

• but it hurts them	True or False?
• but only more slowly than other children of the same age	True or False?
• but only with more help than other children of the same age	True or False?
• but not as safely as other children of the same age	True or False?
• but only because they've got a special technique of their own	True or False?
• but they need more encouragement than other children of the same age	True or False?
• but they need a closer eye kept on them than other children of the same age	True or False?

My child can't do it,

• but other children of the same age can	True or False?
--	----------------

Step 4 If you haven't answered *True* to any of the questions, try the test again with another activity from the list and so on, until you find a statement that is true or you decide that there aren't any.

Step 5 If the answer is **True** to **any** of the questions above in relation to **any** activity then your child may be entitled to DLA. If your child's condition is a variable one, so the answer is sometimes **True** and sometimes **False**, then they may still be eligible for DLA. Read the section **How to explain fluctuating conditions** on page 9.

If the answer isn't **True** to any of the questions, your child may still be eligible for DLA. You can get advice from one of the agencies listed in the **Help, Support and Information** section on page 41.

APPENDIX 2. CLAIM FILE RECORD SHEET

Date	Letter		Phone		Name and section	Details
	To	From	To	From		
6/2/18 EXAMPLE	✓				DLA Unit, Flowers Hill	Claim form and letters from GP and consultant
11/2/18 EXAMPLE				✓	Jenny in Claims Section DLA Unit, Flowers Hill 0117 949671	She said they had received my form

CLAIM FILE RECORD SHEET

Date	Letter		Phone		Name and section	Details
	To	From	To	From		

APPENDIX 3. MEDICAL VISIT RECORD SHEET

Date of healthcare professional's visit

Time healthcare professional arrived

Time healthcare professional left

Who else was present?

Did you feel you had time to answer the healthcare professional's questions fully?
Yes / No if no, please give details.

Did the healthcare professional phrase questions in a way that suggested a particular answer? **Yes / No** If yes, please give details.

Did anything the healthcare professional do, or ask your child to do, cause your child pain?
Yes / No if yes, please give details, including whether your child mentioned they were in pain.

Anything else you wish to record (continue overleaf or on a new sheet if you need to).

Signed (your signature) **Date**

Signed (friend or carer who was present) **Date**

APPENDIX 4. HEALTH PROFESSIONAL'S SHEET

Information for healthcare professionals providing evidence about a Disability Living Allowance claim for the DWP

In order to make a fair decision about a claim, the DWP requires very specific evidence from health professionals.

1. The Agency wishes to know:

- length of time over which the patient has been treated
- confirmation of the diagnoses (not just IBD diagnosis)
- likely future clinical course

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

Symptom

Weakness and lethargy due to anaemia 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 help to take medication and safely carry out activities of daily living such getting in and out of bed.

- 2.** In order to help the health professional supply this evidence, on the reverse of this sheet is a checklist of activities of daily living. The patient's parent or carer may have already completed this form. You may wish to go through it with them.
- 3.** Parents or carers may not have previously revealed to their child's health professional the extent to which the disease affects their child's everyday their life. This may be because much of the additional care they provide for the child is in connection with non-medical activities such as school, social activities, washing, dressing, etc.
- 4.** It is important to bear in mind that Ulcerative Colitis and Crohn's Disease are largely 'hidden' conditions – the disabilities which arise from them are not usually obvious. The evidence from health professionals can help make it clear that this does not reduce their importance.

COMPONENTS AND RATES OF DLA

It needs to be shown that the child's need for attention or supervision is substantially in excess of that of other children of the same age who do not have a health condition or disability.

Lower rate care	For children who reasonably need help (even if they don't presently get it) for at least an hour, on most days. This help can be spread out throughout the day.
Middle rate care	For children who reasonably need (even if they don't presently get it): <ul style="list-style-type: none"> • help with personal care several times throughout the day, or • frequent or regular supervision throughout the day to avoid danger, or • help with personal care at least twice a night, or once for at least 20 minutes, or • someone awake to watch over them at least twice a night, or once for at least 20 minutes
Higher rate care	For children who reasonably need help (even if they don't presently get it) during the day and during the night, as described for the middle rate.
Lower rate mobility	For children aged 5 or over, who can walk but need someone to either supervise or guide them in places they are unfamiliar with.
Higher rate mobility	For children aged 3 or over, who are unable to walk or 'virtually unable to walk'. This is often taken to mean children who cannot walk more than 50 yards at a reasonable pace without pain, fatigue or breathlessness.

CHECKLIST

for the parent/carer to complete concerning their child, to help the health professional's understanding of the problems their child is experiencing.

Activity	Very brief details of the problem your child had with this activity, including variability. <i>'Wakes up in the night because of abdominal and joint pains. At least once a night, sometimes four or more times'</i>
Walking outdoors	
If your child needs someone with them when they are outdoors	
Someone keeping an eye on your child	
Your child's development	
Waking, getting up and going to bed	
Washing and bathing	
Dressing and undressing	
Help with toilet needs	
Communicating with other people	
Eating and drinking	
Help with medication	
Help with therapy	
Help with medical equipment	
Blackouts, fits and seizures	
Your child's mental health	
Movement, co-ordination and moving about indoors	
When your child is in bed at night	
Social and leisure activities in the day and the evening	

NOTES...

NOTES...

HELP AND SUPPORT FROM CROHN'S & COLITIS UK

We produce over 50 information sheets, booklets and guides about all aspects of Crohn's Disease, Ulcerative Colitis and other forms of Inflammatory Bowel Disease (IBD). These are available to download for free on our website:

www.crohnsandcolitis.org.uk/publications

You may be particularly interested in the following publications:

- IBD in Children: A Parent's Guide
- Children and Young People with IBD: A Guide for Schools
- Claiming Personal Independence Payment (PIP)
- Living With IBD
- Fatigue and IBD
- Transition: Moving to Adult Care

If you would like a printed copy of any of our publications, please contact our Helpline - a confidential service providing information and support to anyone affected by IBD.

Our team can:

- help you understand more about IBD, diagnosis and treatment options
- provide information to help your child to live well with their 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.

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

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Crohn's & Colitis UK publications are research-based and produced in consultation with patients, medical advisers and other health or associated professionals. They are prepared as general information on a subject and are not intended to replace specific advice from your own doctor or any other professional. Crohn's & Colitis UK does not endorse or recommend any products mentioned.

Crohn's & Colitis UK is an accredited member of the Information Standard scheme for Health and Social care information producers. For more information see www.crohnsandcolitis.org.uk and the Information Standard website: www.england.nhs.uk/tis.

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

ABOUT CROHN'S & COLITIS UK

We are a national charity established in 1979, fighting for improved lives today and a world free from Crohn's and Colitis tomorrow. We have 40,000 members and 50 Local Networks throughout the UK. Membership starts from £15 per year with concessionary rates for anyone experiencing financial hardship or on a low income.

This publication is available free of charge, but we would not be able to do this without our supporters and members. Please consider making a donation or becoming a member of Crohn's & Colitis UK.

To find out how call **01727 734465** or visit www.crohnsandcolitis.org.uk