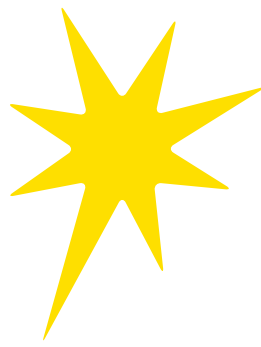




Disability Living Allowance

A step-by-step guide to
claiming DLA for children under
16 with brain conditions



Working wonders for children with brain conditions

Families where a child has a brain condition face challenges every day. Just to learn, play, make friends and experience the world can feel difficult, even impossible. But we don't believe there's any challenge that can't be overcome.

So we listen to families, we learn from them. We carry out research, we design and innovate, we make and share. From new equipment to new learning resources, to new ways to play and support each other, everything we find out together makes life better. It opens doors to discovering the world.

It's an incredibly rewarding journey for everyone involved. Why not be a part of it? You never know what we'll discover together.

www.cerebra.org.uk

Our guides for parents help you find the answers you need. You can view and download the full series of our guides and factsheets completely free from our website www.cerebra.org.uk.

If you would like to make a donation to help cover the cost of producing our guides please just text **CERE12** and the amount you want to give to **70070** or give us a call on **01267 244216**. You can also donate online.

Thank you.

Contents

About this guide	5
Introduction	5
Who is this guide for?	5
Why claim DLA?	5
How DLA works	5
Can my child claim DLA?	5
Getting a claim form	6
Before You Begin	7
Completing the Claim Pack	7
General Tips	7
How to use this guide to help you complete the claim form	7
Questions 1 -24 of the Claim Pack	8
Questions 25 to 31 - Mobility (physical difficulties)	10
Questions 32 to 36 – Mobility... continued	11
Question 37 – Getting into or out of or settling in bed during the day	13
Question 38 – Toilet needs during the day	15
Question 39 – Moving around indoors during the day	16
Question 40 – Washing, bathing, showering and checking appearance during the day	18
Question 41 – Dressing and undressing during the day	20
Question 42 – Eating and drinking during the day	22
Question 43 – Taking medication or having therapy during the day	24
Question 44 –Seeing	26
Question 45 –Hearing	27
Question 46 –Speaking	28
Question 47 – Communicating	29
Question 48 – Fits, blackouts, seizures or similar	31

Question 49 –Supervision	33
Question 50 –Development	34
Question 51 – At school or nursery	36
Question 52 – Hobbies and Activities	38
Question 53 – Help and supervision during the night	39
Questions 54-71 of the Claim Pack	41
The Decision	42
The Dispute Process	43
Mandatory Reconsiderations	43
Appeals	43
Beyond the tribunal	44
Supersessions	45
The DLA434	45
Renewal Claims	46
Personal Independence Payments (PIP)	46
Benefits at Age 16	47
Appointeeship	47
Links to Other Benefits	47
Where to Get Help	48
Appendix 1 - Higher Rate Mobility Component	49
Virtual inability to walk due to refusal episodes	49
Severe Mental Impairment and Severe Behavioural Problems	50
Appendix 2 - Rough Guide to DLA	52

About this guide

Introduction

Welcome to our guide to completing the Disability Living Allowance (DLA) form for children under 16 years of age. It has been designed to make completing the form as straight forward as possible.

Who is this guide for?

This guide is for anyone, parent or professional, who is considering making a claim for Disability Living Allowance (DLA), on behalf of a child under 16 years of age who has a brain condition. This includes conditions like autistic spectrum conditions, ADHD, cerebral palsy, Down's syndrome, epilepsy, learning difficulties, global developmental delay and acquired brain injuries among others.

Covering such a wide range of conditions means that, inevitably not everything in the guide will be applicable to all children. The intention is that you can use whatever is most appropriate and expand on it with your own examples.

Why claim DLA?

If your child has a disability this can create all sorts of extra expenses, such as higher heating bills, special diets, taxi fares, extra laundry etc. DLA can help meet these additional expenses. You can spend DLA on anything you wish, and in some cases DLA is required just to keep families above the poverty line. DLA is a non-means tested benefit and does not have a negative effect on other benefits you may be claiming. However, you should be aware that making a claim for DLA for a child can be a long and emotionally draining process.

How DLA works

DLA is one benefit, but with two components – the care component and the mobility component. The claim form covers both, so you only need to complete one form.

The care component can be paid at one of three rates – lower, middle and higher, whilst the mobility component only has a lower and higher rate.

It is possible to be awarded any combination of the two components. For example one child may be awarded lower rate mobility and higher rate care, another higher rate mobility and middle rate care, and a third child could get lower rate care only depending on their needs and circumstances.

Although there are two components to the benefit, only a single payment is made, usually directly into the parent/carer's bank account every 4 weeks. In the example of the first child above, their 4-weekly payment would be the total of the value of the lower rate mobility component and higher rate care component. Benefit rates are revised by the Government every April and can be found on the [direct.gov.uk](https://www.direct.gov.uk) website.

Can my child claim DLA?

You can make a claim for DLA for your child if they have a long term health condition, disability or developmental disorder which results in them needing substantially more attention, guidance or supervision than a typically developing child of the same age. They have to have had their difficulties for at least 3 months before claiming and be expected to continue having the same level of difficulties for at least the next 6 months. Therefore it follows that the earliest age you can claim DLA for your child is 3 months old.

The mobility component, however, is not payable until the age of 3 years old, for the higher rate, and 5 years old for the lower rate. However, if your child is below these ages and has mobility problems then you should complete these pages anyway to give the fullest possible picture of their difficulties.

To qualify for the care component, your child must require substantially more attention or supervision than a typically developing child of the same age. How much attention or supervision they require will determine what rate of the care component they receive. As a rule of thumb, if they need more than an hour or so a day they may qualify for the lower rate. If they need attention or supervision throughout the day or night then they may qualify for the middle rate. To qualify for the higher rate they should need attention or supervision throughout the day and a substantial part of the night.

The mobility component works somewhat differently. To qualify for the higher rate your child must be unable or virtually unable to walk, or the effort required to walk be a danger to their health. A child who has severe mental impairment and severe behavioural problems may also qualify, as may some autistic children who have frequent and unpredictable 'refusal episodes'. However, this is a technical area, and not something to worry about before completing the claim form! The form is just for you to give as accurate a picture as possible of your child's difficulties.

The lower rate of the mobility component is for children who require substantially more guidance or supervision than a typically developing child of the same age whilst outside in places that are not familiar to them.

Your child does not have to have a diagnosis of a recognised condition or disability in order for you to claim DLA. Increasingly some children are waiting a long time for diagnosis and this should not preclude them from getting DLA. However, they do have to be experiencing the same sort of difficulties as a child with a diagnosis, and you need to be able to demonstrate that they need substantially more guidance, attention and supervision than a typically developing child of their age.

If you have claimed DLA for your child before and been turned down, there is nothing to stop you from trying to claim again. Equally it does not matter if you have been 'advised' that you cannot claim by for instance, the DWP, a doctor, school or social worker. Only a professional welfare rights advisor should make that judgement.

Importantly, as we have already said DLA is **not** a means-tested benefit. This means that it does not matter what you or your family's income or savings are, or what other benefits they are receiving. It is assessed only on the needs of the child.

Getting a claim form

DLA claim forms are available by phone by calling 0800 121 4600, or 0800 587 0912 or from your local Jobs & Benefits Office in Northern Ireland. The form will have two dates stamped on the front of it. The first date is the date that you requested the form – i.e. the day you telephoned the DWP. The second date is 6 weeks afterwards. As long as you get the completed form back to the DWP by the second date then they will pay you any DLA that is awarded to you back to the date of request.

Alternatively, you can either download and print off a form, or complete the form online, at the [direct.gov.uk](https://www.direct.gov.uk) website. The disadvantage to claiming this way is that any DLA will only be paid from the date the completed form is received at the DWP office rather than when you first download it or start completing it.

Before You Begin

There are a few important things it is advisable to do whilst making a claim for DLA for your child:

1. Keep a photocopy of the claim form that you send to the DWP, and any other documents that you send to them. That way, if the claim form is lost, you have another copy. Also, it is useful to have this to refer to if you need to dispute your award (more about this later on). Furthermore, as DLA is usually awarded for a limited period, it is likely that you will at some point have to complete forms again, and having the original to hand makes that a lot easier.
2. Keep a copy of all correspondence between you and the DWP, for similar reasons as above.
3. Keep a written record of all telephone calls with the DWP, and take a note of the name of the person you speak to.
4. Arrange support. Claiming DLA for your child can be an emotionally difficult experience and the form itself is complex. Get help a professional welfare rights advisor or, if there is not one in your area, an advice centre.

Completing the Claim Pack

General Tips

The DLA claim form is a long document and can seem daunting at first glance. However, if you take your time and use this guide then you should be able to complete it accurately. It is tempting when you receive the form just to put it to one side for a while as you have 6 weeks to fill it in. If you can avoid this temptation, though, you will have time to do it bit by bit and not feel rushed.

Remember that your aim in filling in the form is to give as clear a picture as possible of your child's difficulties. Much of the form consists of tick boxes with a few lines for you to describe their problems more clearly. However, you do not have to be constricted by this structure and can carry on writing below the lines if necessary, or even attach an extra piece of paper.

How to use this guide to help you complete the claim form

The first parts of the claim form (parts 1 – 24) are fairly straightforward (although we will look at them in more detail soon). They are asking for basic information about your child and the people involved in their care.

Parts 25–36 are the mobility questions, and parts 37–55 are the care questions. You will see that the basic format of these pages is similar, with a series of tick box questions followed by some space to expand on your answers. In this guide we go through these questions one by one.

This guide is designed so that you can dip in and out of it as necessary and just refer to the parts you need. Equally, you can work through it page by page as it reflects the arrangement of the DLA child claim form. In either case, read through these introductory pages before you start.

Each section is presented in a tabulated format for ease of use and clarity. It may be that you are only having difficulty with one particular question on a section, in which case you should be able to go straight to that question in the guide for help.

The opening question from each page of the claim form is replicated at the top of the corresponding section of the guide, and is then followed by an explanation to help you work out whether that section is applicable to your child.

Below this is the table, which varies somewhat between sections to reflect the varying page layouts of the claim form. (The page for questions 25–31 is different as most of the questions on this

page are self-explanatory and need no further interpretation). Suggestions are given in the right hand column for what you might want to say in the text box. Please pay heed to the note relating to the higher rate mobility component for some children and referring you to Appendix 1.

Most of the other pages have tables consisting of two columns. The first column shows you the questions that run down that page of the claim form. The second column gives examples and explanations for each question, again to help you decide if it's appropriate to tick the yes or no box for that question.

However, in some sections the second column is a bit different as it is dealing with questions on the claim form when you are required to give an idea

of how many times each day and how long each time your child needs help with certain aspects of care. Again, this is reflective of how the claim form is worded for these sections, e.g, Question 37, getting into or out of or settling in bed during the day. In these cases, the second column helps you work out how to properly evaluate the time involved in these care needs.

After the table, we have given you some points to help you complete the additional information box at the bottom of each page of the claim form. If you have ticked yes to any of the questions on the page, it is a good idea to expand upon your answers a little by completing this box. These suggestions should give you some ideas as to the sort of things you may want to include.

Questions 1 -24 of the Claim Pack

Most of these questions are just simple yes or no answers, so we have just listed them here, with a few hints and tips where needed:

1. **Surname or family name**
2. **Child reference number** – this is your child's National Insurance Number, and you will probably only be aware of it if you have previously tried to claim DLA. If you know it, write it in.
3. **Date of birth**
4. **Sex (m/f)**
5. **Address where the child lives**
6. **Are you claiming for the child under the special rules?** – Only tick yes if your child has a terminal condition that means they are not expected to live longer than 6 months.
7. **What is the child's nationality?**
8. **Does the child normally live in Great Britain?**
9. **Has the child been abroad for more than a total of 4 weeks in the last 3 years?**
10. **Other benefits from another European Economic Area (EEA) state or Switzerland**
11. **Other benefits from another EEA state or Switzerland**
12. **Is the child in a hospital or hospice now, or have they been admitted in the past 12 months?**

13. **Is the child in a residential college or similar place now, or have they been in the past 12 months?**
14. **In the last 12 months, has the child seen anyone apart from their GP about their illnesses or disabilities?** – this will often be a paediatrician or hospital specialist, but could be a health visitor, occupational therapist, speech therapist, social worker etc – if there is more than one person, list the others in part 70.
15. **Name of the child's GP**
16. **Has the child had or are they waiting for tests to help diagnose, treat or monitor their illnesses or disabilities?**
17. **Do you have any reports, letters or assessments about the child's illnesses or disabilities** – send these in as long as they are completely supportive of your claim
18. **Name of the child's school or nursery** – the 'person we can contact' should be the person who knows your child best. This could be the SENCO or Teaching Assistant rather than their class teacher
19. **Does the child have or are they waiting to hear about an Educational Health & Care Plan (EHCP – England), Individual Education Plan (IEP), Individual Behaviour Plan (IBP) or statement of Special Educational Needs (Wales)? In Scotland the statement is called a Co-ordinated Support Plan (CSP)**
20. **Statement from someone who knows the child** – this is optional and you do not have to get it completed. Don't delay sending the claim form in. Make sure if you do have it completed that it is completely supportive of your claim.
21. **Consent** – make sure you tick and sign and date this part as well as signing the form at the end. Usually you should give the DWP consent to contact the people you've named on the form unless there's a very good reason not to.
22. **List the child's illnesses or disabilities in the table below** – How long have they had it? This is often from birth with neurological conditions. Treatment can include therapy.
23. **Does the child use or have they been assessed for any aids or adaptations?**
24. **When the child needs help** - Only say that your child's care needs vary if there are marked variations in their needs for a particular reason or it may appear to the DWP that there are often times when they need little or no care. Otherwise, minor variations can be reflected in the main part of the claim form.

Questions 25 to 31 - Mobility (physical difficulties)

25. Can they physically walk?

If the child cannot physically walk at all then tick no under question 25 of your DLA claim pack and continue to question 36 – you do not need to fill out any of the other sections in between. Tick yes if the child can physically walk and continue onto question 26.

26. Do they have physical difficulties walking?

If the child has difficulties walking which affects their speed, health, the way they walk, how long it takes them, how far they can walk or they require a considerable amount of effort to walk then tick yes under question 26 of your DLA claim pack then move onto the following questions. Tick no if the child doesn't have any physical difficulties walking, and move onto question 32 (behavioural difficulties walking).



If your child has severe behavioural problems and a severe mental impairment, or regularly refuses to walk due to a neurological condition, please tick yes to question 26 and use Appendix I of this guide (Higher Rate Mobility Component) to complete questions 27-36.

Tick boxes on the claim form

- | |
|---|
| 27. Please tick the boxes that best describe how far they can walk without severe discomfort and how long it takes them |
| 28. Please tick the box that best describes their walking speed |
| 29. Please tick the box that best describes the way they walk |
| 30. Does the effort of walking seriously affect their health? |

31. **Anything else you want to tell them** (use the suggestions below to help fill in the additional information box at the bottom of the claim form)

- Child may have breathing problems that are exacerbated by walking
- May have a heart condition that makes the effort of walking dangerous
- May be prone to dizziness or epileptic absences that restrict the distance they can walk
- Hypermobility may cause joint pain and restrict walking distance
- If your child walks with a limp/on their toes/with feet turned inwards etc, explain what causes this

Questions 32 to 36 – Mobility... continued

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

Read through the table below and if you decide your child needs extra supervision or guidance when outdoors then tick yes at the top of the page under question 32 of your DLA claim pack. Then go on to complete the yes/no questions below. Only tick no to question 32 if you have looked at the table below and decided you don't have such problems, and then move to question 33 further down the page.

Yes/No boxes on the claim form	Examples and Explanations (use this column to decide whether to select yes or no in the tick boxes)
Answer <u>no</u> if they cannot...	
Find their way around places they know	In familiar places the child would get lost and if on their own they would not be able to find their way without any assistance.
Ask for and follow directions	The child cannot communicate clearly enough to ask for directions, or understand what is being said to them. If lost they could not follow directions to find their way.
Walk safely next to a busy road	The child doesn't know how to behave next to a busy road at all times; they may run off or get distracted by things.
Cross a road safely	Don't know how to check for traffic and use pedestrian crossings on their own in all contexts and situations.
Understand common dangers outdoors	Cannot behave safely around roads, rivers etc. Child is unaware of stranger danger. Child is not able to read and understand warning signs and signals.
Please note phrasing of the question has now changed. Answer <u>yes</u> if they regularly...	
Become anxious, confused or disorientated	Worry about things that would not normally bother other children, not know where they are or what they are doing.
Display unpredictable behaviour	May have tantrums, run off, invade other people's space, get very upset, and be aggressive or verbally abusive.
Need physical restraint	In order to protect the child or others they may need to be strapped into a buggy, on reins, or have someone holding onto them.

33. Do they fall due to their disability?

If your child often trips and falls due to their condition then tick yes and record the number of falls each month. If they do not fall due to their condition continue onto section 34.

Answer <u>yes</u> if they...	
Can get up without help	They get up on their own and don't need someone to physically help them get up, or give them encouragement.
Have had injuries needing hospital treatment	The child has had a trip or fall that is directly related to their condition and as a result has needed to have treatment in a hospital e.g. stitches, casts, brain scans etc.

34. 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.

Anything else you want to tell them (use the suggestions below to help fill in the additional information box at the bottom of the claim form)

- They need lots of encouragement to walk.
- Need supervision to ensure they don't use too much energy or hurt themselves.
- Need to be supervised as they have seizures, you have to monitor them, keep them safe during and help with recovery afterwards.
- Have a visual or hearing impairment and need someone to help guide or supervise them.
- Cannot judge speeds or distance and need help crossing roads.
- Child is easily distracted and has a lack of danger awareness e.g. if they saw someone on the other side of the road they would run without looking.
- Have episodes of incontinence, need guiding to the nearest toilet, and/or help with toileting needs.
- Child is scared to go outside alone due to fears and anxieties related to their condition.
- Inappropriate behaviour such as shouting, kicking, being destructive etc.
- Can be compulsive and want to count things, touch things smell things etc. before walking on
- Have panic attacks and need someone to watch for them and help calm them down.
- Sensory overload e.g. loud sounds, strong smells etc. can distress the child resulting in refusal episodes.
- A rigid routine has to be enforced when outdoors and the environment controlled as much as possible to prevent meltdowns and refusals.
Balance problems mean the child falls over frequently.
- Any bumps or bruises can have a serious affect to their health.
- Need supervision to watch for signs of tantrums and/or attempts to run off.
- They can become confrontational, aggressive and abusive towards strangers.

35. Extra information about mobility.

Use this box to put down any additional information that you couldn't fit in boxes 31 or 34, use the table above and the previous section of the guide to help with this.

36. When did the child's mobility needs you have told us about start?

The age at which you first noticed your child's mobility difficulties e.g. the child not meeting developmental milestones, experiencing pain, refusing to walk or severe behavioural problems.

Question 37 – Getting into or out of or settling in bed during the day

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

If your child needs any extra help or encouragement waking up, lifting their legs into or out of bed, sitting up or settling in bed please tick yes at the top of the page under question 37 of your DLA claim pack. Only tick no if you have read the boxes and examples on the form and have looked at the table below and decided your child doesn't have such problems.

During the day includes putting the child to bed at bedtime and waking them in the morning plus any sleeps during the day but does NOT include any awakenings during the night (when the rest of the household is in bed) – this will be dealt with in section 53.

Yes/No boxes on the claim form	How often each day and how long for (use this column to decide how often each day and how long each time the child needs help with each task)	
Fill in timings if they need encouragement, prompting or physical help to...		
Wake up	Include waking the child up in the morning and from any daytime sleeps. The time it takes from first trying to wake the child until they are fully awake and conscious.	How often each day How long each time (mins)
Get out of bed	Include physically helping the child out of bed, and encouraging/prompting the child to get out of bed. The amount of time it takes from deciding it is time to get the child up until the child is out of bed (including following a routine or refusals).	How often each day How long each time (mins)

Yes/No boxes on the claim form	How often each day and how long for (use this column to decide how often each day and how long each time the child needs help with each task)	
Get into bed	<p>Include physically helping the child into bed and encouraging/prompting the child to get into bed, both at bedtime and for any daytime sleeps.</p> <p>The amount of time it takes from deciding it is time for the child to go to bed (after any care needs such as bathing or toileting) until the child is in bed (include following a routine or refusals).</p>	<p>How often each day</p> <p>How long each time (mins)</p>
Settle into bed	<p>Include settling the child at bedtime and for any sleeps during the day.</p> <p>The amount of time it takes from when the child is first in bed until they are settled and starting to fall asleep.</p>	<p>How often each day</p> <p>How long each time (mins)</p>

Anything else you want to tell them (use the suggestions below to help fill in the additional information box at the bottom of the claim form)

- Need physical help waking, getting up, going to bed and settling.
- A lengthy/rigid routine has to be put in place.
- The child needs watching over as they can be a danger to themselves or others.
- They are too tired to get up due to night time awakenings.
- Lack of motivation to get up.
- They experience physical pain and/or exhaustion making it difficult to get up.
- Emotional distress/worry makes the child reluctant to get up.
- Effects of medication (e.g. drowsiness).
- Need help with covers and pillows.
- Transferring the child from a wheelchair or using hoists.
- Persuading and reassuring the child due to behavioural, sensory or medical issues.
- They are still wide awake and active at bedtime.
- They get out of bed and disrupt the rest of the household.

Question 38 – Toilet needs during the day

38. Do they need encouragement, prompting or physical help to go to or use the toilet during the day?

If your child needs any extra help going to the toilet, managing clothes, getting on or off and using the toilet, cleaning themselves and coping with continence care please tick yes at the top of the page under question 38 of your DLA claim pack. Only tick no if you have read the boxes and examples on the form and have looked at the table below and decided your child doesn't have such problems.

Do NOT include any issues with toileting that occur during the night, such as bed wetting - this will be dealt with in section 53.

Yes/No boxes on the claim form	Examples and Explanations (use this column to decide whether to select yes or no in the tick boxes)
Tick the box if they need encouraging, prompting or physical help...	
Go to the toilet	To go to the toilet during the day, including reminding the child to go to the toilet, guiding them to the toilet or supervising them while going to the toilet.
Manage clothes	When dressing or undressing when going to the toilet, including when managing nappies, pads, catheters, stomas etc. Or changing/cleaning clothes after accidents.
Get on and off the toilet	When getting on and off the toilet, including supervision and transferring from a wheelchair onto/off the toilet (incl. hoists.), and supervision whilst using the toilet.
Wipe themselves	Help the child to wipe themselves after going to the toilet, include supervising and checking that they have wiped themselves properly.
Wash and dry their hands	Help the child to wash and dry their hands, including supervising (eg. making sure child does not burn themselves on hot water, eat soap etc.), and physically helping the child to reach taps.
Manage a catheter, ostomy or stoma	Help the child to manage any continence aids, include emptying, cleaning, checking etc. Instructing/explaining to the child how to use them and/or what they are for.
Manage nappies or pads	Help the child with nappies and pads, include physically changing nappies (including cleaning the child), and helping/supervising a child with pads.

Anything else you want to tell them (use the suggestions below to help fill in the additional information box at the bottom of the claim form)

- Needs supervising when using the toilet for safety reasons and/or because they are easily distracted.
- Cleaning the toilet area after the child.
- Help with trousers, underwear, buttons and fastenings, checking clothing and appearance after going to the toilet.
- Dealing with episodes of incontinence.
- Need help knowing when their bladder or bowels need emptying.
- Painful/frequent bowel movements or urination.
- Comforting the child if they experience pain or distress when using the toilet.
- Help with personal hygiene (including needing to bath/shower after going to the toilet)
- Assisting with medication and creams relating to toileting.
- Suffer from frequent constipation or loose bowels.
- Dealing with smearing, eating or playing with faeces.
- Child goes to the toilet in other places around the home.
- Miss the toilet when urinating.
- Calming and reassuring a child who finds toileting distressing or gets anxious.
- Taking samples for monitoring/medical purposes.

Question 39 – Moving around indoors during the day

39. Do they need encouragement, prompting or physical help to move around indoors, using stairs or getting in or out of a chair?

If your child needs any extra help to move from one place to another when indoors please tick yes at the top of the page under question 39 of your DLA claim pack. Only tick no if you have read the boxes and examples on the form and have looked at the table below and decided your child doesn't have such problems.

Yes/No boxes on the claim form	Examples and Explanations (use this column to decide whether to select yes or no in the tick boxes)
Tick the box if they need encouragement, prompting or physical help...	
Go up and down one step	While moving up and down one step to ensure their safety, help with movement and co-ordination, to enable them to get from one place to another and/or to use any aids.

Yes/No boxes on the claim form	Examples and Explanations (use this column to decide whether to select yes or no in the tick boxes)
Go upstairs	While moving up a flight of stairs to ensure their safety, help with movement and co-ordination and to enable them to get from one place to another and/or to use any aids.
Go downstairs	While moving down a flight of stairs to ensure their safety, help with movement and co-ordination and to enable them to get from one place to another and/or to use any aids.
Move around safely	While moving around indoors to ensure their safety, trying to prevent falls and accidents, guiding the child and making sure they know where they are going and making them aware of their surroundings.
Get into or out of a chair	To get into or out of a chair as they may be unable to do it alone, to ensure their safety and/or because it takes them a long time.
Sit in a chair	To sit safely in a chair, including the use of specialised seating or postural support equipment, regularly moving the child because sitting for prolonged periods may cause pain or stiffness.

Anything else you want to tell them (use the suggestions below to help fill in the additional information box at the bottom of the claim form)

- Child is physically unable to walk or move without help.
- Child may suffer pain, stiffness or flaccidity when they move.
- Child has limited movements/control.
- Child can't stand for long periods of time, may cause pain, fatigue etc.
- Child suffers from uncontrollable spasms and movements.
- Child has poor balance, spatial awareness or motor skills.
- Child becomes exhausted easily.
- They need hand rails or have to hold on to things very tightly to pull themselves up. Child moves very slowly.
- Child is unable to manipulate objects, such as opening and closing doors.
- Child needs objects and aids to steady themselves, such as walkers or canes.
- Child has to use certain techniques when indoors, such as going on their bottom to go up and down stairs, or rolling off chairs onto knees.
- Getting up from sitting is painful or potentially damaging to the child's health.
- Need a lot more encouragement or help to learn skills such as sitting, crawling, standing, walking, running.

Question 40 – Washing, bathing, showering and checking appearance during the day

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

If your child needs any extra help getting in or out of a bath or shower, washing or drying themselves, brushing their teeth and checking their appearance please tick yes at the top of the page under question 40 of your DLA claim pack. Only tick no if you have read the boxes and examples on the form and have looked at the table below and decided your child doesn't have such problems.

Yes/No boxes on the claim form	How often each day and how long for (use this column to decide how often each day and how long each time the child needs help with each task)	
Fill in timings if they need encouragement, prompting or physical help to...		
Have a wash	<p>All times during the day that the child has a wash, including washing in the morning and/or at bedtime and washing before/after certain activities.</p> <p>The time it takes from the start of a wash (including any prior prompting and encouragement) until the child is washed and dried (including following a routine or refusals).</p>	<p>How often each day</p> <p>How long each time (mins)</p>
Clean their teeth	<p>All times during the day that the child cleans their teeth or needs physical help or prompting to do so.</p> <p>The time it takes from the start of teeth cleaning (including any prior prompting and encouragement) until the child's teeth are cleaned (including following a routine or refusals).</p>	<p>How often each day</p> <p>How long each time (mins)</p>
Wash their hair	<p>All times during the day that the child washes their hair or needs physical help or prompting to do so.</p> <p>The time it takes from the start of washing their hair (including any prior prompting and encouragement) until the child's hair is washed (including following a routine or refusals).</p>	<p>How often each day</p> <p>How long each time (mins)</p>

<p>Get in or out of the bath</p>	<p>All times during the day that the child gets in or out of the bath and needs physical help or prompting to do so.</p> <p>The time it takes to get in and/or out of the bath (including any prior prompting and encouragement) until the child is safely/comfortably in or out of the bath (including following a routine or refusals).</p>	<p>How often each day</p> <p>How long each time (mins)</p>
<p>Get in or out of the shower</p>	<p>All times during the day that the child gets in or out of the shower and needs physical help or prompting to do so.</p> <p>The time it takes to get in and/or out of the shower (including any prior prompting and encouragement) until the child is safely/comfortably in or out of the shower (including following a routine or refusals).</p>	<p>How often each day</p> <p>How long each time (mins)</p>
<p>Clean themselves in the bath or shower</p>	<p>All times during the day that the child cleans themselves in the bath or shower and needs physical help or prompting to do so.</p> <p>The time it takes the child to clean themselves in the bath or shower (including any prior prompting and encouragement) until the child is adequately cleaned (including following a routine or refusals).</p>	<p>How often each day</p> <p>How long each time (mins)</p>
<p>Dry themselves after a bath or shower</p>	<p>All times during the day that the child dries themselves after a bath or shower and needs physical help or prompting to do so.</p> <p>The time it takes the child to dry themselves after a bath or shower (including any prior prompting and encouragement) until the child is adequately dried (including following a routine or refusals).</p>	<p>How often each day</p> <p>How long each time (mins)</p>
<p>Check their appearance</p>	<p>All the times that the child needs to check their appearance during the day including brushing hair, shaving, applying cosmetics etc.</p> <p>The time it takes the child to check their appearance from start to finish (including any prior prompting and encouragement) and including following a routine or refusals.</p>	<p>How often each day</p> <p>How long each time (mins)</p>

Anything else you want to tell them (use the suggestions below to help fill in the additional information box at the bottom of the claim form)

- Child is physically unable to cope with any aspects of washing, bathing, showering and checking appearance.
- Have to follow a very lengthy and rigid routine. Have pain associated with getting to and from the bathroom, getting into or out of the bath, while in the bath or shower or while washing.
- Child is resistant to washing, can be aggressive.
- Have problems because they have areas that have to be kept dry, such as dressings, a line into a vein or a stoma appliance etc.
- No danger awareness so need supervising whilst washing to ensure their safety, for example they might leave taps running, eat soap, scald themselves etc.
- Have to wash more often than other children.
- Need someone to check that they have washed properly.

Question 41 – Dressing and undressing during the day

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

If your child needs any extra help with any form of dressing or undressing (except when using the toilet) please tick yes at the top of the page under question 41 of your DLA claim pack. Only tick no if you have read the boxes and examples on the form and have looked at the table below and decided you don't have such problems.

Yes/No boxes on the claim form	How often each day and how long for (use this column to decide how often each day and how long each time the child needs help with each task)	
Fill in timings if they need encouragement, prompting or physical help to...		
Dress	<p>All times during the day that the child gets dressed, including in the morning, at bedtime, for any activities such as sports and swimming, redressing if a child continues to take clothes off during the day, and changing any soiled clothes.</p> <p>The time it takes from the start of dressing the child (including any prior prompting and encouragement) until the child is fully dressed (including following a routine or refusals).</p>	<p>How often each day</p> <p>How long each time (mins)</p>

Yes/No boxes on the claim form	How often each day and how long for (use this column to decide how often each day and how long each time the child needs help with each task)	
Undress	<p>All times during the day that the child gets undressed, including in the morning, at bedtime, for any activities such as sports and swimming, and changing any soiled clothes.</p> <p>The time it takes from the start of undressing the child (including any prior prompting and encouragement) until the child is fully undressed (including following a routine or refusals).</p>	<p>How often each day</p> <p>How long each time (mins)</p>
Manage zips, buttons or other fastenings	<p>All times during the day that the child needs help with zips, buttons or other fastenings, including shoe laces.</p> <p>The time it takes to help the child with zips, buttons or other fastenings (including any prior prompting and encouragement), including following a routine or refusals.</p>	<p>How often each day</p> <p>How long each time (mins)</p>
Choose appropriate clothes	<p>All times during the day that the child needs help choosing appropriate clothing including in the morning, at night, for any activities such as sports and swimming, and changing any soiled clothes.</p> <p>The time it takes to choose appropriate clothing for the child.</p>	<p>How often each day</p> <p>How long each time (mins)</p>

Anything else you want to tell them (use the suggestions below to help fill in the additional information box at the bottom of the claim form)

- Child physically cannot dress or undress themselves.
- Child experiences pain and discomfort when trying to dress or undress.
- Child has fine motor skills problems.
- Need to follow a lengthy or rigid routine.
- Clothes have to be laid out or put on in a specific order.
- Sensory issues with clothing means clothes have to be carefully chosen, for example, labels have to be taken out, specific materials, colours etc.
- Need to check that clothes are put on properly, right way round etc.
- They are easily distracted and dressing and undressing can be a very long process.
- Need special clothing that is easy to get on or off, is medically adapted etc.
- Find dressing and undressing a distressing experience and need reassurance and support.
- The child likes to get undressed at inappropriate times and places.
- Child can be very resistant to getting dressed or undressed, may get aggressive.
- They may not understand which clothes are appropriate for the conditions, e.g. shorts & vest in winter

Question 42 – Eating and drinking during the day

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

If your child needs any extra help getting food into their mouth, chewing and swallowing, using cutlery, cutting up food, holding a cup and drinking please tick yes at the top of the page under question 42 of your DLA claim pack. Only tick no if you have read the boxes and examples on the form and have looked at the table below and decided you don't have such problems.

Yes/No boxes on the claim form	How often each day and how long for (use this column to decide how often each day and how long each time the child needs help with each task)	
Fill in timings if they need encouragement, prompting or physical help to...		
Eat	<p>All times during the day that the child eats, including meals and snacks.</p> <p>The time it takes from beginning the meal or snack (including any prior prompting and encouragement) until the child has finished (including following a routine or refusals).</p>	<p>How often each day</p> <p>How long each time (mins)</p>
Use a spoon	<p>All times during the day that the child has help to use a spoon during the day, including snacks.</p> <p>The time it takes the child to use a spoon with encouragement, help and prompting (including refusals, pauses and breaks).</p>	<p>How often each day</p> <p>How long each time (mins)</p>
Cut up food on their plate	<p>All times during the day that the child has help cutting up their food, including cutting up food in the preparation stages.</p> <p>The time it takes for the child to cut up food on their plate, any help they may need, or cutting food up for the child.</p>	<p>How often each day</p> <p>How long each time (mins)</p>
Drink using a cup	<p>All times during the day that the child has help to drink using a cup.</p> <p>The time it takes for the child to drink using a cup, including and additional help needed.</p>	<p>How often each day</p> <p>How long each time (mins)</p>

Be tube or pump fed	<p>All times during the day that the child needs to be tube or pump fed (each individual feeding).</p> <p>The time it takes from the beginning of the process until the end, including preparing, cleaning and setting up equipment.</p>	<p>How often each day</p> <p>How long each time (mins)</p>
---------------------	--	--

Anything else you want to tell them (use the suggestions below to help fill in the additional information box at the bottom of the claim form)

- Child has problems chewing, swallowing and sucking, which makes it more difficult, time consuming and/or hazardous.
- Child experiences pain and/or discomfort when eating and drinking, and needs comforting, prompting, reassuring etc.
- Additional preparation is required due to specific dietary needs and/or eating difficulties.
- Child is unable or finds it difficult and painful to manipulate objects such as cutlery and cups.
- Child has a special dietary requirement which means avoiding certain foods, precise measuring and monitoring etc.
- Eating and drinking is a very lengthy process due to pain, difficulties, special requirements, child is easily distracted, behavioural problems etc.
- Does medication impact on eating and drinking e.g. affect appetite, types of food that can be eaten, meal timings etc?
- Eating patterns are different from a child of the same age.
- Child has to have constant supervision otherwise they may eat dangerous/inedible things.
- Child will only eat certain foods, presented in a particular way, will only eat from a certain plate, may be brand specific etc.
- They eat in socially unacceptable ways e.g. very noisily or messily, they will only use their fingers etc.
- Child needs to be reminded or prompted to eat and drink during the day.

Question 43 – Taking medication or having therapy during the day

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

If your child needs any extra help to take their medication, be reminded of when, how and the quantity to take or have their therapy please tick yes at the top of the page under question 43 of your DLA claim pack. Only tick no if you have read the boxes and examples on the form and have looked at the table below and decided you don't have such problems.

Yes/No boxes on the claim form	How often each day and how long for (use this column to decide how often each day and how long each time the child needs help with each task)	
Fill in timings if they need encouragement, prompting or physical help to...		
Take the correct medicine	<p>All times during the day that the child needs help to take the correct medicine, including physical help, preparation, supervision, encouragement etc.</p> <p>The time it takes for the child to take the correct medicine (including any prior prompting and encouragement) until the child has taken it (including any refusal episodes).</p>	<p>How often each day</p> <p>How long each time (mins)</p>
Know when to take their medicine	<p>All times during the day that the child needs help to know when to take their medicine, including reminding and reassuring.</p> <p>The time it takes for the child to know when to take their medicine including any prior prompting and encouragement.</p>	<p>How often each day</p> <p>How long each time (mins)</p>
Do their therapy	<p>All the times during the day that the child needs help to do their therapy, including physical help, preparation, supervision, encouragement etc.</p> <p>The time it takes from the child starting their therapy (including any prior prompting and encouragement) until the child has completed it (including any refusal episodes).</p>	<p>How often each day</p> <p>How long each time (mins)</p>

Yes/No boxes on the claim form	How often each day and how long for (use this column to decide how often each day and how long each time the child needs help with each task)	
Know when to do their therapy	<p>All times during the day that the child needs help to know when to do their therapy, including reminding and reassuring.</p> <p>The time it takes for the child to know when to do their therapy including any prior prompting and encouragement.</p>	<p>How often each day</p> <p>How long each time (mins)</p>

Anything else you want to tell them (use the suggestions below to help fill in the additional information box at the bottom of the claim form)

- Child may not like taking medication; get upset and angry, refuse to take it, have a tantrum etc. and need comforting and reassuring.
- Child may need physical help administering medicine e.g. injections, eye drops etc. and using other pieces of medical equipment.
- Cleaning wounds, changing dressings etc.
- Preparing medication and making it more palatable.
- Reminding the child to take medication as they may forget.
- Monitoring for warning signs that medication needs to be taken e.g. temperatures, difficulty breathing, blood sugar levels etc.
- Refusal episodes, as the child experiences pain/discomfort from the medication.
- Calculating timings for medication or therapy.
- Reminding the child to do their therapy and supervising to make sure it is done properly.
- Physically helping the child with therapy, before, during and after.
- Encouraging, reassuring and comforting the child during their therapy.

Question 44 – Seeing

44. Do they have difficulty seeing?

If your child has difficulty seeing when using their aids like glasses or contact lenses then tick yes at the top of the page under question 44 of your DLA claim pack. Only tick no if your child does not have a Certificate of Vision Impairment and any difficulties they do have are corrected perfectly by aids such as glasses.

Yes/No boxes on the claim form	Examples and Explanations (use this column to decide whether to select yes or no in the tick boxes)
Are they certified sight impaired or severely sight impaired?	
Certified severely sight impaired	An examiner would have certified your child sight impaired or severely sight impaired, you would have been made aware of this and given a Certificate of Vision Impairment (CVI). If your child has a severe sight impairment then tick the box and move onto the next question. If your child is certified sight impaired (not severely) tick the box and mark the boxes below that apply. Remember to tell them if you want the copy of your CVI returned to you – write this anywhere on the page.
Certified sight impaired	
Answer <u>yes</u> if they can see...	
Computer keyboard keys or large print in a book	Only tick yes to these boxes if the child can see each thing clearly and does not need, support guidance or any extra help with their vision.
A TV and follow the actions to a story	
The shape of furniture in a room	
Answer <u>yes</u> if they can recognise...	
Someone's face across a room	Only tick yes to these boxes if the child can recognise each thing clearly, rather than just see it vaguely, and does not need, support guidance or any extra help with their vision.
Someone across a street	

Anything else you want to tell them (use the suggestions below to help fill in the additional information box at the bottom of the claim form)

- Vision is made worse in poorly lit places.
- Vision is made worse due to sensitivity to light.
- The child experiences headaches etc. due to poor vision.

- The child needs lots of extra help and support due to difficulty seeing to prevent them from coming to harm and to ensure their needs are met.
- Child gets very anxious and upset due to their sight impairment.
- They can't take part in certain activities due to their vision.
- Eye treatments such as drops, an eye patch etc. have to be monitored and administered.
- Child uses Braille, has a guide or uses other aids and adaptations.

Question 45 –Hearing

45. Do they have difficulty hearing?

If your child has difficulty hearing sound or someone speaking when using their hearing aids then tick yes at the top of the page under question 45 of your DLA claim pack. If your child has not been issued hearing aids but still has problems hearing after any other aid or adaptation they have then also tick yes e.g. the child may have grommets or a cochlear implant but still has difficulty hearing. Only tick no if you have read the boxes and examples on the form and have looked at the table below and decided you don't have such problems.

Yes/No boxes on the claim form	Examples and Explanations (use this column to decide whether to select yes or no in the tick boxes)
<p>Have they had an audiology test in the last 6 months?</p> <p>If they have had an audiology test due to a difficulty in hearing please tick yes. If you have any reports confirming the child's difficulty in hearing then attach a copy if you can.</p> <p>Remember to tell them if you want the copy of your audiology report returned – write this anywhere on the page.</p>	
<p>Answer <u>yes</u> if they can hear...</p>	
A whisper in a quiet room	<p>Only tick yes to these boxes if the child can hear each thing clearly and does not need, support guidance or any extra help with their hearing.</p>
A normal voice in a quiet room	
A loud voice in a quiet room	
A TV, radio or CD but only at a very loud volume	<p>For these last two boxes answer yes if the child can hear these things in all environments e.g. they can hear the TV in a quiet room, loud room, sitting close, sitting further away etc.</p>
A school bell or a car horn	

Anything else you want to tell them (use the suggestions below to help fill in the additional information box at the bottom of the claim form)

- The child cannot hear things if there is a lot of background noise.
- Hearing is made worse by sensitivity to noise.
- The child has frequent medical issues e.g. ear aches due to hearing difficulties.
- The child needs lots of extra help and support due to difficulty hearing to prevent them from coming to harm and to ensure their needs are met.
- Child gets very anxious and upset due to their hearing.
- They can't take part in certain activities due to their hearing.
- Ear treatments such as drops etc. have to be monitored and administered.
- The child uses sign language, has a guide or uses other aids and adaptations.

Question 46 –Speaking

46. Do they have difficulty speaking?

If your child has difficulty saying words out loud and talking clearly then tick yes at the top of the page under question 46 of your DLA claim pack. Only tick no if you have read the boxes and examples on the form and have looked at the table below and decided you don't have such problems.

Yes/No boxes on the claim form	Examples and Explanations (use this column to decide whether to select yes or no in the tick boxes)
Answer <u>yes</u> if they can...	
Speak clearly in sentences	Child can speak in clear sentences that have meaning and are relevant to the situation.
Put words together to make simple sentences	Child can put a few words together to make a meaningful sentence such as 'I want banana'.
Speak single words	Child can speak single words 'dog', 'ball' etc. but cannot build them into sentences.
Answer <u>yes</u> if they can communicate using speech	
With someone they know	The child can effectively communicate with someone who is familiar to them using speech. They may use simple sentences or single words but these can easily be understood by someone who knows them.

With someone they don't know	Child's speech is clear and complex enough to effectively communicate with a stranger. They can talk out loud, clearly and be easily understood by someone who does not know them.
------------------------------	--

Anything else you want to tell them (use the suggestions below to help fill in the additional information box at the bottom of the claim form)

- Child has a physical impairment which means they cannot speak or their speech is difficult to understand.
- They copy and echo sounds rather than use speech to communicate.
- They have the vocabulary/speech of a much younger child.
- Child is receiving speech and language therapy.
- They get angry and distressed if people do not understand what they are saying.
- They are embarrassed, self-conscious about speaking so withdraw from speech, or will only talk to people they are familiar with.

Question 47 – Communicating

47. Do they have difficulty and need extra help communicating?

If your child has difficulty and needs extra help passing on information, asking and answering questions, telling people how they feel and giving and following instructions please tick yes at the top of the page under question 47 of your DLA claim pack. Only tick no if you have read the boxes and examples on the form and have looked at the table below and decided you don't have such problems.

Yes/No boxes on the claim form	Examples and Explanations (use this column to decide whether to select yes or no in the tick boxes)
Answer <u>yes</u> if to communicate they use...	
Writing	Child may sometimes need to write or have things written down in order for them to communicate effectively.
BSL (British Sign Language)	Use sign language and have difficulty understanding and making themselves understood in spoken language.
Lip-reading	Child communicates by reading lips.
Using hand movements, facial expressions and body language	Child uses a series of movements, expressions, gestures etc. to communicate (not Makaton or BSL), these may be specific to an individual, family, group of people or area.
Makaton	Communicating using more basic signs and symbols.

<p>Other forms of communication: Touch pad or computer screen, Picture Exchange Communication System (PECS), use an interpreter or other specially designed communication aid.</p>	
<p>Answer <u>yes</u> if they can communicate...</p>	
<p>With someone they know</p>	<p>The child can effectively communicate their thoughts, needs and feelings with someone who is familiar to them. They may have their own specific way of communicating using sounds, signs and expressions that only certain people understand. Or they may need someone to communicate in a certain way so they can understand e.g. slowly and clearly. The child may be shy, withdrawn, and anxious and only communicate with people they know.</p>
<p>With someone they don't know</p>	<p>The child can effectively communicate their thoughts, needs and feelings with people they don't know. They do not need help with interpretation (including parents), and can be understood by others. Child is not withdrawn or shy and does not need to be familiar with someone in order to communicate.</p>

Anything else you want to tell them (use the suggestions below to help fill in the additional information box at the bottom of the claim form)

- They find it difficult to understand long complex sentences and need people to communicate slowly and clearly.
- Often need things repeated and to be explained in several different ways.
- They need time to process what is being said.
- Child becomes confused by figures of speech, sarcasm, humour etc.
- They struggle to understand non-verbal communication such as facial expressions, gestures and body language.
- You have to get and hold the child's attention when talking to them as they are easily distracted, avoid eye contact etc.
- Become very nervous, anxious or self-conscious when talking to others due to physical, emotional and social issues, they need reassurance and help building self-confidence.
- Child shouts, talks very fast, changes conversation too quickly or cannot keep up with conversation.
- Child talks at you rather than with you, and may talk repeatedly or obsessively about certain topics.
- Use inappropriate language, gestures and body language e.g. they may invade personal space or say things that people may take offence to.
- They find it easier to talk to adults rather than children of their own age.

- Child is shy and often withdraws from social situations and needs lots of encouragement and reassurance when communicating otherwise will become isolated.
- Child gets very upset, anxious and aggressive when communicating and needs a lot of support and reassurances.

Question 48 – Fits, blackouts, seizures or similar

48. Do they have fits, blackouts, seizures or something similar?

If your child has fits, blackouts, seizures or similar, including epileptic, non-epileptic or febrile fits, faints, absences, loss of consciousness or hypoglycaemic attacks tick yes at the top of the page under question 48 of your DLA claim pack AND write what type they have and what happens (you have more space below to explain what happens). Only tick no if you have read the boxes and examples on the form and have looked at the table below and decided you don't have such problems.

Tell us what type they have and what happens – For instance are they absences or tonic clonic seizures? Give a brief description of what happens e.g child collapses, is unaware of their surroundings etc

Yes/No boxes on the claim form	Examples and Explanations (use this column to decide whether to select yes or no in the tick boxes)
Answer <u>yes</u> if they...	
Can recognise a warning and tell an adult	Warning signs are clear and reliable; the child can recognise a warning and have enough time to let an adult know.
Can recognise a warning and take appropriate action	Warning signs are clear and reliable; the child can recognise a warning and have enough time to make themselves safe etc.
Have no warning	They have no warnings or warnings are unreliable.
Have had a serious injury in the last 6 months because of a fit, blackout, or seizure	A serious injury may be concussion, a cut, they may have bitten themselves, bad bruising or been hospitalised.
Display dangerous behaviour after a fit, blackout or seizure.	The child may be confused, upset, exhausted, dizzy, sick, and aggressive after a seizure and need time to recover. This could be 1 hour or 1 day.

Tell them...	
The number of days affected each month	When putting in numbers try to work out an average. If you have a child who on a good day/night fits once but on a bad day/night fits 10 times put down around 5 times.
How many fits they have on these days	
The number of nights affected each month	
How many fits they have on these nights	
Have they had an episode of status epilepticus in the past 12 months?	Persistent epileptic activity for more than 30 minutes or continued seizures without regaining consciousness.

Anything else you want to tell them (use the suggestions below to help fill in the additional information box at the bottom of the claim form)

- Is there a particular time of day the child has them.
- The child loses consciousness, has convulsions or becomes incontinent.
- They need monitoring e.g. how long they are fitting for each time.
- Child may be very anxious about having a fit, blackout, seizure and need lots of support and reassurance.
- You may have to make the environment safe before, during and after the child has a seizure, fit etc.
- Child needs looking after and to be made comfortable after an attack.
- Do they need watching over during the day/night in case of a fit, blackout, seizure?
- Medication has to be administered.
- Clothes may need to be changed afterwards.

Question 49 – Supervision

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

If your child needs supervising because of how they feel or behave, or how they react to people, changing situations and things around them please tick yes at the top of the page under question 49 of your DLA claim pack. Only tick no if you have read the boxes and examples on the form and have looked at the table below and decided you don't have such problems.

Yes/No boxes on the claim form	Examples and Explanations (use this column to decide whether to select yes or no in the tick boxes)
Answer <u>no</u> if they cannot...	
Recognise and react to common dangers	Cannot behave safely around cookers, knives etc. Child is unable to read and understand warning signs and signals.
Cope with planned changes to daily routine	Even if given notice of changes in routine child reacts badly, routines cannot be changed easily with prior notice.
Cope with unplanned changes to daily routine	Any changes to routine cannot be coped with, it is hard to make changes to routine without serious consequences, distress, anger etc.
Please note phrasing of question has now changed. Answer <u>yes</u> if they regularly...	
Feel anxious or panicky	Worry about things that would not normally bother other children.
Become upset or frustrated	Get upset and frustrated over things other children wouldn't. Struggle to understand things or get their point across.
Harm themselves or others	Banging head against things, biting, pinching, scratching, hitting themselves etc.
Feel someone may harm them	A fear of being alone with and meeting different people, paranoia, attachment disorders.
Become verbally, physically aggressive or destructive	Shouting and swearing. Hitting, kicking, pulling hair, punching and biting. Throwing and hitting with the use of objects.
Act impulsively	Running off, unpredictable behaviour.
Have tantrums	Get very angry, refuse to listen to what is being said, ignoring instructions, are uncooperative, and cry/scream uncontrollably for prolonged periods of time.

Anything else you want to tell them (use the suggestions below to help fill in the additional information box at the bottom of the claim form)

- Journeys may have to be rearranged or avoided due to planned and unplanned changes to routine.
- They may over exert themselves which could have serious consequences.
- Have a physical disability and need supervision to ensure safety and enable certain activities.
- They may behave dangerously/aggressively towards other children and adults.
- Have a lack of danger awareness e.g. no fear of heights, hot things, sharp things.
- Child may be a danger to themselves and others around them.
- Any falls cuts or bumps could have serious consequences.
- They self-harm, for example banging their head against a wall or pulling their hair out.
- You have to offer comfort, support or reassurance when they are upset or frustrated.
- Child may express withdrawn behaviour and/or become isolated.
- Child's basic needs would not be met.
- Child may become emotionally distressed.
- Child needs continual supervision, a substantial amount more than a typically developing child of the same age.

Question 50 –Development

50. Do they need extra help with their development?

If your child needs any extra help they need to improve their understanding of people and their surroundings please tick yes at the top of the page under question 50 of your DLA claim pack. Only tick no if you have read the boxes and examples on the form and have looked at the table below and decided you don't have such problems.

Yes/No boxes on the claim form	Examples and Explanations (use this column to decide whether to select yes or no in the tick boxes)
Answer <u>yes</u> if they need help to...	
Understand the world around them	Explain things in a variety of ways, need to provide lots of support and encouragements as the child regularly feels confused or does not take an interest in the world around them.
Recognise their surroundings	Need assistance and prompting as they are often confused and disorientated, they struggle to remember places or notice things around them.

Yes/No boxes on the claim form	Examples and Explanations (use this column to decide whether to select yes or no in the tick boxes)
Follow instructions	Need things to be explained in short clear sentences. Spend time explaining things in different ways.
Play with others	Need help and encouragement to interact with others physically, socially and communicatively. Assist with rules and monitor behaviour.
Play on their own	They need encouragement to play in a more varied and stimulating way. Help them to use play equipment and explain play activities in a variety of ways.
Join in activities with others	Need help interacting with others, for example playing games and group learning exercises.
Behave appropriately	Need help to understand social situations, they often act inappropriately e.g. invade personal space, try and touch people, have tantrums and meltdowns, can be verbally aggressive/inappropriate.
Understand other people's behaviour	Need help to interpret what others mean or want, often get mixed messages, take things the wrong way or are left out due to a lack of understanding,

Anything else you want to tell them (use the suggestions below to help fill in the additional information box at the bottom of the claim form)

- Physical/sensory/learning/social/play skills are delayed.
- Have difficulty manipulating objects e.g. holding, kicking or throwing things.
- Need help learning to read write or do simple maths, may need extra help with school work.
- Play obsessively and repetitively.
- Play games that are for much younger children.
- Dominate others, play wildly and dangerously.
- Child does not understand how to play e.g. rules and turn taking.
- Have a lack of danger awareness e.g. no fear of heights, traffic safety.
- They need extra help to learn and practice new skills.
- Need encouragement to play in a more varied and stimulating way.
- Someone to help facilitate play, explain rules and help the child engage and interact with others.
- The child has to learn different skills such as signing instead of speaking.
- Without additional support they would develop much more slowly and not be able to take part in things.
- Child would become emotionally distressed.

- Would be physically unable to practice new skills.
- Would find it difficult to learn new skills.
- Might be bullied or become isolated.
- Prefers to be alone, cannot socialise with others

Question 51 – At school or nursery

51. Do they need encouragement, prompting or physical help help when at school or nursery?

If your child needs encouragement, prompting or physical help at school or nursery tick yes at the top of the page under question 51 of your DLA claim pack. Only tick no if you have read the boxes and examples on the form and have looked at the table below and decided you don't have such problems.

Yes/No boxes on the claim form	Examples and Explanations (use this column to decide whether to select yes or no in the tick boxes)
Answer <u>yes</u> if they need encouragement, prompting or physical help to...	
Go to and use the toilet	The child needs help with toileting needs, including physical help, preparation, supervision, encouragement. Help managing clothes, reminding them to go, checking they have cleaned themselves etc.
Safely move between lessons	Need assistance to find their way as they get confused and disorientated, physical help to move around, supervision and encouragement to ensure they do not get hurt or distracted.
Change into different clothes for PE and other school activities	They cannot change on their own and need help with buttons, zips, laces etc. Changing can take a long time and they need prompting and encouraging. They need reassuring as they get anxious and upset about getting changed.
Eat meals	They need to be encouraged to eat, monitoring for special dietary requirements or to make sure they eat the right things, help manipulating cutlery and cutting food up.
Take medicine or do therapy	The child needs help with medicine/therapy e.g knowing when and how to take/do it, applying creams, changing dressing etc. including physical help, preparation, supervision, encouragement.
Communicate	The child has difficulty and needs extra help passing on information, asking and answering questions, telling people how they feel and giving and following instructions.

Yes/No boxes on the claim form	Examples and Explanations (use this column to decide whether to select yes or no in the tick boxes)
	<p>What extra help do they need with learning?</p> <p>They need help with reading, writing and simple maths. They have difficulty concentrating and staying on task. Things need to be written down, in pictures or another adapted format. They are put into smaller groups, instructions are simple and repeated.</p>
	<p>What is their behaviour like at school or nursery?</p> <p>They get upset and frustrated. They don't have many friends and are lonely/isolated. They have to follow a very strict and rigid routine. They get angry and aggressive, they have been excluded or have to be removed from classes.</p>
	<p>How do they usually get to and from school or nursery?</p> <p>You walk with them, take them in the car, they go on a school bus, walk with siblings/friends etc.</p>

Anything else you want to tell them (use the suggestions below to help fill in the additional information box at the bottom of the claim form)

- What type of school are they at (e.g. special school, resource base, PRU etc)?
- They have one to one support from a teacher or teaching assistant.
- They have a buddy at school to help them move around.
- They have an IEP, Statement, EHCP, CSP or are on School Action, School Action Plus or a form of specialised curriculum.
- They have social communication lessons/support at school.
- They do certain lessons in a special unit or area e.g. a resource unit.
- A safe space they can go to if they need to.
- Help expressing themselves or communicating so they can learn more efficiently.
- Aids and adaptations such as specialised glasses, laptops, pens etc. so they can learn more easily.
- They attend special after school clubs.
- Additional support is provided in exams and for homework.

Question 52 – Hobbies and Activities

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

If your child needs any extra help with hobbies and activities please tick yes at the top of the page under question 52 of your DLA claim pack. These can be hobbies and activities that they are already doing, or things they would like to do if they had the help they needed.

Only tick no if you have read the boxes and examples on the form and have looked at the table below and decided you don't have such problems.

Activity examples	Help needed (use this column to decide how often each day and how long each time the child needs help with tasks on the left)
At home...	
<p>Painting, drawing, arts and crafts, playing with toys, playing in the garden, riding a bike, cooking and baking, messy play, imaginary play, playing board games, interacting with other children, watching films or cartoons – or 'in all social situations'</p>	<p>Encouragement to use equipment, help getting equipment set up, motivation to keep interested, facilitation of play, help explaining and understanding games and rules, supervision for safety reasons, help or encouragement to clean up after themselves, help doing the activity e.g. using scissors or lifting things</p> <p>Is this something they do or would do every day if they had the help? If not how many times a week would they like to be able to do this activity</p> <p>How often each day, How long each time (mins)</p>
When they go out...	
<p>Dance classes, the play park, go to the cinema, soft play areas, swimming, after school clubs, drama clubs, visiting friends, day trips, church, holidays, shopping for pleasure, playing outdoors, going to the library, brownies, cubs, scouts etc – or 'in all social situations'</p>	<p>A lot of the help needed will be the same as above, however also think about:</p> <p>Help getting to the activity or hobby, supervision and help with care needs when out e.g. reminding them to go to the toilet, help them with eating etc. staying with them during the activity, simple instruction or one to one support in clubs and classes, help with communication.</p> <p>Remember to include time needed for encouragement, accompanying them there, and refusal episodes or tantrums.</p> <p>How often each day, How long each time (mins)</p>

Question 53 – Help and supervision during the night

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

If your child needs any extra help and supervision at night please tick yes at the top of the page under question 53 of your DLA claim pack. Only tick no if you have read the boxes and examples on the form and have looked at the table below and decided you don't have such problems.

During the night – When everyone in the house is in bed e.g. once the carer has gone to bed.

Yes/No boxes on the claim form	How often each day and how long for (use this column to decide how often each day and how long each time the child needs help with each task)	
Fill in timings if they need encouragement, prompting or physical help to...		
Get into, get out of or turn in bed	<p>Include physically helping the child turning, get into or out of bed, and encouraging/prompting the child to turn, get into or out of bed.</p> <p>The amount of time it takes from deciding it is time to get the child into, out of or turn them until it has been done (including following a routine or refusals).</p>	<p>How often each day</p> <p>How long each time (mins)</p>
Get to and use the toilet, manage nappies or pads	<p>All the times during the night that the child needs help with toileting needs, including physical help, preparation, supervision, encouragement, changing bed sheets and clothing etc.</p> <p>The time it takes from the child first identifying a toileting need (including checking, any prior prompting and encouragement) until the child's needs are complete (including any refusal episodes).</p>	<p>How often each day</p> <p>How long each time (mins)</p>
Have treatment	<p>All times during the night that the child needs help with treatment e.g medication, creams changing dressing, therapy etc. including physical help, preparation, supervision, encouragement.</p> <p>The time it takes for the child to have treatment including any prior prompting and encouragement) until the child has taken it (including any refusal episodes).</p>	<p>How often each day</p> <p>How long each time (mins)</p>

Settle or re-settle	Settle the child during the night, do not include when you first settle them in bed as this is included in question 35. The amount of time it takes from when the child is put back in bed until they are settled and starting to fall asleep.	How often each day How long each time (mins)
Fill in the timings if they need watching over because they...		
Are unaware of danger and may harm themselves or others	Child is unaware of dangers such as water hazards, sharp objects, heights, plugs etc. They may put themselves or others in harm's way if not supervised.	How often each day How long each time (mins)
May wander about	During the night the child does not stay in bed. They wander around the house, upstairs and downstairs they may try to get outside. They need to be supervised to ensure this doesn't happen.	How often each day How long each time (mins)
Have behavioural problems	The child gets upset, aggressive, destructive, has tantrums, shouts, becomes anxious during the night and needs someone to watch over them. (Include comforting and reassuring the child)	How often each day How long each time (mins)

Anything else you want to tell them (use the suggestions below to help fill in the additional information box at the bottom of the claim form)

- The child does not go to sleep until very late and needs watching over.
- The child wakes up very early in the morning before everyone else is awake and needs supervision or help.
- The child has problems sleeping/sleep disorders such as sleep walking, night terrors, sleep apnoea, nightmares, intermittent sleep etc.
- The child needs turning to avoid bed sores.
- Need to be moved or have bed sheets adjusted as they cannot do it themselves.
- The child cannot move around, get into or out of bed without help.
- They suffer pain and discomfort at night time.

- Temperature needs to be monitored as they can't do this themselves e.g. they may not remove covers even though they are very hot.
- They have episodes of incontinence or have to be helped with toileting needs during the night.
- The child regularly has accidents and bed clothes and sheets need changing or cleaning.
- The child has therapy during the night.
- The child has to have medication or food given to them during the night (include tube feeding).
- Need watching over because of medical reasons, fits etc.
- They get upset; have lots of anxiety at night time and need lots of comforting and reassurance.
- The child wakes throughout the night and cannot resettle themselves.
- Need constant supervision when not asleep as they may harm themselves or someone else.
- The child would be unable to sleep without help, supervision and encouragement.
- The child needs to be monitored/supervised because of the danger of epileptic seizures.

Questions 54-71 of the Claim Pack

Most of these questions are just simple yes or no answers, so we have just listed them here, with a few hints and tips where needed:

54. **If you want to tell us anything else about their care needs, use the box below** – If there is anything you haven't had room to explain in questions 37-53 it's important that you use this box to do so, and reference your comments back to the relevant question.
55. **When did the child's care needs you have told us about start?** – The date when you first noticed that your child had care needs greatly in excess of typically developing children of their own age. This may be from birth in some cases, later in others.
56. **Your surname or family name**
57. **Your date of birth**
58. **Your National Insurance number**
59. **Address if different to the child's**
60. **If you live in Wales and would like us to contact you in Welsh, tick this box**
61. **Your daytime phone number** – If you don't want the DWP to contact you by phone, don't fill this in.
62. **What is your relationship to the child?**
63. **What is your nationality?** – this can be British, UK, Welsh, English, Scottish, Irish or whatever nationality you describe yourself as being.
64. **What is the Child Benefit number for the child?**

65. Are you getting or waiting to hear about Income Support or Universal Credit?
66. Is anyone within your household getting or waiting to hear about Income Support or Universal Credit?
67. Is anyone within your household getting or waiting to hear about Child Tax Credit or Universal Credit?
68. Is anyone within your household getting or waiting to hear about Working Tax Credit or Universal Credit?
69. Please tell us your account details below
70. **Extra information** – This can be used as a continuation box for anything you couldn't fit in to questions 35 or 54, or to tell the DWP anything else you think is relevant to the claim that hasn't been covered in the rest of the form. You can continue on a separate piece of paper. Remember though that they won't have time to read large amounts so it's best to be as succinct as possible.
71. **Declaration** – Don't forget to sign and date the form before you send it in!

The Decision

Once you have completed your claim form, send it to the DWP in the pre-paid envelope provided. Do not wait for any supporting evidence, this can be sent on once you receive it as adverse delays could affect your payments.

The DWP will then process your claim. This is not a particularly quick process and you can expect to wait up to 11 weeks for a decision, occasionally longer if they are waiting for information from third parties. However, as long as you have returned the form by the second date stamped on the front (see introductory pages of this guide for explanation) then payments will be backdated to your initial date of request.

You will receive a letter from the DWP detailing their decision. The letter will tell you whether or not you have been awarded DLA for your child. If you have it will tell you what rate of the two components (mobility and care) you have been awarded, how much you will receive each week, and when the award runs out (more on that later).

The letter will also give an explanation of why you have or have not been awarded DLA. However, the reasons given are often just generic and do

not relate specifically to your child. Quite often, it is a case of just quoting the regulations and so should not be taken too literally. You may phone the DWP for an explanation, but often the call handler will not be qualified to give you any more than the same generic explanation, which can be frustrating. You have the option of asking to speak to a decision maker, though this will probably involve them having to phone you back. Alternatively you can ask for a full copy of the written decision to be sent to you. This can be a good option as it allows time for the dust to settle, and to form a reasoned argument against the specifics of the decision.

In any case, whether or not you are happy with the decision make sure you keep the letter as it is proof of your award, which may be useful when applying for other things. It also gives, in the top right-hand corner, your child's reference number (actually their National Insurance Number). You will also need to know the date of the decision letter if you wish to dispute the decision, which we'll look at shortly.

As well as the decision letter, the DWP should send you an acknowledgment letter after they

receive your form, telling you that they've received it and informing you that it will take 11 weeks to process. If they cannot make a decision within

the 11 week timescale then they should write to you to explain why (for example, awaiting information from a third party).

The Dispute Process

After receiving your decision from the DWP you need to decide if you are happy with the award. Of course, if it is a non-award then you are unlikely to agree. If however you have been awarded DLA you need to decide if you think the award is fair. It is important to be realistic in your assessment and have regard to the DLA rules and regulations, and put emotion to one side as much as possible. It may be an idea to get an expert opinion on this if you can.

If, after due consideration, you decide that you are unhappy with the decision then you have the right to dispute it. You have one month from the date on the decision letter to make your dispute. As decision letters are generally posted second class this may not give you that much time. If you ask for a full written statement of reasons this extends the time limit by two weeks to allow for their receipt.

Mandatory Reconsiderations

If you decide to dispute the decision then you must ask for a mandatory reconsideration first. It is no longer possible to appeal against a decision until you have asked for a mandatory reconsideration. You can ask for a reconsideration by phone, although it is best to write to them and maybe keep a copy of your letter. Another decision maker – not the person who made the original judgement – will then look at your claim and make a new decision. They may or may not concur with the original. Your letter should include the date of the original decision and your child's reference number, as well as your reasons for asking for a reconsideration. Just saying 'I don't agree' isn't enough, you need to state your argument. For instance, you may say something like 'I think he/she should be entitled to the mobility component as he needs constant

supervision whilst outside to stop him running across roads because of his ADHD'.

Once again the DWP can take up to 11 weeks to process your mandatory reconsideration request and come up with a fresh decision. You will then be notified by post and sent two copies of the 'mandatory reconsideration notification'. The reason for being sent two copies is that you will need one of them if you then decide to appeal (see below). The new decision may be the same as the original, better or possibly worse (although this is rare). It is then up to you to decide, as objectively and dispassionately as possible, if you agree with the new decision. If you do not, then you have one month from the date of the reconsideration notice to lodge an appeal.

Appeals

If you have decided that you do not agree with the mandatory reconsideration decision then the next step is to appeal. If you can, it may be worth getting some welfare rights advice to help you decide if an appeal is worth pursuing. Having decided that it is, you can register your intention to appeal by telephone, but it must be made in writing and the DWP should send you a form SSCS 1 on which to do so. This is a simple form asking you for basic details, the name of any representative you have and a very basic outline of your reasons for appealing (again, just saying 'I don't agree' isn't enough!). You must send this back to them with a copy of your mandatory reconsideration notification.

Within around 6 weeks or so of receiving your appeal, the DWP will send you a large envelope of papers. This is their appeal submission and includes copies of your claim form(s) and any other reports they have had. It also includes the text of their decision and, on the first pages, the

DWP's submission – their argument as to why the decision has been made. You will probably also have an enquiry form asking whether you wish to continue with the appeal, if you can accept a tribunal at short notice, and whether you want an oral or paper hearing.

A paper hearing is one where the members of the tribunal meet on their own, look over all the paperwork and come to a decision. An oral hearing is one where you attend and put your case to the tribunal. The tribunal is a panel of three people who are independent of the DWP. The chairperson is someone who is legally trained and takes charge of proceedings. There will also be a GP on the panel as well as a non-professional member, who is often a carer themselves or has some experience of disability issues. There may also be a representative from the DWP in attendance, although their attendance is sporadic. The panel members will ask you questions about your child's condition pertinent to the disputed decision and then decide whether to change the decision or not. In most cases you will be told their decision on the day, although occasionally the decision will be sent in the post. Any benefit or increase in benefit awarded will be back-dated to the original decision date, or date of claim in the case of a new claim.

So, is it better to opt for a paper or an oral hearing? The statistics are quite clear in so far as success rates at paper hearings are considerably lower than at oral hearings. The best rates of success are achieved by people who attend hearings with a representative. It is important that you get the help of an advisor, if you can, to take you through the appeal process and represent you on the day. However, although going to tribunal can be a scary and intimidating idea, success rates are quite good and they can be a good platform to explain your child's difficulties to people who are independent of the DWP.

In all cases where you dispute a DLA decision, you need to be aware that the DWP and the tribunal have the power to reduce as well as

increase benefit where they see fit. In reality reductions in benefit are rare and need to be substantiated by evidence, but it's something you need to bear in mind and another reason why taking expert advice is important.

Beyond the tribunal

If you are still unhappy with the decision made by the tribunal, you may have recourse to what is known as the Upper Tribunal. However, this cannot be done simply because you disagree, you have to prove that the tribunal has erred on a point of law. This is a very technical area and, at the risk of sounding repetitious, it is vitally important to take expert advice, possibly from a solicitor in this scenario.

The first step, which does not commit you to the Upper Tribunal, is to request in writing within one month of the tribunal, a written 'statement of reasons'. How to do this is detailed on the decision notice issued to you by the tribunal. The statement of reasons is basically the text of the tribunal's decision. It is then up to you (and your advisor) to go through the statement and determine whether or not you believe the tribunal erred on a point of law.

If you believe that the tribunal has erred then you need to write a letter to the Tribunals Service detailing how you think the decision was wrong legally. Your letter must state that you are asking for permission to appeal to the Upper Tribunal, and should include a copy of the tribunal's decision notice and the statement of reasons. Again this must be done within one month of the date the statement of reasons was sent to you.

Once the Tribunal Service receive this letter there will be one of three outcomes. In some cases the original tribunal may agree with your argument and amend their decision. If not, you will either be granted or refused permission to appeal to the Upper Tribunal. If permission is granted then you will be sent a form on which to formally make your appeal, and this must be done within one month of getting the notice granting you permission. If you are refused permission to

appeal, then you still have the right to ask the Upper Tribunal directly for an appeal, and you will be sent a form on which to do this with the refusal notice.

The Upper Tribunal has the power to directly change the original tribunal's decision, or it may refer the case back for a fresh First-Tier tribunal, directing the new tribunal carefully so that the original error of law is not repeated.

Don't forget that the DWP has the same rights of appeal and can also apply for permission to appeal to the Upper Tribunal, in which case any payments of back-dated benefit can be suspended whilst the process is ongoing.

Upper Tribunal appeals are complex and lengthy and should not be embarked upon lightly, but it is important to be aware of your rights and options.

Supersessions

The processes of reconsideration and appeal outlined above allow you to challenge decisions. However, there may be times when you think your child's rate of DLA needs to be revised even though there has been no recent decision. This sort of revision is known as a supersession.

Generally, there are two occasions where a supersession will occur. The first is where there has been a change of circumstances, in other words your child's care or mobility needs have changed part way through their award period. All such changes, whether negative or positive, should be reported to the DWP who will then send you a form DLA434 (see below) to complete. Once they receive this they will revise the benefit and send you a new decision, against which you have full rights of reconsideration and appeal. The general rule of thumb with supersessions is that increases of benefit can only be backdated for one month, whilst decreases can be backdated to the date of change.

The other occasion on which a supersession may be appropriate is when you believe that your child is receiving the incorrect amount of benefit. This may be because you have talked to an advisor.

For instance, your child may be receiving the care component but you believe they should also be in receipt of the mobility component. Again, the DWP will send you a form DLA434 to complete, with the warning that benefit can be increased or decreased.

The DLA434

The DLA434 form has also been re-designed in line with the claim form and is very similar and should be completed in the same way. However, you have the option of only completing the parts that are relevant to your change of circumstances or the additional benefit that you wish to claim.

For instance, you are asked if the help your child needs to physically walk has changed. If the answer is no (not forgetting Appendix I on higher rate mobility component for children with certain conditions) then you go straight to the section which asks whether your child's needs with guidance or supervision outdoors have changed.

Similarly with the care component you are asked if the help your child needs during the day has changed. If the answer is no then you go straight to the section near the end of the form asking you if their night time care needs have changed. In this way you only need complete the parts of the form that are relevant, and therefore minimise the risk of a reduction to benefit.

Renewal Claims

As we mentioned earlier, unless you are lucky enough to get an indefinite award of DLA, then your child's benefit will only be paid for a certain period. This period varies, generally from a minimum of 1 year. Many children have a review set at certain milestone ages like 3, 5 and 11 but there are no hard and fast rules and the renewal date will be notified to you in the decision letter.

Usually the DWP will send out a renewal claim form approximately 4 months before the claim is due to end. If you have not received one three months before the expiration date of the claim then you should contact the DWP. The renewal claim form is almost identical to the new claim form and should be completed in the same way.

It may well be that little or nothing has changed with your child's mobility or care needs since the original claim was made. However, it is vitally important that you put as much time and effort into completing the renewal form as you did the original. You need to fully explain your child's

needs again, it is not enough to just write 'no change' or 'same as on the last form'. Reductions in DLA on renewal are a major problem, and many of these are caused by people selling themselves short. Remember to get help with the form if you need it.

It is also important to get the completed form sent to the DWP in good time as they can take up to 11 weeks to process the form, and benefit will stop at the renewal date if a new decision has not yet been made. Although the DLA will be re-instated and backdated if the decision is favourable, even a temporary cessation of DLA can cause problems with associated benefits (more about them later).

Once your renewal is processed you will receive a decision letter in the same way as with your original claim which will detail the amount and length of the new award. This decision carries full reconsideration and appeal rights.

Personal Independence Payments (PIP)

Disability Living Allowance for people aged 16-64 has been replaced by Personal Independence Payments (PIP). This means that if your child is 16 (or older) and wishes to make a new claim then they will have to claim PIP rather than DLA.

Children who are already receiving DLA and then turn 16 will gradually be re-assessed for PIP.

This is an ongoing process that is not due to be completed until the end of 2020. Once your child reaches 16 they will be invited to claim PIP rather than being sent a renewal DLA form. You must then contact the DWP to 'accept their invitation' otherwise they will assume that you do not want to make a claim. A PIP claim form will then be sent to you.

PIP is assessed by completion of the claim form and then a face to face consultation. Like DLA there are two components, the Daily Living Component and the Mobility Component, but with two rates for each component, standard rate and enhanced rate. For detailed advice on PIP you should contact your local welfare rights advisor.

Benefits at Age 16

Once your child turns 16 then for benefit purposes they are considered to be an adult and can claim benefits in their own right. This is a difficult time as any benefits they claim could impact on benefits that other members of the household receive, so it may be worth contacting an expert benefits advisor to do a benefits check on the household.

Appointeeship

As we have just explained, once a child turns 16 then they are expected to deal with their own benefits. However, many children who claim DLA are not capable of doing this. Remember that dealing with their own benefits encompasses completing forms, actioning correspondence and managing their money.

If your child's DLA is up for renewal then there is a section on the PIP form that allows you to say that they are not capable of dealing with their affairs and that you want to act for them. This means that you are applying for appointeeship. Being their appointee means that you take on responsibility for dealing with all correspondence and forms for their benefits, and managing their benefit income.

Once you have applied to be the appointee, an officer from the DWP will arrange to visit you and will need to see you and your child. This should only take about 20 minutes and is required to ascertain that your child is incapable of dealing with their own affairs, and to explain your roles and responsibilities to you and get you to sign the appointeeship form.

Links to Other Benefits

A successful claim to DLA can be a passport to other benefits or allowances and could lead to other benefits being increased. For instance, any award of DLA leads to a disability addition being added in to your Universal Credit calculation. If your child receives the higher rate care component then you will also get a severe disability addition.

The main passported benefit from DLA is **Carer's Allowance**. This can be claimed if your child is getting the middle or higher rate of the care component (or either rate of the daily living component of PIP). You, or your partner, or even someone else must be caring for your child for at least 35 hours per week. As a parent this is a fairly straightforward test to pass. However, you must either not be working or earning less than £123 per week. Only one person can claim Carer's Allowance for caring for a disabled child, even though more than one may be involved in their care.

Carer's Allowance can have a negative effect on some means-tested benefits, although it is usually still worth claiming. You cannot claim it if you are in full-time education. Carer's Allowance can be backdated by up to 3 months, but overlaps with certain other contributory-based benefits such as State Pension, Maternity Allowance, Widow's Benefits, Bereavement Benefits, contributory-based Jobseeker's Allowance and Employment Support Allowance. In other words, if you receive one of these benefits at more than the level of Carer's Allowance then you won't be able to be paid it, although you may have 'underlying entitlement' which can lead a carers addition to some means tested benefits. This is complicated and it is probably best to get the advice of a welfare benefits advisor.

The **Motability** scheme allows you to exchange your child's higher rate mobility component for a new lease car from the scheme. Depending on what sort of vehicle you want, or the amount of adaptations required, you may need to make additional payments yourself. The motability payments include road tax, servicing, new tyres and breakdown cover.

Furthermore, receipt of the higher rate mobility component should give you automatic entitlement to a **Blue Badge** for your car, allowing

you to park in disabled parking bays. Even if you do not receive the higher rate you can still make a discretionary application if your child has mobility issues that mean they cannot be far from the car. Application forms are available from your Local Authority.

There are many other schemes, grants and discount admissions available. These can vary from area to area. For further information, contact our helpline on 0800 328 1159 or see our **Money Matters guide**.

Where to Get Help

Many local authorities have Welfare Rights Teams. However, provision very much varies from area to area and you should contact your Local Authority to ask if they have a welfare rights team.

There are also independent advice centres in some towns, and the Citizens Advice Bureau can also sometimes provide benefits advice, as can some local charities.

The charity Contact publish a number of useful leaflets for families with disabled children about welfare benefits and these can be downloaded for free from their website <https://contact.org.uk/>

Disability Living Allowance claim forms and change of circumstances forms can be ordered by telephoning 0800 1214600 or 0800 5870912 in Northern Ireland.

DWP Visiting is a service that provides face-to-face contact, through home visits or appointments at suitable premises, for people who meet certain criteria and are unable to access the Department of Work and Pensions services through any other channel, such as telephone, post or online. Their officers will quickly check your entitlements and complete all the necessary paperwork and forms. All DWP Visiting Officers carry proof of identity. If you are unable to access their services independently and would like a home visit regarding completing the DLA forms, then contact the service on 0800 1214600.

Advicenow have published a guide for parents and carers who think the DWP have made the wrong decision about their child's claim for DLA. The guide will help you work out if you should challenge the decision, as well as show you how to do it and win. It can be downloaded free from their website <https://www.advicenow.org.uk/guides/how-win-dla-appeal>

Lasa: the social welfare law and tech charity have a <https://advice.local.uk/> website – this is a free, UK-wide guide to welfare benefits and tax credits; council tax, debt and money advice; housing and homelessness; employment and work issues, disability and social care; and asylum and immigration.

Working Families helps working parents and carers and their employers find a better balance between responsibilities at home and work. Their Legal Helpline gives parents and carers advice on employment rights as well as basic advice on the benefits and tax credits that working parents can claim. To contact the helpline phone 0300 012 0312 or visit <https://www.workingfamilies.org.uk/>

Carers Allowance forms can be obtained by going to the website <https://www.gov.uk/carers-allowance/how-to-claim>.

For details of the Motability scheme go to www.motability.co.uk or telephone 0300 456 4566

Appendix I - Higher Rate Mobility Component

For some children with neurological conditions, claiming the higher rate mobility component is very straightforward, and is covered in the main body of this guide in the section dealing with questions 25-31. However, for others it is much more complex and that part of the claim form is difficult to complete. Firstly, we'll look at the two rules for claiming higher rate mobility for children who have no apparent physical walking problems, where you will have ticked 'yes' to question 25 'Can they physically walk?':

Virtual inability to walk due to refusal episodes

Some children, because of their condition, regularly refuse to walk. If these episodes are regular and unpredictable enough then you may be able to claim the higher rate as they can be said to render your child 'virtually unable to walk'. However, the refusals must be as a result of the child having a physical disability. Some conditions, such as autism and Down Syndrome have been considered physical by DLA case law as they stem from the brain which is a physical organ of the body. Other conditions may not be considered in this way, and certainly higher functioning children with conditions such as Asperger's Syndrome, Dyspraxia, ADHD etc will be very unlikely to qualify under the criteria in this appendix.

So, if you think your child may be considered to be virtually unable to walk due to refusal episodes, the following is an idea of how best to complete questions 26-31 of the claim form:

26. **Do they have physical difficulties walking?** Tick 'Yes'
27. **Please tick the boxes that best describe how far they can walk without severe discomfort and how long it takes them.** Don't tick any of the boxes! Write in the space between the suggestions and the tick boxes something to the effect of 'Regularly and unpredictably refuses to walk'
28. **Please tick the box that best describes their walking speed.** As for question 27, don't tick any boxes and just write 'regularly and unpredictably refuses to walk'
29. **Please tick the box that best describes the way they walk.** Again, don't tick any boxes but you can use the small text box at the bottom to say that your child regularly and unpredictable refuses to walk.
30. **Does the effort of walking seriously affect their health?** Tick 'no' (unless they have a co-morbid condition that means that it does).
31. **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.**

This is where you need to describe the refusal episodes. Start by saying that they are caused by your child's condition; that they happen regularly and unpredictably; that they are not just naughty behaviour (suggest what causes them, e.g. inflexibility of thinking, sensory overload etc); that they cannot just be overcome by punishment or reward; what happens if you try to move your child (eg hits you, smashes their head on the ground etc); how long they last for; how difficult/impossible it is to make any further progress; and, finally, how you consider your child to be 'virtually unable to walk' as a result.

You will probably run out of room in part 31! That's fine, just put 'continued in part 35' and carry on writing there!

Severe Mental Impairment and Severe Behavioural Problems

Some children can be entitled to the higher rate mobility component under this category. Severe mental impairment is not a nice thing to have to say about your child but remember it's just benefits terminology. It is a technical and complex regulation, and they have to satisfy a five point test:

1. They must be entitled to the higher rate of the care component

If this is a new claim you will not know what award of care component they will have, but if they have care needs day and night then you will just have to assume that they will. Don't wait for the award of the care component first and then try to claim under this route later.

2. They suffer from 'a state of arrested or incomplete physical development of the brain which results in severe impairment of intelligence and social functioning'

Again, some conditions are considered as fulfilling this criteria and others are not, as described earlier. You still have to show that your child has a severe impairment of intelligence and social functioning. For some children this is easy and can be related to their IQ, however some children can be reasonably intelligent but unable to use that intelligence (eg non-verbal children) and so could still qualify. Impairment of social functioning relates to how your child interacts with others, how they are able or unable to cope in society. Generally, children who attend mainstream school would not pass this part of the test, although this is not always the case.

3. They exhibit disruptive behaviour which is 'extreme'

This relates to your child's behaviour outside of the home, whilst trying to get about. Extreme means wholly out of the ordinary, things like running off and shouting are not enough.

4. They must regularly need another person to intervene and physically restrain them to prevent them causing physical injury to themselves or others or damage to property

This is fairly self-explanatory, and demonstrates the extremity of behaviour that is required to be shown to achieve higher rate mobility by this route. However, physical restraint can just be a hand on the arm, rather than literally pinning your child down.

5. Their behaviour must be so unpredictable that they require another person to watch over them whenever they are awake

In other words, your child can never be left alone due to the severity of their behaviour. This will include demonstrating that they need this level of supervision at school as well as at home.

So, if you've decided that your child may qualify via this route you need to show that on the claim form! This is a suggestion of how to complete questions 26-31 for the severe mental impairment and severe behavioural problems route:

26. **Do they have physical difficulties walking?** Tick 'Yes'

27. **Please tick the boxes that best describe how far they can walk without severe discomfort and how long it takes them.** Don't tick any of the boxes! Write in the space between the suggestions and the tick boxes something to the effect of 'Has a severe mental impairment and extreme behavioural problems'

28. **Please tick the box that best describes their walking speed.** As for question 27, don't tick any boxes and just write 'Has a severe mental impairment and extreme behavioural problems'

29. **Please tick the box that best describes the way they walk.** Again, don't tick any boxes but you can use the small text box at the bottom to say that your child has a severe mental impairment and severe behavioural problems'
30. **Does the effort of walking seriously affect their health?** Tick 'no' (unless they have a co-morbid condition that means that it does).
31. **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.**
This is where you need to say why you think your child has a severe mental impairment; how you think they have a severe impairment of intelligence and social functioning; how their behaviour is extreme; how they regularly need to be restrained; how they cannot be unsupervised when awake.

Try to use some examples to show how your child meets the criteria.

You will probably run out of room in part 31! That's fine, just put 'continued in part 35' and carry on writing there!

Appendix 2 - Rough Guide to DLA

Mobility Component:

Lower Rate	Age 5	Supervision
Higher Rate	Age 3	Physical walking Refusal episodes SMI/behavioural

Care Component:

Lower Rate	Birth	1 hour per day +
Middle Rate	Birth	Throughout day <u>or</u> Throughout night
Higher Rate	Birth	Throughout day <u>and</u> Throughout night

Copyright

This guide is based on work originally created by Steve Donnison and Holiday Whitehead. All rights reserved. No part of this work may be reproduced or transmitted in any form or by any means (photocopying, electronic, recording or otherwise) without the prior written permission of the authors. While copyright in the context of this publication belongs to the authors, Cerebra has the right, as the authors' licensee, to alter, amend and make it available to carers, health professionals, benefits advisers and others assisting children with neurological problems.

About the reviewer

David Williams is a former welfare rights advisor who spent nine years as a parent support worker and training officer with Cerebra and currently works with the NHS Wales Integrated Autism Service. He has formerly given advice to a member of the Welsh Assembly on benefits issues, as well as helping hundreds of families through every stage of the claims process including representing them at tribunal. A parent of a young person with Asperger's Syndrome himself he has written, and delivered training courses and workshops on welfare benefits to parents and professionals.

The findings of this report are those of the author, not necessarily those of Cerebra.

First edition: 2003

This edition: 2019

Review date: 2022



Working wonders for children with brain conditions

Postal Address

Cerebra
The MacGregor Office Suite
Jolly Tar Lane
Carmarthen
SA31 3LW

Tel: 01267 244200

Freephone: 0800 328 1159

www.cerebra.org.uk

Registered Charity no 1089812 Company no. 4336208

