

Benefits Series

**Disability Living Allowance DLA & Child Disability Payment CDP (Scotland)
Claiming for children aged 3-16 years old.**

Date: April 2024 | Information updated annually

Please see our website for up-to-date information: www.downs-syndrome.org.uk

If you have concerns, please ring the DSA's Benefits Adviser: Helen Wild

Monday & Thursday 10am-4pm Tuesday & Wednesday 10am-12.30pm | Telephone: 0333 1212 300 option 1

What is DLA / CDP?	2
The mobility component	5
Claiming the mobility component.....	Error! Bookmark not defined.
The rules for the lower rate	6
The rules for the higher rate	6
The care component.....	13
Filling in the form	Error! Bookmark not defined.
General questions – age 3 – 16	18
Mobility questions – age 3 – 16	19
Care questions for children aged 3 -16	22
The non-disability conditions.....	27
The "residence and presence conditions"	16
The qualifying periods	16
The special rules	Error! Bookmark not defined.
Challenging decisions	28
Reconsiderations and revisions.....	28
Supercessions.....	29
Appeals.....	30
DLA and other benefits.....	30
Carer's Allowance.....	31
Blue Badge scheme	31

Means-tested benefitsError! Bookmark not defined.
DLA contacts..... 31

Introduction to DLA/ CDP

DLA/CDP is a benefit for children up to age 16 to help with the extra cost of a long-term disability or illness.

It is not means tested so any savings or capital that you have will not affect the award.

An award of DLA may entitle you to extra amounts within means tested benefit you may already be claiming such as Universal credit or Tax credits.

Benefit is made up of two parts, the [care component](#) and the [mobility component](#)

- The care component is paid to someone who needs extra help with personal care. The earliest time that it can be awarded is 3 months of age. The extra care needs should have been needed for 3 months prior to claiming and be expected to last at least for the next 6 months. There are 3 rates, lowest, middle, and highest.
The only time the 3 months qualifying period for care does not apply, is if a child has a terminal illness, these rules are called 'Special Rules'.
- The mobility component is paid to someone who needs help with getting around out of doors. There are 2 rates. The earliest time that it can be awarded is 3 years of age for the higher rate and age 5 years for the lower rate.

You can receive the care component, or the mobility component, or both.

People over age 16 will claim Personal Independence Payment (PIP) or Adult Disability payment if they live in Scotland. This replaced DLA for people of working age (16-64).

Some of our members will still be receiving DLA even though they are over age 16. The DWP will write and advise you to make a claim for PIP which will replace the existing DLA award.

Information about PIP/ADP is available in the Benefits section on www.downs-syndrome.org.uk.

How much is DLA/ADP this year?

April 2024 to 2025

		Per week
Care component:	Lowest rate	£ 28.70
	Middle rate	£ 72.65
	Highest rate	£ 108.55
Mobility component:	Lower rate	£ 28.70
	Higher rate	£ 75.75

What about income and savings?

Income or savings will not affect DLA/CDP as it is not means-tested.

What if I claim other benefits?

DLA/CDP is paid on top of your benefits. If you are claiming Tax Credits or Universal Credit, you may receive extra money because your child is receiving DLA/CDP. You may be able to claim [Carers Allowance](#) once your child receives middle or highest rate care component. You can have a carer amount added to your Universal credit award if your earnings are too high to qualify for carers allowance.

Which rate should my child get?

The award depends on the amount of extra care or mobility needs, you can always call us and chat to our adviser. Most children should be receiving middle rate around age 3. If they are awake at night, you may qualify for highest rate care.

Children may qualify for the higher rate of the mobility component at age 3 if they have physical problems with walking or their behavioural problems are severe enough to qualify.

Most children who have Down's syndrome will receive the lower rate of the mobility component at age 5 - the earliest time lower rate can be awarded.

There are also '[non-disability conditions](#)' such as how long you have needed help, and how long you've lived in the UK.

When to make a claim

From 3 years you can claim for the mobility component.

The level of benefit awarded depends on your child's actual needs. It is not awarded for the diagnosis so provide as much detail as you can.

You need to show that the care your child receives is substantially more than the general needs of a child at this age. Future needs that your child may have in the future do not count.

Claim when you feel that your child has more care than most other children of the same age.

If you would like to discuss when to claim for your child, please call the DSA benefits adviser.

How to claim

You will need to fill in a DLA claim form. Forms are available online on the government website at [GOV.UK](#). Or call DWP on 0800 121 4600.

If you live in Scotland you will need to claim Child Disability Payment which is similar <https://www.mygov.scot/child-disability-payment>

Help with the form

The form may appear complicated, but we can help you to complete it.

Our benefits adviser is available on 0333 12 12 300

Monday & Thursday 10-4 pm.

Tuesdays and Wednesdays 10-12.30 pm.

Renewal claims

Most awards are made for a limited time, often for a period of two to three years and you will need to make a renewal claim.

You must fill in the renewal claim form in detail, as if it were the first claim. The DWP can refuse or reduce benefit on renewal claims if they do not get full information. Sometimes a renewal form will simply ask if needs have changed since last time. If you tick 'no', there is no obligation to give any more detail in that section.

If your child is already getting DLA/CDP, you should be sent claim forms to make a renewal claim about 6 months before your award runs out. If you don't receive a renewal form, contact the appropriate department. You will have their number on your most recent letter.

It is important to send the renewal claims back before the existing award runs out. If you send them back in good time, then the new award should start as soon as the old one finishes. If you send them back a short time before it runs out, there could be a gap in your payments. You will get a back payment once they have dealt with the claim.

If you send back the renewal forms after your child's DLA ends, backdating won't be given for the time between the first award ending and when they get your renewal claim.

Length of award

For young children, benefit is usually awarded for 2 to 3 years. You may feel that the award is not long enough, but it gives you the opportunity to check whether your child may also be eligible for an award of the mobility component. The higher rate mobility can be awarded from age 3 and the lower rate can be awarded from age 5. If someone gets both care and mobility for a fixed period, their awards will end on the same date. Generally longer awards are made after age 5. It is always handy to keep a copy of the last form you filled in. You can then use this as a starting point for the renewal form and add your child's most recent care/mobility needs to it.

The mobility component

The mobility component is for "help with getting around".

Children under the age of 3 cannot get the mobility component. Only fill this in when your child is coming up to age 3.

There are two rates of the mobility component:

- the lower rate which can be claimed from 5 years
- the higher rate which can be claimed from age 3 years.

Children who have Down's syndrome generally receive the lower rate of the mobility component, and some get the higher rate.

Qualifying for the **higher rate** of the mobility component for a child can be problematic. The rules are both strict and complex.

Unlike PIP, the rules are not particularly well suited for our members.

A distinction is made between walking problems caused by behaviour and walking problems for physical reasons. Remember that issues with safety and needing guidance to get around will not on their own qualify someone for the higher rate, only the lower rate.

The rules for the lower rate from age 5

You qualify for the lower rate if you need guidance or supervision walking out of doors.

From the age of 5, your child may qualify if they need a lot more guidance or supervision out of doors than other children of their age, or they need guidance or supervision that other children of their age wouldn't need at all. Guidance is having someone tell you where to go, or help you get to where you're going. Supervision is having someone there to keep you safe.

You need to explain in what way your child needs EXTRA guidance or supervision out of doors, over and above that which another child of the same age would need.

The rules for the higher rate from age 3

From the age of 3 years, your child may qualify for the higher rate if:

- They are [unable to walk](#)
- They are [virtually unable to walk](#)
- The [exertion](#) required to walk would constitute a danger to their life or would be likely to lead to a serious deterioration in their health.
- They have no legs or feet
- They are either severely visually impaired (blind) or both deaf and blind
- They are entitled to the highest rate of the care component and are ["severely mentally impaired"](#) with extremely disruptive behaviour problems.

Someone who has Down's syndrome is most likely to get the higher rate because they are unable to walk, or virtually unable to walk, or because they have serious behavioural problems. You may feel that your child meets more than one of these conditions, or one of the other conditions.

If you are having problems, please contact us.

Unable to walk

A child will get the higher rate of the mobility component if at the age of 3 or over they cannot walk at all.

The test for walking ability is walking out of doors on the level. Having a problem because you happen to live on a hill isn't considered but having to deal with normal obstacles, such as kerbs or uneven ground, does count. Walking is simply putting one foot in front of the other and making progress, without support from another person.

Virtually unable to walk – learning disabilities.

To get higher rate mobility under this condition, you need to show that although your child can walk, their walking out of doors is so limited that they are “virtually unable to walk”. These physical limitations include behavioural problems if they are a result of a child having ‘*a physical disability which prevents the co-ordination of mind and body*’.

It has been accepted that Down’s syndrome can be considered as one of these conditions. Interruptions in walking will be considered if there is no direct conscious control or awareness on the part of the child i.e., they haven’t consciously decided not to walk.

If this is relevant to you, you should provide detail about behavioural problems that happen and explain that this happens because your child has Down’s syndrome. Explain that the behaviour is not their choice and that they are unaware of their behaviour. The best thing to provide would be a description of what happens when your child is walking out of doors. Tell them if your child is distracted and unpredictable and if they do not listen to instruction.

You should show that their behavioural problem stems from a physical disability; and their walking difficulties, including interruptions in their ability to walk, happen so frequently that they are virtually unable to walk.

Virtually unable to walk – physical limitations.

Someone is “virtually unable to walk” if:

“his ability to walk out of doors is so limited, as regards the distance over which or the speed at which or the length of time for which or the manner in which he can make progress on foot without severe discomfort, that he is virtually unable to walk.”

Getting it depends on:

- How far your child can walk
- How fast your child can walk
- How long it takes to cover a certain distance – as well as speed of walking, this includes pauses, rests, interruptions, refusals, time taken to coax the child to go on, etc.
- The way in which they walk, for example, with poor balance or co-ordination, lots of stumbles or falls, etc.
- It is only walking which is done without “severe discomfort” which counts, when you are reckoning up how far your child can walk.

Measuring walking ability starts from the position of someone who can’t put one foot in front of the other. If your child cannot walk at all, they should be awarded. If your child can take steps, it is then a question of looking at all the factors, distance, speed, time taken, and manner of walking, to see if your child is “virtually unable to walk”.

- Distance: If your child regularly walks more than 50-70 metres, it is unlikely (though not completely impossible) that they will qualify as “virtually unable to walk”. The decision maker must also consider the other factors, such as how slowly they walk, how often walking is interrupted for rests, how long the rests or pauses take, poor balance and co-ordination, etc.
- Speed: Normal walking speed is about 6 km or 3-4 miles an hour. Roughly it takes around a minute to walk about 90 metres. If your child can walk this far, but it takes longer, it is very important to say so.
- Time: This involves looking at stops and pauses. Your child might need to rest, or you might have to spend time coaxing them to carry on. How long this takes is very important.
- Manner of walking: Your child may have poor balance and co-ordination, or very low muscle tone that gives them an unsteady gait. This might mean that they have problems with kerbs, steps, or uneven ground. They may fall a lot.
- Severe discomfort: walking which can only be done in “severe discomfort” does not count. “Severe discomfort” is severe pain and can include breathless or tiredness as well as aches and pains. “Severe discomfort” has been described as a level of discomfort that is not reasonable to expect someone to go through daily. Your child may stop walking because they’re tired. Or you may stop your child walking because you know that if they walk for longer, they are going to be very tired and uncomfortable later. If the tiredness comes on soon (that evening, or the next day), only the distance they can walk without risking severe discomfort later counts.

Information you need to give if you think your child is “virtually unable to walk”.

1. You need to give evidence about your child’s actual walking.

You need to give information about all the factors, distance walked without severe discomfort, speed, any interruptions and refusals which affect how long it takes your child to walk, any problems with balance or co-ordination. You also need to think about if your child’s walking varies day to day, and how to describe good days and bad days.

It may help to keep a walking diary over a week or so.

Note down how far your child has walked that day, how long it’s taken, and any problems along the way. The more details the better.

Does your child get tired or breathless quickly, or trip and fall a lot? Do they walk with a different gait or in a different way to other children? Do they have trouble because of other conditions such as a heart problem, or problems with seeing or hearing?

Why do they stop – are they tired? Breathless? Uncomfortable? Just won’t go further. Do they say they are tired or their legs ache? Do they get flushed or go pale? Give details if your child stops because they are in discomfort of any kind.

What happens then – can they be coaxed to walk further? Do you have to pick them up? Do you use a buggy or wheelchair?

How many interruptions to walking (pauses, refusals) are there during this distance? How long do they last?

Do they refuse to walk? Do they try to run off?

A walking diary can be your best evidence.

- Measuring distance

It's difficult to guess distances. Giving a good idea of the distance your child can walk is hard. Don't guess. Anything you write on the form will be taken seriously and it is very hard to convince them you made a mistake afterwards. Measure your child's walking distance accurately.

You may not be sure about how far your child can walk measured in metres or yards. You can check distance in several ways:

- Measure the length of your normal step. Then count how many steps it takes to cover the distance you need to know. Then multiply the length of your stride by the number of steps to get a good, accurate estimate. The average adult step is 75 – 90 cm.
- You can compare distances. For example, a football pitch is about 100 metres long. The average 4 door car is about 4 metres long. A public swimming pool is usually 25 metres long.
- If your child's walking is very limited, you could give the number of steps they take.

Remember, this is walking without severe discomfort. Do not count any distance that your child only manages to walk when they are very tired, or breathless, or otherwise uncomfortable. Or any walking that they can manage at the time, but which will make them exhausted or give them discomfort afterwards.

The question asks how far your child walks before "they have to stop because of severe discomfort". Your child may not show signs of "severe discomfort", they may just not walk very far. In that case, just give how far they walk.

- Good days and bad days

Remember to note down both good and bad days, if your child's walking varies. Your child will get the higher rate if their walking is limited enough most of the time.

If they don't walk at all outdoors on some days, remember to note that too.

2. Explain why your child has difficulties with walking

Your child's walking could be affected by both physical and behavioural problems. Start with the physical ones, for example:

- low muscle tone
- loose ligaments (weak ankles, or knees)

- poor balance and co-ordination
- developmental delay – simply being slower at learning to walk
- sensory impairments, such as poor vision or hearing
- poor stamina because of frequent colds or chest infections

Now consider whether you think behaviour is a factor in limiting your child's walking. It can be hard to know why your child won't walk, especially if their speech isn't very developed yet. For some children, however, it can seem that a behavioural factor is involved. They constantly "refuse" to walk. They may seem physically capable of walking a long way, but in practice, rarely walk very far before they want to stop.

Behavioural problems that limit walking can be considered for the higher rate, if they come directly from a physical cause, for example, having Down's syndrome.

It may seem obvious that any child who has Down's syndrome is showing behavioural problems because they have Down's syndrome, and there is case law stating that a decision maker or tribunal must have very good reasons for ascribing the behaviour to some other cause (e.g., "naughtiness").

Your child must not be "consciously" refusing to walk. A child who walks to places they like, but refuses on other occasions, would not qualify. A child who regularly, for no apparent reason, refuses to walk regardless of where they are or where they're going, may qualify.

However, there is also a case which states that if there is some "minimal" physical element in the limitations on walking, even if they are largely behavioural, someone can qualify for the higher rate.

The main thing to concentrate on is evidence around how far your child walks, the speed they walk, time taken by stops, refusals, interruptions, any problems with balance, co-ordination, seeing, hearing, sensory issues, that affect walking.

My child's walking is a problem because they constantly try to run off. Do they qualify?

Sometimes children both refuse to walk, and constantly try to run off. This is a difficult situation. Getting from A to B isn't considered. Only the ability to walk, that is, to put one foot in front of the other, counts. So, a child who runs off can clearly walk. However, their running off may be very limited as to distance or time, for example, they make short darts away, taking only a few steps. If they also regularly refuse to walk any great distance, they may qualify for the higher rate.

Remember, problems with keeping your child safe don't count towards being "virtually unable to walk". They are considered for the lower rate.

Your child's problems with walking may be partly or mainly behavioural. You need to be open about the fact that physically they can walk and give details about how limited their walking is because of their behaviour. Does it happen every day? Does it happen in every situation? If your child both runs away and refuses to walk, give very detailed information. Don't just say "runs off". Spell out how far they run, for example: "she will run for about 10 steps...."

If you need advice, please ring the DSA benefits adviser on 0333 12 12 300.

Exertion

Someone could qualify under this condition if they had a health problem which was made worse by walking, for example, a serious heart or lung problem. Some children with Down's syndrome do have medical problems like these.

You would need supporting information from a doctor, to show the medical risk to the child's health.

Severe mental impairment (SMI)

To qualify under these criteria, your child needs to be receiving the highest rate of the care component of DLA. Their behavioural problems also need to be serious, needing someone to be alert and ready to always intervene physically (indoors and outdoors) to prevent danger to the child, or other people. It is not just behaviour while walking outside that counts, but behaviour at home, and at school, as well as outdoors.

To get higher rate mobility through SMI, you must show that your child meets several rules. They must satisfy all of them to get it.

The rules are:

- Your child should be receiving the highest rate of the care component.
- Your child is accepted as having "a state of arrested development or incomplete physical development of the brain which results in severe impairment of intelligence and social functioning".

It is accepted that children who have Down's syndrome do have "arrested or incomplete development of the brain." Please contact the DSA Benefits Adviser if this is queried.

"Severe impairment of intelligence" has been defined as having an IQ of 55 or less. However, this is very unhelpful. Many psychologists do not use IQ tests and you may not have an IQ score for your child.

Factors which must be considered when assessing intelligence include no sense of danger, having "useful intelligence", and qualities of "sagacity and insight". Does your child have a statement of special educational needs? If they are at school or nursery, what level are they working to in reading, writing and maths?

Evidence about the level of social functioning could include information about how independent your child is in daily routines, such as washing and dressing. Information about their speech, or other ways of communicating, will be useful. For more information, contact the DSA Benefits Adviser on 0333 12 12 300.

- Your child "exhibits disruptive behaviour" which is "extreme".

Disruptive behaviour can range from aggression such as hitting, kicking, slapping, spitting, etc, to having tantrums, constantly running away, constantly taking clothes off, talking to imaginary friends, throwing things, stripping bed clothes off, wanting constant attention, being hyperactive, sitting down and refusing to move, wanting to engage with others in inappropriate ways (such as playing

too roughly with other children), turning on bath taps, emptying cupboards, putting things down the toilet, behaviour such as head banging, or rocking, or simply behaving in any way that is inappropriate and risks upsetting or disturbing other people. There is no suggestion that your child is being deliberately malicious. You will need to describe what your child does in as much detail as possible, giving details of incidents.

- Your child’s behaviour must “regularly require another person to intervene and physically restrain them to prevent them causing physical injury to themselves, or another, or damage to property.”

Physical restraint could be as simple as a hand on the arm. It does not necessarily mean strong or forceful restraint.

Why does your child need to be restrained physically? Will they not stop when told to? Have they hurt themselves, or someone else, or damaged property in the past? You must show them that this happens regularly. Sometimes it is obvious from the nature of the behaviour. For example, a child who constantly runs away in the street clearly needs to be stopped for their own safety, but you do need to spell out the fact that it must be physical restraint.

- Your child’s behaviour is “so unpredictable that they need another person to be present and watching over them all the time they are awake”.

This rule is quite strict. If your child can be left in another room in the house, for example, watching a video, by themselves, for more than minutes at a time, then they probably won’t satisfy this condition. It’s quite possible that, given the realities of family life, you may leave your child alone in another room more than you feel happy about. But if so, do give details of anything that has happened while your child has been on their own.

The rules for “severe mental impairment” are quite complicated. If you want more information or advice, contact the DSA Benefits Adviser on 0333 12 12 300.

If you think your child might qualify for the higher rate

Some children who have Down’s syndrome are eligible for the higher rate and we don’t want to put anyone off applying.

To give yourself the best chance of success with your claim, we suggest approaching it like this:

Before filling in the mobility questions on the form:

- Read [the rules for the higher rate](#).
- Think carefully – which condition does your child qualify under? Your child may qualify under more than one condition. In that case, think about information relevant to both conditions.
- Using the information and suggestions that we give; make notes of what information and evidence you need to give the DWP.

- Finally, look at the questions on the claim form. Work out where you can put the information you need to give. You can use the spaces later in the form to add more detail.
- It is also a good idea to send supporting evidence with your claim. This could be letters from your child's nursery or school, doctors, or other professionals who know your child well. The DWP usually ask for extra information from the professionals you list on your form if the higher rate of mobility is in question.

You may need to attach extra sheets. Remember to put your child's name, date of birth and National Insurance number (if they have one) at the top of each sheet.

The care component

The care component is for help with personal care and there are 3 rates

The lowest rate

Your child may get the lowest rate if: *[they require] in connection with [their] bodily functions attention from another person for a significant portion of the day (whether during a single period or several periods).*

The middle rate

Your child may get the middle rate if they meet one of the daytime conditions, OR one of the night-time conditions.

These are, **during the day-**

'Frequent attention throughout the day in connection with [their] bodily functions, or continual supervision throughout the day to avoid substantial danger to themselves or others, or during the night

Prolonged or repeated attention in connection with their bodily functions or

In order to avoid substantial danger to [themselves] or others, [they require] another person to be awake for a prolonged period or at frequent intervals for the purpose of watching over [them].'

The highest rate

Your child may get the highest rate if they meet one of the daytime conditions *and* one of the night-time conditions listed above in the middle rate explanation.

To sum up, your child may be awarded the

- lower rate if they need about an hour's extra help during the day. They will be awarded the
- middle rate if they need a lot of extra help *either* during the day or during the night. They will be awarded the
- highest rate if they need a lot of extra help *both* during the day *and* during the night.

Which rate someone receives depends on the amount of help they need, and when they need it.

What needs count for the care component?

The care component is given if someone needs help with personal care. This would be help with their 'bodily functions' in the day and/or night.

They also qualify if they need 'continual supervision' during the day and/or someone to be awake during the night for the purposes of watching over them to avoid harm or danger to themselves or others.

Definitions

Attention

Attention is doing something of a close and personal nature for the disabled person in their presence. It must be "attention in connection with bodily functions". Bodily functions are defined as movement of the limbs, operation of the senses and cognitive functioning. [Mallinson, Fairey and Cockburn: House of Lords]

Attention often involves physical contact, but it can be by the spoken word – encouragement, reminders or reassurance. The help needed may count where it is related to the child both in and outside of the home to lead as 'normal' life as possible. [Fairey: House of Lords]. Attention doesn't usually include help with shopping, laundry, or other household tasks.

Supervision or watching over

Supervision is being there ready to help if needed. It must be needed to prevent danger. The danger need never have happened, but there must be a real, serious risk. Supervision needs to be "continual" – not every single second, but constant.

"Watching over" is supervision at night. You must be awake and getting up to help, or awake and listening out to prevent danger.

Attention and supervision/watching over can clearly overlap. If you are unsure if a particular activity is "attention" or "supervision", just describe what you do in a suitable section of the claim form.

Significant portion of the day:

A "significant portion of the day" is about an hour in total. The help might be given all at once, or at different times during the day. But if you give your child help throughout the day, they could qualify for the middle rate.

Frequent attention throughout the day:

"Frequent" means more than once or twice, and "throughout the day" means exactly what it says, that the help you give your child is spread out at intervals through the whole day. There can be gaps in the day when your child doesn't need help, but the pattern must be over the whole day. It is therefore important to include all the help you give your child, since the Department for Work and Pensions (DWP) look at how often you give that help, as well as what kind of help it is.

Different kinds of help are "added together to meet the "frequent attention" condition.

Continual supervision: All children need a lot of supervision to keep them safe.

To qualify for the [‘extra test for children’](#), you would have to show that your child was more at risk if left alone in another room than a child of that age would normally be. For example, a child with epilepsy, a severe heart defect or breathing problems may need careful watching. There must be a real danger of harm - parental anxieties are not considered. If your child has a NG tube or a catheter, you may have to watch for them pulling it out and so this should count.

Over age 2, children with Down’s syndrome may need more supervision than other children of their age because of their learning disability. For example, they may be much slower to learn about common household dangers (hot water, knives, electricity), or they cannot be left alone safely in the same way that another child of the same age could be.

Prolonged or repeated attention at night:

“Night” had been defined as a time after the whole household had shut down, not starting from your child’s bedtime, but after you and other adults in the household have gone to bed. Recently it has been ruled that ‘night’ should be viewed as being between the hours of 11pm and 7am the following morning. This was because some parents have to be awake regularly and beyond their normal bedtime or be up earlier than they would generally in order to attend to their child’s care needs. [CDLA/127/2018:Upper Tribunal Judge Hemingway, and R(A)1/04: Upper Tribunal Judge Agnew].

"Attention": means the same as for the day-time conditions. Remember it includes soothing someone back to sleep. Prolonged attention is taken to be 20 minutes or more. Repeated attention is twice or more. However, it is usual for young children to need attention at night. To count, the attention your child needs have to be different, or take longer, or be attention that usually only a younger child would need.

You don't have to give this help every night. It just must be "more likely than not" that you will have to get up, whether once for a "prolonged" period, or twice or more. In practice, it appears that the DWP considers that it is not enough if you get up 3 nights out of the 7.

Watching over: - like the day-time condition of "continual supervision".

"Watching over" includes both getting up and checking on someone, and simply being awake and listening out. It must be either "prolonged" - 20 minutes or more - or "frequent" - at least 3 times. You need to be awake – just being asleep in the house isn’t enough.

The reason for someone needing "watching over" must be because otherwise they would be at risk in some way. The danger need not ever have happened, though you need to explain why you think it might.

Remember, when you are thinking about attention and supervision/watching over for children, it has to be a lot more than that needed by other children of the same age in order to count. See [the extra test for children](#).

Help which isn’t considered

Parking and petrol costs for extra hospital appointments, having to turn the heating up or if you have taken the decision not to go back to work does not count.

Another form of help that would not count is any help given that could be made unnecessary by using an available aid or piece of equipment– this could mean things like grabbing sticks or aids to open tins or jars etc. This would apply to

older people with dexterity issues. For our members there is still an issue around cognitive impairment and you would still have to supervise the situation.

Some parents find the form difficult to fill in. It will focus on milestones not yet reached instead of positive achievements. It is important not to underestimate the amount of extra time you give for your child to attain these developmental milestones. You need to give full details, even if it is a renewal form.

If you need information or advice about filling in the form, please call the DSA benefits adviser on 0333 12 12 300.

The non-disability conditions

These apply to both the care component and the mobility component.

If you think you might be “subject to immigration control”, get advice from a benefits adviser before you claim DLA. If you are subject to immigration control, claiming DLA may affect your right to stay in the UK.

The "residence and presence conditions"

To make a DLA claim your child:

- Has to be habitually resident in the UK, the Channel Islands, the Isle of Man or the Republic of Ireland AND
- Be present in Great Britain (but they can be away temporarily) AND
- To have been present in Great Britain for a total of 104 weeks in the past 156 weeks (2 out of the past 3 years). If you claim when your baby is less than 6 months old, they need only to have been present for 13 weeks. This applies until their first birthday. If you claim for a baby aged 6-36 months, the test is 26 weeks in the past 156 weeks (6 months out of the past 3 years).

The upper Tribunal found that it was unlawful to apply a 104 week waiting period for children age 3 to 16 returning to the UK and ruled that this should be 26 weeks as it was before the changes came into effect (in 2013).

This ruling is EK v SSWP CDLA/2019/2018 and TS v SSWP CDLA/2208/2018.

It is also known as EK and TS

The rules about residence and presence are complicated. There are also complicated rules if you are from a European Economic Area country, as residence and presence in a EEA country may count towards residence and presence in the UK. If you are unsure about your own situation, get advice.

The qualifying periods

Your child must have already satisfied one of the disability conditions for at least 3 months to get benefit. Your child also must be likely to satisfy one of the disability conditions for the next 6 months.

This means that although you can apply for the care component for your child at birth, the child cannot usually start to get the benefit until the age of 3 months.

For the mobility component, the lower age limit is 3 years old (higher rate) and 5 years old (lower rate). The three months before your child's 3rd or 5th birthday can count as the qualifying period, if your child meets one of the disability conditions during those 3 months, so that your child can start getting the mobility component from their 3rd or 5th birthday.

The Special Rules

You may notice that there is information in the DLA claim pack about 'special rules.' These are for people who are terminally ill, that is, they are not expected to live beyond the next 6 months. The qualifying periods do not apply for the care component in these cases. The highest rate of the care component is automatically awarded, but there is no automatic award for the mobility component which can be claimed in the usual way from age 3.

Practical tips

- Keep a copy of your completed claim form. It helps if you don't get the decision you want, it can also serve as a prompt when you come to do a renewal claim.
- It can be useful to keep a diary for a while. You could do this before filling in the form, as this can make you aware of the full pattern of your child's needs. It's easy to forget about things because they're so much a part of your daily routine. You may want to include a copy of your diary when you return the form.
- You may not have enough room on the form to give all the information you want to. Continue a separate sheet of paper, attach it to the form, and make sure you note on the form what you have done. Put your child's name, date of birth and reference number (if you have it) at the top of each sheet in case it becomes detached.
- You may want to give the same information in answer to different questions. You can choose to repeat the information, or you can simply put "see page x for details about...." It does not matter where you write things, if the information is on the form somewhere, and your answers are consistent.
- How many times a day/night? and How long for each time? are sometimes the hardest questions to answer. Sometimes you can put "all the time" or "continually", for example, the questions about communication, or development, or if your child needs extra supervision, it is obvious that if the need exists, help will have to be more or less all the time.

However, if your child needs help at mealtimes, or with physiotherapy exercises, or with washing, or at night, it may be possible to give more specific details of how often and how long it takes.

- What if the help your child needs changes from day to day? Try to give an average, and you can also give a range of times. For example, "*On average, it takes 15 minutes, but it can sometimes be as short as 5 minutes or up to an hour*" or "*It takes an hour about 5 times a week*". Don't underestimate.
- It may be helpful to think about your child in comparison with your other children (if you have them), or with other children of the same age you know.

- It is much more important to be clear than to stick to their layout. If you want to explain in detail, and the box isn't big enough, use extra pages if you run out of space. Remember to put your child's name and date of birth on any loose sheets you send in case they become detached at DWP (as they will be easy to link together again).
- If your child doesn't have problems in certain areas, just tick the "no" box at the top of the page and leave it blank.
- Remember that the different kinds of help your child needs are "added together". Nothing is ever too minor to mention. For example, a child might have sticky eyes which need cleaning 2-3 times a day. It may only take 5 minutes each time - but it's worth adding.

Filling in the form for children aged 3 - 16

The claim forms for a first claim and for renewal claims are similar and layouts change from time to time, so although we update every year, your claim form may be slightly different from the order given here.

The first questions on the form relate to personal details and circumstances, medical conditions, medication and therapies. It also asks for the names and addresses of healthcare professionals that may be involved.

Statement from someone else who knows the child.

This can be signed by anyone who knows your child well. It is possibly better to get a professional (GP, nurse, teacher, etc) to sign, but don't delay sending back your form for too long by waiting for a particular person's signature. A relative or friend can sign. You don't have to get anyone to sign, but this may delay your claim.

The best thing to remember is to give information about why your child has *extra* needs.

Remember to concentrate on why the help is different, or takes longer, or is help that usually children only need when they are younger than your child.

Most parents or carers filling in the form for a child aged three and over will have done it before. Most children of this age will already be getting an award.

If your child is already getting an award, you should be sent claim forms to make a renewal claim about 6 months before your benefit runs out. These forms are very similar to the first claim form. If you don't receive a renewal form, ring the DLA/CDP unit.

If you're unsure about what to do, ring the Down's Syndrome Association's Benefits Adviser on 0333 12 12 300, Monday to Thursday for information and advice.

General questions – age 3 – 16

- About your child's illness or disability.

Give information about all your child's conditions. For example, if they have a hearing impairment, or low muscle tone, or dry skin, you can list them separately, even if they are related to having Down's syndrome.

Therapy is treatment, so if your child has speech therapy, physiotherapy etc. list how often you practice the therapy – for example - 3 times a day for 20 minutes each time. List what you do with your child each day. If you are unsure how long these activities take, try keeping a diary of what you and your child do for a couple of days and then you may find these questions are much easier to answer.

- Aids or adaptations.

These would be things that a child of this age would not normally require. For example, hearing aids, glasses, contact lenses, special boots, or shoes.

- When the child needs help

Your child's needs may vary throughout the day and sometimes they may need more help when they have a chest infection for example. However, this would not mean that overall, their care needs varied, they should count as being the same most of the time as the chest infection would be an increase on existing extra care needs.

Mobility questions - age 3 to 16

We suggest that it's a good idea to read about the rules [for the lower rate](#) and [the higher rate](#) at page 7 -15 before filling in the form.

- Can your child physically walk?

This is a simple yes or no. Remember, walking is being able to make progress by putting one foot in front of another out of doors on a reasonably flat surface (hills and slopes aren't considered, but kerbs, uneven ground, etc. are).

If your child can't walk, then please go to the question asking how long your child has been unable to walk.

- Do they have physical difficulties walking?

Older children who have Down's syndrome may be able to walk but have difficulties with walking. If their walking is limited enough (for more details, see the rules for [Virtually unable to walk](#)), then they may be entitled to the higher rate of mobility.

- Describe their walking before the onset of severe discomfort

These questions ask for information about your child's actual walking, how far they can walk without severe discomfort, about their usual walking pace, and about how they walk (limp, poor balance, etc.).

As we suggest in the rules for [Virtually unable to walk](#), it is very important to give accurate information.

But what if my child's walking varies from day to day?

It's common for a child's walking to vary day to day. You could approach these questions by answering the tick boxes for your child's "average" day – that is, not a particularly good or bad day.

You can then explain more about how your child's walking varies in the appropriate boxes. You can say the tick boxes are an "average" day, and then give them an idea of how your child walks on "good" days and "bad" days. For example, "if she's really well, she can walk about 100 metres, but this only happens once or twice a week. On bad days, she can't walk outside at all, which happens two to three days a week.

Attach extra sheets of paper if you need to (remembering to put your child's name, date of birth and National Insurance number on every sheet).

You can give further information by sending in a walking diary covering a week or so as extra evidence.

- Describe their walking speed.

Normal walking speed is around 6 km or 3-4 miles per hour. Roughly it takes around a minute to walk about 90 metres. If you're not sure how long it takes your child to walk a certain distance, don't guess. Time them. You can get so used to your daily routine that you don't realise how long it's taking your child to walk that far.

Remember, even if your child can walk a reasonable distance, if it takes a very long time, either because they walk so slowly, or because of lots of interruptions, your child may qualify.

- Describe the way they walk.

Watch how your child walks and mention all details, do they have a wide based gait, do their feet turn inward, are they flat footed etc. They may have more than one problem with the way that they walk. Also remember that it is independent walking and not walking holding on to something or someone for balance.

- Does the effort of walking seriously affect their health?

This is about whether walking would be harmful to your child's health, for example, if they had a serious heart or lung condition. You will need confirmation from a doctor.

- If you want to tell us why you've ticked the boxes, how their needs vary, or anything else you think we should know.

It will be helpful to include the reasons for your child's physical problems with walking, for example, low muscle tone, poor stamina due to frequent colds / chest infections, pain from loose ligaments, etc. You can give this information here.

If your child also has behavioural problems which limit their walking, give the information about how far they walk, how long it takes, etc, in earlier questions and explain here that walking limitations are partly caused by behaviour. You can give further details about behavioural problems in the relevant section.

- Do they need guidance and supervision most of the time when they walk outdoors?

If a child needs more guidance and supervision than other children of their age, they will get the lower rate of mobility (from the age of 5). See the rules [for the lower rate of mobility](#).

All children who have Down's syndrome need more guidance and supervision than their peers. It is important to explain why your child has greater needs. You can use the additional info box or attach an extra sheet of paper.

Reasons why your child's needs are greater may include:

- Children who have Down's syndrome have developmental delay. Many children have limited speech compared to their peers, (who would be able to ask for help if they were lost and give their name and address).
- Some children may not be able to talk even in short sentences and may rely on Makaton sign language for communication. Although parents and carers involved with the child can understand them, it may be difficult for strangers. Similarly, even those children with some speech are likely to be difficult to understand for people who aren't familiar with them.
- Some children may have hearing problems as well as having Down's syndrome and so have difficulty understanding other people.
- Many children with learning difficulties are particularly vulnerable as they are not aware of 'stranger danger'. They may be a lot more trusting than a child would otherwise be at their age.
- Some children may not be fully aware of the danger of traffic and the consequences of running into a busy road. They might need a lot more physical supervision, for example, always holding hands, or being reminded of danger. Children at 5 and older would usually have a degree of road sense and potential danger.

There could be other reasons. Do not assume that the decision maker knows much about Down's syndrome or about the development of children without a disability. You must explain why your child needs the supervision and why this differs from a child of the same age without learning difficulties.

The second set of tick boxes gather information related to getting the higher rate of mobility as "[severely mentally impaired](#)", as well as information relevant to the lower rate of mobility.

If you think that your child meets the criteria for "Severely mentally impaired", you need to give as much detail you can about disruptive behaviour, unpredictable behaviour, the need for regular physical restraint, and why they have to have someone with them all the time they are awake. Please have a look at "[Severely mentally impaired](#)" for more information.

You can use the additional info boxes or attach extra sheets of paper.

If you think that your child may qualify under this rule, you need to get further information from other people, for example, a letter from someone who knows how your child behaves, for example a teacher or social worker or a health professional.

Remember your child must get the highest rate of the care component to be considered under the “Severely mentally impaired” rules.

- Do they fall due to their disability?

If your child falls, then this question asks how often and if they need help with getting up. If your child falls frequently then it may be a good idea to keep a diary for a week or so to work out an average.

- Start of mobility needs.

Estimate when your child’s difficulties with walking started.

Higher rate mobility can be awarded at age 3. Lower rate mobility can be awarded from age 5. There is a 3-month qualifying period for DLA, but it can be satisfied by the 3 months before the 3rd or 5th birthday, so an award can start immediately.

Usually, if the higher rate of mobility is being considered, you or people who know your child will be asked for more information.

Care questions for children aged 3 -16

This section takes you through the claim form.

Remember, focus on:

- a. any help that takes longer with your child
- b. any help that most other children don’t need
- c. any help that usually only younger children need

Some questions ask how often help is needed a day, and how long it takes. If the help isn’t the same every day, give details of how it varies in the text boxes.

- Getting in and out of bed, settling in bed, during the day

This is about getting up in the morning, going to bed in the evening, and naps during the day. If your child gets up in the night (after you have gone to bed, roughly 11pm to 7am), see question ‘Do they wake and need help at night, or need someone to be awake to watch over them at night’ later in the form.

Remember that the needs should be over and above those normally required by a child of the same age. It is important to give specific information about times. You may find it easier if you keep a diary for a few days. Your child may need:

- Physical help if their motor skills are delayed (younger children)
- More help settling and reassurance than other children of their age
- More help with prompting, reminding and encouragement to wake up or settle to sleep than other children of their age.

- Toilet needs

Your child may have extra toilet needs because they may still be in nappies at an age when most children are toilet trained. They may have more accidents as they are learning. It may take more time and effort to teach them to use the toilet. Once they are older, they may still need some help, for example, cleaning themselves, for a lot longer than other children, or they may continue to need supervision, checking that they are OK, at an age when most other children don't. If you repeatedly remind your child to go to the toilet (at an age when most children would be able to decide for themselves) mention this here. Give information if your child needs to go to the toilet more than other children.

Some children are born with bowel blockages that need surgery. They can be left with significant toileting needs which affect their day and night care.

- Moving around indoors

Your child may be delayed in learning to walk so they need help getting around indoors when most other children would be walking well. Low muscle tone, hypermobile joints and loose ligaments may also make moving around more difficult for older children. Explain why your child has difficulties in the additional info box.

- Washing, bathing, looking after your appearance

Your child may need extra help with washing and bathing. This could be things like help washing their face or brushing their teeth at an age when most children are doing it themselves. It may take longer than for most other children because your child has low muscle tone and does things slowly, or perhaps because they dislike certain activities or have sensory issues and must be persuaded. Older children may need lots of prompting and reminding, and checking that they have washed, etc, to a reasonable standard. They may have very dry skin, so you need to spend extra time applying creams after a bath. Or they may need more supervision in the bathroom, for example, because they might scald themselves, or put things down the toilet. If your child has allergies or there is a reason why they must be washed more often then you need to say that here.

Give specific details about the time the activity takes.

- Dressing and undressing

Your child may need extra help with getting dressed and undressed. As with washing and bathing, this may be because they still need help from you at an age when most children are doing it for themselves. Most children at 3 can dress and undress to some extent. Your child may be slower because of poor muscle tone, or because their fine motor skills aren't fully developed. They may need more help deciding on the right clothes for the weather. Can they manage buttons or laces? They may have favourite clothes and be reluctant to wear others. Your child may need more changes of clothes than other children, perhaps because they are still in nappies, or tend to have more accidents than other children. Most older children in this age group would be completely independent in dressing and undressing, so any help, encouragement, prompting your child needs is considered.

- Eating and drinking

Your child may need extra help with eating and drinking. Younger children in this age group may still need to be fed, or to have their food cut up for them. Children may need a lot of help learning to feed themselves, which may make mealtimes longer. Some children may just eat very slowly so mealtimes take a lot longer than usual. Some children may be resistant to eating solid food, or different food, and may need lots of prompting and encouragement to try new foods.

- Medicines and therapy

This question applies to those children who must take medication on a regular basis. For example, a child may need to take tablets several times throughout the day due to a heart condition. They may need to have regular tests to monitor their blood or they may need help with an inhaler.

You would also list any therapies that your child has, such as physiotherapy, speech therapy or portage/play therapy. It is the time that **you** spend doing these therapies with your child daily, not the visits from the therapists, that is important. If you are not sure, just keep a notebook and write down the times spent. It makes it much easier when completing the form.

- Vision

If your child needs glasses or contact lenses and they still have trouble seeing clearly or focusing, you need to list it here. Some children have nystagmus or trouble focusing even if they wear glasses. There can also be the additional problems of children not co-operating with wearing their glasses, especially younger children, or the stressful situation of trying to put contact lenses into your child's eyes. The time you spent on helping your child with these things counts towards DLA.

- Hearing

Your child may have impaired hearing. They may need to wear a hearing aid and you can write about this here. If your child routinely pulls their hearing aid out, mention this also.

- Speaking

It is important to be aware of the normal range of speech development when completing this section, especially for younger children. Most children who have Downs Syndrome will have a delay in their speech. Sometimes this can be due to a problem with hearing.

At the earliest stages of speech development, babies will coo and babble. At the age of 9 months they start to make sounds such as 'dada' and 'mama' even though they may not understand their meaning. At age 12 months they should be able to imitate sounds. Most toddlers will have around 20 words in their vocabulary by the age of 18 months and around 50 words by the age of 2 years when they will start to string a couple of words together. After the age of 2, a child's vocabulary will increase, and they will be able to talk in sentences of two and three words. From 4 onwards, a child would normally be expected to speak clearly and to make themselves understood.

You can give an indication in the text box of how delayed your child's speech is compared to most children of their age. You can give more detail, for example, your child may speak more than single words, but only use 2 - 3-word phrases, but not simple sentences.

Speech difficulties in older children are easier to recognise and describe.

- Communication.

This is about how your child communicates and about their understanding of verbal and written communication.

Parents should be able to understand around half of their child's speech at age 2 and three quarters of their speech at age 3. Probably most children in this age range who have Down's syndrome need extra help understanding and being understood. Some may be unwilling to communicate as well.

Use the text box to give specific information. Speech delay and their learning disability both affect communication. Even if your child speaks well, as many older children do, they may find it hard to understand instructions or to convey what they mean. Do they find it easier if they are spoken to slowly, or more simply? Do they need speech therapy?

- Blackouts and seizures.

If your child has any type of seizure or fit, write about this here. Obviously for very young children they will not have awareness and will be totally dependent on their parent or care giver. If your child has frequent fits, note down the times over a week or so, it makes it much easier when completing the form.

- Does your child need extra supervision?

All young children need to be supervised in order to keep them safe.

Children with Down's syndrome aged 3 - 16 will almost always need "continual supervision throughout the day in order to avoid substantial danger to themselves or others" at a level of supervision which is greater than most other children of the same age.

Your child may need more supervision than other children because:

- they are later to learn about common dangers in the home, such as electric sockets, hot water, the cooker, knives, etc.
- they don't respond to verbal commands, but have to be physically stopped from doing something dangerous
- they can't be left on their own but need help to keep busy and follow a routine
- activities which most children of their age could do independently still need to be supervised
- they may do very well in a structured routine, but not be able to cope with well with changes
- they may be vulnerable to "stranger danger", even at home, if someone came to the door
- older children may need more emotional support than their peers or they become very anxious or distressed

- Help with development.

If your child has 1:1 support at nursery or school and must be shown how to play and share, you should write about this here.

Your child may be delayed in learning to walk, jump, or run. They may walk unsteadily with a lot of falls, at an age when most children are walking well. They may have poor balance and co-ordination, so they can't cope with steps or kerbs or uneven ground. They may get tired more quickly than other children because of their poor muscle tone. They may have difficulty with fine motor skills, for example, grasping a pencil, or picking up small objects. They may be seeing a physiotherapist and do exercises every day. They may have problems because of poor vision or poor hearing.

Their language development may be delayed, and they may see a speech therapist.

For older children, it may be useful to give details of the level they have reached in school. They may need a great deal of support to continue developing their understanding of themselves and the world around them, especially as they become adolescents.

- Prompting and help at school.

If they need 1:1 help whilst at nursery or school, mention this and why they need the help, for example with understanding simple instructions or help eating their food, or to participate in lessons and activities. Remember that it would have to be help over and above the needs a child would normally require at this age. Many older children who have Down's syndrome will need help to access lessons and continue learning and to be able to participate with in activities with their peers.

- Encouragement to engage in hobbies / activities

This question is not relevant for very young children as they all need a level of help to take part in activities. These questions are on the form because the help your child needs with social or leisure activities – any help they need to live “a normal life” - counts for DLA. Help to take part in social and leisure activities becomes more important for older children as their peers grow up and become more independent.

- Night needs

“Night” refers to the time when the whole household has shut down for the night, that is, after you and other adults have gone to bed, not when your child goes to bed. It is often thought of as between 11pm and 7am. It is helpful if you keep a diary of the amount of times you wake during the night. The needs must be over and above the needs a child would normally require at this age.

Try to be specific about why you must get up with your child and how long it takes. Your child's needs may vary, so it may be helpful to give an average, and a range of times as well. For example, “he wakes up 4-5 nights a week, once or twice. It usually takes about 20 minutes to settle him back to sleep, but it can range from 10 minutes to 2 hours. It probably takes 2 hours once or twice a week.”

The night-time need for “watching over” is about an adult being awake during the night. You are being asked about the need to wake up, or to be awake, to make sure that your child is safe. You may need to wake up

and go to check your child, or to wake and listen out for them. This may be because they have sleep apnoea, or they get up and wander at night, or they tend to throw their covers off. Or they may get up and play or disturb other members of the household. Or you may have to get up to them to keep them safe while they are awake during the night.

All children need adults to be in the same house during the night. Many children who have Downs Syndrome take a longer time to settle down, some may not understand the night-time routine and simply want to play. However, some children take so long to settle that you may feel you would go to bed earlier yourself, if your child didn't need this attention. If this is the case, say so.

- Extra information.

If there is anything that you haven't had the chance to explain, then this is the place to put it. If you run out of room then carry on writing at question 70 or on an extra sheet of paper. You can attach this to the form. Remember to put your child's name, date of birth and National Insurance number on any extra sheets.

- When did the care needs start?

There is a three-month qualifying period for DLA and so the earliest that new or increased care needs can be considered is after they have existed for 3 months. It can be difficult to think of an actual date when your child's extra needs started.

Remember to keep a copy of your completed form.

Challenging decisions

What to do if you are unhappy with a decision

When you apply for DLA/CDP for your child, you may not be happy with the decision. For example:

- Your child may be refused completely
- Your child may be given a rate you are unhappy with
- Your child may be given a limited award, for example, only for two years
- The award may start from a date which you feel is not right

This could happen whether it is your first claim, or a renewal claim. It is possible to get your decision changed.

The Department can [revise](#) a decision. This means that they agree that the original decision was wrong. The revised decision takes effect from the date of the original decision.

They can [supercede](#) a decision. This means they agree that something has changed since the original decision and that it should be changed. The new decision takes effect from the time that it is made. This can only be done if you already have an award of DLA- you cannot ask for a previously rejected claim to be superceded because your needs have since increased. You would have to make a fresh claim.

Both revisions and supercessions are called “reconsiderations” , since they involve a decision maker looking at a case again.

Reconsiderations and revisions

If you are unhappy with the new decision, you can make a request for a reconsideration. This must be received within one calendar month of the date after the date on the decision letter.

For example, if the decision letter is dated 2 April, your request must be received by 2 May. If there is no corresponding date in the following month, your deadline is the last day of that month. For example, if your letter is dated 31 May, your deadline is 30 June.

This deadline can be extended in some circumstances. The most common one is that you ask for **written reasons for the decision**. This extends your deadline for asking for a reconsideration by 14 days. Often the written reasons are not very helpful in giving an insight into why a decision was made.

If you miss the one-month deadline, you can ask for a late revision in very limited circumstances. Don't delay and get advice in this situation.

How do I get a reconsideration?

The easiest way to apply for a reconsideration is to download form CRMR1 from the gov.uk website, or in Scotland, <https://www.mygov.scot/disagree-decision> to fill in online, or print and send in.

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

If you intend to send in supporting information after submitting the form, you can tell them and they will give you a date that they need it by. If you send it in later, a decision may be made without considering the new information. It is helpful to send in extra information at this stage.

A different decision maker will look at your case again. The decision maker does not have to consider any point you don't raise specifically. Think about:

- How your child's needs are relevant to the rules
- Explaining any information which looks inconsistent
- Explaining clearly how your child's needs vary (if they do)
- Setting out information in the form of a diary
- Sending reports from professionals who know your child. Though be careful – often medical or education professionals describe things in a positive way, and this can be used to say that your child's needs are not that great.

A different decision maker will look at your case again. They may decide to change the decision. This is called a revision. It will take effect from the date of the original decision.

If they do not revise the decision, you can ask for an [appeal](#). You can do this within one month of the date of the reconsideration decision.

If you want to go to appeal, you must ask for a reconsideration (a revision or a supercession) first.

Supercessions

If you want your child's award of changed, but you are not within one month of a decision, you can ask for a supercession.

You can only get a supercession for certain reasons, for example, your child's needs have increased, or you think the original decision was wrong because they did not know important facts, or they made a mistake.

You need to write, explaining the grounds for the supercession. Then you will usually have to fill in another form. This gives you the chance to include new information about your child's needs. You can contact DLA at **FREEPOST DWP DLA CHILD**. CDP can be contacted at Social security Scotland, PO box 10303 DD1 9FY OR calling 0800 182 2222.

A decision maker will look at the new form and decide whether to supercede.

If the decision is superceded, backdating of any increased benefit will only go back to the date you asked for the supercession.

If they will not change the decision, you then have the right to appeal. You have to ask for an appeal within one calendar month of the day after the date on the decision letter.

If I ask DLA/CDP to look at my child's benefit again, can I lose out?

Often when you ask for a revision, supercession or appeal, the DWP say you could lose the benefit you already have. This is possible, but in practice, it is very rare for children with Down's syndrome.

It can be difficult to know what to do, especially if you are refused benefit completely.

Appeals

If the decision has not been revised or superceded, you can then ask for an appeal. You can do this within one calendar month of the day after the date of the revision or supercession decision.

Appeals are made to the Social Security and Child Support Tribunals of HM Courts and Tribunals Service. Going to appeal allows your case to be looked at by an independent body and gives you the chance to discuss your case to someone face to face, (if you decide to go to the hearing in person).

You need to include a copy of the reconsideration decision that you are appealing against.

<https://www.appeal-benefit-decision.service.gov.uk/benefit-type>

If you want to appeal, get advice. The process is complicated, and statistics show your chances of success are greater if you get advice.

Contact the DSA Benefits Adviser on our helpline 0333 12 12 300.

If you challenge a DWP decision, keep copies of letters, and make a note of the dates of phone calls, a summary of what was said, and the name of the person you spoke to.

DLA/CDP and other benefits

You may get more money in your existing benefits once your child gets benefit.

If your child gets the middle or higher rate of the care component, you may get Carer's Allowance and if you are in receipt of Universal credit, you may get the carer amount added plus an amount for your child's award.

It can also positively impact Child tax credit or any income-based benefit you may receive. As soon as you have an award, let the appropriate office know. If you are awarded Higher rate mobility component, you may qualify for a motability vehicle and also an automatic entitlement to a blue badge through your local council. Check with:

- your local DWP office (for Income Support, Jobseeker's Allowance, Universal Credit) or
- your local council (for Housing Benefit and Council Tax Support) or
- the Tax Credit Helpline on 0345 300 3900 for Child Tax Credit and Working Tax Credit

[Carer's Allowance](#)

Blue Badge scheme

DLA contacts

Disability Living Allowance Unit

Tel: 0800 121 4600 |

For children under 16:
Disability Benefit Centre 4
Post Handling Site B
Wolverhampton
WV99 1BY

For age 16 and over – PIP
0800 121 4433

Child Disability Payment (Scotland)

[Tel:0800](tel:0800182222) 182 2222

Carer's Allowance Unit

Tel: 0800 731 0297
Palatine House
Lancaster Road
Preston
PR1 1HB

[MENCAP National Office](#)

Tel: 0808 808 1111
123 Golden Lane
London
EC1Y 0RT

[Motability Car Scheme](#)

Tel: 0300 456 4566 Minicom: 0845 675 0009
Motability Operations
City Gate House
22 Southwark Bridge Road
London
SE1 9HB

[HMRC Tax Credits Helpline](#)

Tel: 0345 300 3900
Text phone: 0345 300 3909

