Claiming Disability Living Allowance for children

Information for families in England, Northern Ireland, Scotland and Wales



Introduction

Disability Living Allowance (DLA) is the main benefit for disabled children and is there to help meet any extra costs of being disabled. Any ill or disabled child may be able to qualify, even those who don't have a diagnosis. It is not means tested so your financial situation will not be taken into account. DLA is also not taxable or treated as income for other benefits.

Instead, DLA can sometimes lead to an increase in other benefits, or help families qualify for them if they don't already get them. In short, DLA can make a real difference to a family's overall income.

You will find this guide helpful if you are thinking of claiming DLA for your child for the first time, or if you are already getting DLA for your child and want to check if they're entitled to a higher rate. We also give information about challenging a decision if you are unhappy with the outcome.

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Information in this guide

Disability Living Allowace (DLA) for adults is in the process of gradually being replaced by a new benefit called the Personal Independence Payment (PIP). However, this only applies to claimants of working age and not to disabled children aged under 16. The government will consider whether to move disabled children onto the PIP at a later date once they can evaluate how PIP is working for disabled adults. For more information about PIP, call our freephone helpline.

🐙 🛛 0808 808 3555 🚽 helpline@cafamily.org.uk

Who can claim?

Any ill or disabled child may qualify and you don't have to wait for a diagnosis to make a claim. However, to make a successful claim for Disability Living Allowance (DLA) you have to show that your child needs substantially more care, attention or supervision than other children of the same age who don't have a disability or health condition.

Your child will also need to have had the extra care or mobility needs for at least three months and be expected to have them for at least six months more. This means the earliest DLA can be paid from is three months of age. If your child has a terminal condition and you've been told they may not live for more than six months, there are special rules which mean the benefit can be paid from birth. Please see page 8 for more information about this.

Your child will also need to meet certain tests linked to their residence and presence in the UK. If your child is out of the country now, or has been out of the UK for more than two out of the last three years, call our freephone helpline for further advice.

Warning!

If you think your child may be subject to immigration control, call our freephone helpline for more advice. You should not claim DLA for a child who is subject to immigration control without first speaking to a specialist adviser as a claim could affect their right to stay in the UK.

How much is DLA?

DLA has two main parts called 'components'.

Care component

The care component is paid for children who need extra care and attention. It can be paid at one of three weekly rates, depending on how much extra help your child needs. During the period April 2015–16 it is paid at the following weekly rates:

Mobility component

The mobility component can be paid for children who either have problems with walking or with getting around in unfamiliar areas. During the period April 2015–16 it is paid at one of the following two weekly rates:

Mobility component

- Lower mobility £21.80
- Higher mobility £57.45

Care component

- Lowest care £21.80
- Middle care £55.10
- Highest care £82.30

A child can get one or both components at the same time.

Terminology

To assess what rate of DLA should be paid, some of the words in the rules have a specific meaning:

- **Bodily functions:** includes anything to do with how the body works, like breathing, eating, drinking, hearing, seeing, walking, sitting, dressing, undressing, washing, bathing, toileting and sleeping. If the help can be done in another room, away from the child, it is unlikely to count unless it is closely connected to something personal, for example changing bedding after a child has wet the bed.
- **Supervision:** someone present to prevent any accidents or harm to your child or others.
- **Substantial danger:** there must be a realistic possibility that without supervision your child could seriously risk harming themselves or others. This situation may arise infrequently or be a one-off.
- **Night:** starts from when the whole household goes to bed and ends when everyone gets up.

The care component

If your child needs a lot of extra looking after, or help with their personal care because of a physical or mental disability, they should qualify for the care component of DLA.

• The lowest rate care component is paid if your child needs help with personal care for a 'significant portion of the day'. This means for at least an hour on most days – for example, help with washing and getting dressed in the morning. This help may be given all at once or be spread out through the day.

• **The middle rate care component** is paid if your child has either 'day-time needs' or 'night-time needs'. Day-time needs means they need either:

- 'frequent' help with personal care, in connection with their bodily functions. This means several times throughout the day, or
- continual supervision throughout the day to avoid substantial danger to themselves or others. Continual supervision means frequent or regular supervision, rather than non-stop supervision.

Night-time needs means that during the night your child requires either:

- 'prolonged' help with their personal care. This means for at least 20 minutes, or
- 'repeated' help with personal care during the night. This means at least twice, or
- to avoid danger to themselves, or others, another person needs to be awake and watching over them for either a 'prolonged' period or at 'frequent intervals' (this means more than twice).

The highest rate care component is paid if your child has day-time and night-time care needs, or if they qualify under the 'special rules' (see page 8).

To qualify for DLA care component, your child's care needs must ultimately stem from a disability. And they must need **substantially more** help than a child of the same age without a disability.

The mobility component

If your child needs help getting around they may qualify for the mobility component.

The lower rate mobility component is for children who can walk but who need someone to supervise or guide them. It is paid from five years of age. Your child may still qualify even if they can get around places they know well, because the test is whether they need guidance or supervision in places they don't know well. It is often claimed for children with visual or hearing impairments, or learning disabilities, but others can qualify.

To get the lower rate, the help your child needs with supervision and guidance must be greater than that for a child of the same age without a disability.

The higher rate mobility component is for children who are unable to walk or are 'virtually unable to walk'. This can be paid from the age of three years. Things that are taken into account in deciding if your child is virtually unable to walk include the speed, length of time and manner of walking, as well as the distance they can cover before they start to experience severe discomfort (for example, breathlessness or pain). It is also for children:

- who are both deaf and blind, or
- whose health would deteriorate with the exertion of walking, or
- who have severe mental impairments (see below), or
- who have no legs or feet, or
- who have a severe visual impairment. Your child will qualify if their best corrected visual acuity is less than 3/60. Or if more than 3/60, is less than 6/60 with a complete loss of peripheral visual field, and a central visual field of no more than 10 degrees in total.



The higher rate mobility component and children with severe mental impairments

The higher rate mobility component can also be paid to some children with severe mental impairments. To qualify your child must be:

- entitled to the highest rate care component of DLA, and
- have 'a state of arrested development or incomplete physical development of the brain which results in severe impairment of intelligence and social functioning'. You are likely to need evidence from a professional showing this is the case, and
- 'exhibit disruptive behaviour' which is 'extreme' and 'regularly requires another person to intervene and physically restrain them to prevent them from causing physical injury to themselves or another person, or damage to property', and



• be so unpredictable, they need another person to be there watching over them whenever they're awake.

Some children with learning difficulties who don't qualify on the above grounds, can qualify because they are 'virtually unable to walk'. This may apply to children who have a condition on the autistic spectrum, or a learning disability like Down syndrome, who often simply refuse to walk. If you think this applies to your child call our freephone helpline for advice.

• We have a *Guide to Disability Living Allowance – claiming the higher rate mobility component for children with learning difficulties and autistic spectrum disorders* available free to parents who call our freephone helpline, or you can download it from our website at www.cafamily.org.uk/pdfs/DLA_learningdisabilities.pdf

Special rules

Special rules if your child has a terminal illness

If your child has a terminal illness and is not expected to live for more than six months, you can claim under a fast-track procedure known as the 'special rules'. DLA can be paid straight away (there is no threemonth qualifying period), and you will only need to fill in certain parts of the DLA form. See question 23 of the form for more details.

You will need a DS1500 medical certificate from your GP or hospital specialist. A child who qualifies under the special rules will automatically get the highest rate care component once a claim is made. But to get the mobility component, your child will need to meet one of the tests for it, described on page 6.

'Special rules' awards of the care component are normally made for a fixed period of three years. If your child also qualifies for the mobility component, a decision maker has to consider whether to award it for the same amount of time or indefinitely.

Children undergoing renal dialysis

There are specific rules for some kidney patients who have renal dialysis to help them qualify for the middle rate of the care component. To qualify, your child must have this treatment regularly for two or more sessions a week. You also need to show that:

- either the dialysis is a type which needs another person (other than hospital staff) to be there to watch over them or attend to their needs, or
- because of particular circumstances like age, another person needs to be there while they are dialysing.

🦳 For further advice, please contact our freephone helpline.

0808 808 3555 helpline@cafamily.org.uk

Children under 16

If your child is under 16 years of age, use claim form DLA1A Child, available from local benefit offices or by calling the Disability Living Allowance helpline.

You can also download a claim form from the GOV.uk website, but is preferable to phone the DLA helpline and ask for a form. This is because the form they send you will be date-stamped with the date you made your call and this will help ensure the benefit is paid from the earliest possible point. See information on page 10 on deadlines and backdating for more details.

At the time of writing it is not possible to claim DLA online. But this is something that may change over time, so call our freephone helpline for an update.

Children older than 16

From age 16 a young person must claim Personal Independence Payment rather than Disability Living Allowance. This applies everywhere except Northern Ireland. See page 39 for more information or call our freephone helpline.

In Northern Ireland there is a different DLA claim form for young people aged 16 and over, and adults. It is planned that Personal Independence Payment will eventually replace DLA claims by adults aged 16 and above in Northern Ireland but a timetable for its introduction has not been announced. Call our freephone helpline for updates.

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Call the Disability Living Allowance helpline to make a new claim for DLA or enquire about an existing claim. They also have a service for people whose first language is not English. 0345 712 3456 Textphone 0345 722 4433

Families in Northern Ireland can call: 0800 22 06 74 Textphone 028 9031 1092



Deadline for claiming DLA and backdating a claim

At the time of writing, DLA can't be backdated. The earliest it can be paid is the date the form was requested or issued. Forms sent from the DLA helpline will be 'date-stamped' on the day you call and you are given six weeks to complete and return the form. If your child qualifies, DLA will be paid from the date it was stamped. Otherwise, the earliest it can be paid is from the date the benefits office receives your form, so it's always better to call and ask for a form to be sent to you.

Claiming for babies

Three months is usually the earliest you can get the DLA care component (unless your child has a terminal condition).

All very young children need a lot of care and attention, so the younger your child, the harder it can be to show they need more help than other babies of the same age. But you can still get DLA if you show that your baby needs a different type of care than other babies, or if that care has to be provided more frequently, or over a longer period.

For example, all babies need help feeding but if your baby takes longer to feed, has feeding problems or needs feeding by a tube or drip then they are likely to qualify for the care component.

Other common situations where a baby is likely to qualify include:

- babies with severe visual or hearing impairments
- those who have seizures
- those with renal failure
- babies with severe multiple disabilities, and
- babies who are born very premature.

Babies who need suctioning, oxygen treatment, or who have had a surgical procedure, such as a tracheotomy or colostomy, are also likely to qualify.

This list is not exhaustive, other babies may qualify. Because of the difficulties getting DLA for babies, get specialist help to fill in the form.

Completing the DLA1A Child form

The form has 41 pages. Not surprisingly this can be off-putting for a lot of parents. You may also feel that certain parts of the form are not relevant to your child. But it is important to read all the questions carefully just in case. Not saying that your child needs help at night, even if it is for just 20 minutes, could make a big difference to the decision that is made on their claim.

It is worth reading the Information Booklet which comes with the form, and try using the 'daily diary' sheet at pages 29–31 of the booklet.

The following section is a brief explanation of some of the more difficult parts of the DLA1A Child form with comments about the kind of information to include.

When you fill in the form try to use examples and anecdotes to describe your child's needs wherever possible. Don't just rely on the tick boxes.

When you fill in the form you may feel that some of the pages don't have enough space to capture the complexity of your child's needs. There are extra boxes at pages 18, 36 and 40 if you need to give more information about your child's needs. You can also attach extra pages of information if you feel this is necessary.

Please remember that a decision on your child's claim will be made by someone who has never seen your child and who may have little or no knowledge about your child's condition. It is important that you make clear all the extra care and support that your child needs – don't assume that the decision maker will already have this understanding.



Get help to complete the form. Call our freephone helpline for details of local organisations that can help

0808 808 3555

helpline@cafamily.org.uk

www.cafamily.org.uk

General tips on completing the DLA form

Take your time and don't try to finish it in one go. The form is long and needs lots of information. Read through it first before putting pen to paper so you have an idea of what's needed.

If possible get specialist advice from a welfare benefits adviser or someone else who is familiar with completing the form. This will increase the likelihood of your child being awarded the right level of DLA. Call the Contact a Family freephone helpline if you would like details of local organisations that can help.

Keep a diary for a week before tackling the form. Include details of the amounts and types of care your child needs during the day and night. This will be useful when you fill in the form and can be used as evidence. It will also be a useful aid in helping you think about all the extra help your child needs. (See pages 29-31 of the Information Booklet that comes with the claim pack).

Cross out mistakes rather than using correcting fluid.

Give as much information as possible. You can write outside of the boxes and attach extra sheets if you run out of space.

Don't play down your child's condition. Although it's hard, try not to include details of your child's abilities and achievements. Include the bad days, as these will give the decision maker's an insight into the full extent of your child's needs.

If your child has a fluctuating condition use the terms 'bad days' and 'better days' to describe the changes in their condition. Using terms like 'good days' or 'normal days' can imply your child needs no extra help on these days.

Say how often your child needs help, rather than how often they get help.

Show how your child's needs are different to those of other children of the same age. Is your child's level of competence age-appropriate for different tasks? If you have older children compare their needs at the same age or compare your child's needs with those of a friend or family member's child.

Ask yourself – have you included enough detail to convince someone who hasn't met your child? The application will be assessed by someone who hasn't met your child and who may not be familiar with your child's condition. If they have a rare condition, you may have information about it you can include to help the decision maker understand more. We have information on hundreds of conditions, including rare ones, on our website at www.cafamily.org.uk, or you can call our freephone helpline and ask for a copy to be sent to you.

Include supporting evidence with the form if you have it. This can be medical reports, speech and language assessments, psychological reports, and a statement of special educational needs – anything that supports what you've said in the form. But don't delay making a claim if you haven't got these reports yet, as DLA can't be backdated and you could lose out. If you write on the form that you'll be sending further information the decision makers should accept it.

Read through the form before you send it. Have you included enough information? Have you answered all the relevant questions? Are your contact details correct? Have you missed anything? Is the professionals' evidence complete?

Keep a copy of the form and any supporting evidence for your records. You might need it if you are unhappy with your award and wish to challenge the decision. It will also help you when the claim is due for renewal or if you want to apply for a different rate later on.

Reward yourself when the form is finished. Filling in the DLA form can be time consuming, and because you're concentrating on the things your child can't do, stressful and demoralising. But if you get the DLA it will be worth it in the end.

> QUESTIONS 1–18: General information about your child

These questions gather general information about your child including details about their identity, nationality, disability, and details of any medical or health professionals involved in their care. This section also asks you about any stays your child has had in hospital or residential care within the last 12 months.

> **QUESTION 19:** Statement from someone who knows the child

A paid carer, relative or friend, health care professional, social worker or a teacher can fill this in. Ideally, it should be written by a professional with regular involvement in your child's care, like a medical specialist, or if your child's needs are mainly to do with learning, ask a specialist teacher.

It is very important to check that the statement is supportive and not harmful to the claim. Copy the blank statement page and give it to the person writing the statement. You can attach it to your claim. If you're unhappy with what they have said, you can ask them to change it, but if they won't, you can ask another professional to write this part or just leave it blank.

> QUESTION 21: Your child's

illnesses or disabilities

You don't need to enter a lot of detail here but make sure you write the name of each condition your child has been diagnosed with, for example 'ADHD' or 'Down syndrome'.

If your child doesn't have a diagnosis, or if they have difficulties separate from a diagnosis you've already mentioned, put a general description of these too (for example 'eating and feeding problems' or 'behavioural problems').

> QUESTION 24

If your child's condition varies, you can still get DLA as long as there is a pattern of substantial care needs or mobility problems. They might have days or weeks when they need less help.

When filling in the form, tick any of the boxes which apply to your child, even if it doesn't apply all the time. You can explain more about any variation in needs in the boxes below each set of tick box questions and at question 65 about 'more information'.

It is a good idea to keep a diary over a period of a week or longer if your child's condition varies a lot. Use the terms 'bad days' and 'better days' to describe the changes in your child's condition if they have a fluctuating condition. Using terms like 'good days' or 'normal days' can imply your child needs no extra help on these days.

> QUESTIONS 25–36: Mobility

Remember, help with mobility applies to children whose problems getting around are caused by learning or behavioural conditions, as well as children with a physical disability.

If your child has physical problems which affect their walking outdoors, you should answer questions 25–31 and questions 33–36.

If your child can walk it is important to describe how they walk (for example with a limp or shuffle).

List the effects walking has on their condition. This may include fatigue, breathlessness or nausea, or that walking makes their condition worse.

When assessing how far your child can walk, remember that any distance covered after they've started to feel severe discomfort is not counted. Ask yourself:

- does your child walk more slowly than other children of the same age?
- does their manner of walking make it difficult to get along?

- do they get uncomfortable or tired after a short distance?
- do they fall or stumble a lot?
- does the effort of walking seriously affect their health?

If your child can walk but needs guidance or supervision, you should answer questions 30–36.

The notes on page 13 of the form suggest that you should only complete questions 32–34 if your child is aged five or over. But if your child is aged three or four and has severe behavioural problems or refuses to walk, you should fill in these questions. Some children with learning disabilities or autism spectrum disorders can qualify for higher rate mobility because of severe behavioural problems from age three. See the earlier section of this guide at page 7.

Think about why your child needs more guidance or supervision than children the same age.

- does your child have behavioural problems which could lead to danger?
- do they have a learning or communication problem which means they could get lost or are more vulnerable to danger?
- does your child have a visual or hearing impairment and need extra help with following directions and avoiding obstacles?
- does your child's hearing impairment mean they can't hear dangers coming from behind?
- are they likely to stumble or fall without someone's help?

• Help with mobility applies to children whose problems getting around are caused by learning or behavioural conditions, as well as children with a physcial disability.

> QUESTION 32

Also asks about unpredictable behaviour, the need for restraint and refusal to walk. These questions relate to the higher rate mobility and severe behavioural problems. See page 7 for more details.

If this describes your child's behaviour then it is important to give as much detail as possible. Here are some examples:

- does your child regularly refuse to walk, or do they have to go through rigid regimes to get anywhere?
- do they get distressed and likely to hit out at you or other people, or harm themself in some way?
- do they run away suddenly without attention to dangers like traffic?

> QUESTION 36

This asks you the date your child first started to have the problems with getting around you have described. Your child must have had mobility problems for at least three months before they can get any payment of the mobility component. An exception to this is made if a child is terminally ill under the special rules.

> QUESTIONS 37–53: Your child's personal care needs

These sections cover the extra help your child needs with their day-to-day care. Fill them in not only if your child needs physical help or support but also if they need encouragement or verbal prompting, with tasks.

Try to think about how your child's needs differ from a child of the same age without any disabilities. Make clear if you have to do more to help your child or if things take longer to do.

> QUESTION 37: Getting into and out of bed

Explain any discomfort your child experiences because of pain or stiffness when waking up.

They may be physically unable to get out of bed without help. Or they might not have the motivation to get up because of their condition and need lots of reassurance and persuasion to get out of bed. Medication may also affect your child's sleep and waking up.

Explain if you have to get up straight away in case they do something dangerous or are disruptive.

Think about similar difficulties when going to bed. Your child may still be wide awake when put to bed or refuse to settle.

Explain what help you give them to overcome this, like comfort and reassurance techniques, or medication, or treatments. You should also say how long this takes.

> QUESTION 38: Toileting needs

You will need to explain any difficulties during the night at Question 53. As well as writing about what help you give your child to stay clean and manage their continence (washing, bathing, applying creams, changing pads, checking clothing or changing bedding), you also need to give information about any difficulties. These can include:

- more frequent bowel movements or episodes of wetting
- any resulting pain or distress
- constipation
- problems with transfer to and off the toilet
- not wiping themselves
- playing with faeces or missing the toilet
- problems with undoing zips or buttons
- taking underwear or clothing on and off
- prompting and reminding your child to use the toilet and to wash their hands afterwards
- help with any equipment
- refusing to use the toilet.

> QUESTION 39: Your child's

needs when moving about indoors

Include here a description of the help your child needs getting around inside. For example, your child may have mobility difficulties that mean they:

- need extra help moving from room to room, or
- getting on and off chairs and other furniture, or
- getting up and down internal stairs, or
- need help transferring in and out of a wheelchair they use indoors, or
- if they have a visual impairment they might need help to get around safely
- if your child does not have mobility problems indoors they might need prompting to move around, or reminded which room to go to, or they might need you to go with them.

> QUESTION 40: Bathing, showering and hygiene

Washing and bathing includes all issues with personal hygiene.

Your child may need extra help bathing, washing, or showering and they might take longer than other children of the same age. For example:

- they may need help to stand to wash or shower
- if they're sensitive to touch, then brushing teeth or hair may be painful so could take longer
- you might have to supervise them while they bathe or wash, if for example, they can't tell the difference between hot and cold, and risk being burnt
- your child may refuse to get in or out of the bath or may be too tired
- they may need to wash more often than other children, or you may

need to remind and encourage them to wash

- washing and bathing may be difficult because of dressings, or a line into a vein that needs to be kept dry or sterile
- or you might need to take off other equipment which makes it more difficult for you to communicate with your child.

> QUESTION 41: Getting dressed or undressed

Include things like:

- help your child needs with fastenings like buttons, zips, buckles and laces which may be painful or problematic for them
- help they need if reaching to pull items of clothing on or off is difficult
- if they are uncomfortable with dressing or undressing in front of others because of a physical difference
- if they are visually impaired or have a learning difficulty, they may need help to choose clothes that are appropriate for the weather, that match, and help to put them on in the right order
- if your child needs to follow a rigid routine which can make dressing or undressing take longer
- if your child has a behavioural difficulty and becomes easily distracted and needs lots of persuasion and encouragement to come back to the task.

> QUESTION 42: Eating and drinking (including breastfeeding)

Here you should list any problems your child has with sucking, chewing and swallowing, and any equipment like a feeding tube to help overcome those difficulties. For example:

- does your child have a special diet which needs special and careful preparation?
- do they have to eat regularly at specific times of the day?
- does eating cause pain or nausea which discourages them from eating?
- children with visual impairments may need help to locate and eat food
- children with learning difficulties, visual impairments or food allergies may need supervising to make sure they don't eat anything harmful.

> QUESTION 43: Your child's medical and therapy needs

Medications

As well as giving details about medicines, include any difficulties your child has receiving them or taking them by themself (forgetfulness, discomfort, distress, side effects). Describe how you help overcome this (encouragement and reassurance, even after medication has been given).

As well as injections and tablets, include information about any eye drops, creams, dressings and enemas your child needs.

Therapy

Include details of any physiotherapy, speech therapy, hydrotherapy, play therapy, counselling and behavioural therapy. Include any exercises you have to do at home.

Therapy also means help with any medical equipment. This includes nebulisers, monitoring equipment, meters, needles for injections or blood tests, thermometers, tube feeding, catheters and breathing equipment.

List any difficulties with using equipment, help you give to your child and the length of time it takes. Include time spent on preparing and cleaning equipment.

> QUESTION 44: Difficulties with seeing

This section gathers information about the extent of any visual impairment your child has.

As well as filling in this section, it's important to make sure you also explain how your child's visual impairment impacts on any of the specific areas covered in the other parts of the form.

For example, a child with a visual impairment may need help with dressing, with washing, teeth brushing and looking after their appearance, help at mealtimes and help to get around safely both indoors and outside. Young children with a visual impairment may also need more help in learning through play.

If a child can't see everyday objects, they are less likely to become spontaneously curious about things around them. As a result, you may need to spend much more time actively introducing objects through touch or verbal description. This should be taken into account as extra care and support.

School-age children may require help with reading, not only school books and texts but also from boards and projectors. They may need help in describing graphs, pictures, charts or scientific experiments.

They may also need guidance and supervision, not only to get to and from school but also to get around the school and playground, and to take part in physical education (PE).

If your child has a certificate of visual impairment you should send a copy of this along with the form.

It is important to say what help your child needs because of problems with vision or hearing. You may have to spend more time explaining everyday things such as what is happening on the television.

> QUESTION 45: Difficulties with hearing

This section is to find out the extent of your child's hearing impairment.

As well as completing the questions on the form, it is important to explain help your child needs because of hearing loss. You may be able to explain their need for extra help or supervision throughout the rest of the form.

Perhaps it takes longer for your child to receive instructions about how to carry out certain activities. You may have to spend more time explaining everyday things such as what is happening on the television, or bringing to their attention certain sounds such as traffic, alarms or announcements.

Things to consider might be your child's need for extra supervision because they can't hear danger approaching. They may become upset easily as they don't get a warning of when things happen.

You might have to make more effort to get their attention so that you can speak to them face to face. They may need help with hearing aids – taking them off, putting them on and adjusting them.

Include any evidence from a specialist which shows the extent of your child's hearing loss.

If your child needs help to communicate with other people fill in questions 46–47.

> QUESTIONS 46–47: Speaking and communicating with people

A child may be unwilling to communicate because they have a limited understanding of their environment, or only choose to talk about things they feel are relevant to them and are comfortable with. Your child may become angry or frustrated trying to communicate. For example:

- a child with hearing loss may only be able to communicate with people who sign, or may be able to lip read, but only people they know well
- a child with a learning difficulty may also depend on a form of non-verbal communication but find this difficult with people they don't know
- they may have difficulties understanding facial expressions and body language.

Write down the different ways your child is helped with communication and what would happen without this help.

> QUESTION 48: Blackouts, fits and seizures

This applies if your child has symptoms like fits, convulsions, fainting, dizziness, loss of consciousness, or asthma attacks.

Explain when these attacks happen, how often, and if there are any warning signs beforehand. What happens during and after an attack? For example:

- is your child incontinent?
- do they injure themselves?
- do you need to clean up after them, change bedding, clothing, and attend to injuries? How long does this take?
- are they left feeling dizzy, exhausted, or aggressive and take a long time to fully recover? How long do they need to rest or need reassurance?

Remember – if your child has attacks and needs someone to keep an eye on them all the time, write this here.

> QUESTION 49: Supervision your child needs during the day

This section looks at whether your child needs someone to watch over them during the day to make sure that they are safe and to ensure that they are not a risk to themselves or to others.

All young children, whether disabled or not, routinely require supervision. So the younger your child is, the more important it is for you to say how the supervision they need is greater, or different, to another child of their age.

Think about what could happen to your child without regular or frequent supervision. For example:

- a child with poor coordination may fall and hurt themselves
- children with hearing or sight difficulties may not be able to hear or see dangers
- a child may have seizures, asthma

attacks or breathing problems, particularly if they over-exert themselves or become excitable and no-one's there to stop and calm them

- eating the wrong food or drinking the wrong amount of liquid may have serious consequences
- your child may be prone to dribbling, or there are other bodily fluids you need to check to make sure they are constantly dry to avoid sores and other complications
- a child with behavioural problems may harm themselves or another person.

> QUESTION 50: Help with development

This section includes help that your child needs to interact with and make sense of the world around them.

For example, your child may find it difficult to interact or play with others. This may be due to problems with understanding or communication.

They may need to spend time on their own because their behaviour becomes aggressive or inappropriate. This may affect your child's development through play. They may need help to play with other children and in how they should behave.

Any physical difficulties can also make it harder for children to play because of difficulties with coordination or manipulation. A visually-impaired child may need more attention than others. Specially adapted toys or tactile toys don't necessarily mean difficulties with play are resolved, because your child might need help finding or manipulating the toy, otherwise they'll become frustrated. They might need help maintaining their interest which means you need to give them extra attention. Or you may need to supervise to prevent harm to your child or other children.

> QUESTION 51:

Encouragement, prompting or physical help at school or nursery

This section gathers information about any extra support, care or supervision your child needs at school or nursery.

This can include any extra support to help them learn, but also any extra help they need to manage behaviour, get around the school or nursery safely or to mix with other children in the playground. You should also think about whether they need help at school with things like using the toilet, taking medication or having their lunch.

If your child has a statement of special educational need, Individual Behaviour Plan, Education, Health and Care plan, or in Scotland a co-ordinated support plan the claim form asks you to send these (see page 6 of claim form). However, if you feel that your child's statement or plan does not fully reflect all of their needs it is important that you make this clear somewhere on the claim form and highlight any other needs not identified in the school or nursery report.

If you feel that the school report misrepresents your child's needs you may choose not to submit it at all. Call our freephone helpline for further advice.

> QUESTION 52: Help with hobbies and social activities

Include here details of any help your child needs when they go out during the day or night for social and leisure activities, and any support needed for hobbies.

This includes visits to the park, clubs, sport activities, going to the cinema, swimming, visiting relatives, drawing, playing on the computer, and watching television. These are just some examples and you should include any interests that your child has and what help they need.

If there are activities your child would like to do if only they had extra help, then list the additional support that would be needed to allow this.

> QUESTION 53: Any help your child needs during the night

Complete this section if you have to get up in the night to help with your child's care needs.

Night-time is the time between when you go to bed until you get up. If you stay up later than you want to because your child does not settle in bed, or if you get up very early, these times also count as night-time.

These are just some examples of night-time needs:

- some children require physical help to get back into bed after falling out, or to turn over during the night
- re-arranging bedclothes if they become tangled or fall off
- your child may have problems with continence or night sweats and you need to change the bedding and to deal with any wetting or soiling
- your child may need help with medication or equipment at night, such as an inhaler or nebuliser, or feeding tube.

Use this section to say if you need to get up at night to give comfort to your child because they wake up upset and agitated, if they have a disturbed sleep pattern and can't settle or if they get up and wander.

> QUESTION 55

This asks you the date that your child first started to have the care needs that you have described.

Normally your child must have needed extra care or supervision for at least three months before they can receive any payments of the care component. An exception to this is made where a child is terminally ill and claiming under the special rules – see page 8.

> QUESTIONS 54 AND 70 EXTRA INFORMATION AND DETAILS OF ANY ATTACHED ADDITIONAL DOCUMENTS TO SUPPORT YOUR CLAIM

You may wish to use the space provided to explain more about your child's condition and how it affects them. For example, how their condition might vary, or how their mental health is affected by their condition.

Any document, letter or statement can be sent with the claim but it is very important to check that any evidence you send accurately describes your child's needs. If it doesn't then this may harm your claim.

Evidence can include information from a health professional involved with your child's care, like a GP, nurse, paediatrician, speech and language therapist, or occupational therapist. Call the Contact a Family freephone helpline for more information.

Giving detailed medical information may lead to a quicker decision and reduce the chances of the Department for Work and Pensions (DWP) arranging for more reports on your child's condition (see section on page 6 of the form, 'Do you have any reports, letters or assessments about the child's illnesses or disabilities?').

Evidence of your child's special educational needs can also be attached (but see Question 51).

You can ask friends, carers or relatives to give supporting evidence.

A diary of the past week giving an account of your child's difficulties, the help you gave and how long it took each time can be very helpful.

If you're nearing the six week deadline, you should send the completed form off without waiting for additional evidence. Attach a letter saying you will send more evidence and when they can expect it.

If further medical information is needed for your claim

Your claim will be assessed by a 'decision maker.' If they're still unclear about how your child's condition affects their care and mobility needs, they can arrange for a DWP approved doctor to visit you to examine them and prepare a medical report. This can lead to delays.

If you feel the claim is taking too long, then you can make a complaint to the customer services manager at the office dealing with your claim.

Mental Health

There are no specific questions in the form about your child's mental health.

Children with disabilities, coping with their condition, can feel frustrated, isolated and upset at times. These can be described as mental health difficulties.

This could apply if your child is withdrawn, anxious or depressed, behaves aggressively or gets angry and is uncooperative.

They might act impulsively, have nightmares, or have difficulty coping with routine changes.

You may have been able to fit this into your answers to some of the other questions but if not, then it is important to give more details at Question 63 'Extra Information', or as an attached sheet.

Say what the difficulties are that your child experiences and also what help you give to overcome or minimise their effects. You might include:

- providing encouragement, motivation and reassurance
- techniques to manage any difficult behaviour like taking 'time out'
- monitoring your child's mood
- helping them to plan their day and to help them to deal with their feelings.

Getting a decision

Once you've sent your form to the office dealing with your claim you should get an acknowledgement within two weeks. You should also get a decision within three months.

Decision makers aren't medically qualified and will rely on medical information you supply with the claim, plus guidance on disability in children. If more evidence is needed, they may write to your GP or hospital consultant. The DWP will send you a decision letter outlining the reasons for the decision.

How long will my child be awarded DLA for?

DLA awards are sometimes made for an indefinite period but a child's award is usually made for a fixed period, for example, three years. Towards the end of that time the DWP will normally write inviting you to reapply for DLA. See page 32 on 'Renewal claims' for more information.



Unhappy with the decision?

If your child is refused DLA or awarded at a lower rate than expected, you can challenge the decision that has been made on their claim. There are two possible stages when challenging a decision.

- first you can ask for the decision to be looked at again. This is known as a reconsideration request
- then, you can lodge an appeal if you are not happy with the outcome of the reconsidered decision.

Please note that you cannot ask for an appeal until after you have had a reconsideration. The only exception to this are if you live in Northern Ireland. At the time of writing different rules on challenging decisions apply in Northern Ireland, so call our freephone helpline for further advice



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If you'd like help with asking for a reconsideration or appeal call our freephone helpline

0808 808 3555

helpline@cafamily.org.uk

www.cafamily.org.uk

Asking for the decision to be reconsidered

If you are not happy with a DLA decision you can ask the DWP to look at their decision again. This is known as a reconsideration. You can request this over the telephone or in writing, and you need to do this within one month of the date of the decision letter.

It is very important that you ask for a decision to be reconsidered within the one month timescale as a late request will only be accepted in certain limited circumstances.

As part of having a decision reconsidered you can volunteer, or you may be asked to give, further information. Or the DWP may ask for a short factual report (usually from a doctor), on any aspects of your claim that weren't clear. Another decision maker will then have a fresh look at the case.

If the decision maker feels that they are unlikely to change the decision in your favour they may try to call you. During the call, they will ask you about any aspects of your case which are unclear, and will also ask if you have any further evidence which might help.

The decision maker will then go on to finalise their decision on your reconsideration request, taking into account any new evidence you have provided. They will make at least two attempts to contact you by phone. If they are not able to make contact they will carry out the reconsideration based on the information available.

Once the DWP has made a decision on your reconsideration request they will send you two Mandatory Reconsideration Notices in the post. One is your copy, the other copy is for you to send to the Courts and Tribunal Service if you decide to appeal. The notice contains details of the reconsidered decision alongside details of your appeal rights.

Asking for a written statement of reasons

If the DLA decision doesn't include reasons for the decision, you can ask for a written statement of reasons. You must ask for this within one month of the date on the DLA decision letter. If the written statement of reasons is provided within that month, then the one month time limit for disputing the decision is extended by 14 days. If it is provided outside of the month time limit, you have 14 days from the date it is provided.

Warning: if reasons were included in the original decision letter then the time limit to ask for a reconsideration will not be extended. This remains the case even if you did not realise that reasons were included because they were so brief and general. Because of this we recommend that you always ask for a reconsideration with the one month timescale, unless you have spoken to the DWP and they have confirmed that the time limit will be extended because they are sending a written statement of reasons to you.



Asking for an appeal



If the DWP decide not to change the outcome of their decision, or change it but don't give you what you were looking for, you have the right to ask for an appeal. But remember you can't ask for an appeal unless you have asked for a reconsideration first.

Your appeal request must be made in writing and you will need to explain why you think the decision you are appealing against is wrong. It must include a copy of the Mandatory Reconsideration Notice sent to you by the DWP.

You can appeal using form SSCS1 which can be downloaded at www.gov.uk – type 'SSCS1' into the search bar. You must send your appeal request directly to the Courts and Tribunal Service and it must be received by them within one month of the date on the reconsideration notice. If you miss this deadline seek advice about making a late appeal.

An oral hearing or a paper hearing?

One of the questions on the appeal form is whether you would like a 'paper hearing' (where you don't go to the meeting and the tribunal look at the papers and make a new decision), or an oral hearing (where you are invited to attend a meeting to discuss your appeal and a new decision is made). It is always best to ask for an oral hearing. Statistically, oral hearings are more successful than paper hearings.

Preparing for the appeal hearing

If you can, get specialist advice to help you prepare your case, as tribunals make decisions based on legislation and case law, as well as information about your child's needs. A specialist adviser will be familiar with the law, may write to medical professionals for supporting evidence, and help you to concentrate on giving a clear picture of your child's needs. They may also be able to come along to the tribunal and put your case with you.

At the appeal hearing, it is important that you give as much information as possible about why and how you think the decision is wrong – make sure you don't contradict what you've already said on the claim form!

You may want to prepare a written submission and send this in advance to the tribunal, although if you have a representative make sure that you discuss this with them first. A written submission is when you put in writing why you should win the appeal.

The tribunal hearing

The tribunal can only consider the circumstances that existed at the time of the decision you are appealing about, so if you feel the circumstances have changed you should consider making a new claim. Seek specialist advice about this.

If you have chosen a paper hearing, the tribunal will decide the appeal on the evidence of your submission papers and any additional written evidence.

If you have chosen an oral hearing, you must be given at least 14 days' notice of the time and place of the hearing. You can ask for a postponement if the date is inconvenient – but don't count on this unless you have a very good reason. You can claim travel expenses and compensation for loss of earnings. Ask the tribunal clerk what else you can claim for.

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To find a specialist adviser who can help you appeal call our freephone helpline

0808 808 3555

helpline@cafamily.org.uk

www.cafamily.org.uk

Take someone with you

If you don't have a welfare rights representative to come with you, take a friend or relative to help you feel more relaxed.



Who is on the tribunal panel?

The tribunal usually consists of a legally qualified tribunal judge, a doctor and a person with experience of the needs of disabled people.

An officer from the DWP might also be present. This is usually a decision maker but they are not likely to be the one who made the decision on your claim. A tribunal clerk may also be there to deal with paperwork and expenses.

An informal hearing

The hearing is meant to be fairly informal and you will have the opportunity to explain your child's situation. You may find it useful to make notes before you go to the hearing, with the points you want to make and the supporting evidence you want to provide. Take your time when you're asked to speak – the judge will usually try to make you feel at ease.

You might be asked questions while you're giving your evidence, but you can ask for any questions to be left until you've finished if you're worried they'll interrupt your train of thought.

Back up any arguments with supporting evidence, like a doctor's letter. Make sure that you tell the tribunal which components, (care or mobility or both), and what rates of each component you think your child should be awarded.

Getting a decision on your appeal

You should get a decision on the day of the hearing, or soon after. If you are unhappy with the decision you may be able to appeal to the Upper Tribunal. Talk to your representative about this or call our helpline, as the Upper Tribunal can only deal with cases where the tribunal decision includes an error of law.

Getting an existing DLA award changed

If your child already gets DLA but their circumstances have changed and they now need more help, it may be possible to get their award increased.

You can contact the DLA office to ask them to look at your child's award again. This is known as a 'supersession request'. Any decision (including a tribunal decision) can be superseded by a decision maker.

You can ask for a supersession at any time. If you are not happy with the outcome of a supersession you have the right to ask for a reconsideration and an appeal against that new decision in the usual way. Please see page 26.

If your child is aged 16 or above, then reporting a change of circumstances that may affect their DLA award will lead to them coming off DLA and being assessed under the Personal Independence Payment rules instead. This does not yet apply in Northern Ireland.



To find your local Citizens Advice Bureau or welfare rights service call our freephone helpline

0808 808 3555

helpline@cafamily.org.uk

www.cafamily.org.uk

Warning

If you have an existing award of DLA and you ask for it to be looked at again, there is a risk your award could go down rather than up. Because of this, it is always best to get help from a Citizens Advice Bureau (CAB), or local welfare rights service.

Renewal claims

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It's very important that you return the renewal forms before the current award finishes or you could lose benefit. If your child has been awarded DLA for a fixed period of time, you will normally be contacted 20 weeks before the award ends and invited to re-apply. You will be sent a renewal claim pack to complete.

If your child's award is due to end within 20 weeks and you have not been sent a renewal claim pack contact the office dealing with your DLA claim as soon as possible. It's very important that you return the renewal forms before the current award finishes or you could lose benefit. A renewal claim is treated as a new claim, so it's still important to get help to fill in the form and to keep a photocopy.

If you disagree with your child's renewal award you can challenge the decision in the same way as challenging an original decision, as described on pages 25-30.



Stays away from home

DLA can be affected by overnight stays away from home. There are different rules depending on whether your child goes into hospital, or into a residential school, or residential care.

When your child is in hospital

At the time of writing, the DLA rules say that payments of DLA care component and mobility component stop after 12 weeks if a child under 16 is a hospital inpatient. They also say that if your child is in hospital when you first claim DLA, it can't be paid until they leave hospital.

However, in July 2015 the Supreme Court found that the human rights of a severely disabled child called Cameron Mathieson had been breached when his DLA payments were suspended in hospital. As a result of this judgment it is possible that the Department for Work and Pensions may amend these rules. At the time of writing they have not explained what their response to the judgment will be.

In the meantime families who continue to provide a high level of care to their child while they are in hospital, should be able to use the Mathieson judgment to get their DLA payments reinstated. Call our freephone helpline for further advice on this issue.

When your child is in a residential school or care

If your child is currently in a residential school or residential care (including for short-term breaks) and this is paid for from 'public funds' then the DLA care component stops being paid after 28 days. The mobility component is not affected.

If your child's stay in residential accommodation is being funded by your health board under NHS continuing care, then phone our freephone helpline for further advice.

Counting the number of days away from home

When counting the number of days away from home, the day your child enters residential accommodation and the day they leave are both treated as days at home. For example, if your child goes into a residential school on a Monday and comes back on Friday, then only Tuesday, Wednesday and Thursday will count as days away from home. This is a total of three days.

The same rules apply to hospital stays.



Call our freephone helpline for more details about the 'linking rules' for DLA and stays away from home.

0808 808 3555

helpline@cafamily.org.uk

www.cafamily.org.uk

Going in and out of hospital or residential care

When working out whether your child's DLA will stop, it is important to know that any stays in hospital or residential accommodation separated by 28 days or less at home will be added together. This is known as the 'linking rule'.

For example, your child goes into hospital for nine weeks, before being discharged home. After two weeks at home, they have to be re-admitted to hospital for another six weeks. Because the two hospital stays are separated by less than 29 days at home they are 'linked' together. This means that DLA will stop being paid after three weeks during your child's second hospital stay (that is, nine weeks in hospital + three more weeks = 12 weeks in hospital).

When your child comes home for at least 29 days, the 'link' is broken, and DLA can be paid again for another 12 weeks during any future hospital admissions.

It is also important to understand that different types of residential stays can be added together in a similar way. This might apply if your child goes to residential school and sometimes goes to a respite care unit for overnight stays during school holidays. Those stays can be added to the days spent at school, unless the child comes home for 29 days.

When a child spends time in both hospital and residential accommodation, these stays can also be linked.

Getting paid for days at home

If your child's DLA stops because they are in hospital (but see page 33 – the Mathieson decision) or a residential setting, they are still entitled to DLA payments at a daily rate for the days they spend at home.

For example, your child has been away at residential school for more than 28 'linked' days, so payments of DLA care component have stopped. When they come home from school on Friday and go back on Monday, DLA care component should be paid at a daily rate for Friday, Saturday, Sunday and Monday (four days).

If they stay at home for more than 28 days, the care component should not be stopped again until after they've spent another 28 days in residential school.

When a child is in hospital or a residential setting this can impact on any Carer's Allowance paid to their main carer. But even if your child is in hospital or a residential setting for long periods, you may still be able to carry on getting Carer's Allowance if they regularly spend at least two days at home. You must provide at least 35 hours care during the 'benefit week' they come home. A benefit week for Carer's Allowance runs from Saturday midnight to the following Saturday midnight. Time spent preparing your home for your child's visit or cleaning up afterwards count towards the 35 hours' care.

It's a good idea to keep a record of the dates you travel to and from your child's place of stay.

Be careful!

This is a complex area of the benefits system which can sometimes result in families being overpaid DLA. This usually happens when families unknowingly fail to tell the DLA Unit about their child's stays away from home.

To avoid any confusion, we strongly advise you to tell the DLA Unit about any stays away from home in the places above. It's a good idea to keep a record of the dates you travel to and from your child's place of stay. The DLA Unit need to be clear about how many days have been spent away from home to decide when these rules apply.

Families should also be aware that stays away from home may also have an effect on other entitlements, like tax credits or Income Support. These are very complex areas so seek further specialist advice. Call our freephone helpline on 0808 808 3555.

DLA and how it affects other benefits

Getting DLA can lead to an increase in other benefits or help you qualify for other entitlements. Even if you get DLA for your child already, you may find that getting an increased rate will lead to something else.

The following is a checklist of benefits and entitlements which may become available following an award or increase of DLA.

Carer's Allowance (CA)

If your child gets the middle or the highest rate of the DLA care component, you may be able to get Carer's Allowance (CA). You must be caring for your child for at least 35 hours of each week. To get CA, you must not be treated as a full-time student and not earning more than a set amount, after certain deductions. This is currently £110 per week.

Carer's Allowance can be backdated in line with the DLA award, as long as you apply within three months of getting the DLA decision. If you apply later, Carer's Allowance can only be backdated for three months.

Application forms (DS700) are available from local benefits offices or the Carer's Allowance Unit on 0345 608 4321. For Northern Ireland call 0800 220 674.

CA can affect entitlements like Income Support and tax credits. In most cases you will still be better off. If you get Incapacity Benefit, or contributory Employment and Support Allowance, it could also be in your interest to apply for CA, even though it can't be paid on top of these benefits. Call our freephone helpline for advice.

Child Tax Credit (CTC)

Child Tax Credit is assessed more generously when a child gets DLA. Families will qualify for an extra disability element (and a severe disability element if your child is on the highest rate DLA care component). The disability and severe disability elements can be backdated in line with the DLA award if you tell the tax credit office within one month of a decision to award DLA.

If you have previously been refused or never claimed tax credits because your income was too high, you may find that you qualify for the first time as a result of your child being awarded DLA (or having their care component increased to the highest rate). Call our freephone helpline to check your tax credit entitlement.

Income Support (IS)

For families still getting payments for their children in their IS, getting DLA will lead to extra money being added to your IS, known as a disabled child premium (and an enhanced disability premium if your child is awarded the highest rate of the care component). You will need to let the office dealing with the IS claim know about the DLA award. If your child gets Employment and Support Allowance in their own right, an award of the highest rate of the care component of DLA may lead to an increase in this benefit. Let the office dealing with these benefits know about a new award of DLA or any change to the existing award. If your child gets Income Support in their own right, then an award of DLA can lead to an increase in their benefit. This is because they will qualify for the disability premium (and the enhanced disability premium if they're awarded the highest rate of the care component).

Help with rent and council tax

If you get Housing Benefit or support with council tax, then getting DLA for your child may lead to extra benefit if you are not already getting your rent and council tax met in full. If you don't get these benefits but are liable for rent or council tax then you may find that getting DLA will help you qualify for the first time.

If your disabled child cannot share a bedroom and because of this your Housing Benefit is reduced under the bedroom tax or local housing allowance rules, getting DLA care component at the middle or highest rate for them may help you get more Housing Benefit. Call our freephone helpline for further advice.

Both Housing Benefit and support with council tax are means-tested and any award will depend on your income and circumstances. Call our freephone helpline for further information.

There are other ways of getting help with council tax which don't depend on income or savings but do depend on there being a disabled occupant within your household. Our guide *Help with council tax bills* has more advice. Call our freephone helpline for a copy.

Universal Credit

Universal Credit is a new benefit that will replace tax credits and other means-tested benefits for people of working age. If you receive Universal Credit and a child who is included in your Universal Credit claim gets DLA, you will qualify for extra Universal Credit payments.

Although the national roll-out of Universal Credit has started, initially this only applies to new claims by single job seekers. Families with children making new claims for benefits are being asked to claim Universal Credit in some pilot areas. However, for the time being this does not apply to families who have a child on DLA/PIP or who is registered as blind or severely visually impaired. Existing benefit claimants are scheduled to start being moved onto Universal Credit during 2016 but this timetable may change.

Call our freephone helpline for updates on the timetable for Universal Credit's introduction.

Exemption from 'benefit cap'

If you have a dependent child (that is, a child aged under 16, or aged 16–19 if they are still treated as part of your family for benefit claims) who is in receipt of DLA, you will be exempt from the 'benefit cap' which restricts the total amount of benefit payments that an out of work family can receive.

Help with parking

If your child is awarded the highest rate of the DLA mobility component, then you should qualify for a Blue Badge for help with parking. You might also qualify if your child is aged two and over and is either registered blind, or has severe walking problems. In England, Wales, and Scotland, you may also qualify if your child is aged under three (under two in Northern Ireland), and needs to be accompanied by bulky medical equipment, or kept near a vehicle for medical reasons.

Help with road tax

If your child is awarded the highest rate of DLA mobility component, you may be exempt from paying Vehicle Excise Duty. Claimants are usually told about this when they are notified about the award of high rate DLA mobility component. If you haven't received any information and you think you qualify, contact the Disability Living Allowance helpline on 0345 712 3456.

Help with getting a car

If you're interested in getting a car and your child is awarded the highest rate of the mobility component of DLA, then you can lease a car through the Motability Scheme.

To access this scheme your child's award of the high rate mobility component must have at least 12 months left to run.

If you're unable to drive and need help with paying for lessons or require help in getting a deposit for a car through the scheme then you may qualify for a grant.

To find out more contact Motability on 0300 456 4566, or visit www.motability.co.uk.

Help with bus travel

All local authorities operate schemes for disabled people of any age to apply for a bus pass or voucher for free bus travel. In some areas, an essential, named carer accompanying the disabled person is also entitled to free travel. The scheme operates differently from one local authority to another, so get in touch with your local council to check out what's available in your area.

Other concessions

To see what other schemes or facilities are available in your area, call our freephone helpline

🔮 0808 808 3555

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- www.cafamily.org.uk

What happens when your child turns 16?

DLA for those aged 16 and over is gradually being replaced with a new benefit called Personal Independence Payment (PIP). DLA will remain for children aged under 16.

England, Scotland and Wales

A young person who is 16 or over and not already getting DLA needs to claim PIP instead of DLA.

If your child is already getting DLA and is turning 16 they will be invited to claim PIP shortly after their birthday. This will apply to all children turning 16 even if they have an indefinite award of DLA. Young people turning 16 who get DLA under the special rules for the terminally ill are exempt, and will continue to get DLA.

The Department of Work and Pensions will write to you when your child is 15 years and 7 months explaining what will happen and to check whether your child will need an appointee to act on their behalf (see page 40) They will then follow this up with a second letter once your child is 15 years and 10 months. Once they turn 16 a letter will be sent inviting them to claim PIP.

If your son or daughter is invited to claim PIP, they (or you acting as their appointee) must do so within 28 days by phoning the PIP claim line on 0800 917 2222. Their DLA payments will continue until a decision is made on their PIP claim. This applies even if their DLA award was scheduled to run out when they turned 16. However, if they fail to claim PIP when invited, their DLA payments will stop

PIP has different qualifying rules to DLA. For some claimants, it will be harder to qualify for and most people will have to attend a face-to-face assessment with a health care professional.

Adults aged 16 or over who already get DLA will also gradually be reassessed for PIP.



If your child is already getting DLA and is turning 16 they will be invited to claim PIP shortly after their birthday.

Northern Ireland

It is planned that PIP will also be introduced in Northern Ireland but at the time of writing no timetable has been provided for when this will happen. In the meantime, if your child is in Northern Ireland and their current DLA award is due to run out when they turn 16, they should be sent a DLA renewal claim form to complete.

Payments when your child turns 16

When your child reaches 16, there may also be changes in how benefit is paid – this applies regardless of whether they claim PIP or they live in Northern Ireland and continue to get DLA. Before 16, a parent or other main carer is automatically authorised to act on their child's behalf, as an 'appointee'. This means you are responsible for filling in forms and making claims for your child.

When your child is nearing 16 years of age, you will be contacted by someone from your local Jobcentre Plus office, to decide if you will continue to be your child's appointee. If your child is considered capable of handling their own affairs, the DLA/PIP will start to be paid to them directly and your appointment to act for them will end. Otherwise, parents are usually asked to carry on managing the DLA/PIP alongside any other benefits the young person chooses to claim after 16, like Employment and Support Allowance (ESA).

For information about young people claiming ESA and how this might affect a parent's benefits, call our freephone helpline.

If your child can manage their benefits claims but can't physically collect their benefit, then they can nominate someone – known as an 'agent' – to do this for them.

For more information about appointees and managing benefits please call our freephone helpline.

For more information about PIP, call our freephone helpline for a copy of our guide to Personal Independence Payment and other benefits at 16.

0808 808 3555

helpline@cafamily.org.uk

www.cafamily.org.uk

Further sources of help

It is important to make sure that any information you have about allowances or benefits is up to date as they change so often. Your local Citizens Advice Bureau, welfare rights adviser or advice agency will have detailed information about DLA, benefits and other financial help which may be available. They will also be able to help you with any claims. For help over the telephone, call:

Contact a Family Helpline

0808 808 3555

CarersLine

0808 808 7777

Some national organisations for specific conditions produce their own information on DLA or provide help to fill in the form. These include the National Deaf Children's Society, Down's Syndrome Association, National Autistic Society, Diabetes UK, and Afasic. For contact details of these and other organisations, please call our helpline.

Other useful booklets from Contact a Family

This guide is one of a series produced for parents and groups concerned with the care of disabled children. Other guides include:

- Money Matters checklist when your child has additional needs
- The tax credits guide
- Help with council tax bills
- Help with fuel bills and keeping warm
- Understanding your child's behaviour
- Relationships and caring for a disabled child
- Fathers
- Siblings
- Grandparents
- Living with a rare condition
- Living without a diagnosis
- Growing up, sex and relationships
- Holidays, play and leisure.

Contact a Family publications are available free for parents from our helpline, or can be downloaded from our website

0808 808 3555

helpline@cafamily.org.uk

www.cafamily.org.uk





Get in contact with us

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- www.twitter.com/contactafamily
- www.youtube.com/cafamily

Free helpline for parents and families:

🕸 0808 808 3555

- Open Mon–Fri, 9.30am–5pm
- ₩ helpline@cafamily.org.uk

Access to over 200 languages

Our free family linking service

www.makingcontact.org



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The photographs in this guide do not relate to any personal accounts.

Written by Marian Gell, Derek Sinclair and Jesslyn Parkes

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