

Getting in contact with us

Free helpline for parents and families:

0808 808 3555

Textphone:

0808 808 3556

Open Mon–Fri, 10am–4pm
and Mon, 5.30–7.30pm

Access to over 100 languages

www.cafamily.org.uk
www.makingcontact.org

Contact a Family Head Office:

209-211 City Road, London EC1V 1JN

Tel **020 7608 8700**

Fax **020 7608 8701**

Email **info@cafamily.org.uk**

Web **www.cafamily.org.uk**

Chief Executive
Srabani Sen



Other information booklets available

This booklet is one of a series produced for parents and groups concerned with the care of disabled children. A full list of Contact a Family publications is available on request or can be downloaded from our website www.cafamily.org.uk

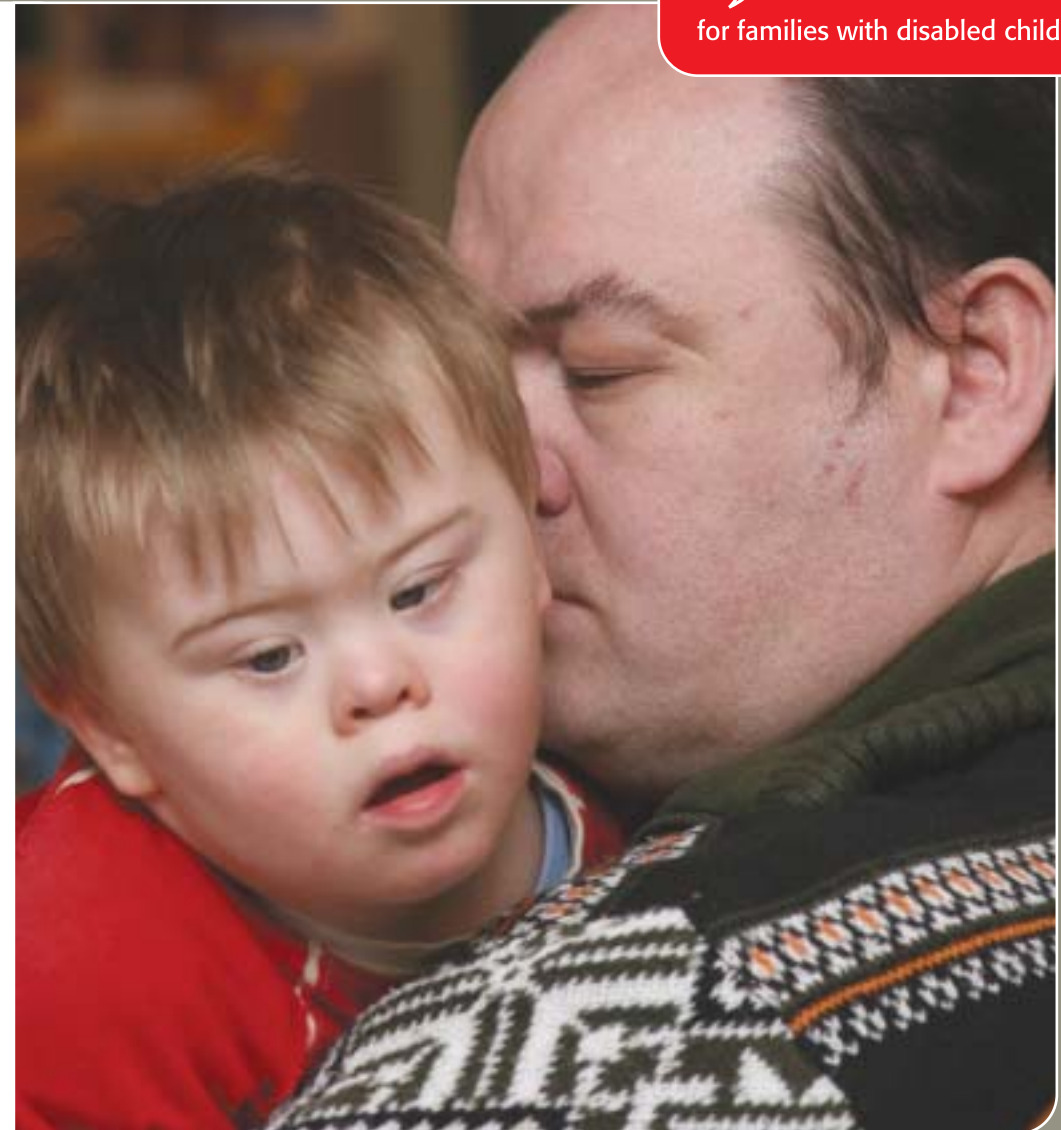
- The tax credits guide ^(UK)
- Fathers ^(UK)
- Understanding your child's behaviour ^(UK)
- Living without a diagnosis ^(UK)
- Grandparents ^(UK)
- Siblings ^(UK)
- Special educational needs ^(England/Wales)
- Additional support for learning ^(Scotland)



Registered Office: 209-211 City Road,
London EC1V 1JN
Registered Charity Number: 284912
Charity registered in Scotland No. SC039169
Company limited by guarantee
Registered in England and Wales No. 1633333
VAT Registration No. GB 749 3846 82

Although great care has been taken in the compilation and preparation of this information booklet to ensure accuracy, Contact a Family cannot take any responsibility for any errors or omissions.

With thanks to True Colours for funding to publish this factsheet.



A guide to claiming Disability Living Allowance for children

Introduction

For many families, looking after a disabled child costs more money. This may be because of disability related costs like buying special aids or because things like childcare and transport can be more expensive. Disability Living Allowance (DLA) is the main benefit for disabled people and is there to help meet any extra costs of being disabled. It is not means-tested so your financial situation will not be taken into account. It is also not taxable or treated as income for other benefits.

Instead, DLA can sometimes lead to an increase in other entitlements 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.

Disabled adults can claim DLA too although this guide is for claiming for a child. You will find this factsheet 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.

Contents

Who can claim?	3
How much is DLA?	3
The rules for getting DLA	4
How to claim	7
Completing the form (DLA1)	7
Getting a decision	17
Challenging a decision	17
Stays away from home	21
DLA and how it affects other benefits	23
What happens at 16?	25
Further sources of help and advice	26

Who can claim?

Any ill or disabled child may qualify. But to make a successful claim for DLA you have to show that your child needs substantially more attention or supervision than other children of the same age who are not disabled.

Your child will also need to have had 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. For children who have terminal conditions there are 'special rules' which mean the benefit can be paid from birth, please see page 6 for more information about this.

Warning! If you think your child may be subject to immigration control, or is out of the country or has been for more than 26 weeks of the past 12 months, ring our helpline for more advice.

How much is DLA?

DLA has two main parts, called 'components'.

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:

lower care	£17.75
middle care	£44.85
higher care	£67.00

The **mobility component** can be paid for children who have problems walking or getting around in unfamiliar areas. It is paid at one of two weekly rates:

lower mobility	£17.75
higher mobility	£46.75

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



Freephone helpline: **0808 808 3555**
Web: **www.cafamily.org.uk**

The rules for getting DLA

The care component

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

The **lower 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 throughout 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 during the night they need 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
- in order 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 **higher 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 6).

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

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 risk seriously 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 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 by 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 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'. 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.

The earliest it can be paid is from three years of age.

"The advice was second to none. It's nice to know there's someone out there who can help you."

Parent caller to the helpline

Freephone helpline: **0808 808 3555**
Web: **www.cafamily.org.uk**

The higher rate mobility and children with severe mental impairments

The higher rate can also be paid to some children with severe mental impairments.

To qualify your child must be:

- entitled to the higher 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'. This may be assessed with various tests; **and**
- 'exhibit disruptive behaviour' which is 'extreme' and 'regularly requires another person to intervene and physically restrain him/her to prevent him/her causing physical injury to themselves or another, 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 ring the helpline for more advice.

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 three month qualifying period) and you will only need to fill in certain parts of the DLA form.

"The extra money's made a huge difference – I nearly cried when I got the letter."

Parent

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

'Special rules' awards of the care component are 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

Special rules for some kidney patients undergoing renal dialysis help them to 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 of a type which needs another person 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 the helpline.

How to claim

If your child is under 16 years of age, use claim form DLA1(Child), available from local benefit offices or by calling the Benefits Enquiry Line (BEL)

Tel: 0800 88 22 00, Textphone: 0800 24 33 55, open from 8.30am-6.30pm Mon- Fri; Sat 9.00am-1.00pm.

Families in Northern Ireland should call Tel: 0800 22 06 74, Textphone: 0845 24 37 87, open 9am-5pm Mon, Tues, Weds & Fri; 10am-5pm Thurs.

Forms are also available from regional Disability Benefits Centres. Contact the helpline for information about a centre covering your area.

DLA can also be claimed online at Web: <http://www.dwp.gov.uk/eservice> For young people of 16 years of age and over and adults, there is a different claim form also available from the BEL.



Deadline for claiming DLA and backdating

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 BEL or Disability Benefits Centres will be 'date-stamped' and you are given six weeks to complete and return the form. If your child qualifies, it will be paid from date-stamp. 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.

The government has announced plans to scrap 'date-stamping' of DLA claim forms and instead allow DLA claims to be backdated two weeks from the date the completed form is returned. At the time of writing we do not know when this change will be introduced.

Completing the DLA1(Child) form

The form has 42 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. Failing to mention 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.

Freephone helpline: **0808 808 3555**
Web: **www.cafamily.org.uk**

The following section is a brief explanation of some of the more difficult parts of the DLA1(Child) form with comments about the kind of information to include – try to use examples and anecdotes to describe your child’s needs wherever possible.

New simplified DLA form in the pipeline

The government has recently launched a simplified version of the claim form for adults, which also covers young disabled people aged 16 years or over. It is now also looking at developing a simpler version for the children’s claim form too. The information below relates to the current claim form for children as of May 2008.

Parts 1 – 3: General information about you and your child

Parts 4 & 5: Your child’s condition, disability and/or additional needs

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 you don’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’).

Parts 6 & 7: Walking outdoors

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 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 it 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?
- is your child’s ability to walk affected by their refusal to walk? Or the need to go through rigid routines?
- does your child have a visual or hearing impairment and need extra help with following directions and avoiding obstacles?
- or does your child’s hearing impairment mean they can’t hear dangers coming from behind?

Part 8: Supervision your child needs during both the day and night

If your child needs help during the night as well as the day they could get the higher rate of the DLA care component. It is important to read the rules on page 4 and think about how this applies to them.

Note the night care conditions are different to the day. For example, a child only needs supervision for 20 minutes or more during the night to satisfy the night care rule, but for the day time rule there needs to be a pattern of extra care or supervision throughout the day.

As children get older they usually need less care or 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 the same age.

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

- a child with poor co-ordination 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 or breathing problems, particularly if they over-exert themselves or become excitable and no-one’s there to stop 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.

Part 9: Your child’s development

You will need to write down your child’s physical difficulties. These include problems with sitting and standing, running, walking and crawling, and throwing and kicking. Also any difficulties with hearing, seeing, touching and using hands. Problems with using their hands include difficulties with coordination and manipulating things, like picking things up, holding a pen, cutlery, using a keyboard and turning the pages of a book.

You also need to list problems with learning everyday skills like reading, writing, dressing, washing, eating, and understanding and following instructions.

Socially your child may find it difficult to interact or play with others. This may be due to problems with 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.

Any physical difficulties can also make it harder for children to play because of difficulties with co-ordination 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.

Parts 10 – 15: Your child’s personal care needs

When waking up explain any discomfort your child experiences because of pain or stiffness. They may be physically unable to get out 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.

Freephone helpline: **0808 808 3555**
Web: **www.cafamily.org.uk**

“Generally we can afford bits and pieces that we couldn’t before.”

Parent

When going to bed think about similar difficulties. Your child may still be wide awake when put to bed or refuse to settle. Explain what help you give to your child to overcome this, like comfort and reassurance techniques or medication or treatments. You should also say how long this takes.

Washing and bathing includes all issues with personal hygiene. Your child may need extra help bathing, washing or showering and it 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 burns;
- 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 do so;
- 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 harder for you to communicate with your child.

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/undressing in front of others because of 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, and matching, and help to put them on in the right order;
- if your child needs to follow a rigid routine which can make dressing/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.

Toileting needs You will need to explain any difficulties during the night as well as the day. There are separate boxes for this information. 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/episodes of wetting;
- any resulting pain or distress;
- constipation;
- problems with transfer to and off the toilet;
- refusing to use the toilet;
- not wiping themselves;
- playing with faeces or missing the toilet;
- problems with undoing zips, buttons, taking on and off underwear/clothing;

- prompting and reminding your child to use the toilet and wash their hands afterwards.

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 problems 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.

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?
- your child may 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 or visual impairments may need supervising to make sure they don’t eat anything harmful.

Parts 16 – 20: Your child’s medical needs

Medications. As well as giving details about medicines, include any difficulties your child has receiving them or taking them by themselves (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 they need. Write about help needed during the night as well



Freephone helpline: **0808 808 3555**
Web: **www.cafamily.org.uk**

as the day and the length of time it takes. During the night your child may need extra supervision or help with medication because they're sleepy.

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

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. It may take longer if they need help during the night. Include time spent on preparing and cleaning equipment.

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 lots of attacks and needs someone to keep an eye on them all the time write this here.

Mental health This applies if your child is withdrawn, anxious and panicky, depressed, behaves aggressively or gets angry a lot, is uncooperative, impulsive, has nightmares, or can't cope with routine changes.

Children with disabilities, coping with their condition, can feel frustrated, isolated and upset at times. These can be described as mental health difficulties so give information about them here and what help you give to overcome or minimise their effects. It might include:

- providing encouragement, motivation, and reassurance;
- techniques to manage any difficult behaviour like taking 'time out';
- monitoring foods and medication.

Explain if your child sees a counsellor or other mental health professional.

Part 21: Your child's movement and co-ordination

List any problems your child has with movement, for example they may be prone to falling or have lots of accidents, or may have limited or uncontrolled movement. Note down any pain, tiredness and discomfort they feel when they move.



Part 22: Your child's needs when moving about indoors

Include here a description of the help your child needs getting around inside your property. 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 assistance transferring in and out of a wheelchair used indoors; or
- a child with a visual impairment might need help to safely negotiate getting around.

Part 23: 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. For example:

- 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 soiling.

Freephone helpline: **0808 808 3555**
Web: **www.cafamily.org.uk**

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, or if they have a disturbed sleep pattern and can't settle.

Part 24: Help with 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, like any support needed for hobbies. This includes visits to the park, clubs, and sport activities, going to the cinema, swimming, and visiting relatives.

Include routine appointments to see specialists at any hospitals or health centres. If there are social 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.

Part 36: Statement from someone else who knows your 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, a specialist teacher.

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

Part 41: Details of any attached additional documents to support your claim.

Any document/letter/statement can be sent with the claim but it is very important to check that any evidence you send is supportive and won't 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.

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 16 'If further medical information is needed').

A statement of your child's special educational needs (a co-ordinated support plan for children in Scotland) can also be attached. 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.

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 the form first before putting pen to paper so you have an idea of what's needed.

Get specialist advice when completing it

It is important to get help from a welfare benefits advisor or someone who is familiar with completing the form. This will increase the likelihood of your child being awarded the right level of DLA. Contact the helpline if you would like details of local organisations that can help.

Keep a diary for a week before tackling the form, with 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 refresh your memory of the care you're providing.

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 give insight into the full extent of your child's needs.

Use the terms 'bad days' and 'better days' to describe the changes in your child's condition if they have a fluctuating

"The money's made a lot of difference: it's eased the pressure on my husband. We were relying on him to do overtime to see us through, but now he's able to spend more time with my daughter."

Parent

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 differ from those of other children of the same age Is your child's level of competence age-appropriate for different tasks? The DWP produces a useful chart to the milestones a child without disabilities would be expected to reach up until six years of age. This is available to download from their website at Web: <http://tinyurl.com/2c65ct>

Freephone helpline: **0808 808 3555**
Web: **www.cafamily.org.uk**

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 then perhaps you have information about it you can include to help the decision maker understand more.

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 they 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 professional's 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 Completing 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.

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. Because of the difficulties getting DLA for babies, get specialist help to fill in the form.

If further medical information is needed

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.

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.

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 write inviting you to reapply for DLA. See section on page 20 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 this. The time limit for challenging a decision is one month from the date on the DLA decision letter. It is very important that you respond



within this timescale as late challenges are only accepted in certain circumstances. Get specialist benefits advice to help you decide whether to challenge a decision and help you prepare an appeal if necessary.

Ask for a written statement of reasons

It's useful to ask for a 'written statement of reasons' for the decision if it wasn't included with the original decision. This can help if you want to challenge a decision. You must request 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, you have an extra 14 days from the date it is provided.

Two main ways to challenge a decision

If you are unhappy with a decision on your child's DLA you can challenge it in two main ways. You can ask for the decision to be revised, which means that it is looked at again by someone in the DLA office who will issue a new decision. Or you can ask for an appeal (this is where it is referred to a tribunal for a new decision).

Freephone helpline: **0808 808 3555**
Web: **www.cafamily.org.uk**



Asking for the decision to be revised

You can ask for a revision within one month of the date on the decision letter. A decision maker will look at your case to see if it can be changed. You can volunteer, or you may be asked to give, further information. Or they may ask for a short factual report (usually from a doctor) on any aspects of your claim that weren't clear.

If you ask for a revision you might be contacted by a member of the Explanation Team who will explain how the decision was reached, but you don't have to accept what they say. You can tell them you still wish to continue with your challenge.

Once the DLA office carries out a revision they will write to you with a new decision. If they don't change the outcome or change it but don't give you what you were

looking for, you can then appeal. You must appeal within one month of the date on the new decision letter you've been sent.

Appealing against the decision

You can lodge an appeal straight away if you are unhappy with the very first decision on your claim. Or if you asked for the first decision to be revised, you can appeal if you're unhappy with the new revised decision. The relevant benefit office must receive the appeal within one month of the date the decision was sent to you. You must appeal in writing using the GL24 appeal form.

On receiving your appeal, a decision maker will check to see if they can change the decision before going to appeal. If the decision is changed, but you're still unhappy with it, you must submit a new appeal.

An oral hearing or a paper hearing?

If the decision stays the same, your appeal will go to an independent tribunal. The appeal service will write to you and you must reply to this letter within 14 days or your appeal might not be considered. They will ask if 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 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 form! You may want to prepare a written submission and send this in advance to the tribunal.

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 advisor 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.

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 the 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 if you're not sure what you can claim for.

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 panel?

The tribunal panel usually consists of a legally qualified chairperson (usually a lawyer), a doctor and a person with experience of the needs of disabled people. An officer from the Department for Work and Pensions 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. The tribunal clerk may also be there to deal with paperwork and expenses.

Freephone helpline: **0808 808 3555**
Web: **www.cafamily.org.uk**

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 chair 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, and reinforce the decision you want the tribunal to make at the end of your evidence.

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 social security commissioner. Talk to your representative about this or ring our helpline, as the commissioner 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. Some parents may decide to request a supersession because it is too late for them to ask for an appeal or a revision of the original decision.

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 citizen's advice bureau (CAB) or local welfare rights service.

Renewal claims

If your child has been awarded Disability Living Allowance for a fixed period of time, you will be contacted up to six months before the award ends and invited to reapply. 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 copy.

Renewal forms can be sent out before a milestone age, for example before a child's third or fifth birthday, when they may be entitled to the lower or higher mobility component, or before a child's 16th birthday, when they may have to claim as an adult.

If you disagree with your child's renewal award you can challenge the decision in the same ways as challenging an original decision, described above.

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

In hospital, payments of DLA care component **and** mobility component stop after 12 weeks of your child becoming an inpatient. But if you have a Motability car agreement the payments to Motability should continue, even if your child is in hospital for more than 12 weeks. If your child is in hospital when you first claim DLA, it can't be paid until they leave hospital.

When your child is in a residential school or care

If your child is 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.

"It's been a tremendous help. I'm paying for my seven year old to attend a youthclub, and for football three nights a week."

Parent

Counting the number of days away from home

When counting the number of days away from home, the day your child enters hospital and the day they are discharged are both treated as days at home. For example, if your child goes into hospital 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.

Our understanding is that the same rules should apply to residential care. Contact the helpline for further advice if your child goes into a residential setting and the DLA office don't apply these rules.

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 less than 28 days 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 28 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).

Freephone helpline: **0808 808 3555**
Web: **www.cafamily.org.uk**

When your child comes home for at least 28 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 28 days.

When a child spends time in both hospital and residential accommodation, these stays can also be linked. Contact the helpline for more details.

Getting paid for days at home

If your child's DLA stops because they are in hospital 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. However, even if your child is in hospital or a residential setting for long periods, you may still be able to continue getting Carer's Allowance if your child regularly spends at least two days at home. You must provide at least 35 hours care during the 'benefit week' they come home.



"It's made a real difference. Now we don't have to worry about food or bills, we have no financial worries."

Parent

A benefit week runs from Saturday midnight to the following Saturday midnight. Time spent preparing your home for your child's visit or cleaning up afterwards can count towards the 35 hours.

Be careful!

This is a complex area of the benefit system which can sometimes result in families being overpaid DLA. This usually happens when families unknowingly fail to inform 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. If you're unclear about your situation, contact the helpline for further advice.

Families should also be aware that stays away from home may also have an effect on other entitlements, like tax credits or Income Support. This too is very complicated so seek further specialist advice. Again, contact the helpline.

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. You must be giving at least 35 hours care each week to your child. To get CA you must not be a full-time student (more than 21 hours supervised study a week) and not earning more than £95 (after certain deductions and costs) each week.

CA 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 BEL.

CA can affect entitlements like Income Support and tax credits. In most cases you will still be better off. If you get Incapacity Benefit it could also be in your interest to apply for CA, even though it can't be paid on top of Incapacity Benefit. Contact the helpline for further advice.

Freephone helpline: **0808 808 3555**
Web: **www.cafamily.org.uk**



Child Tax Credit (CTC)

Child Tax Credit is assessed more generously when a child receives DLA. This is because families will qualify for an extra disability element (and a severe disability element if your child has been awarded the highest rate DLA care component). Whether this actually leads to you getting more tax credits still depends on your income and personal circumstances. But many families do get extra payments after a DLA award.

Don't wait for a DLA decision before contacting the Tax Credit Office. Instead let them know as soon as you have claimed DLA. So long as you do this, and get back in touch to let them know when your child's been awarded DLA, any increase in tax credits will be backdated in line with the DLA award.

Income Support (IS)

For families 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 IS in their own right (sometimes paid from 16 years of age) 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 Council Tax Benefit 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.

Both Housing and Council Tax Benefits are means-tested and any award will depend on your income and circumstances. Contact the 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 the household. Our booklet 'Help with council tax bills' contains further advice. Contact the helpline for a copy.

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. Contact social services to apply.

Help with road tax

If your child is awarded the highest rate of DLA mobility component, you may be eligible to 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 DLA Unit on Tel: 0845 7123456.

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 hire or buy a car through the Motability Scheme. **In order 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 grant assistance. Contact Motability on Tel: 0845 456 4566 or visit Web: <http://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/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.

Employment rights

If you work and have a child getting DLA you may have additional employment rights. Our guide 'Working and caring for a disabled child' contains further advice. Contact the helpline for a copy.

Other concessions

It is also worth checking to see if there are any special schemes, concessions or facilities available to families with disabled children in your area. Ring our helpline for local contacts.

What happens when your child turns 16?

DLA can still be paid after your child turns 16 but you may need to make a renewal claim for it to continue. You should not assume they'll get the same rate of DLA, so it is very important to get help if you need to complete a renewal at this time.

When your child reaches 16 there may be changes in how the benefit is paid. Before 16, a parent or other main carer is automatically authorised to act on their child's behalf, as an 'appointee'. This means you're responsible for filling in forms and making claims for your child. When they're 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 their appointee.

If your child is considered capable of handling their own affairs, the DLA 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 alongside any other benefits the young person claims after 16, like Incapacity Benefit (IB).

Freephone helpline: **0808 808 3555**
Web: **www.cafamily.org.uk**

For information about young people claiming IB and how this might affect a parent's benefits ring our helpline.

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

Further information about responsibilities as an appointee and other ways of managing benefits can be found in DWP leaflet 'A helping hand for benefits'. Copies are available from your local benefits office or call our helpline.

Further sources of help and advice

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 CAB, 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**

Tel: 0808 808 3555

Textphone: 0808 808 3556 (Mon-Fri, 10am-4pm; Mon 5.30-7.30pm)

- **CarersLine** Tel: 0808 808 7777

(Weds & Thurs, 10am-12pm & 2-4pm)

- **The Benefits Enquiry Line**

Tel: 0800 88 22 00 Textphone:

0800 24 33 55 (Tel: 0800 22 06 74

Textphone: 0845 24 37 87 in Northern Ireland) can help with filling out forms

and fax them to your local benefits office.

The BEL provides a service for people whose first language is not English.



For details of any local advice agencies which can help with benefit problems call the Contact a Family helpline. Some national organisations for specific conditions produce their own guide on DLA or can provide help with filling in the form. This includes the **National Deaf Children's Society, Action for Blind People, Down Syndrome Association, National Autistic Society, Diabetes UK,** and **Afasic**. King's Lynn & West Norfolk Borough Council has also produced 'DLA – a guide to claiming for children with ADHD'.

For a copy and for contact details of these and other support organisations please call our helpline.

Freephone helpline: **0808 808 3555**
Web: **www.cafamily.org.uk**