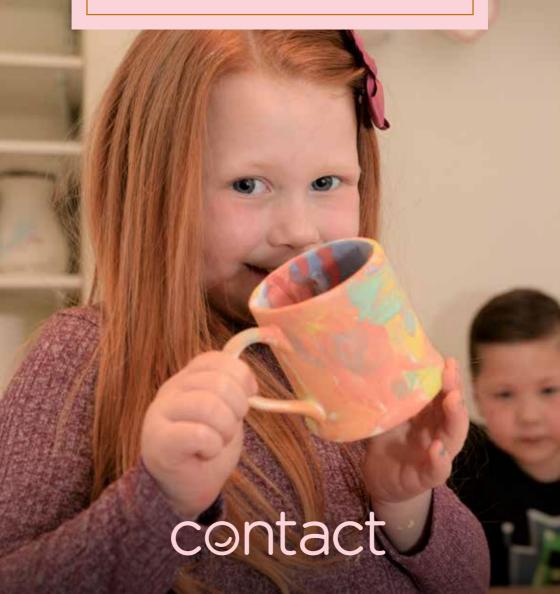
# CLAIMING DISABILITY LIVING ALLOWANCE FOR CHILDREN



INFORMATION FOR PARENTS OF DISABLED CHILDREN



"DLA means my son gets the chance to do the same things other kids do."

Parent carer

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### 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 can be claimed by children with learning difficulties, developmental delay, autistic spectrum disorders or mental health conditions, as well as by those with physical disabilities. 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.

DLA only applies to children who are aged under 16. Older disabled children need to claim Personal Independence Payment instead.

### CHILD DISABILITY PAYMENT IN SCOTLAND

DLA in Scotland has been replaced by a new benefit called the Child Disability Payment (CDP). Child Disability Payment has already replaced all new claims for DLA in Scotland and Social Security Scotland has now transferred most existing child DLA cases onto Child Disability Payment.

Young people in Scotland who turn 16 and who are getting Disability Living Allowance or Child Disability Payment immediately before their 16th birthday continue to receive DLA or CDP until they turn 18, when they can claim the Adult Disability Payment instead.

0808 808 3555 <u>helpline@contact.org.uk</u>

## 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 might meet this test if they need greater care than other children of the same age, or if they need types of care that would only normally be required by younger children.

### HOW LONG MUST MY CHILD NEED THIS EXTRA HELP FOR?

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 twelve months, there are special rules which mean the benefit can be paid from birth. Please see page 13 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 26 weeks out of the last year, call our freephone helpline for further advice.

### 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. It is paid at the following weekly rates:

Lowest care	£28.70
Middle care	£72.65
Highest care	£108.55

### **MOBILITY COMPONENT**

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

Lower mobility	£28.70
Higher mobility	£75.75

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

### 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.



## THE RULES FOR GETTING DLA

### 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

This is paid if your child needs help with personal care for a 'significant portion of the day'. This is usually taken to mean 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. Sometimes less than an hour's care will be sufficient to meet this test – for example if the help is spread over a number of short periods or is particularly intensive in nature.

### WORDS USED IN THE DLA RULES

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. It also includes any help your child needs with speech, communication and their learning, development, social skills and play. 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 household closes down at the end of the day; this is usually when the parents go to bed. Night time ends when the majority of the household gets up in the morning. Night-time is normally assumed to start around 11 pm and end around 7 am.

### The middle rate care component

This 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

Paid if your child has day-time and night-time care needs, or if they qualify under the 'special rules' (see page 13).

To qualify for the 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

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, including children with autism, ADHD and behavioural difficulties. 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 paid for children who are unable to walk or are 'virtually unable to walk'. This can be paid from the age of three years. In deciding whether your child is virtually unable to walk the Department for Work and Pensions (DWP) should take into account the speed, length of time and manner of walking, as well as the distance your child can cover before they start to experience severe discomfort (for example, breathlessness or pain). In practice the DWP are often reluctant to accept that a child is virtually unable to walk if they can walk more than 50 metres without severe discomfort. This may be open to challenge where a child can walk more than 50 metres but takes a long time to cover that distance. The higher rate mobility 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. If your child does not meet this test indoors but has significantly worse eyesight when outside, call our free helpline for more advice.

# The higher rate mobility component & children with severe mental impairments

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

- · be entitled to the highest rate care component of DLA, and
- exhibit 'a state of arrested development or incomplete physical development of the brain which results in severe impairment of intelligence and social functioning'. It is accepted that autism satisfies this criteria but you are likely to need evidence from a professional showing this is the case and demonstrating the severity of your child's needs, 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, for example because they sleep through the night and do not qualify for the higher care rate, can qualify because they are 'virtually unable to walk'. This may apply to children who have autism or a learning disability like Down syndrome, who often simply refuse to walk. If you think this applies to your child, call our free helpline for advice, or read our guide below.



Our free guide <u>Disability Living Allowance – claiming the higher rate</u>

<u>mobility component for children with learning difficulties and autistic</u>

<u>spectrum disorders</u> explains more. Get it from our helpline 0808 808 3555

or at www.contact.org.uk/dla-learning-disabilities-guide

### SPECIAL RULES

### Special rules if your child has a terminal illness

If your child has a terminal illness, you may be able to 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. See Question 2 of the form for more details. You can only apply under the special rules if your child's death could be expected within 12 months.

To apply under the special rules you will need to ask your child's clinician (for example, GP, hospital doctor, specialist doctor, or senior practice nurse) to give you an SR1 medical report form or to send one directly to the DWP/SSA. They can send the SR1 form by the NHS spine portal, via email or by post. The SR1 form has replaced the DS1500 certificate previously used. 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 normal tests for it.

'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.



## HOW TO CLAIM

### **CHILDREN UNDER 16**

Use claim form DLA1 Child (ALT), available from local benefit offices or by calling the Disability Living Allowance helpline (see page 16).

You can also download a claim form from the GOV.UK website, but it is preferable to phone the DLA helpline and ask for a form. This is because the form they post out to 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 16 on deadlines and backdating for more details.

At the time of writing it is not possible to claim DLA online.

### **CHILDREN OLDER THAN 16**

From age 16 a young person must claim Personal Independence Payment rather than Disability Living Allowance. Different rules apply in Scotland. See page 65 for more information or call our freephone helpline.

### **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 prematurely.

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.



To make a new claim or enquire about an existing claim, call the DLA helpline. They can also speak to you if your first language is not English:

0800 121 4600 Textphone 0800 121 4523

If you live in Northern Ireland call:

0800 587 0912 Textphone 028 9031 1092

### DEADLINE FOR CLAIMING DLA AND BACKDATING A CLAIM

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 normally given six weeks to complete and return the form. If your child qualifies, DLA will be paid from the date it was stamped. If you don't call and ask for a form to be sent out but get it by some other means, the earliest DLA can be paid is from the date the benefits office receives your completed form. As it may take time to complete the form and get any medical evidence you may need, it's always better to call and ask for a form to be sent to you.

## COMPLETING THE DLA1 (ALT) CHILD FORM

The information in the following section relates to the DLA 1 child (ALT) claim pack used in England and Wales. There may be some differences in the DLA 1A claim form used in Northern Ireland. The form has 39 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 page 28 of the booklet.

The following section is a brief explanation of some of the more difficult parts of the DLA1 (ALT) Child form, with comments about the kind of information to include.

### **GIVING ALL THE INFORMATION YOU CAN**

The current DLA1 (ALT) child claim form has less text boxes for adding information than previous versions of the claim pack and largely relies on tick boxes instead.

If you feel the form doesn't have enough space for you to describe your child's needs in detail – there are extra boxes at pages 19, 34 and 37 where you can give more information. Use the question number as a heading for each additional section of information that you add.

### Attach examples of your child's needs

You may also wish to consider attaching extra pages of information if you feel this is necessary to capture the complexity of your child's needs. It can be really useful to provide examples and anecdotes of the types of help that your child needs rather than simply relying on tick boxes. This can help ensure that the decision maker has a more detailed and clearer understanding of the help that your child needs.

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. We can give you details of local organisations who can help: **0808 808 3555** helpline@contact.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 our free 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 27 29 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 just rely on ticking the
  boxes that apply, try to provide more details about the help your child 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.
- Don't play down your child's condition. It's important that you provide
  as much detail as you can about your child's needs. Include details of your
  child's needs during bad days, as well as better days, so the decision maker
  has an insight into the full extent of your child's needs.
- 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. Contact us
  for more information on rare conditions.
- Include supporting evidence with the form if you have it. This can be medical reports, speech and language assessments, psychological reports, and an Education, Health and Care plan 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. Before submitting any reports you should also check that you agree that they are an accurate picture of your child's needs. If you feel that a report minimises the amount of support your child requires you may choose not to submit 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.



# TOP TIPS FOR EACH QUESTION

### QUESTIONS 1-37: 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 as well any school or nursery that they attend. This section also asks you about any stays your child has had in hospital or residential care within the last 12 months.

# QUESTION 38: 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 40: 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'). As well as providing details of your child's condition(s) also provide brief details of any treatments or medications they have.

### **QUESTION 42**

You can use this section to give an overview of your child's condition and their needs. 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 70 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 43-53: 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 43–48 and question 51.

You may feel that there isn't sufficient space to fully describe your child's mobility needs. If so use the boxes at questions 53 and 89 or add extra sheets of paper with additional information.

If your child can walk it is important to describe how they walk (for example with a limp or shuffle). List the impacts 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?
- does your child regularly refuse to walk and is it difficult to overcome these episodes.

If your child can physically walk without major problems but needs guidance or supervision in places they are unfamiliar with, you should answer questions 49-53.

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

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

Even if your child is of an age where no child would be allowed out of doors by themselves, they may still need more guidance or supervision than other children of the same age.

Question 49 asks about unpredictable behaviour and the need for restraint. These questions relate to the higher rate mobility and severe behavioural problems. See page 12 for more details.

If this describes your child's behaviour then it is important to give as much detail as possible about these issues in the box at question 53. For example:

- do they get distressed and likely to hit out at you or other people, or harm themselves in some way?
- do they run away suddenly without attention to dangers like traffic?
- do they exhibit any other behaviours that might be alarming to others or behaviours that are inappropriate?
- does your child need to be physically restrained to avoid a risk to themselves or a risk they will harm others?
- are they highly unpredictable and need to be watched over the whole time?

Question 51 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.

### **QUESTION 52**

If your child is awarded the higher rate mobility component you will have the option of using that money to lease a car or wheelchair under the Motability scheme. Complete this question if you would like to receive information about the Motability scheme and how it works.

### QUESTIONS 54-72: 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.

Remember don't just rely on the tick boxes – use the boxes at questions 72 and 89 to provide more detailed information about your child's needs or consider attaching extra sheets of paper with more information. The following pages give examples of the sorts of additional information that can be provided

### QUESTION 54: 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. Some children may need to follow very rigid and time consuming routines when going to bed.

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 even if this is several hours.

### QUESTION 55: Toileting needs

You will need to explain any difficulties during the night at Question 70. 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 constipation or episodes of wetting
- any resulting pain or distress
- problems with transfer to and off the toilet or refusing to use the toilet
- · not wiping themselves, or playing with faeces or missing the toilet
- problems with undoing zips or buttons or taking 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 or refusing to use unfamiliar toilets if you are out or when they are at school
- additional supervision in the bathroom

### QUESTION 56: Your child's needs when moving about indoors

Think about the help your child needs getting around inside, for example not only at home but at school, nursery or places they go while pursuing leisure opportunities. 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 physical 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 or supervision if they place themselves at risk by running around indoors.

### QUESTION 57: 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 or because they are at risk of falls, seizures or blackouts
- 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
- they may need help with shaving, grooming their hair or applying cosmetics.

### QUESTION 58: Getting dressed or undressed

### Consider 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, or if they will undress at inappropriate places.

### QUESTION 59: Eating and drinking (including breastfeeding)

Think about 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
- are they receiving parenteral nutrition or tube feeding
- do they have sensory needs around food and specific textures?

### QUESTION 60: 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). You may also have to monitor your child's condition and make adjustments to the dosage and timings of medication they require.

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.

If your child has a condition like diabetes they may not only need help with administering injections but also with monitoring blood glucose levels, adjusting insulin levels and adjusting diet and exercise.

### QUESTION 61: 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, or bringing to their attention certain sounds such as traffic, alarms or announcements.

### QUESTION 62: 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. 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 63–64.

# QUESTIONS 63 – 64: 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.
- your child may chose not to speak to others or only speak to friends and close family.

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

### QUESTION 65: 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, make this clear.

### QUESTION 66: 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
- a child may have no awareness of common dangers and place themselves at risk e.g. by climbing on high objects, putting objects in their mouth or poking fingers into electrical sockets.

### QUESTION 67: 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 visuallyimpaired 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 68: 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, for example if they have dyslexia, 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 pages 8-9 of the 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.

DLA looks at the help your child needs, even if they do not always receive this help. 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 69: 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 70: 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 a feeding tube or inhaler or nebuliser. They may become extremely breathless and this could leave them distressed.
- some children may be in pain during the night and benefit from being massaged
- your child may sleep very little or wake up frequently and want to play, meaning they require supervision or settling back to sleep.

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 71**

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 13.

# QUESTIONS 53, 72 & 89: 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 and underestimates their needs 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.

Giving detailed medical information may lead to a quicker decision and reduce the chances of the 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 notes to Question 68). 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

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 89 '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. Where this
  is substantially more than other children need it will count as extra
  attention with tasks in the same way as physical care.
- 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.
- watching over your child because of the risk of self-harming behaviour.



# RENEWAL CLAIMS

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.

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. The DLA Unit are unlikely to read your previous forms when making their decision – complete the form as if you are making a new claim and put as much evidence as possible. Assume that the decision maker doesn't know anything about your child. It is ok to copy what you have written on your previous forms – as long as it still reflects your child's needs.

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 43-49.

The renewal form is 23 pages long rather than 39 and there are some notable differences between the initial claim form and the renewal form. Please see overleaf for details.



It's very important that you return the renewal forms before the current award finishes, or you could lose out on benefit payments in between.

## QUESTION 23: Supporting evidence

This section asks for evidence from school and medical professionals.

There is space for one health professional and a further section to add their school details. You can add details of additional medical professionals at Question 64.

Don't assume that DLA will look at any evidence you have sent with your original or previous claims. Send recent evidence that describes your child's care and support needs. This can include your child's EHCP and school or medical letters and can include evidence you have sent before if it is still relevant to your child's current needs.

## QUESTION 32: Changes in your child's condition

This section asks for details about how your child has changed. Remember your child's needs may have changed as they have got older, even if they have the same health condition or diagnosis. It is helpful to look back at copies of your old DLA application forms to see how your child has developed.

You should also state if they now have additional or new night-time or mobility needs that you would like DLA to consider.

# QUESTION 34: What help does the child need?

You can use this space to give an overview of your child's needs and the help that they need.

## **QUESTIONS 35-37: Mobility**

This section asks about your child's physical difficulties walking and whether they need supervision and guidance when walking out of doors.

These pages do not mention needing help if your child has a severe mental impairment, a visual impairment or if they are in pain or need to use a wheelchair when out of doors. You can and should add information about help your child needs in these circumstances – see page 22.

## QUESTION 39: Care needs during the day

This questions asks about the help your child needs with washing, dressing, eating, drinking, taking medication, using the toilet, moving around indoors and getting in and out of bed. There is a small space in which to put many areas of information.

You can use the spaces on page 15, at question 64 and on the back of the form to write more detailed information; you can also use additional sheets of paper.

Don't rely on the tick boxes, you need to describe the help your child needs. You should label each section of information – washing, using the toilet and so on, so that the information is clear.



# 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 get a decision within three months, but it may take longer than this.

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 Department for Work and Pensions (DWP) or Social Security Agency (SSA) in Northern Ireland, 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/SSA will normally write inviting you to reapply for DLA. See page 39 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.

#### ASKING FOR THE DECISION TO BE RECONSIDERED

If you are not happy with a DLA decision you can ask the DWP/SSA 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.

If you choose to make your request in writing, then in England and Wales you can either do this using the CRMR1 mandatory reconsideration request form on GOV.UK or by writing a letter. In Northern Ireland you should use form MR2(NI) available at nidirect.GOV.

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

## Providing more information about your child's needs

As part of having a decision reconsidered you can volunteer, or you may be asked to give, further information. Or the DWP/SSA 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.

#### When a decision has been made

Once the DWP/SSA 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 (or the Appeals Service in Northern Ireland) if you decide to appeal. The notice contains details of the reconsidered decision alongside details of your appeal rights.



For help with asking for a reconsideration or appeal contact our helpline: **0808 808 3555**helpline@contact.org.uk

#### 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 for the decision 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 time scale, unless you have spoken to the DWP/SSA 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/SSA 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.

#### **HOW DO I APPEAL?**

You can appeal online at Gov.uk or in writing using form SSCS1 which you can also download at Gov.uk. Type SSCS1 into the search bar. In Northern Ireland use form NOA1 (SS) available at NIdirect.gov.uk.

If you appeal online you will need the date at the top of your Mandatory Reconsideration notice. If you send your appeal by post you will need to send a copy of the notice with your application form.

Whether you appeal online or by using the form, you must send your appeal directly to HM Courts and Tribunals Service (HMCTS)/Appeals Service in Northern Ireland. They must recieve it within one month of the date on the reconsideration notice. If you miss this deadline seek advice about making a late appeal.

In your appeal request explain why you think the decision you are appealing against is wrong. You can send further evidence to support your case. You can upload it as part of your online application or send it with form SSCS1.

#### AFTER YOU HAVE SUBMITTED YOUR APPEAL

If you request your appeal online you can opt to receive updates by text message and email. You will then receive notification that your appeal request has been received by HMCTS. If your request was made in writing you will receive a letter confirming that the request has been made.

The DWP will be expected to respond to your request within one month of the date it is received. They will do this by sending a set of appeal papers to HMCTS. A copy will then be sent to you. The papers contain all the evidence related to your child's case, including copies of their claim form and any evidence you have already sent to DLA. The DWP will also explain the reasons for their decision in more detail.

The paperwork may look daunting, but try to not to be put off by this. Try to read through it and make a note of any parts you disagree with.

#### 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. If you choose an oral hearing this can be in person, a video hearing or by telephone. Whilst attending in person is always the best option, an online or telephone hearing may make it easier for you to participate.

If you are not sure which option would be best for you then contact our free helpline to discuss it further and for updates on **0808 808 3555**.

#### PREPARING FOR THE APPEAL HEARING

It may take several months to receive a date for your tribunal 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.



Advice Now produces a free guide **How to win a DLA 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. A hearing in person will usually be held at the most local venue to you. If you have opted for a video or telephone hearing then the panel may be anywhere in the country.



To find a specialist adviser who can help you appeal call our free helpline **0808 808 3555** helpline contact.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.

#### WILL MY CHILD BE EXPECTED TO ATTEND THE HEARING?

Children will not usually be expected to attend the tribunal hearing, especially young children or those with a severe disability. If your child is older and able to articulate their views, then they can choose to attend. Remember that DLA focuses on the areas where your child needs support and this can be difficult for your child to listen to, as it can feel very negative. If the tribunal panel feels that they need to hear from your child or young person then they can adjourn the hearing and ask them to attend another hearing at a later date; they will usually only do this for older teenagers.

# Take supporting evidence

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 your appeal is successful any additional benefit you are entitled to will be backdated to the start of your claim. If you are unhappy with the decision you may be able to appeal to the Upper Tribunal, but you will first need to request a full statement of the Tribunal's reasons for its decision. You must do this within one month of the date on your decision notice. 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 43.



#### 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.

If your child has been awarded both components of DLA but you are only unhappy with the rate of one of the components, make this clear when you ask for the award to be reconsidered. Tell them that you do not wish the component you are happy with to be looked at again. Hopefully this will minimise the risk that the DWP also look again at the component you are satisfied with.

However, unfortunately this doesn't guarantee that the DWP won't look at both components. This is because they may feel that they already have grounds to look at both.

Because of this risk it is a good idea to get help from a Citizens Advice Bureau (CAB), or local welfare rights service if you want an existing DLA award looked at again.



# STAYS AWAY FROM HOME

DLA can be affected by overnight stays away from home, in a residential school, or residential care.

#### 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':

- 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 different rules may apply; contact our free helpline for further advice.

#### GETTING PAID FOR THE DAYS THEY COME HOME

If your child's DLA stops because they are in a residential setting, they are still entitled to DLA payments at a daily rate for the nights they spend at home.

For example, your child has been away at residential school for more than 28 days, so payments of DLA care component have stopped. If 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, for instance during the long summer holiday, the care component should not be stopped again until after they've spent another 28 days in residential school.

#### COUNTING THE NUMBER OF DAYS 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 you child goes into a residential school on a Monday and comes back on a Friday, then only Tuesday, Wednesday and Thursday will count as days away from home. This is a total of three days.

# IF THEY HAVE REGULAR SHORT BREAKS IN A RESIDENTIAL SETTING

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

## For example

If your child has regular short breaks in a residential setting, these separate breaks can be added together.

Once your child has spent a total of 28 'linked days' in a residential setting they will stop being paid the care component during any subsequent days in care – but they will still get payments as normal for days at home.

However, if your child has at least 29 days at home in-between these short breaks then the 'link' is broken. This will mean that if they go back into residential accommodation for short breaks they will be allowed another 28 days in care before their DLA care component is once more suspended.

If your child has regular short breaks in a residential setting and you want to ensure that DLA payments are never affected, you may need to ensure that your child occasionally has a gap where they spend at least 29 days at home in between these short breaks.



Our helpline can give you more details about the 'linking rules' for DLA and stays away from home: **0808 808 3555** <a href="helpline@contact.org.uk">helpline@contact.org.uk</a>

#### **EXAMPLE**

Daljit goes into a residential unit once every three weeks. He enters the residential unit on a Friday and returns home on a Monday. Since both the day he enters and the day he leaves care are treated as days at home, he is treated as spending two days in care each time he has a short break.

As his short breaks are separated by fewer than 29 days at home, they are 'linked' together. This means that once he has had 14 short breaks (14 x 2 days = 28 days), his DLA care component payments will be suspended for any subsequent stays in care. However, if Daljit then has a period where he spends at least 29 days at home the 'link' will be broken and he can once more be paid DLA for a further 28 'linked days' of care.

#### WHEN YOUR CHILD IS IN HOSPITAL

# Children aged under 18 in hospital

So long as a child is aged under 18 on the date that they first become an in-patient, their DLA continues to be paid as normal while they are in hospital. Also, if a child first claims DLA while they are an in-patient, their payments can start despite the fact that they are in hospital – they do not to need wait until they are discharged home before payments can start.

## Young people aged over 18 in hospital

The situation is different for adults. If an adult gets either DLA or PIP and they became an in-patient after they turned 18, their DLA/PIP payments will be suspended after they have spent 28 days in hospital.

#### **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 in a residential setting.

It is your responsibility to tell the DLA Unit each time your child is away from home in a residential setting where the costs are being met from public funds. The DLA Unit need to have clear information about how many days your child has been in care in order to decide if DLA payments should be suspended.

# EFFECT OF STAYS AWAY FROM HOME ON CARER'S ALLOWANCE (CA)

# If your child is in residential accommodation

This can impact on any CA paid to their main carer. But even if your child is in a residential setting for a long period, you may still be able to carry on getting CA 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.

**NOTE:** It's a good idea to keep a record of the dates your child goes in and out of residential accommodation so you can tell the DLA Unit.

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 counts towards the 35 hours' care.

## If your child is in hospital

Not only should DLA payments continue but you should also continue to get CA so long as you are still providing at least 35 hours a week care to them. If you stop providing 35 hours a week care to your child while they are in hospital you can continue to receive CA for a temporary period of up to 12 weeks — although this may be restricted to a shorter period if you have already had other breaks from caring in the previous six months.

#### **EFFECT ON OTHER BENEFITS**

Families should also be aware that stays away from home may also have an effect on other entitlements, like tax credits, Universal Credit, or Income Support. If you receive Universal Credit payments for your child then these are likely to stop if they are away from home for six months or more – including where this is because they are in hospital.



These are very complex areas so seek specialist advice if your child is in residential accommodation or in hospital long-term. See our free factsheets, *Benefits if your child is in a residential setting* and *Disability*<u>Living Allowance when your child is in hospital</u>. Or contact our helpline on 0808 808 3555

helpline@contact.org.uk



# DLA & 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 £151 per 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, CA can only be backdated for three months.

CA can affect entitlements like Universal Credit, Income Support and tax credits. In most cases you will still be better off claiming it. If you get 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.



You can <u>claim Carer's Allowance online</u>, or ask for application form DS700 from the CA Unit on **0800 731 0297**. <u>Claim online in Northern Ireland</u> or call **0800 587 0912**.

#### 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.

### **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.

#### 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 your disabled child cannot share a bedroom and because of this your Housing Benefit (or help with rent via Universal Credit) 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 help with rent. 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.

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.



For advice call our helpline or see our guide *Help with Council Tax bills* 

#### UNIVERSAL CREDIT

Universal Credit is a new benefit that is replacing 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 an extra Universal Credit payment known as the disabled child addition. This is paid at a higher rate if your child is severely sight impaired or blind or if they qualify for the highest rate of the DLA care component.

The disabled child addition should be backdated either in line with your DLA award or from the date your Universal Credit award started – whichever date was more recent. This should apply even if you delayed in telling the DWP/SSA about your child's DLA award.



For more information call our helpline or see our factsheet Universal Credit — the essentials

#### **EXEMPTION FROM 'BENEFIT CAP'**

If you have a dependent child 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 higher 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 registered blind. 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. It is sometimes possible to qualify for a Blue Badge for other reasons although the rules vary between the different parts of the UK. For instance, in England your child should qualify for a Blue Badge if they are two or over and either have considerable difficulties in walking (which may include psychological distress) or if they are at serious risk of harm when walking or pose a risk of harm to others. Contact your local authority to apply for a badge.



Our website has more information on the Blue Badge parking scheme

#### **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 higher rate DLA mobility component. If you haven't received any information and you think you qualify, contact the Disability Living Allowance helpline on 0800 121 4600.

#### HELP WITH GETTING A CAR

If you're interested in getting a car and your child is awarded the higher rate of the mobility component of DLA, you have the option of leasing a car through the Motability Scheme.

To access this scheme your child's award of the higher 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 visit Motability or call 0300 456 4566

#### **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.

# FREE EARLY EDUCATION FOR TWO-YEAR-OLDS IN ENGLAND

If you live in England and have a two-year-old who is awarded DLA, this should mean that they qualify for 15 hours a week free early years education and childcare. See www.gov.uk/help-with-childcare-costs/free-childcare-2-year-olds-benefits for more details.



To find out what other schemes or facilities are available in your area, call our helpline **0808 808 3555** helpline **3contact.org.uk** 



# WHAT HAPPENS WHEN YOUR CHILD TURNS 16?

Once a young person on DLA turns 16 they are asked to claim Personal Independence Payment (PIP) instead. A young person who is 16 or over and not already getting DLA needs to claim PIP instead of DLA.

#### IF YOUR CHILD IS GETTING DLA AND IS TURNING 16

# In England and Wales

Normally your child 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. However, young people turning 16 who get DLA under the special rules for the terminally ill continue to get DLA until their existing award runs out – they should be contacted by the DWP and invited to claim 20 weeks before their award ends.

If a child turning 16 is an in-patient they won't be invited to claim PIP until they have left hospital. The Department for Work and Pensions will usually write to you when your child reaches the ages of:

- 15 years and 7 months to explain what will happen and to check whether your child will need an appointee to act on their behalf (see page 40)
- 15 years and 10 months to follow up with a second letter
- 16 years to send a letter 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 to, their DLA payments will stop.

#### In Northern Ireland

Young people turning 16 in Northern Ireland are also invited to claim PIP. You should be contacted by the SSA before your child's 16th birthday and advised what you need to do.

#### IF YOUR CHILD HAS TURNED 16 AND DOES NOT GET DLA

Once your child turns 16 it is too late for them to make a new claim for DLA. They will need to make a claim for PIP instead.

# WILL MY CHILD GET THE SAME RATE OF PAYMENT WHEN THEY CLAIM PIP?

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

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



We have a free indepth guide, <u>Personal Independence Payment and other</u> <u>benefits at 16</u>. Call **0808 808 3555** for copy

#### PAYMENTS WHEN YOUR CHILD TURNS 16

When your child reaches 16, there may also be changes in how 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 are responsible for filling in forms and making claims for your child.

If your child on DLA is nearing 16 years of age, you will be contacted by the DWP and asked if your child has the capacity to manage their own benefits. If you say that your child lacks capacity the DWP will want to visit you and your child before deciding if you will continue to be your child's appointee.

# If your child is considered capable of handling their own affairs

The 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 PIP alongside any other benefits the young person chooses to claim after they have turned 16.

# If your child can manage their benefits claims but can't physically collect their benefit payments

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.

# 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. 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, Cerebra. For help over the telephone, call:

**Contact Helpline** 

0808 808 3555

CarersLine

0808 808 7777

# GET IN CONTACT

Our helpline advisers can support you with any issue about raising your disabled child: help in the early years, diagnosis, benefits, education and local support.

- Ø 0808 808 3555
- (h) contact.org.uk
- twitter.com/contactfamilies
- (f) facebook.com/contactfamilies
- youtube.com/contactfamilies

Contact Head Office G.07 Wenlock Studios 50-52 Wharf Road London N1 7EU



We are Contact, the charity for families with disabled children.

We support families with the best possible guidance and information

We bring families together to support each other.

We help families to campaign, volunteer and fundraise to improve life for themselves and others.

