

Introduction

Disability Living Allowance (DLA) is a benefit awarded by the Department of Work and Pensions (DWP) to meet the additional expenses of raising a disabled child under the age of sixteen.

The Equality Act 2010 defines a disability as 'a physical or mental impairment that has a "substantial" and "long-term" negative effect on your ability to do normal daily activities'.

Disability Living Allowance is designed to contribute towards the costs of caring for a child who needs more care and supervision than a child of the same age who does not have a disability or condition. It is made up of different components.

It is not a reflection on the diagnosis of the condition or disability your child has and a medical diagnosis does not need to have been made to make an application.

Your child must have required additional care for three months prior to application (unless claiming under Special Rules – see below). The mobility components are awarded from three years of age for the high rate and five years of age for the low rate.

There are two parts to a DLA award – care and mobility. Care has three rates – low, middle and high which are calculated using the time spent managing the additional care needs your child has.

Mobility has two rates – low and high. Low rate is awarded for children who require additional supervision while out of the house in places they don't know well and high rate is awarded for children who have limited physical mobility.

DLA is paid every four weeks. It is not means tested. You will not be asked about your personal financial situation in your application.

A DLA award can affect other means tested benefits you receive and may make you eligible for additional benefit components known as disability premiums. This could **increase** the amount of any existing awards you receive, such as Child Tax Credits, Income Support, Universal Credit or Housing Benefit.

In some circumstances a DLA award can enable you to apply for Carers Allowance. A DLA award will also exempt your immediate household from the benefit cap.

Important things to remember

You need to give an accurate account of your child's additional needs in your own words. This guide and the examples given are for guidance only and will not guarantee an award.

It is vital you keep copies of everything – the completed form, letters from the DWP and any supporting information you include. This is especially helpful should the DWP not receive your form or if you wish to appeal the decision. It may also be a useful reference for completing renewal forms.

Any award is only backdated to either the date you requested the form or the date of receipt by the DWP regardless of how long your child has had additional needs. You are usually given about six weeks to complete and return the form.

It can be helpful to keep a diary of the care you provide for a week before completing the form. You can also send this in as supporting information. Often it is easy to lose track of exactly how much time you actually spend providing additional care on a day to day basis.

If you or a member of your immediate household are subject to immigration control, seek expert advice as an application may affect your right to stay in the UK. Additionally, ensure you meet the rules about time spent resident in Great Britain.

For children under six months old, they must have lived in Great Britain for at least 13 weeks; children aged between six months and three years must have lived in Great Britain for at least 26 weeks out of the last 156 weeks. Children over three must have lived in Great Britain for at least two out of the past three years.

There are some exceptions to this rule – for example, children whose parents serve in the British armed forces.

Completing this form is emotionally draining – you are asked to answer questions about what your child cannot do, not the achievements they are making in difficult circumstances.

Do not be tempted to play down your child's condition and the care and support you provide.

Do not be concerned about repeating yourself. You will find that you are writing the same things down in many of the questions you are asked. It is also fine to be putting things down in your own words. Explain things as you would to a friend.

The Community Support Team at DEBRA will be happy to help and support you in making your application and can provide advice on eligibility.

DLA as a passport benefit

A DLA award will entitle you to other forms of support.

If your child is awarded DLA, you will be entitled to parental leave (as long as you meet the minimum employment conditions) and exemption from the Benefit Cap. You can also apply for free carer's tickets to family attractions and other leisure activities. A high rate mobility award will usually entitle you to a fast access ride pass at theme parks to avoid standing in queues.

Care component

If you are awarded the **low rate** you can then get:

- Disabled child element of Housing Benefit
- Lower rate disabled child element of Universal Credit
- Disabled child premium of Child Tax Credits

If you are awarded the **middle rate** you can then get:

- Carers Allowance (providing you meet the requirements)
- Carers Credit (should you not meet Carers Allowance criteria)

- Disabled child element of Housing Benefit
- Lower rate disabled child element of Universal Credit
- The Carers eligibility element of Income Support
- Disabled child premium of Child Tax Credits

If you are awarded the **high rate** you can then get:

- High rate disabled child element of Universal Credit
- Severely disabled child premium of Child Tax Credits
- Disabled child element of Housing Benefit
- Carers Allowance (providing you meet the requirements)
- Carers Credit (should you not meet Carers Allowance criteria)
- The carers eligibility element of Income Support

Mobility component

If you are awarded the **low rate** you can then get:

- Disabled child element of Housing Benefit
- Lower rate disabled child element of Universal Credit
- Disabled child premium of Child Tax

If you are awarded the **high rate** you can then get:

- Exemption from paying vehicle tax
- Eligibility for the Motability scheme
- Automatic qualification for a Blue Badge
- Disabled child element of Housing Benefit
- Lower rate disabled child element of Universal Credit
- Disabled child premium of Child Tax Credits

The questions you will be asked

The first section of the form will ask you to provide details of the child you are claiming for and questions to establish your eligibility to receive DWP benefits.

If your child spends periods away from home, for example in residential care, discuss this further with your EB Community Support Manager at DEBRA as there are challenges that can be made to enable a successful claim.

You will also be asked for contact details of professionals involved with your child. Ensure you mention everyone you have had contact with in the past twelve months. If you do not have enough space, provide their details in the extra information section at the end of the form.

Special rules

If your child has a terminal illness and is expected to have a life expectancy of six months or less, you can apply for DLA under the special rules criteria.

Your application will be processed quickly and if awarded, you will receive the high rate care element. You will not need to answer the care component questions in the form.

In addition to ticking the special rules box on the form, you will need to ask your child's doctor or consultant to complete a form called a DS1500 (this does not need to be sent in at the same time as the DLA application form). You will need to fill in the mobility section of the DLA application form if you want to claim this element.

Listing your child's illnesses and disabilities

Please ensure you include everything here, not just their primary illness or disability. This can include problems like anxiety, social difficulties, and help with learning, seasonal asthma, extreme tiredness, etc. Your child does not need to be receiving professional help with these conditions.

You will be asked about what treatment your child has for their condition – do not worry about listing every single cream, dressing and medication. Ask for a copy of your child's prescription list from your GP and include it with the form (just write "*see enclosed prescription list*") and only list the additional items you use (for example, over the counter pain relief). For conditions such as social anxiety or help with learning detail the support your child needs. For example, "*one to one support at school; emotional support from me when we go out.*"

Aids and adaptations

You will need to think of what you have in your house or things your child uses that are different from a child of the same age without a disability or condition. As well as items your child may have been assessed to use (a wheelchair, for example) include things your child uses to help them day to day.

Common overlooked items are:

- Sheepskin fleeces or other soft throws
- Padding on seatbelts or push chairs
- Soft grip pens and pencils (including wrapping prescribed tape around them)
- Cushions
- Towels in the bath for cushioning
- Using a scooter or skateboard for mobility

- Additional grab rails for support around the home
- Seating in the shower (even a garden chair)
- Soft grip cutlery
- Touchscreen tablet, laptop or phone
- Attaching prescribed padded tape to Xbox or Playstation controllers

When your child needs help

Do not underestimate the care you provide. You must compare what is a normal day for you with a family with a child of a similar age without additional needs. If you do tick the box “it varies”, make sure you explain in the box these times, following hospital admissions or infections for example, where you have to provide significantly more care.

For example:

“Every two or three months, my child tends to get infections in the raw areas between their toes. This is incredibly painful and needs careful management. It makes changing their dressings take twice as long as usual and I have to do this more often. They will have additional medication which I have to make sure they take at the appropriate times during the day. They are unable to put any weight on their feet during this time and I have to carry them around the house.”

Mobility section

Initially you will be asked how many metres your child can walk outdoors. Consider how far they can walk without it causing them to stop because of pain or severe discomfort, not how far they struggle on to enable them to try to do the things other children do.

A double decker bus is approximately 10 metres long so imagine a few parked outside your house and think of how far your child could walk down the road.

Timing your child walking is also a difficult question to answer. So consider that for an adult to walk 100 metres (or ten double decker buses), bearing in mind an adult has a longer stride, it would take roughly one minute at an average pace.

If your child could only manage four double decker buses and you were walking much slower than you would if you were out by yourself, you would tick the 50 metres or less box and any of the top three boxes for timing, depending on how much slower you are compared with your normal walking speed and stride.

Tick as many boxes as appropriate to describe how your child walks. You can clarify in the box below that it varies depending on where your child has blistering or wounds.

A typical answer would be:

“My child will walk on their toes when they have blistering and open wounds on their heels and backs of their ankles. However, this will cause friction and further blistering to the toe area and they will try to put their weight on an area of less discomfort (perhaps the sides of their feet). It is a cycle of waiting for one area to heal, causing damage to the area they are walking on during this time. This also causes them to have poor balance and they are

always at risk of tripping or stumbling. In addition to the blistering and wounds, they constantly feel that they are walking on thorns and that their skin is burning.”

You can describe how walking causes friction and therefore further damage to their skin (no matter how many dressings you apply) in the box below ‘Does the effort of walking seriously affect their health?’

Include examples of how it will cause them to have to be off their feet completely for a day or two following a few short walks.

If you keep a wheelchair or push chair for your child to help with getting out and about, include this in the ‘anything else you think we should know’ box.

You can use this space to add to what you have already told them and describe things such as:

- *Any friction will cause the skin to blister and shear away and there are no dressings I can use on their feet to fully protect them from this*
- *When they have areas of raw, open wounds on their feet, they are unable to put their weight on their feet at all*
- *Infections in the areas of broken skin make it far more painful and difficult to walk even a few steps*
- *If they are going out with their friends, I have to drive my child to and from the location (Eg. cinema) as they cannot keep up walking with their friends or use the bus. This upsets my child as they cannot have the same independence as their friends.*
- *The school have made special arrangements for my child due to their limited mobility*
- *During the summer, my child cannot walk at all as the heat makes their EB worsen*

The next questions in this part ask about your child requiring guidance and supervision outdoors and falling due to their disability.

Depending on your child’s age, most children will always require an adult with them outside so you may wonder why these questions are included.

Points to consider here are:

- Whether your child needs you to be there to physically support them as they are walking
- Providing emotional support as they become anxious while out of the house
- If outdoor activities need to be supervised to avoid knocks and to step in if other children’s play is more physical
- Whether you need be there in case they stumble or fall

Ensure you elaborate on why you have ticked any of the boxes.

An example would be:

“Due to my child’s poor mobility, they always need an adult with them as they require physical support when they are walking the short distances without going in the wheelchair. This is because they are so unsteady on their feet and to prevent falls and stumbles – even a slight knock would result in serious damage to their skin. Whenever we cross a road at a pelican crossing, we often hold up the traffic as the lights usually change before we have been able to cross the road. They often become anxious and upset (especially in busy areas) as they feel that everyone is looking at their skin so a lot of emotional support and encouragement is required.”

Care section

This section of the form breaks down the day into very specific questions so it is easy to blur one part into another. So, for example, if you do your child’s dressings while they are still in bed in the morning, you would split this time between the questions about getting out of bed and managing medicine and therapy.

Keeping a diary for a week or so can help you enormously to complete this section as you can break down the time spent to the relevant questions. Tick it off as you go and you can then include anything you have missed in the extra information section at the back of the form.

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

Please remember this includes any naps your child has so remember to put these in too.

A typical example of an answer to this question is:

“Although they wake up by themselves, I have to have pain relief ready to administer to help manage the pain they are in. It can take a while for them to become aware of their surroundings due to their lack of restful sleep. After taking their pain relief, they will rest in bed for at least ten minutes to enable it to start working; I stay with them during this time to provide reassurance. I have to physically help them out of bed as the skin missing from the soles of their feet makes standing up very painful and causes them to be unsteady. Settling them in bed takes a long time as it is very difficult to find a comfortable position and I am constantly moving pillows around. I have to provide reassurance and comfort due to the pain they are in and most nights I will sit with them until they drift off to sleep. This can take over 90 minutes”*

*Remember to include this again in the later question about medicines and treatments.

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

Include all aspects of help and support you provide. You may have to constantly prompt your child to use the toilet as blistering in this area may have caused a fear of the pain of going to the toilet, they may need help cleaning themselves due to their medication, you might have to lance blisters and reapplying dressings each time they go or you may have to help your child on and off the toilet. For young children, explain the problems you have with nappy changing. Always include the time it takes you to provide this care.

Do not forget to say what other help you provide, such as managing clothing, helping to wash and dry hands, washing clothes due to soiling. Constantly cleaning the toilet and bathroom to prevent the risk of infection is also commonly overlooked.

For very young children, nappy changing may be the time you manage blistering in this area and use specialist nappy liners. Explain here how much longer it takes and the additional things you have to do. Even with liners, blistering occurs around the leg and waist so make sure you put this in too.

Do they need encouragement, prompting or physical help to move around indoors, use stairs or get in and out of a chair during the day?

Do not worry about repeating your answers to the earlier mobility questions – it's ok to do this.

In addition, you can describe the difficulties your child has with stairs and the support you provide – for example, they are so unsteady on their feet, you walk behind them or carry them up and down stairs. You may also help them get in and out of a chair due to their poor balance and the severe pain caused by initially putting weight on their feet. If they use furniture to support them around the home, remember to include this.

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

This activity is broken down into specific tasks which make it particularly difficult to answer so think carefully how long each task takes. Again, do not underestimate the time it takes you to support your child, including providing encouragement to take part in each activity. For children who use bath time to soak off dressings, include the extra time they spend in the bath and the emotional support you provide during this time. Some children will spend time each morning and/or evening soaking their feet in a bowl of warm water before starting any treatment, so if your child does this make sure you explain that here.

Painful wounds and blistering on the feet especially make bath or shower time difficult. Even older children need someone to be nearby in case they fall or stumble – just being around takes up your time. Children whose hands are affected can find taps and shower controls difficult and will need you to spend time doing this for them.

Also detail any additional time you spend cleaning the bathroom to prevent the risk of infection to wounds.

Another common factor that is often missed when completing the form is that it takes significantly longer to dry your child after a bath or shower as rubbing them with a towel would cause significant damage to their skin. Prescribed soaps or body washes can also make bath time take longer as they have to be left on the body longer.

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

You can talk in detail about the difficulties your child has with clothing here.

Examples would be:

- *Prescribed undergarments to hold dressings in place*
- *Loose fitting clothing*
- *Turning items inside out, to prevent friction to the skin.*

- *Particular footwear*
- *Avoiding items with fastenings*

It is easy to underestimate the time spent providing help getting dressed and undressed. Think of the whole activity, including putting shoes and socks on. You can write about the problems your child has dressing themselves. Perhaps their fingers are badly affected they cannot manage fastenings or due to the dressings on their feet they cannot put on their shoes and socks.

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

As well as detailing any special dietary requirements, include the extra time it takes you to prepare separate meals. If your child is following a soft diet, they are unlikely to need help to cut up their food so explain that they would need this help at mealtimes (for example if they have wounds to their hands and fingers) if they were to eat an average meal. For example:

"...unless they are having a bowl of plain, overcooked pasta as a meal (which they can eat by themselves with a spoon), I have to ensure their food is cut up into small manageable pieces and remove any hard bits which would cause damage to the skin in their mouth and throat. This is because the skin on their hands is so fragile and using a knife and fork would cause the skin to blister and shear away."

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

In this section of the form, you can go into detail about your child's blister and dressings management routine. In working out how long it takes you, remember to include the time it takes to prepare dressings and soak off the old ones. It can be useful to refer to the clinical guidelines in your answer which you can download from the DEBRA website via this link and include with your application.

www.debra.org.uk/woundcareBPG

Lancing and dressing blisters can be time consuming with young children, especially with the use of sterile needles which have to be appropriately disposed of.

Children don't tend to keep still and some parents wait until they are taking a nap to do this. With older children, it may be the prompting and encouragement to get them to manage their blisters that takes up your time or removing medication from blister packs they are unable to open.

With older children help is usually required to manage hard to reach places like the feet and areas on the back of the body.

If it is helpful for you, refer to your child's prescription list in your answer which will illustrate the amount of dressings, creams and lotions you use when changing dressings and managing their condition. Do not forget the number of times a day you are administering pain relief as well as what you have in place at school when you are not around.

Do they have difficulty seeing?

For children who are certified sight impaired, make sure you include a copy of the certificate with the form. If your child is not sight impaired, you can also use this part of the form to

detail any difficulties which affect your child's ability to see. This may include blistering to their nose or around their ears caused by wearing their glasses or blistering to the surface of the eye.

Do they have difficulty hearing?

A common problem with children who wear a hearing aid is the blistering it causes around the ears. Remember to include this in addition to details about their hearing impairment.

Do they have difficulty speaking?

Sometimes, when blistering occurs in the mouth, it makes speaking clearly or making themselves understood difficult for the child. If you find you are explaining what your child is saying to people your child does not know (or those that they do know) then include details or examples in this question.

Do they have difficulty and need help communicating?

In addition to the previous answer, children can also have problems with communicating or they may choose only to interact with people they know well. This could be perhaps because they are very self-conscious of their appearance or have difficulties with their speech. If this is something you recognise in your child, make sure you include it in this answer. If they are getting support from someone else, for example at school, include details about this too.

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

If any of the examples in the list below this question on the form apply to your child, then explain further in the box below and perhaps include some examples.

Children with fragile skin need additional supervision to keep safe as the slightest knock or bump will cause them significant harm. Although this is not referred to directly in the wording of the question, it is worth reiterating this here.

Do they need extra help with their development?

As with the previous question, it is worth explaining how your child needs additional supervision to prevent damage being caused to their skin.

For example, this may be from another child while playing or additional measures taken while learning at school. Or this might include a careful hand washing routine following painting.

Sometimes children reach developmental milestones later due to their lack of mobility, pain they are experiencing or their ability to play unsupervised and explore the world around them.

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

It is useful to have any help your child has at school or nursery documented and included with your application. If you do not have a Special Educational Needs (SEN) or Care Plan, asks your child's teacher to write a supporting letter detailing the additional help they receive. You can refer to this in this question and include any additional support they receive.

Some examples of help at school are:

- *Your child is allowed to leave lessons early to avoid the rush between classes*

- *Additional help is provided with changing clothes*
- *Limited involvement in activities in PE and only when they feel up to it*
- *Use of a separate toilet to prevent risk of infections*
- *Their own private area to manage dressings*
- *Relaxing of school uniform rules so they can avoid wearing seams or can wear less formal shoes to minimise blistering*
- *Use of an iPad to reduce writing and therefore damage to the skin on their hands*
- *Additional time in exams and homework extensions*
- *Local authority transport*
- *Wheelchair kept at school*

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

This question is divided into two parts with examples – at home and when they go out. Briefly explain the additional help your child requires.

Some examples might be:

- *Using soft grips on colouring pencils*
- *Gently washing their hands after painting*
- *Additional supervision when they are playing with a friend*
- *Extra padding on exposed areas when at the playground*

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

This part of the form is about the time you would normally be in bed, not your child. It is easy to lose track of time when you have to get up in the night or be unaware of how long things take you.

Your diary can help enormously for this question, especially if you ensure you keep a log of the times you get up and go back to bed. Use the box to describe in detail the care you provide during the night, such as giving them some pain relief, helping them to get comfortable, using the toilet, adjusting or changing their dressings or applying creams to help with itching.

Sending in your form

Once you have gathered all of your supporting information and have filled out the form, make sure you have a copy of everything before putting it in the post. It is always worth calling the DWP after a week or two to make sure it has been received. This will enable you to send in a copy in plenty of time if there are any problems and prevent any delay in payments if you are awarded DLA.

If you are waiting for some supporting information, you can send this in later (make a note on the form that you will be supplying additional information) and make sure you put your child's reference number (if you know it) or their full name and date of birth on every page.

Getting help with your application

The Community Support Team at DEBRA will be happy to support you in making an application and help you to fill out your form. If you are unsure who your local Community Support Manager is please call the Membership Team on 01344 771961.

References

As mentioned, getting a DLA award can make you eligible for other forms of support and different elements of other benefits.

These references are included for information. It may be helpful to show them to professionals working with your child.

Eligibility for:

- Disabled child element of Housing Benefit: DWP, 2010, HBGM-BW3-assessment of needs – www.gov.uk/government/uploads/system/uploads/attachment_data/file/236964/hbqm-bw3-assessment-of-needs.pdf
- Lower rate or high rate disabled child element of Universal Credit (ref: www.gov.uk/universal-credit/what-youll-get)
- Disabled child or severely disabled child premium of Child Tax Credits: HMRC, 2014, Tax Credits: disability help sheet TC956 – www.gov.uk/government/publications/tax-credits-disability-helpsheet-tc956
- Carers Allowance – www.gov.uk/carers-allowance
- Carers Credit, should you not meet Carers Allowance criteria – www.gov.uk/carers-credit
- Disabled child element of Housing Benefit, DWP, 2010, HBGM-BW3-assessment of needs – www.gov.uk/government/uploads/system/uploads/attachment_data/file/236964/hbqm-bw3-assessment-of-needs.pdf
- The carers eligibility element of Income Support – www.gov.uk/income-support
- Exemption from paying vehicle tax – www.gov.uk/financial-help-disabled/vehicles-and-transport
- Eligibility for the Motability scheme – www.motability.co.uk/about-the-scheme/allowances
- Automatic qualification for a Blue Badge, DoT, 2013, Can I get a Blue Badge? – www.gov.uk/government/publications/blue-badge-can-i-get-one